

# VIEWPOINTS



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## SUMMER 2021

A QUARTERLY NEWSLETTER  
BY PARKINSON SOCIETY  
BRITISH COLUMBIA

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MINDFULNESS  
PRACTICE FOR  
CAREPARTNERS

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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 network of over 50 volunteer-led support groups provide people with Parkinson's, and their caregivers and families, an opportunity to meet in a friendly, supportive setting. For our full support group listings, visit [www.parkinson.bc.ca/groups](http://www.parkinson.bc.ca/groups).

100 Mile House, Abbotsford, Bereavement, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Duncan/Cowichan Valley, Gabriola Island, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, 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, West Vancouver Carepartners, White Rock, White Rock Carepartners, Williams Lake, 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.

## RESEARCH

### The gut microbiome in Parkinson's: species level resolution and function

Although Parkinson's disease kills brain cells that affect our ability to move and to reason, the trillions of micro-organisms living in our gastrointestinal tracts may be important contributors to the illness.

At the University of British Columbia and with her colleagues at the University of Calgary, Dr. Silke Appel-Cresswell, a neurologist and associate professor, uses high-resolution screening tools to study the bacteria in the guts of people with Parkinson's. This colony of bacteria, fungi, and viruses is known as the microbiota.

Appel-Cresswell is pinpointing the particular strains of bacteria driving inflammation or allowing too many toxic proteins to move from the gut to the brain.

If particular strains of bacteria cause inflammation, for example, it could trigger the body to mount a too-aggressive immune response. This could also lead to the accumulation of the protein alpha-synuclein, damaging brain cells, including those that produce dopamine. Lack of dopamine-producing cells causes the stiffness, tremors, and difficulty walking that characterize Parkinson's disease.

*"From the evidence we have so far, it really seems that the microbiota in people with Parkinson's are different from those in people who do not have Parkinson's."*

Certain strains of bacteria may also cause the gut wall to leak, enabling toxins to reach the blood and eventually the brain. A malfunctioning gut can also cause constipation, which leads to more inflammation and leaky gut.

"We're working on all those pieces of the puzzle to prove what is happening," Appel-Cresswell says.

Appel-Cresswell and her colleagues Dr. Davide Martino and Laura Sycuro in Calgary are analyzing fecal and blood samples donated from 300 people in Vancouver, and more than 100 others in Calgary.



#### PROJECT GRANT

\$50,000 over 1 year, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

#### RESEARCHER

Dr. Silke Appel-Cresswell

#### INSTITUTE

University of British Columbia

If she can confirm mechanisms that link gut bacteria and Parkinson's, her work could lead to treatment that attacks gut dysfunction, including constipation, early and aggressively to interrupt the vicious cycle. The research could also lead to recommended changes in diet and nutrition, including the use of probiotics. The role of nutrition in Parkinson's is a closely linked research interest for Appel-Cresswell.

A screening tool could also be developed to identify those at higher risk of the disease.

"The Holy Grail would be to look at people who might be at risk, test their fecal microbiome, and if they show changes that point in the same direction, intervene early, when there are mostly symptoms at the level of the gut and the brain isn't completely involved in the disease yet," Appel-Cresswell says.

Appel-Cresswell is also motivated in her work by her father's advanced-stage Alzheimer's.

"It's my personal mission to work on prevention of neurodegenerative diseases in general, especially with lifestyle interventions such as nutrition and exercise, given my family history and athletics background," she says.

*Reproduced with permission from Parkinson Canada.*

## ASK AN EXPERT

### Dr. Naaz Parmar discusses dementia in people with Parkinson's disease



**Dr. Naaz Parmar, MD**, is a geriatrician at Vancouver General Hospital, where she specializes in dementia, mobility, falls prevention, and polypharmacy. She is also a Clinical Assistant Professor at the University of British Columbia (UBC), and an attending for the UBC Geriatric Medicine Longitudinal Fellows Clinic. Her commitment to improving access

to geriatric care across the province led Dr. Parmar to founding the Pacific Geriatricians Group, which provides comprehensive care and assessment for patients across BC both virtually and in-person at their Vancouver clinic.

#### *What is the difference between Parkinson's disease dementia and other types of dementia, like Alzheimer's?*

Parkinson's disease dementia (PDD) differs from Alzheimer's disease (AD) in the changes that occur at the level of the brain cells. Parkinson's dementia is associated with changes called Lewy bodies or Pick bodies, whereas Alzheimer's results from tau protein plaques. PDD is caused by the same changes in the brain that cause motor symptoms (namely the decrease in dopamine), and as such, the memory changes in PDD follow a timeline associated with the motor changes in Parkinson's. Usually, PDD presents with changes in walking (gait) and fine motor tasks first. Over several years, memory changes then begin, usually affecting language (naming of people or objects) and executive function (being able to do complex or multi-step tasks). Alzheimer's presents with short-term memory problems first, and changes in mobility happen in later stages of the disease.

#### *What are some warning signs of cognitive decline and dementia?*

One early warning sign is losing track of time; for

example, this may mean missing an important appointment or forgetting to pay bills on time, when this was not an issue previously. Other common changes include repeating questions or telling the same story over and over again, thinking that these things haven't been said before. Losing an ability that you had before, such as using the remote to turn on the TV correctly or operating the microwave correctly, are other examples.

#### *What should people with Parkinson's and their caregivers do if they notice signs of cognitive decline? What is the process for getting diagnosed with dementia?*

If you have concerns about memory change, even if you are not sure if they are minor or something else, it's important to bring them up with your doctor. Early assessment means we can rule out other causes, such as depression or medical issues (like low Vitamin B12) quickly, before they cause long-term damage. Early treatment for dementia is also important to slow progression of the disease.

When discussing memory changes with your doctor, they will begin with some questions about your memory changes, and may do a short memory test. Your family doctor can then refer you on to a specialist for formal diagnosis and follow-up. This may be a specialist in Geriatric Medicine (Geriatrician) or a Geriatric Psychiatrist. In BC, there are specialists in these fields across many communities, and if there are none in your area, memory assessment can also easily be done via telephone or video conference through organizations like the Pacific Geriatricians Group.

#### *What are some ways that people with Parkinson's can maintain and improve their cognitive health, and avoid cognitive decline? How can their caregivers support them?*

The most important and effective way to minimize or avoid memory changes is to stay active. Both physical and mental activity help to protect the brain. Cardiovascular activity, such as walking, swimming, or stationary bikes, is an excellent form of exercise to prevent heart disease and promote brain health. A target of 150 minutes of cardiovascular activity a week is suggested. It is important to note that you do not have to be doing vigorous exercise – just doing



*Early diagnosis and treatment is important to slow the progression of dementia.*

extra physical movement outside of your regular routine is enough to be helpful. I should also point out that daily chores, like walking up and down the stairs with the laundry, or yard work, do not count as exercise. Exercise has to be extra movement.

Staying mentally stimulated with hobbies or daily tasks is also important. Even if you are having early trouble with your memory, try to keep track of your own calendar or shopping list. The old cliché, “if you don’t use it, you lose it,” is true for memory as well. Reading, followed by discussing what you’ve read, is a great way to challenge your memory. Hobbies that can help with memory include card games, crosswords, artwork, crafting, singing, knitting, sewing, and other activities that require a great focus of attention. It’s not helpful to force yourself to start new things, however, as this can cause additional stress. If you previously enjoyed a hobby, make it a priority now, but don’t try to pick up new ones that could cause anxiety.

### ***What treatments and therapies are available to people with dementia?***

Dementia currently does not have any cure, but we do have strategies to slow the progression. The foundation of treatment is what we call non-pharmacological, or lifestyle changes. This would be the same as the preventative measures of regular cardiovascular activity and mentally-stimulating activities. Optimizing other risk factors

such as cholesterol, blood sugars, and blood pressure are a focus as well.

There are medications specifically targeted for dementia called cholinesterase inhibitors. The first line of these in BC is donepezil. The role of these medications is to slow the progression of the symptoms of dementia. This helps people maintain their independence for longer, and stay in their own home for, hopefully, the rest of their life. The decision to start these medications is based upon the results of memory testing

and other medical issues that a person may have, and your specialist can discuss whether they are an appropriate option for you.

### ***Dementia is highly stigmatized. What is your message to those who may be frightened or worried about experiencing cognitive changes?***

Dementia does have a heavy cloud around it in popular culture, and in our society in general. The true meaning of the word, however, is simply memory change. Dementia does not necessarily mean that a person will lose who they are, change in personality, or become completely dependent on others. It does not mean that a person is destined for a nursing home either.

Similarly to how diabetes and heart disease had very negative connotations in the past, but are now managed as common diseases with good outcomes, dementia is also changing. We now have better understanding of dementia, and can work towards slowing its progress. We have better ways to provide dignified care for those with memory changes, and much research is being done on potential cures. Over 11% of Canadians are currently living with dementia, and that number is increasing with our aging population. We understand it better than in years past, and as such, the prognosis of dementia is not a dire one any longer. There is much we can do, and there are many supports available, so it is important to seek out assessment and treatment from your doctor if you have any concerns.

# LIVING WELL

## Journaling for Parkinson's

To maintain mental wellness, it is important to take time to pause and reflect on different situations, struggles, and joys present in your life. Looking inward and reflecting on your experiences can help you better understand your thoughts and feelings. By clarifying your emotions through self-reflection, you can grow more self-aware and better equipped to cope with feeling stressed, worried, or overwhelmed.

Journaling has been found to reduce intrusive thoughts, freeing up cognitive capacity for things like memory and coping with negative emotions (Carpenter, 2001). Journaling is a powerful means of self-reflection because it allows you to externalize thoughts and feelings that may be too personal to share with others. It also gives you an option to track your changing perspectives over time, simply by returning to old entries; many people find it motivating to record their personal growth.

A journal can also be a tool for self-care. Writing things down has long been understood as an effective way to remember – the simple process of externalizing a thought and putting it in motion by writing, drawing, or typing, can strengthen memory. With this in mind, journaling can be a great way to remind yourself of what you're grateful for, things that make you happy, and positive affirmations that help you feel empowered.

### Getting started

While you may feel hesitant or nervous about journaling, remember that you do not need to be a good writer to journal. A journal can be anything you want it to be – a general description of your day, emotions you experience, one-word reflections or observations, or sketches and doodles. The most important thing is that it provides a private outlet for self-expression.

To help you stay on track, make journaling easy by using the medium that best works for you. Whether you prefer sketchbooks, computer documents, index cards, or voice recordings, there is no 'right' way to journal.

When you journal, your main goal is to honestly and candidly express what you're thinking and how you're feeling. You can stop there, or you may wish to delve deeper and reflect more thoroughly. You might consider some of the following questions (Bennett, 2019):

- How long have I been feeling this way?
- Where did this feeling come from?
- What belief formed this thought or feeling?
- Have experiences in my past triggered similar feelings? How did I overcome or manage them?
- Am I being too hard on myself? Can I use more empowering language?

If you are looking to practice journaling as a means of self-care, expressing the things you are grateful for is a good place to start. No matter how small the positive experience, focusing on the good things in life can help inspire more joy and motivation.

People with Parkinson's and carepartners alike can greatly benefit from gratitude journaling as a means of coping with life with Parkinson's, and the changes it brings. Living with the disease, or caring for someone who does, can be overwhelming; journaling can help bring life back into perspective, and remind you that Parkinson's disease does not define you.

Try using some of the following prompts while gratitude journaling (Therapist Aid, 2017):

- "The best part about today was..."
- "Three good things that happened today were..."
- "Today I smiled when..."
- "Something I can be proud of is..."
- "A reason to look forward to the future is..."
- "Something about today I'll always want to remember is..."

### Tracking exercise, goals, and accomplishments

Journaling can be used to track exercise, goals, and accomplishments. Before you begin a new exercise or habit, create a journal entry that expresses your reasons for engaging in that new activity. Written or visual representation of your motivation and progress will show how far you have come, and help keep you on track. Don't forget to celebrate your successes and milestones!

You can also apply the SMART system to your journal entries to help you set clear, attainable goals –

SMART stands for specific, measurable, achievable, relevant, and timely. While these five elements can be adapted to meet your specific needs, following these general principals can help avoid vague or unrealistic goal setting and instead lead to a focused, measurable path forward.

### **Journaling & Parkinson's disease management**

Beyond the general mental and physical health benefits of journaling, people with Parkinson's and their carepartners can also journal to track PD-specific matters. For example, keeping a food diary may help identify dietary changes that could improve non-motor symptoms, such as constipation. Recording medications and upcoming appointments may help you stay organized and ready to effectively communicate with your healthcare team.

If you are a support group member, try taking your journal with you to note anything that stands out in your meetings. You may hear an important piece of advice, or an uplifting story that you won't want to forget. After meetings, you can revisit your entries to reflect on how you feel, what you learned, and questions you would like to ask your peers or facilitators next time.

Another journaling tool that may be useful is Parkinson Society BC's Comprehensive Care Plan Checklist – this resource can help you pinpoint existing symptoms you may have under control and/or new symptoms you would like to address. Completing this checklist before beginning a new medication, treatment, or exercise regime, and then revisiting it several months later, can help you and your healthcare team assess improvements and tailor your care plan to best meet your needs. Download yours at <http://bit.ly/pdsymptomchecklist>.

### **Additional resources**

Self-Care for Parkinson's Caregivers  
Part 1 | Video | <https://youtu.be/Pza6mNwpSb8>  
Part 2 | Video | <https://youtu.be/cIQOenZBh30>

Self-Management as Self-Care | John Murphy  
Video | <https://youtu.be/DwwNUdANMKE>

Self-Care for Parkinson's Carepartners & Managing Non-Motor Symptoms | Kaitlyn Roland, PhD  
Presentation Slides | <http://bit.ly/TOFCselfcare>

Gratitude Journal Worksheet | Therapist Aid  
<http://bit.ly/gratitudejournalworksheet>

## **SMART GOAL SETTING**

### **S – Specific**

Goals should be clear and precise, including who, what, when, where, and why.

*"I will go on a walk to the park with my friend three times this week to ensure I stay active and healthy."*

### **M – Measurable**

The ability to track goals will help you stay on track and disciplined.

*"I will increase my weight-lifting by two pounds."*

### **A – Achievable**

Goals should be realistic and attainable, while pushing your abilities.

*"I will learn to use a new program on the computer."*

### **R – Relevant**

Ensure your goals are aligned with where you are in life, and with other goals.

*"I will eat the recommended daily serving of vegetables to support my health."*

### **T – Timely**

Establish a target completion date, and set time aside to work on goals.

*"I will walk three times a week, and be able to walk 5km at a steady pace by the end of the month."*

### **Sources**

Bennett, T. (2019). *How Can Journaling Help Me? Tips for Keeping a Self-Care Journal*. Thriveworks. Retrieved from [www.thriveworks.com/blog/journaling-tips-keeping-self-care-journal](http://www.thriveworks.com/blog/journaling-tips-keeping-self-care-journal)

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CHAR RICHARDSON AND FAMILY, LANGLEY  
WONG FAMILY CELEBRATES PARKINSON SUPERWALK



## Our Mission

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

## What is Parkinson's Disease?

Parkinson's disease is caused by a loss of dopamine in the brain and is the second most common chronic neurodegenerative disorder after Alzheimer's disease. Both motor and non-motor symptoms may be experienced, such as tremor, rigidity, slowness of movement, difficulty with speech, sleep disturbance, and mood disorders. There is currently no known cure.

It is estimated that there are approximately 13,000 individuals living with Parkinson's in British Columbia. Experts predict that the incidence of Parkinson's will double by 2040. While the vast majority of people with Parkinson's are over 60, 20% are diagnosed before the age of 50, and many are in their 30s and 40s.



# PARKINSON SUPERWALK®

## Save the Date!

Parkinson SuperWalk will return to British Columbia the weekend of September 11 & 12, 2021.

For more information and to register, visit: [www.parkinson.bc.ca/superwalk](http://www.parkinson.bc.ca/superwalk)



Parkinson Society  
British Columbia

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### MARTIN MCKEOWN

Medical Advisor

# Executive Message

The past year has presented us with challenges that no one could have predicted. With the onset of the COVID-19 public health crisis in early 2020, we were confronted with an immediate need to pivot our operations in order to continue serving the Parkinson's community. We are proud of what we were able to achieve in the last year – both as a community and internally as staff.

## Progress was made to further empower BC's Parkinson's community in the following ways:

- successfully moving our programs and events online – including increasing exercise, activities, and education – to combat isolation, and keep people active and engaged while at home
- engaging those without computers or internet through mailouts and phone calls
- assisting many of our 47 support groups to begin meeting online, via Zoom
- improving access to Duodopa® therapy by lifting the annual limit on procedures (previously 5) from BC PharmaCare's Special Authority listing
- hosting major events virtually, including our provincial conference, Parkinson SuperWalk, and AGM
- providing training in Motivational Interviewing for healthcare professionals to assist in their care of people with Parkinson's disease
- expanding team-based care in movement disorder clinics by funding a full-time speech pathologist in Victoria, and part-time speech pathologist, physiotherapist, and social worker in Kelowna. These are five-year commitments, with local health authorities taking over funding after five years
- continuing to fund leading-edge research through both Parkinson Canada and the Michael Smith Foundation for Health Research

Despite these challenging times, your support of Parkinson Society BC has remained steadfast. We thank you for your donations, volunteer hours, sharing of stories, and feedback on our operations. We are deeply grateful.

Signed,



Jean Blake CEO  
*Jean Blake*



Andrew Davenport CHAIR  
*Andrew Davenport*

# Message from Finance Committee

The Statement of Financial Position for the year ended December 31, 2020 presents very healthy working capital with current assets significantly exceeding current liabilities. Parkinson Society BC was the fortunate recipient of two unanticipated gifts. We received a very large bequest in 2020 of ~\$1.7 million from the late Elizabeth Fast, and a very significant donation of \$500,000 from the Fraternal Order of the Eagles Aerie #2075. The Society's investment portfolio now has a market value of \$3,849,230 (2019 \$1,666,462) and continues to generate modest returns.

Overall, the 2020 Statement of Revenue and Expenses presents an excess of revenue over expenses of \$2,255,616 compared to the 2020 budget that was approved with a planned deficit of \$374,439. Fundraising revenue, excluding bequests and the gift from the Eagles was \$962,806 and although down from \$1,120,351 in 2019, continues to be an important part of PSBC's financial well-being. We are grateful for the continued commitment and support of our event participants, volunteers, donors, and sponsors especially during this unprecedented time.

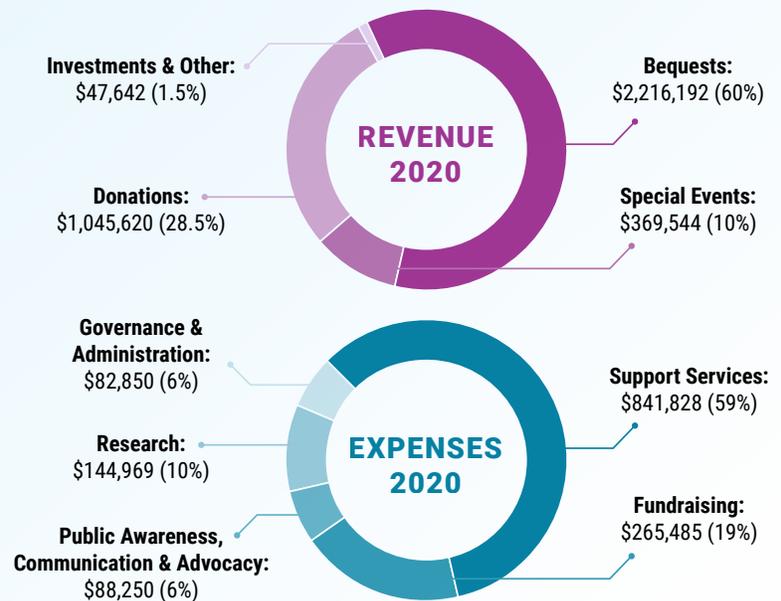
During 2020, the Board invested in an innovative approach to advocacy by providing incentive funding to two health authorities for provision of a team approach in the Victoria and Kelowna Movement Disorder Clinics. We invested \$500,000 over five years (2020–2024) in each of these health regions to improve care. A similar proposal is being discussed for 2021 with Vancouver Coastal for the Movement Disorder Clinic at UBC.

As well, we have already committed to investing a minimum of \$354,241 in research from 2021 through 2023, in addition to \$144,969 in 2020. While we continue to fund research through the Parkinson Canada Research Program, we also partner with the Michael Smith Foundation for Health Research (MSFHR), which matches our research contributions.

The Society enters 2021 with reserves equal to 26 months of its historical expenses, which provides the Board with further opportunity to actualize our strategic priorities. The Board continues to review opportunities to further increase the Society's impact and reach throughout BC.

## Our Picture of Financial Accountability

To view a copy of our audited 2020 Financial Statements, visit [www.parkinson.bc.ca](http://www.parkinson.bc.ca)



# Our Year in Review



85

referrals from healthcare professionals through our PD Connect program



350

attendees at our virtual provincial conference, Moving Forward, Together



186

exercise, activity, and education webinars serving 4,635 participants\*



2,566

information and referral calls and emails



802

hours of counselling

100

new counselling clients



147

in-depth consultations

\$301,275

raised across 26 communities from Parkinson SuperWalk in BC



\$2,286,191

given from the estates of six individuals

Thank you to our volunteers who assist with the Society's programs, services, advocacy, and fundraising.

\*Total webinars including those that were part of a series.



Doug, Norm, and Colin Plumb with loved ones at White Pine Beach for Grit Day



Jim Smerdon leads the 4th annual Full Throttle ride to Whistler



Parkinson Society British Columbia CEO, Jean Blake (left), and Board Director, John Hougan (right), accept cheque from Donald Chunn (middle) on behalf of the Fraternal Order of Eagles Aerie #2075

 Parkinson Society British Columbia  
 Date: June 5, 2020  
 Pay to the order of: Parkinson Society British Columbia  
 Amount: Five Hundred Thousand xx/100 \$500,000.00  
 Per: Fraternal Order of Eagles #2075  
Charitable Registration No. 11880 1240 RR0001



A&W Cruisers participating in Parkinson SuperWalk



Sally Pollock (right) with her team members for Parkinson SuperWalk in Lion's Bay

# Special Thanks to Our Supporters

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- CN Employees' and Pensioners' Community Fund
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- Kamloops Lodge No. 1552 Loyal Order of Moose
- Lee & Associates
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- Quiring Trucking and Gravel Sales Ltd.
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- Fraternal Order of Eagles Vancouver Aerie No. 2075

*Note: We strive to ensure that each name is appropriately listed and spelled. Please let us know if we have made an error so we may correctly recognize you in the future.*

## CAREPARTNER'S CORNER

### Mindfulness for carepartners

Mindfulness is a practice that is focused on being fully aware and present in the current moment. Traditionally a Buddhist practice, mindfulness has been implemented in a variety of disciplines due to its positive effects on mental health.

Mindfulness meditation encourages you to notice your thoughts as they drift through the mind. The intention is to pay attention to your thoughts without judging them. To simply be aware of each mental note as it arises. When you practice mindfulness, you become aware of how your thoughts, feelings, and behaviours tend to move in particular patterns. As humans, we are quick to label an experience as good or bad, etc. With practice, we hope to develop more awareness and a deeper balance within.

#### *What are the benefits of mindfulness for carepartners?*

Caregiving can be a very demanding responsibility, one that can be unexpected or misunderstood. Transitioning into a caring role may bring emotions like anger, worry, and sadness. The Parkinson's journey is made up of change and losses that often must be grieved. As a carepartner, it is important to ensure you are taking the time to process these changes so that you can maintain a positive, intimate relationship with your loved one.

Mindfulness can help carepartners acknowledge their emotions and maintain mental well-being so that they can provide the best possible care to their loved ones. Start small – even just 5 minutes of mindfulness practice a day can lead to more happiness, enthusiasm, and peace of mind (Dissanayaka et. al., 2016).

#### *How can I implement mindfulness into my daily life?*

You can practice mindfulness informally during daily tasks such as eating, drinking, folding laundry, or washing the dishes. Consider trying one of the following exercises to include mindfulness into your daily life:

- *The 5 Senses Exercise* – Notice 5 things you see, 4 things you hear, 3 things you smell, 2 things you touch, and 1 thing you taste (in any order). This practice is very grounding and orients you in your current space.
- *Mindful Walks* – Start by noticing how your body feels as you take each step. You can then use other senses to notice your surroundings, such as sounds, smells, and sights. Immersing yourself as you walk using all your senses is a fantastic and simple mindfulness practice that can be done individually or with another person.
- *Mindful Eating* – Notice the way a food looks, smells, feels, tastes, and even sounds as you eat it. This can be a simple yet effective way to slow down, be present, and enjoy the current moment.

Alternatively, you may consider trying a more formal practice of mindfulness, which involves focused meditation time with attention to your body and breath. Follow these tips to begin practicing mindfulness meditation (Therapist Aid, 2017):

- *Time & Place* – Make sure that you practice mindfulness meditation at a time and a place that is free from distraction and interruption. You will also want to be alert enough to stay awake as this is an active practice. Regular daily practice is most beneficial – even 5-10 minutes per day is a great start.
- *Position* – Assume a comfortable position and focus on relaxing all muscles in your body. If seated, place both soles of your feet on the ground. Let your arms fall naturally to your sides; your palms can rest on your thighs if seated, or by your side if laying down. If your pose becomes uncomfortable, feel free to readjust yourself as needed.
- *Breathing Awareness* – Breathing is an ever-present tool that you can use to help you focus on the moment. Start by noticing the sensation of your breath flowing in through your nose or mouth, filling air into your belly, and feeling your breath release as you exhale slowly. You can also notice the sound your breathing makes as you inhale and exhale.
- *Wandering Mind* – Your mind will likely wander during your mindfulness practice, but this is normal. Try not to engage in a constant battle between your thoughts and trying to stay focused. Rather, simply notice your thoughts without judgement, and gently bring your focus back to your breath.

CONTINUED ON PAGE 19...



# MOVING FORWARD *together*

Our provincial conference returns this fall! Featuring presentations from prominent Parkinson's specialists and researchers across North America, this year's *Moving Forward, Together* will be a fully virtual experience. Plenary speakers include:

**Dr. Silke Appel-Cresswell, MD, FRCPC**, is a movement disorder neurologist, Associate Professor of Neurology at the University of British Columbia, and a founding director of the BC Brain Wellness Program. She has a particular interest in the role of the gut microbiome in neurodegenerative disorders, with a goal of finding new approaches to treatment.

**Dr. Gary Leo, MD**, is a neurologist based in Wisconsin. He specializes in sleep wellness and Parkinson's, and has been in practice for more than 20 years. He sees patients at four different clinic locations in Milwaukee, focusing on holistic treatment plans that lead to a more fulfilling life.

**Dr. Suneil Kalia, MD, PhD, FRCSC**, is a scientist at Krembil Research Institute, a neurosurgeon specializing in deep brain stimulation, and an Assistant Professor of Neurosurgery at the University of Toronto. His research focuses on protein function and neurodegeneration in brain disorders, and his team is involved in developing new therapies designed to slow or halt the progression of Parkinson's.

**Dr. Lorraine Kalia, MD, PhD, FRCPC**, is an Associate Professor of Neurology and Clinician-Scientist at the University of Toronto, and a Senior Scientist at the Krembil Research Institute. Dr. Kalia's work focuses on Parkinson's disease and other related movement disorders. She heads a research team that is dedicated to identifying the process of neurodegeneration in Parkinson's and developing therapies that can target degeneration in brain disorders.

Stay tuned to [www.parkinson.bc.ca](http://www.parkinson.bc.ca) for more information coming soon!

# PARKINSON SUPERWALK®

At Parkinson Society British Columbia, we are inspired every day by the strength and resilience of our community. Together, we are united in our commitment to the advocacy, research, and fundraising efforts that are bringing us closer to a future without Parkinson's disease. We invite you to join us and champion the cause again this year for the 31<sup>st</sup> annual Parkinson SuperWalk.

We are adapting to the new normal this year by bringing you an engaging virtual SuperWalk experience, with walk weekend taking place September 11<sup>th</sup> and 12<sup>th</sup>. As we continue to practice physical distancing for the health and safety of our communities, the event will help us carry on providing the programs, support services, educational resources, and advocacy that people with Parkinson's, their families, and carepartners rely on.

Help us reach our fundraising goal by collecting donations online, then join us for SuperWalk's opening ceremonies, which will be held online, on Saturday, September 11<sup>th</sup> at 10:00am.

## *Who do you walk for?*

Undeterred by COVID-19, two SuperWalk participants, Jerry Joseph and Debbie Hartley, are prepared to gather their teammates once again to raise funds and awareness for Parkinson's this summer. Although in-person walks will not be hosted this year, Parkinson SuperWalk remains a vital cause close to the hearts of many British Columbians. We may not be able to see one another on walk day, but our community is committed to keeping ties strong.

This summer, join other walkers like Jerry and Debbie to celebrate and honour all those touched by Parkinson's across the province. Online registration is coming soon to [www.parkinson.bc.ca/superwalk](http://www.parkinson.bc.ca/superwalk).



## **SAVE THE DATE:**

## **PARKINSON SUPERWALK OPENING CEREMONIES**

**SATURDAY, SEPTEMBER 11<sup>TH</sup> AT 10:00AM**

# NO MATTER WHAT

## **Jerry Joseph**

*Team Hope, Prince George*

Jerry Joseph was working at a long-term care facility when he first heard of Parkinson SuperWalk. In 2018, a number of residents were participating in the Prince George walk, so Jerry decided to join them.

As a healthcare provider, and a family member of individuals with Parkinson's (PD), Jerry had seen firsthand the impact of the disease on those he cared about, and he wanted to be part of increasing public awareness. Jerry says he was honored to offer his support, and he enjoyed seeing the smiling faces of the care facility's residents during the event.

After attending SuperWalk in both 2018 and 2019, Jerry decided to take his involvement in SuperWalk a

step further by volunteering at the Prince George walk. But when the event went virtual last year due to the COVID-19 pandemic, he knew it would create some limitations in getting the message out to the public.

Last year, Jerry teamed up with his friend, Matthew, and created Team Hope. Together, they produced a short video championing the cause on social media, and highlighting the importance of exercise for people with PD.

Team Hope raised an impactful \$1,500, and demonstrated their commitment to empowering the Parkinson's community despite the unique circumstances surrounding the 2020 event.

## **Debbie Hartley**

*Good Vibrations, Kelowna*

Debbie Hartley first attended Parkinson SuperWalk in 2013. She had been diagnosed with Parkinson's disease earlier in the year, and reached out to ask some friends if they would join her at SuperWalk in the fall. At the time, Debbie says she truly had no idea the walk was such a big deal!

There were tents, balloons, and over a hundred people wearing bright t-shirts celebrating SuperWalk. The enthusiastic walkers were a diverse mix of families, children and grandchildren, caregivers, friends, doctors, support staff, volunteers, curious strangers, and of course, the Parkinson's crowd – all there to raise funds and awareness, and show support for one another.

Since her first walk, Debbie has become increasingly engaged with the Parkinson's community. She is a

member of the ladies-only Good Vibrations support group and SuperWalk team, which has played an especially important role in her journey with the disease. Over the years, the group has supported each other and participated in SuperWalk wearing red capes sewn by group member, Carole Taylor. Each year, the Good Vibrations team has been increasingly successful in exceeding their SuperWalk fundraising goals. And when they win prizes for their outstanding fundraising efforts, the group pays it forward by donating their winnings to local charities and outreach programs.

SuperWalk is the team's annual opportunity to not only fundraise, but to bring the Parkinson's community together. For Debbie, this important day is one of fun and compassion, strength and giving, acceptance and bravery, and generosity.

**REGISTRATION COMING SOON AT  
[WWW.PARKINSON.BC.CA/SUPERWALK](http://WWW.PARKINSON.BC.CA/SUPERWALK)**

# NEWSWORTHY

## UPCOMING EDUCATION EVENTS

### *June Symposium Series*

Parkinson's is a unique and complex condition. To assist in expanding your knowledge of the disease, Parkinson Society BC is hosting this symposium series to provide our community with the opportunity to learn from leading experts.

*Thank you to our symposium series sponsor:*

**abbvie**

### *Pain in Parkinson's*

*Dr. Brenda Lau, Physician*

Pain is a non-motor symptom that people with Parkinson's may experience. In this session, Dr. Lau will discuss common types and causes of Parkinson's-related pain, as well as strategies for self-managing pain. This presentation will also offer tips on how people with Parkinson's can change their mindset about their pain to reduce its intensity.

Date: Monday, June 14  
Time: 11:00am - 12:00pm PT  
Capacity: 500  
Cost: Free

### *Non-Motor Symptoms*

*Leila Goharian, Nutritionist*

Proper nutrition can play an important role in managing Parkinson's symptoms. In this session, Leila Goharian will discuss nutrition management, highlighting the prevalence and consequences of malnutrition, and how and why people with Parkinson's are vulnerable to it. She will also cover dysphagia and texture modifications to prevent the risk of aspiration, as well as how to identify and combat malnutrition.

Date: Friday, June 25  
Time: 11:00am - 12:00pm PT  
Capacity: 500

## UPCOMING ACTIVITIES

### *SongShine with Joani - June & July Classes*

This program harnesses the power of the brain, breath, and emotion to reclaim voices. Joani Bye will engage participants in six uplifting sessions of SongShine, a program using singing, breath work, diction, articulation, and creative imagination exercises to strengthen voices affected by Parkinson's or other neurological challenges. SongShine's goal is to help you communicate more easily and clearly, while facilitating a sense of community, camaraderie, and confidence in the process!

Join Joani for immersive, holistic, and fun sessions that will include the following:

- Singing your favourite songs
- Relaxation
- Breathing exercises
- Tongue exercises (for articulation and swallowing)
- Linguistic and vocal instruction
- Imagination exercises

Dates: Wednesdays, June 2 - July 14  
Wednesdays, July 21 - August 25  
Time: 12:30pm - 1:30pm PT  
Capacity: 50  
Cost: Free

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

## UPCOMING EXERCISE CLASSES

### *Dancing with Latin Rhythms*

Come explore Latin rhythm and movement in a fun and creative dance series led by Dance for PD certified choreographer, Trina Frometa. Through a joyful and non-judgemental process, dancers learn to enhance awareness of grace while focusing on Parkinson's-specific concerns such as balance, flexibility, coordination, gait, and posture. All you need is yourself and some space to move around.

Dates: Thursdays, June 3 - 24  
Time: 1:00pm - 2:00pm PT  
Capacity: 50  
Cost: Free

### Balance & Falls Prevention Exercise Class

Join PSBC's Shelly Yu, neuro physiotherapist, for this 8-week balance and falls prevention exercise class. Exercises in this series will focus on lower extremity strength, and agility-type activities required for falls prevention, like multidirectional stepping and weight shifting.

All exercises will be done in a standing position in order to simulate real-life scenarios. However, participants are welcome to hold on to a chair or table for support as needed. No equipment needed.

Dates: Tuesdays, June 8 - July 27  
Time: 11:30am - 12:30pm PT  
Capacity: 500  
Cost: Free

### Balance & Falls Prevention Exercise Class

Join Kathryn Kimmins, Certified Laughter Yoga Teacher, as she leads you through laughter exercises to boost good health! Living with a chronic illness such as Parkinson's can negatively impact one's mood and stress levels. Research shows that laughter can help combat low mood and manage stress, which can improve Parkinson's symptoms.

Dates: Thursday, July 15  
Time: 1:00pm - 1:45pm PT  
Capacity: 100  
Cost: Free

### Stretch & Strengthen: Low-Impact Exercise Series

Stretch & Strengthen is a low-impact exercise series led by PSBC's own neuro physiotherapist, Shelly Yu, designed for those who prefer a slow-paced class.

Exercises will start in a seated position and progress to standing, although there is an option to remain seated for the duration of the class. Participants can expect to focus on ranges of movement of the trunk, upper limbs, and lower limbs, in a strength-controlled manner. No equipment needed.

Dates: Thursdays, August 5 - 26  
Time: 11:30am - 12:30pm PT  
Capacity: 500  
Cost: Free

## Thank you to our fundraisers & donors!

### Me-N-Eds Sweetheart Pizza Sales

This Valentine's Day, Me-N-Eds donated \$2 from each sale of their special heart-shaped pizzas, totalling \$338 raised in benefit of the Society. Thank you to Me-N-Eds for their generosity and ongoing support!

### Greeting Card Sales

Chris Olsen rediscovered her love of art after living with Parkinson's for nearly 20 years. She incorporates her work in greeting cards, which she sells at local art fairs with her husband, Harold. Thank you to Chris and Harold for their recent donation of \$110 from card proceeds!

### Additional thanks to...

- Leah Roberts, for hosting a fundraiser raising \$305

### Interested in organizing your own fundraiser benefitting Parkinson Society British Columbia?

Visit [www.parkinson.bc.ca/champions](http://www.parkinson.bc.ca/champions) or contact Caroline Wiggins, *Special Events & Fundraising Officer*, at [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330 to learn more about planning your own fundraising event!

## CAREPARTNER'S CORNER CONT'D

### Other Resources

Mindfulness Exercises | Therapist Aid | Worksheet  
<http://bit.ly/mindfulnessmeditationsheet>

Mindfulness for Parkinson's | Video Series  
<https://bit.ly/mindfulness-with-judy>

Mindfulness for Carepartners | Video  
<http://bit.ly/mindfulnesscarepartners>

### Sources

Dissanayaka, N.N.W. et al. (2016). *Mindfulness for motor and nonmotor dysfunctions in Parkinson's Disease*. *Parkinson's Disease Journal*. Retrieved from <http://dx.doi.org/10.1155/2016/7109052>

Therapist Aid. (2017). *How to Practice Mindfulness Meditation (Worksheet)*. Retrieved from <https://www.therapistaid.com/therapy-worksheet/how-to-practice-mindfulness-meditation>



SAVE THE DATES

# GLOBAL SYMPOSIUM SERIES

Wednesdays, November 3<sup>rd</sup>, 10<sup>th</sup>, & 24<sup>th</sup>

Join us this November for Parkinson Society BC's first Global Symposium Series, featuring presentations by world-renowned Parkinson's experts. Session details and registration coming soon. Speakers include:

**Dr. Bas Bloem, MD, PhD**, is a neurologist, movement disorder specialist, and professor from the Netherlands. In 2002, he founded and became the medical director of the Parkinson Centre Nijmegen (ParC), recognized as a center of excellence for Parkinson's disease. Alongside Dr. Marten Munneke, he co-developed ParkinsonNet, an innovative healthcare concept of professional networks for Parkinson's patients in the Netherlands. Dr. Bloem has also written over 500 peer-reviewed international papers and co-authored the book, *Ending Parkinson's Disease: A Prescription for Action*.

**Dr. Rebecca Gilbert, MD, PhD**, is the Chief Scientific Officer at the American Parkinson Disease Association (APDA), the largest grassroots organization dedicated to the fight against Parkinson's disease. She is also a member of the International Movement Disorder Society and attends to patients at the Movement Disorder Clinic at Bellevue Hospital in New York. Prior to joining the APDA, Dr. Gilbert was an Associate Professor of Neurology at the Fresco Institute for Parkinson's and Movement Disorders, where she participated in clinical trials and other research initiatives for Parkinson's and lectured widely on the disease.

**Dr. Alfonso Fasano, MD, PhD**, is a neurologist with a special interest in movement disorders. After completing a PhD in neuroscience at the Catholic University of Rome, he joined the Movement Disorder Centre at the Toronto Western Hospital, where he co-directs the surgical program for movement disorders. Dr. Fasano is a Clinician Investigator at the Krembil Research Institute, a world leader in research and clinical care for brain disorders. He has authored more than 300 scientific papers and book chapters, and was honoured with the Bocelli Award for Young Investigators from the European Federation of Neurological Societies in 2009.

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