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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 BC 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, 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, New Diagnosis, New Westminster, North Shore, Parkinson's Disease Online, Parksville/Qualicum, Parksville/Qualicum Caregivers, Powell River, Prince George, Quesnel, Richmond, Sechelt/Sunshine Coast, South Delta, South Okanagan, Surrey, Trail/Castlegar, Tri Cities Caregivers, Tri Cities/While Rock, Vancouver Carepartners, Vancouver Downtown, Vancouver West Side, Vernon, Young Onset Parkinson's Online

EDITORIAL STATEMENT

Articles contained in Viewpoints are for information only. Parkinson Society British Columbia does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

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Message from our CEO

Dear friends of Parkinson Society BC,

With immense gratitude and reflection, I share the news of my upcoming retirement after more than a decade dedicated to serving the Parkinson's community in British Columbia. This decision has been made with a heart full of appreciation for the myriad experiences that have marked my tenure — each rewarding, exciting, challenging, and occasionally tinged with heartache.

Throughout these years, I have had the privilege of forging connections with individuals and families navigating the complexities of life with Parkinson's disease. The strength, courage, and vulnerability exhibited by those who have reached the end of their journey during my tenure are etched in our collective memory.

Notably, I pay tribute to the impactful efforts of Paddi Wood (in memory) and Chris Olsen, who shared their fragile lives with the government, community, and media. Their advocacy led to the BC Ministry of Health providing coverage for Duodopa therapy, a significant advancement in Parkinson's treatment. Equally, recognition goes to Jim Smerdon, Sue Allan (in memory), Maureen Hafstein (in memory), and Richard Mayede for their instrumental role in highlighting the importance of Deep Brain Stimulation (DBS) surgery. To the countless exercise advocates who led by example, fostering movement and support, I extend my heartfelt appreciation.

Collaborating with exceptional individuals, including members of our Board of Directors, support group facilitators, clinical professionals, Parkinson SuperWalk organizers, and dedicated staff, has been a truly enriching experience. The unwavering support from donors, enabling the expansion of our impact year after year, has been instrumental.

Reflecting on our achievements over the past decade, such as doubling the number of DBS surgeries, securing Duodopa coverage, and establishing several new movement disorder clinics, fills me with pride. Our commitment to comprehensive team-based care, virtual programs, and awareness campaigns has made a significant impact on the Parkinson's community in this province.

As we celebrate these accomplishments, it's crucial to acknowledge the work that lies ahead, including the need for more neurosurgeon availability and the expansion of team-based care. However, exciting advancements in therapies on the horizon, such as subcutaneous delivery of levodopa and MRI-guided ultrasound, promise a brighter future.



I am confident that Parkinson Society BC will continue to thrive under new leadership, launching more ambitious campaigns with the ongoing support of individuals like you. Thank you for a remarkable ten years of shared dedication and impactful collaboration.

With gratitude,

Jean Blake, Chief Executive Officer Parkinson Society British Columbia

Jean Blake

Research

An Individualized Multi-Modal Approach for Detection of Medication "Off" Episodes in Parkinson's Disease via Wearable Sensors



RESEARCHER

Dr. Martin McKeown,
University of
British Columbia

FUNDING AMOUNT

\$72,561 over one year, funded in partnership with Parkinson Canada Researchers at the University of British Columbia have embarked on an exciting study that could revolutionize the way individuals with Parkinson's disease (PD) manage their medication. For those affected by Parkinson's, the medication L-dopa has been a staple treatment for over half a century. Despite the long-standing use of this medicine, patients commonly face key questions, such as how much and how often they should take their medication. This study aims to provide clearer answers, particularly to the latter.

Medical professionals commonly recommend a strict schedule for taking L-dopa, such as a pill at specific times throughout the day. While beneficial, this method does not account for the varying durations of L-dopa's effectiveness, which can be influenced separately by dietary protein intake and physical activity, among other lifestyle and physiological factors. Therefore, there is a pressing need for more personalized dosing strategies.

A less advised, but frequently adopted approach, is for patients to take another dose of L-dopa when they begin to notice the effects of the previous dose wearing off. This strategy is far from optimal, as it can lead to discomfort while waiting for the new dose to take effect, which can take up to 45 minutes. In addition, a more consistent maintenance of L-dopa levels is believed to prevent complications later in the disease's progression. Imagine a wearable device, much like a wristwatch, that alerts the wearer it's time for their next dose before they start feeling the discomfort of wearing off — this is the innovative solution this study seeks to develop.

This study uses the Empatica EmbracePlus, a sensor-equipped wristband that tracks various physiological parameters, including sweat, heart rate, and skin temperature. Dr. Martin McKeown's laboratory has previously demonstrated that by analyzing data from such devices, it is possible to distinguish when a patient's medication is active ("On") and when it's not ("Off"). This analysis, however, needs to be personalized for each individual.¹

The study, extending prior results, will involve 25 individuals with Parkinson's wearing the sensor for 24 hours. Participants will, in parallel, complete an online questionnaire throughout the day to report symptoms commonly experienced when their medication is wearing off, such as sweating or anxiety. Researchers will then analyze the sensor data to determine if they can predict the onset of these symptoms before the patients are aware of them.

This project is a step toward personalized health monitoring and management for Parkinson's disease, leveraging cutting-edge wearable technology to improve quality of life.

¹ E. Arasteh, M. S. Mirian, W. D. Verchere, P. Surathi, D. Nene, S. Allahdadian, M. Doo, K. W Park, S. Ray, & M. J. McKeown (2023). An Individualized Multi-Modal Approach for Detection of Medication "Off" Episodes in Parkinson's Disease via Wearable Sensors. *Journal of Personalized Medicine*, 13: 2. 265.

Ask an Expert

British Columbia's newly-appointed Deep Brain Stimulation neurosurgeon, Dr. Stefan Lang, discusses this surgical treatment for people with Parkinson's



Dr. Stefan Lang (MD, PhD, FRCSC) completed an undergraduate degree in Neuroscience and Cognitive Neuropsychology at the University of Guelph. He then attended medical

school at the University of Ottawa, followed by his neurosurgical residency at the University of Calgary. During his residency, he joined the Clinical Investigator Program and completed a PhD with a specialization in Neuroscience and Medical Imaging. He has won multiple national and international awards for his research and has published over 30 peer-reviewed papers. On completion of his neurosurgical residency, he obtained specialized training in Stereotactic and Functional Neurosurgery at the University of Toronto under the supervision of Dr. Andres Lozano, Dr. Suneil Kalia, and Dr. Mojgan Hodaie. He was then recruited to the University of British Columbia as an academic functional neurosurgeon, which involves performing Deep Brain Stimulation surgeries. He will work closely with the existing functional neurosurgery team and the Deep Brain Stimulation (DBS) clinic.

Can you tell our readers a little bit about yourself and your background, including where you studied and what specific training you have acquired to become a neurosurgeon focused on DBS?

After completing my undergraduate degree, I attended medical school followed by a neurological residency and a PhD. This is where I learned how to be a safe and competent neurosurgeon and scientist. I then went back to Ontario and did a yearlong fellowship in DBS at the Toronto Western Hospital. During this fellowship, I performed approximately 100 DBS surgeries.

Can you provide a brief overview of Deep Brain Stimulation, its risks and benefits, and what would make someone a good candidate?

Deep Brain Stimulation is a neurosurgical procedure where electrodes are placed deep in the brain to treat abnormal brain circuits. The electrodes are attached to extension wires that connect to a small battery. Everything is implanted underneath the skin and is minimally visible.

DBS is used in Parkinson's disease to help treat the movement symptoms. For example, patients with tremor, rigidity, or slowness of movement may have significant benefit. This is especially true if the symptoms are fluctuating during the day. Deep Brain Stimulation can help level out these fluctuations, so that someone spends more time in the 'on state' during the day. It can also be helpful for the motor complications from too much levodopa, including dyskinesia (involuntary rhythmic movements). This is a 'quality-of-life' surgery – we do not change the course of the disease, but we hope to improve quality of life for many years.

The risks are small but should be considered carefully. These include infection, bleeding, or stimulation-related side effects, such as slurred speech or balance issues. We must determine whether the benefit will significantly outweigh the risks. Unfortunately, not everyone is a good candidate for this procedure.

Can you describe what a Deep Brain Stimulation surgery is like, for both the person with Parkinson's and the neurosurgeon?

For the neurosurgeon, the surgery is routine. We have performed many of these surgeries and are familiar with each step along the way.

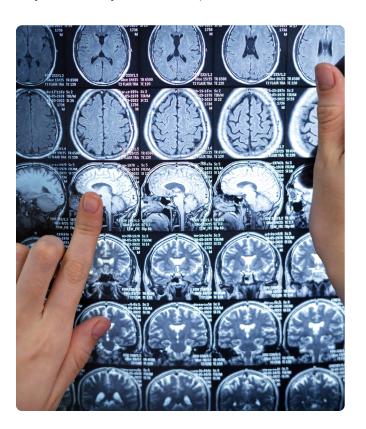
However, for the patient, this is a unique experience. The morning of the surgery, they will meet the team members, who will introduce themselves. A frame is attached to the head to help us with our precise targeting. We perform a short MRI scan with the frame on. They will then be moved into the operating room, where they will meet several other members of the team. Then, patients will be placed on the operating room bed

and their head will be secured so that it does not move. None of this is painful and we do our best to keep the person comfortable.

During the procedure, the patient will be looking forward towards one of our highly trained nurse practitioners. They will be with the patient the entire way. In the background, they will hear myself and other members of the surgical team discussing details about the surgery. We will talk to the patient and guide them through each step. We like to have a patient's cooperation during the procedure to help us safely place the electrodes. We may ask them to speak out loud and will carefully observe their symptoms. After we successfully place the electrodes, the patient will go to sleep with general anesthetic, and we will implant the battery. Typically, they will go home the next day.

Can DBS also help with non-motor symptoms of Parkinson's?

The effect of Deep Brain Stimulation on nonmotor symptoms is complex and an area of active investigation. In some cases, DBS can aggravate pre-existing psychiatric or cognitive issues. This is why we are very careful with patient selection.



It should be clear that the goal of the surgery is to improve movement rather than non-motor symptoms. However, some patients can experience improvements in mood, pain, and sleep following Deep Brain Stimulation. I am particularly interested in trying to figure out why some patients may benefit and why others may not. We will be launching a prospective study of this issue soon.

What inspired you to specialize in neurosurgery, particularly DBS for Parkinson's disease?

I specialized in Neurosurgery, and specifically in Deep Brain Stimulation, because I am excited about what the future holds for this field. This is an area that we are actively learning about and improving every year. I take pride in the fact that our patients are often very satisfied with the procedures we provide. Most patients who are carefully selected for DBS will have significant improvement in the quality of their life.

For a very long time, British Columbia has only had one neurosurgeon performing DBS, creating significant delays in accessing this life-changing procedure. Your recruitment has given renewed hope to many. What further steps or actions can the province take in continuing to increase access to DBS for individuals in need?

Unfortunately, there are still obstacles present that are limiting our ability to further decrease wait times. This has to do with the fact that the surgeon does not work in isolation. We are part of a multidisciplinary team, including highly-trained nurse practitioners. While the recruitment of an additional surgeon has been an important step towards increasing access, there have not been corresponding increases in the other team members at the DBS Clinic. The nurse practitioners of the clinic now are working harder to accommodate the extra patients being seen by myself. An additional nurse practitioner and additional office space would help facilitate the flow of patients through the system.

The province of British Columbia has been underserved with respect to access to Deep Brain Stimulation. The wait list is now decreasing and patients who have been waiting years are getting timely access to a consultation.

Viewpoints · Spring 2024 Ask an Expert



Are there any recent advancements regarding DBS that you find promising or exciting?

There are many recent advances in Deep Brain Stimulation that I find exciting. A recent innovation allows us to record brain signals directly from the electrodes that we implant. This can allow us to better understand abnormal brain activity and to tailor treatments more precisely for individuals.

Another innovation is the compatibility of the new hardware with powerful MRI machines. It is now possible to take pictures of the brain with the stimulators implanted and turned on. We are planning to utilize this to study how the stimulation impacts brain networks.

Lastly, new techniques are allowing us to stimulate and lesion the brain without having to open the skull. These techniques include high-intensity focused ultrasound. We do not have access to this technology in British Columbia at the current time, but are working to see if this is feasible.

What are you looking forward to achieving or exploring further in the future regarding Parkinson's treatment and DBS?

The long-term goal is to minimize the invasiveness of our procedures to increase safety and to be able to provide these therapies to more patients. We have much work to do and none of it can be done without the involvement of our patients. A major goal of mine is to offer research opportunities to my patients so that we can progress the field for future generations.

April is Parkinson's Awareness Month

Every year, April is recognized by the Province of British Columbia and Parkinson Society BC 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 impact it has on the lives of over 17,500 British Columbians touched by this illness.

Watch out for us!

Our **Parkinson's Awareness Month video project** involves the personal stories of three diverse people touched by Parkinson's disease, with an aim to educate and raise awareness about the realities of living with PD, as well as its lesser-known symptoms.

A day of meaningful connection unfolded as Parkinson Society BC staff spent the day with these members of the PD community. Graciously welcoming us into their homes, they opened up with candid sincerity, sharing their personal stories of challenges and triumph.

The videos will be shared in the month of April on our website and YouTube channel.

parkinson.bc.ca/awareness

youtube.com/@ParkinsonSocietyBC

THE STORIES FEATURED WILL INCLUDE:



Jeanette Fisher Pynn, a Bowen Island mother of three. Originally misdiagnosed with a serious form of parkinsonism called multiple system atrophy in 2017, Jeanette and her loving family celebrated a revised diagnosis of Parkinson's, as it meant hope for the future. On April 11, World Parkinson's Day, in 2023, Jeanette underwent Deep Brain Stimulation (DBS) surgery, which has given her significant improvements in her symptoms, as well as a new lease on life.



Jim Wu, Parkinson Society British Columbia Board Member and a dedicated employment lawyer.

Diagnosed with Young Onset Parkinson's Disease (YOPD) at the age of 30, Jim refuses to let it hinder his pursuits. He continues to passionately engage in his hobby of Brazilian jiu-jitsu, and trains his German Shepherd, Hachiko, in the sport of herding. Jim's resilience exemplifies that a Parkinson's diagnosis does not define the vibrancy of one's life.



Sandra Alexander, who is a carepartner to her husband with PD, Gary.

The Langley couple have three children and are doting dog owners to their pup, Daisy. Gary was diagnosed with Parkinson's in the fall of 2007, and while they have had to adapt to his limitations, they have met every challenge head on as a united front. Sandra's story highlights the unique carepartner perspective in navigating the Parkinson's journey together.



Jim and his German Shepherd, Hachiko



Jim working at his law office



Jim practicing Brazilian jiu-jitsu



Sandra and Gary at their Langley home



Gary, a motorcycle enthusiast, with his Triumph bike



Jeanette, her husband, Barry, and two of their children



Jeanette and Barry, strolling the beaches of Bowen Island



Jeanette, an avid runner, enjoying a jog

Our social media campaign will include short-form video interviews (one-minute segments), covering various aspects of Parkinson's experiences and treatment, such as caregiving, mental health, speech-language pathology, and physiotherapy. In addition, throughout the month of April, we will be sharing a series of illustrations of symptoms, facts about Parkinson's, and quotes from the community. Make sure to follow along at:

- Facebook: @ParkinsonSocietyBritishColumbia
- Instagram and Twitter: @ParkinsonsBC

Public transit advertisements will be featured in:

- Vancouver: Skytrain (interior train advertisements, station posters at Metrotown and Commerical-Broadway, and a wall mural at Waterfront station), bus (interior bus advertisements)
- Victoria: bus (interior bus advertisements)
- Kelowna: bus (interior bus advertisements)

Radio partnerships with several radio stations across the province have been established, specifically for the broadcasting of public service announcements that will help shed light on the diversity of symptoms experienced by people with PD. Our emphasis is in regions boasting substantial listenership, particularly in areas with a higher prevalence of Parkinson's disease. Partnerships have been established with:

- 980 CKNW (Lower Mainland)
- 107.3 Virgin Radio (Victoria)
- Move 101.5, Virgin Radio 99.9, AM 1150 (Kelowna)
- Radio NL, K97.5, New Country 103.1 (Kamloops)

Public library displays across the province will feature varied displays, including informational brochures, posters highlighting lesser-known PD symptoms, and book displays with content related to Parkinson's disease. These displays are tailored to each library's capacity and audience, aiming to educate visitors about the disease and expand awareness of the Society. A full list of participating libraries is on our website at www.parkinson.bc.ca/awareness.

Landmark lighting will take place at various monuments and structures across the province, in collaboration with the PD Avengers' "Spark the Night" project, which is seeking to symbolize solidarity and spread awareness on a global scale. Look for landmarks lit in mid-toned blue! A full list of participating landmarks is on our website at www.parkinson.bc.ca/awareness.

A broadcast partnership has been secured with Global BC, which will feature Parkinson's Awareness Month in the Global BC on-air community 'L' frame, community events page, social media channels, and possible on-air interview coverage.

Proclamations have been secured provincially, as well as for several municipalities across BC. For a full list, please see www.parkinson.bc.ca/awareness.

Support group activities have been mailed to groups, featuring a "postcard" members can fill out to reflect on their journey with PD. These cards, once returned to the Parkinson Society BC office, will be featured on social media to broaden the narrative and understanding of Parkinson's disease.



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



Sandra and Gary playing fetch with Daisy, their dog

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

Share Your Parkinson's **Experience**



This April, we are encouraging British Columbians affected by Parkinson's to submit content that tells their story, their way. Whether it is through painting, poetry, or some other medium, we believe that the unique voices of our community members deserve amplifying.

Please visit bit.ly/ShareYourPDStory24 to submit your original content, and help raise awareness of the experiences of people with Parkinson's disease.

We are also collecting experiences and reflections from members of the Parkinson's community through a digital version of our "Your Parkinson's Experience" postcard, found at bit.ly/PDPostcard24.

You may answer as many or few questions as you like. Responses will be shared on multiple channels, such as Parkinson Society BC's (PSBC) website and social media platforms, to expand awareness on living with Parkinson's disease as well as spread messages of hope in the community.

Newsworthy

Upcoming Education & Exercise Events

Tuesdays, March 5 - April 30

Rock Steady Boxing with Doug Pickard (Level 3)

Online

This class is a total workout for both mind and body, as it incorporates cardio, strength, balance, hand-eye coordination, and speed.

Wednesdays, March 27 - May 1

DOPABEATS

Online

Express your feelings with easy-to-follow beats and rhythms, and add drumming to your toolbox of therapies and self-management strategies!

Saturday, April 6

Communication & Swallowing Workshop (Kamloops)

© Coast Kamloops Hotel & Conference Centre

This workshop, led by Sherri Zelazny, registered speech-language pathologist, addresses communication and swallowing difficulties in individuals with Parkinson's using clinically-proven methods from the Lee Silverman Voice Treatment®. Member pricing available.

Saturday, April 13

Nanaimo Regional Conference

♥ Vancouver Island Conference Centre

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. Member pricing available.

Events Hosted in Person Online Events

Tuesday, April 16

Intimacy with Parkinson's

Online

Explore strategies for navigating intimacy and sexual health challenges in Parkinson's disease with expert guidance from social worker Elaine Book and clinical counsellor Tricia Wallace in this insightful webinar.

Tuesday, April 30

Community Talk: Mental Health (Cranbrook)

© Cranbrook (Location TBD)

Discover practical strategies and compassionate guidance for managing mental health challenges in Parkinson's disease. Member pricing available.

Thursday, May 2

Deep Brain Stimulation and Non-motor Symptoms with Dr. Stefan Lang

Online

This webinar will be led by Dr. Stefan Lang, British Columbia's newly-appointed Deep Brain Stimulation (DBS) surgeon. Alongside an introduction to DBS, Dr. Lang will discuss non-motor symptoms related to Parkinson's.

Thursdays, May 9 - May 30

Move with Shelly – Seated Exercises (Level 2)

Online

Join Parkinson Society British Columbia's own neuro physiotherapist, Shelly Yu, for a fun and energetic online Parkinson's exercise class, designed to challenge your strength, balance, and mobility to improve overall daily function and quality of life. This seated class is suitable for those who prefer a slower pace, as all exercises will be completed in a sitting position.

Thursdays, May 9 – June 13

SongShine

Online

This program harnesses the power of the brain, breath, and emotion to reclaim voices. Joani Bye will engage participants to help improve communication while facilitating a sense of community, camaraderie, and confidence!

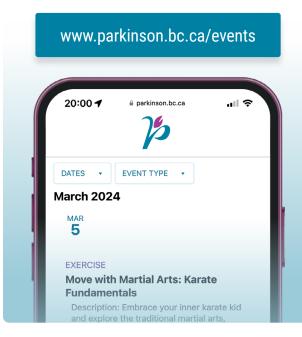
Tuesdays, June 4 - June 18

Move with Shelly – Standing Exercises (Level 2)

Online

Join Parkinson Society British Columbia's own neuro physiotherapist, Shelly Yu, in a three-week standing exercise circuit class. This class is fun, energetic, and will challenge your endurance and balance. Some dual-tasking challenges may be given throughout.

For registration and a full list of upcoming events, visit us online at



Thank You to Our **Fundraisers & Donors**



A big thank you to everyone who attended and supported the Agnes Parke Memorial Golf Tournament. We are very grateful for the remarkable efforts of Walter and Stewart Parke in organizing this event, which led to a fundraising total of over \$14,800.

A special thanks to Queen Elizabeth Secondary School for organizing the Pull for Parkinson's fundraiser and raising over \$7,000 for the past two years.

A special thank you to Donate a Car for raising \$255 for our cause.

Thank you to the Thirsty Moose Pub for their burger and beer night fundraiser in October 2023 in support of the Society.

Awareness to Action: Making BC "Parkinson's Ready"

In collaboration with the World Parkinson Coalition, Parkinson Society British Columbia (PSBC) will launch the "Parkinson's Ready" training program to promote informed care and increase awareness of Parkinson's disease (PD). Beginning with an April awareness campaign, the initiative will involve training sessions in May. Led by a person with PD and a physiotherapist, the training will equip city workers and service professionals with a deeper understanding of PD and the skills to support those affected by it, aiming to reduce prevalent misconceptions and stigma.

The campaign will utilize social media and community partnerships to extend its reach, making educational tools and information widely available. This online engagement is essential for advancing knowledge of PD and addressing stigma. The "Parkinson's Ready" initiative embodies PSBC's dedication to improving life for those with Parkinson's through education, advocacy, and community engagement, emphasizing the power of empathetic, educated, and compassionate care.

Save the Date

2023 Annual General Meeting

We welcome all members of Parkinson Society British Columbia (PSBC) to join us for our 2023 Annual General Meeting (AGM) this spring.

Following the meeting, Dr. Martin McKeown from the University of British Columbia will join us to share his expertise and knowledge looking back on the past ten years of advances in therapy and milestone discoveries in research. He will also take a look forward to some of the promising new therapies and exciting research on the horizon.

This year's AGM will be hosted virtually via Zoom. Register today at www.parkinson.bc.ca/agm.

DATE

Saturday, April 20

TIME

9:30am - 12:00pm 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



