

# VIEWPOINTS



## WINTER 2021

A QUARTERLY NEWSLETTER  
BY PARKINSON SOCIETY  
BRITISH COLUMBIA

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ADVOCACY UPDATE:  
DISCRIMINATION &  
ADVANCED THERAPIES

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## 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.

## YOUR SUPPORT IS ESSENTIAL

Parkinson Society BC would not exist without the support of our members, donors, and volunteers. Here are a few of the ways you can support your 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](http://www.parkinson.bc.ca/donate).

## SUPPORT GROUPS

Our peer support groups provide people with Parkinson's, their caregivers, and families an opportunity to meet in a friendly, supportive setting. To learn more and join a group, visit [www.parkinson.bc.ca/groups](http://www.parkinson.bc.ca/groups).

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

## EDITORIAL STATEMENT

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# HOLIDAY MESSAGE

Dear friends,

As we look back at another challenging year for the Parkinson's community, we do so with astonishment at the passion, resilience, and solidarity you have shown in the face of hardship. Without you, our Society would not have the impact it does today.

Throughout COVID-19, we have been introduced to stories of those who champion our cause to empower every British Columbian touched by Parkinson's with the knowledge, tools, and resources they need to live well. Every day, these stories inspire the work that we do; and in these especially difficult times, they humble us profoundly.

After our peer support groups were suspended last year in adherence to public health guidelines, group facilitators from across the province generously volunteered their time to transition meetings online. Their efforts have helped make our online groups – and in turn, other virtual resources – more accessible. More people than ever before have tuned in to attend our educational webinars, which have featured presentations from world-renowned Parkinson's experts, such as Drs. Lorraine and Suneil Kalia, and Alfonso Fasano; local doctors and allied healthcare professionals, such as Deep Brain Stimulation (DBS) neurosurgeon, Dr. Christopher Honey, movement disorder specialist, Dr. Jonathan Squires, and social worker, Elaine Book; as well as people with Parkinson's and their carepartners. This year, we also offered many activity-based and exercise classes, like SongShine, drumming, dancing, Pilates, improv, laughter yoga, and tai chi. We are grateful to all those who participated in these events, and in our support groups, as well as to every individual who has accessed our resources, volunteered their time, made a donation, or shared their story.

At Parkinson Society British Columbia, we believe every person touched by Parkinson's disease should have access to the support they need. While we have made strides to expand our own reach, many Parkinson's-specific treatments and therapies remain largely inaccessible, due to financial and geographic barriers. That is why we launched our new virtual physiotherapy service this year, serving those who would otherwise not have the opportunity to see a physiotherapist with experience in movement disorders and neurodegenerative conditions, or at all. We are also proud to continue supporting groundbreaking research, through partnerships with the Parkinson Canada Research Program and the Michael Smith Foundation for Health Research, including studies into new treatments, evaluation tools, and technologies, that give us hope for a future without Parkinson's.

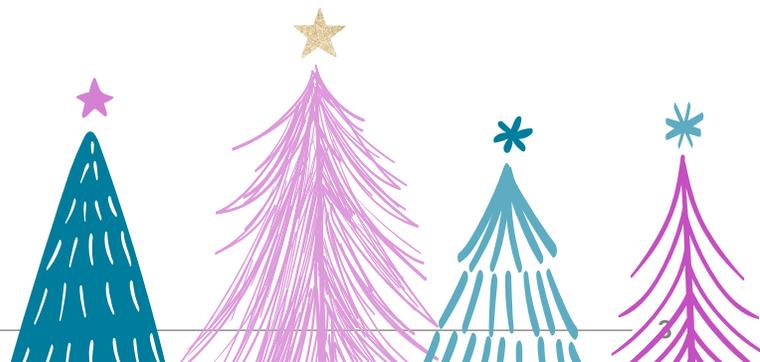
Thank you for trusting us to serve you during this most unusual time. As we continue to navigate through the pandemic, we look forward to the opportunity to meet in person again soon.

Best wishes for a joyful holiday season and a happy new year!

With gratitude,



Jean Blake, *Chief Executive Officer*  
Parkinson Society British Columbia



## ASK AN EXPERT

### Dr. Brenda Lau discusses pain in Parkinson's



**Dr. Brenda Lau, MD**, is a pain specialist and anesthesiologist with over 20 years' experience. She was a founder and board member of the Pain BC Society that formed in 2008. In 2011, she became the first chair of the Fraser Health Authority (FHA) region-wide pain services division. Two years later, she co-founded CHANGEpain Clinic, a Vancouver-

based pain centre that provides multi-disciplinary care. She has led numerous national, provincial, and hospital-based initiatives to improve understanding of pain while improving treatments and care training. In 2015, Dr. Lau became the first Program Director of the Pain Medicine residency program at the University of British Columbia. Earlier this summer, Dr. Lau spoke at Parkinson Society BC's June Symposium Series about pain in Parkinson's disease (PD).

#### *What causes pain in Parkinson's disease?*

There are many types of pain experienced by people with PD, including musculoskeletal (involving the soft tissue, bones, and joints), neuropathic (nerve pain, caused by pressure, compression, and narrowing of nerves), and central pain (pain signaling derived from the brain itself). Pain is the most common non-motor symptom experienced by people with PD, with research suggesting that approximately 68-83% of patients experience some degree of pain. However, just because a person has Parkinson's does not mean they are guaranteed to experience any specific type of pain throughout the course of their illness.

Dystonia is the leading cause of pain affecting people with PD because of muscle rigidity, which can cause gait changes and muscle stiffness. A close second is neuropathic causes of pain, often caused by tight muscles. The nerves that pass through these muscles have trouble sending normal signals. Over time, due to repeated pain signals, the brain becomes more sensitive to pain not just at the originating site, but throughout

the entire body. This can lead to a phenomenon called central sensitization, where pain becomes widespread and does not just follow one nerve root.

Pain is often aggravated by non-motor symptoms of PD, such as mood dysregulation, sleep issues, and autonomic dysfunction, which can vary widely between individuals. Risk factors for experiencing pain in PD – and which may impact the severity or nature of pain – include an early age of onset, long disease duration, motor complications, depressive symptoms, and other associated medical conditions. In advanced stages of Parkinson's, people may experience pain if using high doses of medications like Levodopa, which may alter pain signaling.

#### *How can care providers better treat pain?*

When approaching a patient's pain, it is important to look at it like the layers of an onion. Is the pain originating from the body level – is it coming from the skin, nerves, or muscles? Are movement patterns causing nerve compressions? Could there be any side effects from medications?

Pain services should be multi-dimensional to address the biopsychosocial issues. Medical therapy may include medication management, pain interventions, infusion therapy, and

disease management. The interdisciplinary team should include allied healthcare professionals, such as movement specialists, physiotherapists, chiropractors, yoga coaches, kinesiologists/somatic therapists, exercise physiologists, psychologists, and pain coaches. Each of these professionals bring a different clinical perspective to a patient's experience. Care providers must also take a holistic approach by examining factors such as relationships, relaxation, nutrition, mental health, movement, and sleep, and their respective impacts on pain.

#### *What can carepartners do to help with pain?*

Carepartners can support people with PD by being knowledgeable about pain, including pertinent resources from [www.painbc.ca](http://www.painbc.ca). In healthcare settings, carepartners can also be powerful advocates, helping to connect their loved ones with multidisciplinary pain teams, and other specialists who may best serve their needs. They can offer their support for the self-management and wellbeing of people with

PD, such as by encouraging improved nutrition and sleep, meditation and self-care practices (such as mindfulness or box breathing), and time in nature.

### ***What research is being done on pain in PD?***

Repetitive Transcranial Magnetic Stimulation (rTMS), magnetic stimulation that alters brain neurotransmitters. This treatment has shown potential in treating rigidity. Other studies have found that it may help with upper limb bradykinesia (Lomarev et al., 2006). The benefit from rTMS for Parkinson's may be derived from its inhibition of dopaminergic systems (Mi et al., 2020; Shimamoto et al., 2001). Normally, rTMS is a private-pay treatment option, but new university-based research studies are offering it at little to no cost.

Burst spinal cord stimulation, where electrodes like those in a pacemaker are placed in different parts of the brain or spinal cord. This may help change the signaling within muscles and, in some people, may help with rigidity. Recent studies have also found that newer methods of administering this therapy may improve pain, posture, and mood without the side effect of causing "pins and needles" sensations that could occur with older administration methods (Cai et al., 2020; Kobayashi et al., 2018).

The microbiome and the gut-brain connection, which have become prominent topics of interest in the last decade due to their impact on inflammation and the immune system. Research has also found that changes in the microbiome may influence the types of pain that people with PD experience (Rajoka et al., 2017; Romano et al., 2021).

### ***How can people with PD self-manage their pain?***

In BC, Group Medical Visits (GMVs) are ways for patients to access physician and specialist expertise in a group setting, and are funded under the Medical Services Plan (MSP). Due to increased time with the physician and the sharing of knowledge in a group setting, a wider breadth of topics are covered compared to the one-on-one physician appointment.

At CHANGEpain clinic, their GMVs cover pain and pain-related topics involving sleep, energy, mood, trauma, post-traumatic stress disorder, anxiety, nutrition, gut health, and safe movement, as well as various other pain syndromes. They enable patients to understand their condition more holistically, empower

patients with self-management tools, and are a source of community for individuals facing similar issues.

A healthy, balanced diet may also help people with PD better self-manage their pain due to the effect of nutrition on the microbiome. A diet rich in prebiotic fibre, B vitamins, antioxidants, Omega 3s, and minerals such as magnesium may also help to support gut health. Additionally, certain foods, such as fresh fruit and vegetables, nuts, seeds, and fish, have been found to slow the progression of Parkinson's (Mischley et al., 2017). Studies so far strongly suggest that changes in gut health may impact neuroinflammation. Bacterial imbalances in the gut could influence PD patients' disease course and response to medications like Levodopa. However, more research is required to assess gut-related therapies in Parkinson's patients.

### ***Can alternative therapies, like massage therapy, tai chi, and acupuncture, help pain in Parkinson's?***

These therapies certainly have the potential to help pain. However, it is hard to precisely quantify the benefit of any alternative therapy, as not enough research has yet been funded to study their effects.

If, after three to four months of consistently working with a therapy, a patient is not improving, or worsening, it is advisable to stop and reevaluate. If the therapy is helpful, it is the patient's decision whether or not it is worth their time and money to continue. However, if the benefit is short-lived, questions should be asked about what else can be done to prolong that benefit. Can more be added to the treatment plan? For example, if a patient experiences a short-lived benefit from massage, can they better optimize their sleep or nutrition to extend this benefit?

### ***How can you and your clinic help people with PD manage their pain?***

CHANGEpain Clinic offers the breadth of evidence-based pain and function recovery services that apply the best science, knowledge, and technology from medicine, nutrition, brain health, and movement. The clinic offers many GMVs led by their multi-disciplinary team about various topics pertaining to pain, movement, and rehabilitation. They also offer a multitude of targeted treatments, which may assist people with PD in managing their pain or pain-related disabilities. MSP-covered therapies include medication management, ultrasound, and fluoro-guided pain procedures for

**CONTINUED ON PAGE 17...**

## LIVING WELL

### A palliative approach to Parkinson's care

As a condition with no presently-known cure, Parkinson's disease (PD) is treated with therapies, medications, and lifestyle changes aimed at managing the severity of symptoms, and slowing their progression. People with PD benefit most from holistic care delivered by a skilled team of healthcare professionals – particularly those specializing in movement disorders and neurodegenerative conditions. Members of the Parkinson's healthcare team can include general practitioners, neurologists, nurses, physiotherapists, occupational therapists, speech-language pathologists, clinical counsellors, social workers, and other allied healthcare professionals. These experts work together to ensure people with Parkinson's and their carepartners have the tools, resources, strategies, and support that they need to maximize their quality of life.

Parkinson's management does not end at clinical care, however. Living well means addressing all of the challenges you encounter on your journey with PD.

#### *Palliative approach to care*

*Palliative care is focused on providing comfort and quality of life. Often, this type of care is considered to be reserved for end-of-life or those suffering from terminal illness, and delivered in hospice. However, the attitudes of healthcare professionals around the world are changing on the matter.*

"Palliative care is really a philosophy, rather than a place," says Kathleen Yue, Clinical Lead, Education at the BC Centre for Palliative Care (BCCPC).

"Palliative care used to be a specialty offered only near the end of life, particularly for those with terminal cancer. Today, we focus on a palliative approach for any type of care" (PSBC, 2019).

Palliative care addresses any issues that may reduce one's quality of life. According to the World Health Organization (WHO), this can include any challenges one may face, "whether physical, psychosocial, or spiritual" (2020). By taking into consideration



#### PALLIATIVE CARE SERVICES:

- medical services with a holistic approach (i.e., involving the entire healthcare team, or accommodating alternative treatments)
- emotional support resources (counselling, spiritual support, etc.)
- advance care planning (with doctors, case managers, family, etc.)
- hospice care, residential/long-term care facilities, palliative care units in hospital
- safety support services (i.e., home safety assessments by home & community care workers/volunteers)
- support for carepartners and family (all services above, in collaboration with carepartners/family, or with consideration to their needs, as well as respite care)

your body, mind, spirit, relationships, and any other important factors in your life, your healthcare team can adopt a palliative approach to provide you with holistic Parkinson's care.

A Parkinson's care plan should take into consideration all aspects of a patient's life. For example, one's income may be a barrier to accessing specialized services, while their religious beliefs may preclude them from certain treatment options. Healthcare professionals are specially trained to help their patients navigate

## QUALITY PALLIATIVE CARE:

- focuses on the needs and concerns of patients and their families;
- pays close attention to physical symptoms, such as pain, nausea, loss of appetite, and confusion;
- considers the emotional, social, cultural, and spiritual concerns of patients and families;
- ensures that care is respectful and supportive of patient dignity; and
- uses a team approach that may include volunteers, social workers, and spiritual leaders, in addition to medical staff (BCCPC).

supports available to them, and identify those that best align with your priorities, beliefs, and values. This is often referred to as the palliative approach to care.

At the BCCPC, Yue works to educate healthcare professionals across the province on how to best support their clients by adopting a palliative approach to their specific field of care. In a recent interview with Parkinson Society British Columbia (PSBC), she discussed the benefits of a palliative approach to treating and managing PD.

“When I worked in the hospital, there was a clear distinction between curative and palliative care,” she recalls. “I noticed that when the focus changed to palliative care, the whole atmosphere around the patient, family, and healthcare team completely changed. The anxiety levels went down, in general, and I really felt a marked difference in the approach to care.”

Similarly to Yue’s experience, many people with Parkinson’s will encounter very different approaches to care based on where, and from whom, they are accessing it. Movement disorder clinics, and professionals with Parkinson’s-specific training and experience, are equipped with a better understanding of all the ways in which PD can affect one’s life, and the lives of their family members and loved ones.

“Most healthcare involves a team, but this is especially true in palliative care,” says Yue.

“Each person on the team brings a toolbox of

knowledge and resources. Your healthcare team can help you with advance care planning, assessments of your health, safety, and wellbeing, equipment to assist you with daily living, symptom management tools and strategies, and social and spiritual support.”

### *The patient’s role in palliative care*

Not all healthcare professionals may understand the extent to which PD varies. Parkinson’s can present very differently from one individual to the next – someone’s most prominent symptom may be one that another person with Parkinson’s has never developed. Even the most experienced professionals must understand their patient before beginning to treat their PD.

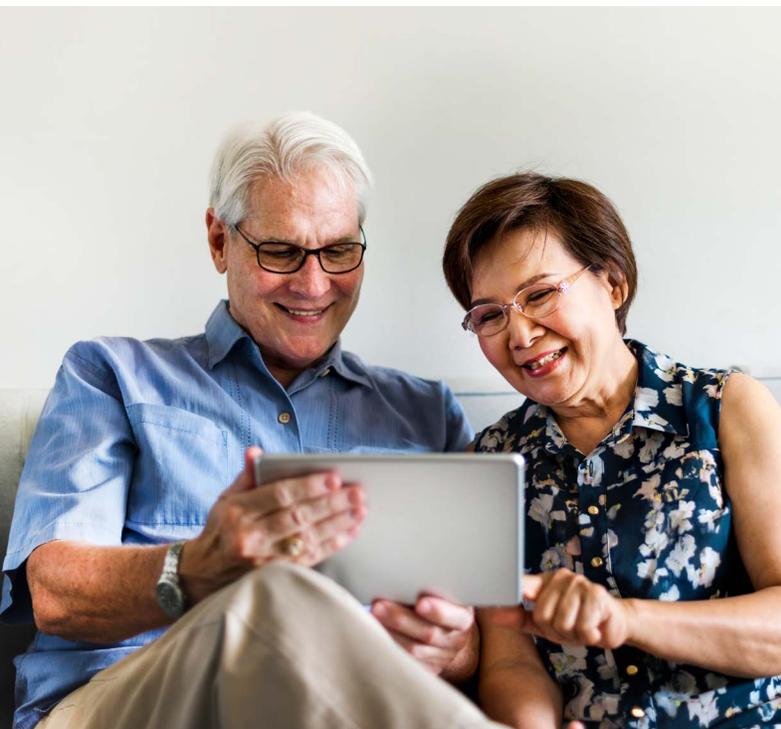
The crucial first step in managing any chronic condition is being an active agent in your own care, where “agency” is a patient’s power to make choices about their care in any context (Walach et al., 2018). Beyond their responsibilities of assessment, diagnosis, and treatment, healthcare professionals must provide advice to inform their patients’ decision-making. According to Walach and Loughlin (2018), “no amount of medical expertise can make [healthcare professionals] experts on which trade-offs are the right ones for [a] person to make in the context of [their] particular life goals.”

Being an active agent in your care means working alongside your healthcare team every step of the way. By staying informed about your condition and care options, and voicing your opinions, preferences, and concerns, you have the power to decide how your healthcare team can best serve you. While advocating for yourself may feel daunting, it is an important part of helping healthcare professionals make informed decisions and tailor their approach to best suit your needs. You are your own best advocate.

### *Be candid*

In order to create a comprehensive and holistic care plan, your healthcare team needs to understand all of the ways PD affects your life. This includes tracking your symptoms and experiences with PD, and keeping your team informed of changes to your condition. Do not hesitate to share any of your concerns with the healthcare professionals you trust – no matter their specialty, doctors, nurses, and allied healthcare professionals (AHCPs) across BC are trained to take a person-first approach to their work. Your healthcare team can provide referrals and

CONTINUED ON NEXT PAGE...



help you navigate specialized services, treatments and therapies, financial supports, and other options available to address your unique needs.

### *Stay informed*

Across the globe, Parkinson's researchers are continuing to make new discoveries about the causes, development, effects, and outcomes of the disease. Our understanding of PD is ever-evolving, and studies are frequently revealing novel treatment options to slow disease progression, manage symptoms, and improve function and mobility.

It is important for people with Parkinson's and their carepartners to understand the disease and how it affects them, as well as all of the possible supports they may be able to access. However, some skepticism is always necessary. When researching Parkinson's, always be sure to find credible and trustworthy sources, such as health authorities, healthcare professionals, medical journals, and non-profit organizations who work with medical advisors. Be wary of biased information that may be coming from sources that are selling or advertising alternative treatments.

For help finding information about PD, get in touch with your healthcare team, or your local health authority. Parkinson Society BC's friendly and knowledgeable staff are also available to connect you with the resources you need at 1-800-668-3330 or [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca).

### *Plan for the future*

Parkinson's is a degenerative and chronic disease. Most people with Parkinson's will require some level of support at some point in their journey with the disease. Planning for your future is the best way to stay proactive in your care.

It is never too early to plan for what may come next. While these can be difficult conversations to have, being prepared for the future can make a huge impact on improving quality of life for you and your loved ones.

As PD progresses, it may cause cognitive changes that can impact an individual's legal authority to make healthcare decisions. In that case, a loved one can be appointed power of attorney to make these decisions for them. It is important to make your loved ones aware of the type of care you wish to receive in later stages of the disease, so they are prepared to advocate for you should they need to.

Talk to your loved ones and your healthcare team about the decisions you would like made about advanced treatments, hospitalization, in-home support, long-term care placement, mobility aids, home adaptations, and end-of-life. If you do not have one already, you should also explore your options for a comprehensive insurance plan to cover medical expenses and support services. It is never too early to begin planning and saving money for the future, and as your PD progresses, you can revisit your financial plans to ensure you are prepared for any next steps.

### *Beyond healthcare*

The palliative approach goes well beyond clinical care, providing psychological, social, emotional, spiritual, and practical support (Health Canada, 2018). Each of these factor into a holistic picture of overall health and wellness, comfort, happiness, and quality of life.

### *Psychological*

Many people with PD will encounter mental health issues related to changes in their brain chemistry and function, or as a side effect of certain medications. However, the difficulties of coping with the disease, and all of the changes it brings about in one's life, can also significantly affect one's mental health.

Mental health requires the same care and attention as physical health. People with Parkinson's can often self-manage their own mental health by maintaining healthy

habits, though it is crucial to have somewhere to turn for support when needed, such as counselling services, support groups, social networks, or community access and assessment centres (which provide drop-in mental health services and multidisciplinary crisis intervention).

Any changes to, or concerns about, your mental health should be communicated to your healthcare team. There are many medications, therapies, tools, and resources available to help you manage any mental health issues you may encounter. Your healthcare team can help you explore the options that best suit your preferences.

### *Social*

Social isolation among older adults is a significant public health concern across the globe. People with Parkinson's, as well as carepartners, may be particularly vulnerable as a result of many compounding factors that make social connection, mobility, and community engagement more challenging.

Those who spend little time with loved ones, friends, and neighbours may be isolated and at risk for poorer physical and mental health. Social isolation can present a serious issue for the health, safety, and mental wellbeing of people with PD. A strong sense of community, and a tight-knit support network, are significant determinants of health outcomes.

Focus on spending time with family, friends, and loved ones to combat feelings of isolation. If you are not comfortable discussing your PD with the people in your life, consider joining a peer support group. They provide a safe, friendly, and supportive space to share with others experiencing similar difficulties. To learn about Parkinson Society BC's network of over 50 support groups, visit [www.parkinson.bc.ca/groups](http://www.parkinson.bc.ca/groups).

### *Emotional*

Palliative care prioritizes the patient's happiness. At every stage of your journey with PD, you should feel empowered to make informed decisions that leave you feeling confident and resolute. However, uncertainty and doubt are normal feelings to have towards your condition, and the decision-making often required of you as a patient. When working with your healthcare team, it is important to ensure that your emotional state is always taken into consideration.

Heightened emotions can cause us to misinterpret information. A positive outlook is necessary to plan

for positive outcomes. Healthy coping strategies and self-care methods can help you maintain a balanced emotional state. Any activities that support you in doing so can be considered a part of your palliative care.

### *Spiritual*

Spirituality offers us a way to interpret and understand our experiences; in general, it involves a search for meaning in life. For many people with PD, their beliefs are a central part of their identities, and inform their disease management, healthcare decision-making, and lifestyle. Prayer, meditation, and other spiritual or religious practices can also play a role in coping with challenges brought on by PD.

Unantenne et al. (2013) propose that spirituality and religion can encourage personal responsibility for one's health and wellbeing, provide social connections and support networks, and promote feelings of hopefulness.

### *Practical*

Parkinson's can impact much more than your health, like your finances, housing, relationships, career, and family planning. A palliative approach to care ensures that you have access to resources to help you maximize your quality of life in all areas that PD may affect. Parkinson Society BC has a wide variety of educational tools available to help you find the practical support you need. Visit our website at [www.parkinson.bc.ca/resources](http://www.parkinson.bc.ca/resources) to view our full collection of resources.

### *Additional Resources*

Talking to Doctors | [www.bit.ly/paceframework](http://www.bit.ly/paceframework)  
Advance Care Planning | [www.bit.ly/pdadvancecareplan](http://www.bit.ly/pdadvancecareplan)  
Symptom Tracker | [www.bit.ly/careplanchecklist](http://www.bit.ly/careplanchecklist)

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# PARKINSON SUPERWALK®

This year, Parkinson SuperWalk in British Columbia celebrated its 31<sup>st</sup> anniversary. Despite the challenging circumstances, your incredible support has helped raise \$292,205 – *and counting!* These funds directly support Parkinson Society BC's mission to empower people with Parkinson's by providing resources and services to enable self-management, self-reliance, and self-advocacy. Thank you to everyone who participated, donated, and volunteered this year. Your resiliency, particularly in these uncertain times, demonstrates your unwavering commitment to the cause.

Total: **\$292,205**  
*...AND COUNTING!*





## TOP TEAMS

### BC Teams (Raised \$1,000+)

A&W Cruisers, Century House Parkinson's Group, Doug's Crew, Elliott Walkers, Evergreen, **Good Vibrations (Top Fundraising Team in BC)**, Hope, Marla's Motivators, ParKrahn, Pop's Posse, Remembering The Dude, Rock 'n' Mama and the Followers, Rock Steady Boxing, Schroeder family, Shake Señora, Shake, Rattle & Roll, Shakyvanguy, Shrimp, Stan the Man, Stir It Up, Team Chapow, Team Elizabeth, Team Gran, Team Hennebery, Team Janet, Team McDonnell, Team Mojo, Team PD Avengers Vancouver, Team Val, The Taylor Family, Victor's Striders

### THANK YOU TO OUR MEDIA SPONSORS



All results have been alphabetically sorted by category, then name. For a list of monetary totals, please visit [www.parkinson.bc.ca/sw-totals](http://www.parkinson.bc.ca/sw-totals).

We endeavour to provide accurate listings using the information available at the time of publishing. If there is information you are aware of that has been overlooked, please contact us.

## TOP INDIVIDUALS

### SuperStar Superb Walkers (Raised \$5,000+)

Terry Gorsuch, Deborah Hartley, Elizabeth Holroyd, Charlotte Kennedy, Carolyn Krahn, Eva Moser, Wendy Murray, Jane Osterloh, Holly Parrish, Janet Stuehmer, Valerie Swannell, **Garry Toop (Top Fundraising Individual in BC)**, Colleen Vollan, Jim and Deb Yeates

### SuperStar Supreme Walkers (Raised \$2,500 - \$4,999)

Elspeth Banerd, Jack Blachford, Rheanna Corpuz, Edith Elliott, Margaret Elson, Ruth Konrad, John Manuel, Margaret Mutch, Sally Pollock, Nancy Pow, Shelley Schreyer, Allen Sundvall, Bryan White

### SuperStar Walkers (Raised \$1,000 - \$2,499)

Stella Atkins, Peter Baigent, Wayne Benning, Barry Bowen, Sylvia Bull, Dolores Bzdel, Peter Chappell, Paula Clarke, Linda Dawson, Richard English, Nigel Fitzpatrick, Jean Flintoft, Larry Gifford, Rebecca Gifford, John Hallam, Don Henderson, Margaux Hennebery, Janice Hobbs, Angela Hutchinson, Lauren Jenkins, Jerry Joseph, Philip Konrad, Deborah Lang, Zachery Longboy, Kathleen Lynn, Leanne Mah, Richard Maki, Barry McBride, Wray McDonnell, Marla Neufeld, Harry Oda, Wendy Olinger, Renny Olthuis, Chris Parrish, Clifford Roulston, Patricia Rupper, Emma Scales, Sophie Schreder, Gary Schroeder, Karla Seaward, James Stevenson, James Taylor, Kim Van Haren, Courtney Vasquez, Todd Wallace, Laura Wilson

# THANK YOU, BRITISH COLUMBIA!

## ADVOCACY UPDATE

### Discrimination and healthcare issues affecting people with advanced Parkinson's

Parkinson's disease (PD) is difficult to predict, and its progression can be a vastly different journey for each person with the disease.

Each stage of Parkinson's requires a different type of care. During early stages, people with PD can receive treatment from a general neurologist, and self-manage with oral medications and exercise. As the disease progresses, many healthcare professionals will also refer their patients with PD to allied healthcare professionals (AHCPs) including physiotherapists, occupational therapists, speech-language pathologists, counsellors, and social workers, depending on their needs. In advanced stages, many people with PD will lose their independence in some aspects of life, and require additional support from their carepartners, or home and community care workers.

Symptom management in the later stages of Parkinson's can be challenging without specialized care and multi-drug regimens. Sometimes, device-aided therapies like Duodopa® (levodopa-carbidopa intestinal gel) or Deep Brain Stimulation (DBS) are also necessary for people with PD to maintain their quality of life.

Standard PD treatments, including levodopa drug therapy, exercise, and AHCP services, are not always enough to manage severe motor and non-motor symptoms. Due to the inaccessibility of many advanced therapies, people with PD across the province are forced to endure debilitating symptoms with little or no means of managing them.

#### *Discrimination against people with Parkinson's*

When not treated effectively, PD can manifest itself similarly to other conditions or circumstances that can cause others alarm or confusion. Unfortunately, in tense situations, misunderstandings can cause undue stress, exacerbating Parkinson's symptoms. Conflict arising from such misunderstandings can

escalate quickly, as people with PD – regardless of their stage of disease progression – will often find it difficult to communicate clearly when under pressure. This is particularly the case when communicating with those who may be prejudiced against them. A person with PD facing the accusation of being drunk, for example, may become more dyskinetic and anxious, making it difficult to speak clearly, and making them appear aggressive to their accuser. In severe cases, people with PD have even had the police called.

The Society works tirelessly to expand the public's understanding of PD, increase access to AHCPs, and empower our community with the resources and tools they need to self-advocate, and self-manage their symptoms. However, in response to the staggering rates of violence against persons with disabilities in Canada\*, it is crucial to advocate for the safety of our community directly to policymakers, agents, and officers responsible for protecting it.

We invite you to add your voice to call on local authorities to better educate law enforcement about Parkinson's disease, and enact policies to protect against discrimination, violence, and unjust charges. Write a letter to your local police force or RCMP detachment using the template provided, and join us in promoting a more compassionate and disability-informed approach to law enforcement in BC.

To find your local police or RCMP detachment, visit [www.bit.ly/bcpolice](http://www.bit.ly/bcpolice).

### FREE-OF-CHARGE LEGAL AID

The law firms of Blake, Cassels & Graydon LLP and Hayman Faith E. Law offer free legal services to members of Parkinson Society BC, for issues such as discrimination, denial of services, and denial of disability insurance.

For more information, please contact Jean Blake, CEO, at [jblake@parkinson.bc.ca](mailto:jblake@parkinson.bc.ca).

*\* The rates of violence against persons with disabilities are nearly three times higher than those without (Cotter, 2021). In 2018, criminal incidents involving victims with disabilities were reported more likely to be violent (69% of cases) than not (Moreau, 2019).*

To Whom It May Concern,

Across the province, there are nearly 15,000 people living with Parkinson's disease (PD), a chronic and degenerative neurological disorder with no currently known cure. Symptoms can include slurred, quiet speech; severe tremors, rigidity, slowness of movement, and dyskinesia; and a frozen, mask-like facial expression sometimes misunderstood for anger, fear, contempt, or apathy.

An individual experiencing severe PD symptoms – such as during “off” periods between regular medication doses – can be mistaken as being intoxicated, aggressive, or in crisis, by those unfamiliar with Parkinson's, and experience discrimination as a result.

Over the years, our community has been shaken by stories from people with Parkinson's around the world who have been unjustly detained by law enforcement officers responding to conflicts arising from discrimination. Even in British Columbia, these cases are not infrequent. Until there is adequate public awareness of Parkinson's disease, and other chronic conditions and disabilities, individuals will likely continue to call 9-1-1 to ease tensions that may be better addressed by social workers, carepartners, or informed peers.

Below is a list of actionable policy proposals, as recommended by Parkinson Society British Columbia, that would improve crisis response procedures involving people with PD and other disabilities, who are vulnerable to bias and discrimination:

- examining and addressing root causes of police interacting with people with Parkinson's and other disabilities, rather than continually addressing the symptoms of the problem
- facilitating a change of organizational attitudes surrounding Parkinson's disease and other disabilities through ongoing education, training, and accountability measures
- ensuring that police interactions involving people with Parkinson's reflect sensitivity to issues affecting the PD community
- establishing productive relationships between local police or RCMP detachments and the healthcare system, advocacy groups, and organizations like Parkinson Society BC
- publicly communicating and demonstrating a culture of compassion, inclusion, and equity within police and RCMP forces
- establishing documentation and measurement procedures to improve research, transparency, and accountability

If implemented, these policies would begin to address the deep-rooted biases that continually put people with Parkinson's at risk of undue persecution. With incidence of the disease expected to double by 2040, the safety of British Columbians with PD must be secured today.

For more information about Parkinson's disease in British Columbia, please visit [www.parkinson.bc.ca](http://www.parkinson.bc.ca) or call 1-800-668-3330.

Thank you for your time and consideration.

CONTINUED ON NEXT PAGE...



*On World Parkinson's Day, April 11, 2019, we hosted a luncheon with BC policymakers, featuring presentations on our advocacy efforts to increase access to advanced therapies across the province.*

### **Advanced therapies**

The Society aims to be an effective lobbyist for issues affecting the entire PD community. Unfortunately, those at greatest risk of complications arising from Parkinson's continue to be those in advanced stages of the disease – many of whom, despite severe symptoms and profound disability, still struggle to access the same basic services that remain so largely inaccessible to the entire PD community. Advanced therapies are even more difficult to access than other specialized services, due to limitations in our provincial healthcare system.

This year, we celebrated a number of significant victories towards our advocacy goals, and we anticipate many new achievements on the horizon. However, there remains much to be done to ensure the best possible quality of life for all people with PD, and particularly those in advanced stages of disease progression.

With the grassroots support of our community, we will continue to champion the right of all British Columbians touched by Parkinson's to access the services they need.

### **Deep Brain Stimulation**

DBS is a surgical procedure involving the insertion of an electrode device into the brain, connected by wire to a pacemaker which sits under the skin, usually in the chest. When turned on, electrical pulses are produced by the pacemaker and sent to the tip of the electrode, causing brain cells in the region to "turn off," which then reduces motor symptoms caused by these same cells.

There remains only one neurosurgeon, Dr. Christopher Honey in Vancouver, qualified to perform Deep Brain Stimulation surgery in British Columbia. In 2019, the Ministry of Health announced it would be doubling Dr. Honey's operating room time, allowing for 72 procedures to be performed annually. While this has greatly reduced wait times for those approved to receive DBS, the waitlist for those who have yet to be assessed for their eligibility continues to grow.

Two years ago, along with their announcement to increase the number of surgeries performed, the Ministry of Health also committed to hiring an additional qualified neurosurgeon. Their promise has yet to be fulfilled. We ask our network of advocacy volunteers to continue to write their provincial elected officials to honor this important commitment.

## Duodopa®

At the end of 2020, the Ministry of Health announced it would be lifting the yearly limit on the number of British Columbians who can receive Duodopa® therapy. Previously, BC PharmaCare only covered five individuals per year for this therapy, resulting in a two-year waitlist for Parkinson's patients experiencing debilitating symptoms.

Duodopa® is used to treat patients with advanced Parkinson's who have severe and disabling motor symptoms that cannot be well controlled with available combinations of medications. It is a levodopa and carbidopa drug combination delivered in the form of a gel through an intestinal pump.

Prior to February 2017, the therapy was not covered by BC PharmaCare, and cost approximately \$60,000 per year, out-of-pocket. In February 2017, recognizing the opportunity for the BC Government to minimize or avoid costs for home care, emergency services, hospitalization, and/or long-term care, it was announced that the treatment would be covered for a limited number of patients identified and prioritized through the Pacific Parkinson's Research Centre. British Columbia was the only province that capped the number of Duodopa® patients annually. This cap created great hardship for the few patients anxiously waiting their turn, who were experiencing symptoms including excruciating pain, sudden falls, as well as difficulty breathing, swallowing, and/or speaking.

We are grateful to the Ministry for this monumental decision, which will improve the lives of so many people with advanced Parkinson's across BC. As we look forward to the years ahead, we hope to see Duodopa® become even more accessible, particularly by hiring and training more healthcare professionals to offer the treatment in clinics all around the province.

## Apomorphine

Like DBS and Duodopa®, apomorphine is a treatment option available to those who cannot manage their motor symptoms with levodopa and dopamine agonists alone. Depending on the formulation, it can be administered as an injection or a film dissolved under the tongue. As of late November 2019, apomorphine hydrochloride injections, sold under the name Movapo, have been made available as a part of BC PharmaCare's Limited Drug Coverage Program under Special Authority.

Special Authority grants coverage to a drug, medical supply, or medical device that otherwise would not be eligible for full coverage. Limited coverage drugs are not generally considered to be first-line therapies, or there may be more cost-effective alternatives available.

To be eligible for coverage of drugs like apomorphine, the patient must meet criteria pre-defined by PharmaCare, including evaluation by a neurologist, and exhaustion of all other appropriate medication or therapy options. Because of the chronic and degenerative nature of PD, any barriers to timely treatment – even in the form of additional paperwork and assessments – can cause undue stress on the healthcare system, and have life-altering effects on the patient.

Access to appropriate medications helps people with PD stay independent for longer, and retain more of their strength, mobility, speech, and cognitive abilities. Without effective treatment, Parkinson's can bring severe complications, such as falls and injuries, reduced communication, increased risk of choking, and prolonged hospitalization or confinement to bed. We hope to see BC Pharmacare continue granting coverage and Special Authority to more Parkinson's-specific medications, and expanding access to timely and effective drug therapies overall.

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# NEWSWORTHY

## UPCOMING EVENTS

### *Virtual Open House*

Meet some of our Education & Support Services staff and learn about what we do, as well as how to connect and be involved with our Society!

The Open House will showcase membership benefits, educational resources, support services, programs, exercise classes, events, volunteer opportunities, and more! The event will also feature a website navigation demonstration, as well as a question and answer period.

Date: Tuesday, November 30  
Time: 2:00pm – 3:00pm PT  
Cost: Free

### *SongShine with Joani*

Joani Bye will engage participants in three uplifting series of SongShine, a program using singing, breath work, diction, articulation, and imagination exercises to strengthen voices affected by Parkinson's. SongShine's goal is to help you communicate more easily and clearly, while facilitating a sense of community, camaraderie, and confidence in the process!

Dates: Thursdays, November 4 – December 16  
Thursdays, February 3 – March 10, 2022  
Thursdays, March 17 – April 21, 2022  
Time: 10:00am – 11:00am PT  
Cost: Free

### *Dance the Holidays*

Enjoy dancing through the winter with holiday music and movement that will inspire, guide, and organize the body-mind connection to create a joyful practice of mobility, balance, coordination, and imaginative playfulness. Join Megan Walker Straight in exploring and expanding the physical and expressive landscape of movement and gesture. No dance experience required.

Dates: Thursdays, November 18 – December 16  
Time: 2:30pm – 3:30pm PT  
Cost: Free

### *PD Warrior 10 Week Challenge*

PD Warrior is a Parkinson's-specific exercise program based on the principle of neuroplasticity and is designed to help you live better. The 10 Week Challenge is a moderate- to high-intensity exercise program suitable for those who are able to walk independently with or without a walking aid, as well as follow verbal and visual instructions. The program will use a variety of physical and cognitive activities to challenge your stamina, strength, balance, and dual-tasking abilities. For details, visit [www.pdwarrior.com](http://www.pdwarrior.com).

The 10 Week Challenge requires participants to complete two individualized exercises daily, and partake in a weekly group exercise class.

To register, an initial consultation session with Shelly Yu, physiotherapist, is necessary to determine eligibility and safety, as well as to obtain an individualized exercise program to complement the weekly group class.

Please contact [syu@parkinson.bc.ca](mailto:syu@parkinson.bc.ca) or call 1-800-668-3330 ext. 232 for registration, available through December 22.

Dates: Tuesdays, January 4 – March 8  
Time: 1:00pm – 2:00pm PT  
Cost: Free

### *Parkinson's Pilates*

Join physiotherapist and Australian Physiotherapy and Pilates Institute trained instructor, Shelly Yu, for four weeks of morning Pilates! Pilates is low-impact, and can help improve mobility, posture, and balance, and reduce fall risk. This series will explore gentle yet challenging movements in both sitting and lying positions.

Dates: Thursdays, January 6 - 27, 2022  
Time: 11:30am – 12:30pm PT  
Cost: Free

### *Drumming for Parkinson's*

Doug Pickard joins us again in the new year for two six-week drumming classes! Express your feelings with easy-to-follow beats and rhythms, and add drumming to your toolbox of therapies and self-management strategies. No musical experience necessary.

Dates: Wednesdays, February 2 – March 9, 2022  
Wednesdays, March 16 – April 20, 2022  
Time: 2:00pm – 3:00pm PT  
Cost: Free

## Thank you to our fundraisers & donors!

### Grit Day

A huge thank you to everyone who participated in and donated to Grit Day this year, raising a total of \$64,535! Your dedication and resilience were absolutely inspiring! Thank you so much to Colin, Doug, Norm, and the entire Grit Day community for your incredible efforts in planning and executing this event. We can't wait to see you again next year!

### Full Throttle

The fifth annual Full Throttle motorcycle and car ride raised \$16,415! The group took a scenic drive along the Sea to Sky Highway on May 30, travelling from Vancouver to Whistler. Thank you to Jim Smerdon and his family for continuing to host such a wonderful event.

### Additional thanks to...

- the UBC PATHS (Parkinson's & Alzheimer's Targeted Hope & Support) club, for raising over \$380 this summer!

TO VIEW OUR FULL EDUCATION EVENT LISTINGS & REGISTER ONLINE, VISIT [WWW.PARKINSON.BC.CA/EVENTS](http://WWW.PARKINSON.BC.CA/EVENTS)

## Community Needs Survey

Visit [www.parkinson.bc.ca/communitysurvey](http://www.parkinson.bc.ca/communitysurvey) to provide your feedback, and help guide the planning of Parkinson Society British Columbia's future programs, services, events, and advocacy priorities.



## ASK THE EXPERT: PAIN CONTINUED

muscles, ligaments, and joints (ie., procedures using continuous x-rays and other "video" imagery to study moving body parts). Private-pay therapies include infusion therapy for depression or nerve pain and Botox for headaches, as well as prolotherapy (targeted injection treatment) or regenerative therapies for joint problems. Extended healthcare, WorkSafeBC, and/or ICBC may cover other therapies, including physiotherapy, kinesiology, somatic therapy, psychology, chiropractic treatment, and pain coaching.

### Additional Resources

CHANGEpain | [www.changepain.ca](http://www.changepain.ca)  
Pain in PD | Video | [www.bit.ly/painandpd](http://www.bit.ly/painandpd)  
Symptom Tracker | [www.bit.ly/careplanchecklist](http://www.bit.ly/careplanchecklist)

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# RESEARCH

## Graduate Student Awards

Parkinson Society British Columbia is proud to support three new graduate student awards through the Parkinson Canada Research Program.

Each project will receive \$20,000 in funding from the Society through 2023. Read their summaries below.

### *Exploring the efficacy of the Effortful Swallow maneuver for improving swallowing safety and efficiency in people with Parkinson's disease*



*Pooja Gandhi, University Health Network*

Swallowing impairment, called dysphagia, is a common symptom of Parkinson's (PD), which can result in severe complications including aspiration pneumonia, malnutrition, and dehydration. Targeted interventions to prevent and treat dysphagia in PD are needed to reduce patients' risk of adverse outcomes. Exercise-based treatments have shown promise in improving swallowing efficiency and muscle strength. The Effortful Swallow maneuver is one commonly used exercise-based treatment for airway protection and dysphagia, but it has not been validated among patients with PD to date. This study will be the first to evaluate the Effortful Swallow maneuver as an intervention to prevent and treat swallowing impairment in patients with Parkinson disease, and to establish its feasibility for future studies and application in clinical practice.



### *Eye tracking as a source of behavioural biomarkers for Parkinson's disease*

*Heidi Riek, Queen's University*

A tool that could automatically detect Parkinson's, and determine how far one's symptoms have progressed, would greatly enhance doctors' ability to diagnose and treat the disease. Such a tool could be based on eye movements, because parts of the brain which control them overlap with those affected by

PD. In this study, two groups – one containing people with PD, and the other without – will complete three simple tasks, while researchers track their eye movements to determine how they differ based on the presence and duration of PD, genetic variants (participants' genetic samples will also be tested), or the presence of dementia. Researchers expect to see unique eye movement patterns related to each of these variables. These patterns would ultimately enable the development of a tool measuring eye movements and automatically comparing them to the PD eye movement patterns the findings produce. Observing how closely one's movements match the established PD patterns would enable the tool to determine the probability of them having PD, how far their symptoms have progressed, and whether dementia is present. In turn, this would help doctors more quickly and easily diagnose PD, and create more accurate and personalized care plans based on their patients' unique symptoms.



### *The relationship between Parkinson's severity and quality of life: the role of social functioning*

*Esztella Vezer, Ryerson University*

Although many people with Parkinson's disease (PD) experiencing severe symptoms also report poorer quality of life than those with milder symptoms, this is not always the case. This study aims to better understand the relationship between the symptom severity and quality of life. Specifically, it explores the influence of two factors – social support and social participation. Electronic questionnaires will assess the severity of respondents' symptoms, the level of social support they receive, and their engagement in social activities. Individuals with greater symptom severity, and higher levels of social support and participation, are predicted to report greater quality of life than those with lower levels of social support and participation. In other words, researchers predict these social factors may protect against the negative effects of symptom severity on quality of life. The findings of this study may help identify ways to improve quality of life in people with advanced PD symptoms, alongside treating the symptoms themselves. 🎨

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# 2022 AT A GLANCE

Parkinson Society British Columbia (PSBC) is pleased to announce our tentative education and support services plan for the upcoming year.

More details will be provided on our website as they become available. Schedule is subject to change.

## Upcoming Events

### Provincial Conference

- October (*tentative*)

### Webinars

- New Diagnosis Series: February
- Intimacy & Parkinson's: February
- Debriefing the Caregiver Role: December
- Virtual Open House: *quarterly, dates to be decided*

### Online Workshops

- Improv for Parkinson's: January/February
- SongShine with Joani: February & March/April
- Drumming for Parkinson's: February & March/April
- Gardening Group: March/April

### Online Exercise Classes

- PD Warrior 10 Week Challenge: January
- Parkinson's Pilates: January
- Dance for Parkinson's: February
- Hand & Dexterity Exercise: March
- April Challenger
- Seated Exercise: April/May
- Boxing for Parkinson's: *to be decided*
- Exercise for Balance: *to be decided*

### Symposium Webinar Series

- March, June, & September
- Global Symposium Series: April

**Information and Referrals:** Ongoing service is available by telephone or email. If we are unable to answer your questions or concerns immediately, we will research your inquiry and get back to you.

**Counselling:** We continue to offer free, confidential short-term counselling to people affected by Parkinson's. These services are available in person, over the phone, and via video conferencing. Due to increased demand, we extended the availability of this service from two days per week to four days per week.

**Support Groups:** We will continue to check in by phone and virtually with our support groups throughout the year, to maintain regular contact with group facilitators and ensure ongoing support; to write the GroupLink monthly publication; and to schedule facilitator webinars/teleconferences as needed. We will also continue to foster our support group needs and participation. We welcome all invitations to visit, however please connect with PSBC for updated details of each support group.

**Step by Step:** 12-week walking program in communities across British Columbia.

**PD Connect:** We will continue to increase awareness of PD Connect, a referral program intended to help healthcare professionals connect individuals diagnosed with Parkinson's disease and their carepartners to PSBC's support services at the time of diagnosis or at any point in the disease progression.

**PDLink:** We will continue with this peer program that connects persons living with Parkinson's and carepartners on a one to one basis for support. Individuals will be connected based on similar experiences. Connections are maintained through phone and email only.

### Healthcare Professional Scholarship Program:

- Continuing Education Scholarships (6 X \$1000.00)

**Online resources:** We will continue to produce up-to-date resources for people affected by Parkinson's, as well as healthcare professionals. In addition to making recordings of presentations available on our website and YouTube channel, we will distribute them through our publications, like Good News, GroupLink, and Pathways. 

# STAY CONNECTED TO THE PARKINSON'S COMMUNITY

It's that time of year again! Renew your membership with Parkinson Society British Columbia and continue to be part of our friendly, caring, and supportive community.

For only \$25, you will receive an annual membership for you and your household, valid until December 31, 2022. Reasons to renew your membership:

- **Get discounts.** Your membership provides you with great discounts on events that are not to be missed!
- **Stay informed.** Get the latest information on research, medication, caregiving, exercise, wellbeing, and nutrition when you receive our quarterly magazine, Viewpoints, and other publications.
- **Be heard.** Vote at our Annual General Meeting and add your voice to the community to garner support from donors, sponsors, and politicians.
- **Gain support.** Link to our provincial network of over 50 support groups, and speak with our knowledgeable and compassionate staff.

Get an annual membership for only

**\$25**

Questions? Call or email Susan Atkinson, Donor & Member Services Coordinator  
604-662-3240 ext. 263 | 1-800-668-3330 ext. 263 | [satkinson@parkinson.bc.ca](mailto:satkinson@parkinson.bc.ca)

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