

# VIEWPOINTS



APRIL IS  
PARKINSON'S  
AWARENESS  
MONTH

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*Pictured:  
Dean & Glenni Tweedle*

## SPRING 2020

A QUARTERLY NEWSLETTER  
BY PARKINSON SOCIETY  
BRITISH COLUMBIA

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CAREPARTNER'S  
CORNER:  
AMBIGUOUS LOSS

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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.

**Special Events:** Ticket sales from our educational and fundraising events support the Society's programs and services.

**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 benefitting 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, Burnaby, Campbell River, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox, Cranbrook, Duncan/Cowichan Valley, Fort St. John, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, Nelson, New Diagnosis (Vancouver), New Westminster, Online Carepartners, Online YOPD, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Princeton, Quadra Island, Quesnel, Richmond Carepartners, Sechelt, Shuswap/Salmon Arm, Surrey, Terrace, Trail/Castlegar, Tri-Cities, Tri-Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Working Professionals, Vancouver West Side, Vernon, Vernon Carepartners, West Vancouver, West Vancouver Carepartners, Williams Lake, White Rock, White Rock Carepartners

## 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

### LRRK2 activity in health and disease: Elevated ROS levels in inflamed, LRRK2 mutant brain

Two key factors can contribute to the development of Parkinson's disease: inflammation and genetics. The former is a response to injury or infection, while the latter is one of the unique physical features that defines each of us.

Neither factor alone may be sufficient to cause this disease and its steady breakdown of the nervous system, which means if you can correct one of the two factors, you might halt the entire process.

Dr. Michael Schlossmacher, a member of the University of Ottawa Research Institute, is focusing on the link between inflammation and the mutation of a specific gene, called LRRK2, found in people with Parkinson's disease.

This work changed profoundly with the discovery that the LRRK2 mutation also showed higher levels of particular chemicals known as Reactive Oxygen Species (ROS) when there was an inflammatory stimulus, the body's response to an inflammation.

"These molecules apparently respond to inflammation throughout the body, including in the brain and the central nervous system," says Schlossmacher.

The results of this work were recently published in the high-profile journal *Science Translational Medicine*, where a Canadian team concluded the LRRK2 gene could represent a crucial controlling mechanism for inflammation within the body.

Restoring the gene's function could help identify the underlying problem in Parkinson's disease.

*"I wanted to work in a field that makes a difference. I want something that I know can make a meaningful difference. For me it was the link to patients, so that you can put a face on your project."*

#### PROJECT GRANT

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



#### RESEARCHER

Dr. Michael Schlossmacher

#### INSTITUTE

Ottawa Hospital Research Institute

Schlossmacher and his team, where Dr. Bojan Shutinoski is the key co-investigator, are now examining these biochemical processes in mice that have the mutated form of the LRRK2 gene. If they can identify a specific mechanism that is responsible, it might be possible to halt the progression of Parkinson's by eliminating this cause.

In the meantime, the presence of elevated inflammation in the body, in combination with LRRK2 mutation, could mean an increased risk for developing Parkinson's disease.

Schlossmacher and his colleagues are eager to find the causes of Parkinson's disease and discover ways to treat and diagnose it as early as possible..

"I have confidence that it's possible to improve the treatment of Parkinson's disease," he says.

*Reproduced with permission from Parkinson Canada.*

#### DONOR SPOTLIGHT: MAUREEN HAFSTEIN

This research project is funded in part by a generous donation of \$25,000 from Maureen Hafstein, a woman living with Parkinson's in Salmon Arm. Read about Maureen's journey from the Deep Brain Stimulation waitlist to funding groundbreaking research on page 12.

## ASK AN EXPERT



### Judy Zhu Discusses Mindfulness and Meditation for Parkinson's Disease

**Dr. Judy Zhu, RCC, Dr. TCM**, is a clinical counsellor at Parkinson Society BC (PSBC). For over a decade, she has used a holistic approach to help her clients with

anxiety, depression, stress disorders, past trauma, and chronic health issues get on a path of physical and emotional wellbeing. As a counsellor, Judy uses mindfulness-based therapies, along with Buddhist philosophy.

#### *What is mindfulness, and how is it practiced?*

The word “mindfulness” is the translation of the term “Sati” from an ancient language, Pali. It refers to awareness of the present moment, experienced with the attitude of acceptance and kindness.

Mindfulness practice has been an important part of Buddhist meditation. However, because it benefits many aspects of wellbeing, it has been widely used not only in the field of medicine and psychotherapy, but also in the workplace, in schools, in athlete training, and even in parenting. To put it simply, mindfulness means paying attention to what is happening in the moment, without judging or identifying with the experience. It can be practiced informally in your daily life, like when you eat, drink, fold laundry, wash dishes, or listen to music. You can also have a formal practice, which involves devoting 30-60 minutes a day to mindfulness. Those who have practiced mindfulness for a while, and want to deepen their experience, can look into participating in a meditation retreat that lasts from a weekend to two weeks or more.

#### *How can mindfulness help people with Parkinson's?*

There are many benefits to practicing mindfulness. Research has shown that it can activate brain circuits associated with feeling happy, and lead one to engage in life with greater enthusiasm. It can also improve one's attention span. The long-term practice

of mindfulness can increase grey matter density (GMD) to prevent aging and illness in the brain.

Some may find mindfulness practice helps regulate emotions, and reduce anxiety and the effects of stress on the body. Ongoing practice helps to cultivate empathy, love, and kindness; therefore, it can improve our sense of emotional wellbeing, as well as the quality of intimate relationships and connectedness in the community. The acceptance aspect of mindfulness allows one to better cope with aging and illness. In short, the practice enables us to live a life with more ease and fulfillment.

Mindfulness practice can have positive effects on cognitive and motor function in people living with Parkinson's disease (PD). The loss of grey matter density is associated with motor and cognitive symptoms in PD.

A study by Pickut et al. (2013) showed that increased GMD was found in a mindfulness-based Intervention group, in the neural networks that play an important role in PD. Another study by Dissanayaka et al. (2016) indicated that mindfulness intervention tailored for PD was associated with reduced anxiety and depression, as well as improved cognitive and motor function. Further, another study by Pickut et al. (2015) also indicated that mindfulness training may help to restore some degree of self-determination in the experience of living with PD.

#### *How can people with PD and their caregivers incorporate mindfulness in their everyday lives?*

There are many different mindfulness techniques that one can incorporate in their everyday lives, such as breathing practice, body scans, listening practice, mindful walking, mindful eating, and loving-kindness practice. I would suggest people start with the breath practice which is basic, but very helpful.

As long as we are alive, our breath is always with us. It is a wonderful reminder of the present moment because we all have to inhale and exhale. No matter what kind of rush we are in, we have to take one breath in and one breath out. Any moment we notice ourselves getting caught in worrying thoughts, or feeling stressed, we can simply take a breath and bring our attention to following the process of breathing in and breathing out. As you are doing this, remind yourself that no matter what distress you feel, in this moment, you have this

breath with you and you have this life with you. Please bring a sense of gratitude towards this breath that we often take for granted.

### *How do you prescribe mindfulness to your counselling clients?*

In order to be an effective therapist, I strive to be present for my clients. To do this, I practice being mindful and having an attitude of acceptance and kindness.

Through mindfulness, I hope to create an environment that is conducive for clients to be accepting of their experience during the session. I use the principle with every client, which can manifest in many different ways. For example, if I notice that a client seems distressed when talking about their frustrations and struggles, and they seem caught in the stress of daily life, I may simply ask them to take a deep breath, to bring them back to the present moment. For some clients, I may also guide them to do one or two short, 3-5 minute mindfulness practices during our sessions together. I decide when and how much mindfulness to use depending on the issues each client struggles with, and how receptive they are to this type of therapy.

### *How does mindfulness differ from cognitive behavioural therapy?*

Cognitive behavioural therapy (CBT) is a very popular therapeutic approach. The biggest difference between mindfulness-based intervention and CBT is the relationship we have with our internal experiences. CBT emphasizes becoming aware of negative thoughts, and changing those unhelpful thoughts into helpful ones. On the other hand, mindfulness-based intervention involves clients acknowledging their thoughts without identifying or engaging with them, as a way to create more ease. It can increase clients' awareness of their internal processes, and facilitate acceptance and self-compassion, which is the foundation of any successful therapy.

For therapists who practice different modalities, to start adopting mindfulness, it is crucial that they first practice it themselves in order to be more present for their clients and conduct more effective therapy.

### *Do you have any advice or recommendations for those looking to try practicing mindfulness?*

I would say that mindfulness is good for everybody who is willing to practice it. To start, I recommend that

you join a class or a meditation group. You can look into a mindfulness-based stress reduction course, or check out local Buddhist meditation groups. The former is more focused on using mindfulness to handle stress and other chronic health issues, while the latter is more spiritually focused.

Many places offer mindfulness or meditation groups. I recommend trying these out to see which one is more suitable for you, and then commit for a few months. The benefit you get from practicing mindfulness is directly proportional to how much you practice.

Start small – even 5 minutes a day is useful, and you can start to build on that over time. The most important thing is practice, practice, and practice. When you begin, remember to be kind to yourself as you are trying something new, so it will take some time to learn. Your mind may wander, and that is normal. If this happens, look to bring your mind back to your breath with gentleness and kindness.

Another important thing about mindfulness is that it is not just about the mind – it is also about the body. When you practice mindfulness, you will start to feel your body more, including your Parkinson's symptoms. You may feel some sensations that you probably want to avoid, reject, or resist. You may feel uncomfortable when they arise. This is normal. The practice of mindfulness is about allowing them to be there, and to reconnect with your body. If you feel too overwhelmed about feeling these sensations and need more guidance and support, please consider reaching out to a counsellor.

Mindfulness is to be practiced with a loving kindness toward yourself. It is not only useful for coping with life's many challenges, but also a way of living that welcomes ease and joy.

### *Additional resources*

**Parkinson Society BC Counselling**  
[www.parkinson.bc.ca/counselling](http://www.parkinson.bc.ca/counselling) | 1-800-668-3330

**Center for Mindfulness Canada**  
[www.mindfulnessstudies.com](http://www.mindfulnessstudies.com)

**Mountain Rain Zen Community, Vancouver**  
[www.mountainrainzen.org](http://www.mountainrainzen.org) | 604-462-0604

**Vancouver Shambhala Center, Vancouver**  
[www.vancouver.shambhala.org](http://www.vancouver.shambhala.org)

**Turning Point Bodymind Wellness**  
[www.turningpointacupuncture.ca](http://www.turningpointacupuncture.ca) | 604-738-5288

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# LIVING WELL

## Subsidized and assisted transportation for people with Parkinson's

Transportation arrangements can be a challenge for many people with Parkinson's disease (PD). For those experiencing advanced symptoms, driving may no longer be an option. For others, navigating public transit can also be difficult due to mobility issues, medication concerns, and affordability. Fortunately, there is a wide range of cost-efficient transportation options for people requiring extra assistance when traveling locally.

### *Finding your best options*

When planning a trip using public transit, consider all of the concerns you may typically encounter when traveling by car, bus, or train including:

- Are you travelling during peak transit times, or during your medication "off" times?
- Do you require extra time to get in and out of your seat?
- Which vehicle type will offer you the most comfortable ride?
- Is your destination within a comfortable walking distance from a bus stop or train station?
- Which routes would require you to make transfers to reach your destination?

Regardless of your chosen mode of transportation, the distance you are travelling, or your trip's duration, it is important to always consider your wellbeing. It is helpful to bring a back-up dose of your medications with you wherever you go, along with medical information on your condition and specific needs, in case of an emergency.

If you are unable to travel with a carepartner, friend, or loved one, there are options available across the province for community care services that can connect you with staff or volunteers to accompany you on transit when needed. These services can help you reach your destination in a safe, enjoyable, and low-cost manner.

### *BC Bus Pass Program*

On January 1, 2018, the Province introduced the BC Bus Pass Program, granting people receiving disability assistance an additional \$52 each month for transportation, to be used for a transit pass or other transportation needs. This program also offers a reduced-cost bus pass for low-income seniors. The pass, called a Compass Card, is valid in areas covered by TransLink (Metro Vancouver) and BC Transit (the rest of BC).

TransLink users can tap to scan their Compass Card when entering buses, and when entering and exiting Skytrain and Canada Line stations. BC Transit users receive an annual validation sticker for their



Compass Card, which needs to be shown to the driver in communities outside of Metro Vancouver.

To apply for the BC Bus Pass, contact the Ministry of Social Development and Poverty Reduction at 1-866-866-0800.

### **HandyDART**

HandyDart provides door-to-door, shared-ride services to those with physical or cognitive impairments, for whom conventional public transit can be difficult to use without assistance. Drivers arrive at the passenger's home or other departure point, help them board the vehicle, and assist them to their destination.

This service is available across BC, with independent services operated by BC Transit and TransLink. Visit your local transit authority's website to learn more and apply.

### **HandyCard & handyPASS**

If you require an attendant to travel with you, they can ride for free on TransLink vehicles if you have a HandyCard, or on BC Transit if you have a handyPASS. These are picture identification cards that are provided to eligible individuals who can provide verification of their medical condition. To learn more and register for a card, visit your local transit authority's website.

### **Taxi saver program**

The taxi saver program is available across the province, offering a 50% subsidy towards the cost of taxi rides for you and your carepartner or travel attendant. To qualify for this program, passengers must have a HandyCard or handyPASS.

### **Volunteer ride programs**

Volunteer ride services provide reliable assisted transportation through various agencies across the province. Many are available through the Better at Home program, funded by the Government of BC, and managed through the United Way of the Lower Mainland. Local organizations within the Better at Home network also provide additional support services, like help with housekeeping, groceries, yard work, and minor home repairs, as well as friendly visits.

### **Navigating local services**

To find transportation services or subsidies available in your community, contact your local health and transit authorities. Most major communities across the province can also access bc211, a 24/7 information hotline that can connect you with support services locally. Call 2-1-1 to access the hotline.

TransLink users across Metro Vancouver can request station assistance on the SkyTrain by calling 604-520-5518, or the Canada Line, at 604-247-5703. For those using the SeaBus, attendants are available at the ferry terminal to assist as needed.

BC Transit users can also access the Community Travel Training Program, which offers free guidance to seniors and people with disabilities looking to use regular transit services. This program trains individuals how to use their local transit system independently and confidently. A similar program is available in Vancouver through the Coast Mountain Bus Company, which offers sessions to those using mobility aids on the bus.

To find more information on transportation services available through your transit authority, visit the links below.

#### **TransLink (Metro Vancouver only)**

HandyDART | [bit.ly/HandyDART](https://bit.ly/HandyDART)

HandyCard & TaxiSaver | [bit.ly/HandyCard](https://bit.ly/HandyCard)

Wheelchairs & Mobility Aids | [bit.ly/translinkmobilityaids](https://bit.ly/translinkmobilityaids)

#### **BC Transit**

handyDART & Taxi Saver | [bit.ly/BChandyDART](https://bit.ly/BChandyDART)

Community Travel Training | [bit.ly/bctraveltraining](https://bit.ly/bctraveltraining)

#### **Additional resources**

BC Bus Pass Program | [www.gov.bc.ca/buspassprogram](https://www.gov.bc.ca/buspassprogram)

Star Canada | [starcanada.ca](https://starcanada.ca)

Better at Home | [betterathome.ca](https://betterathome.ca)

*For help navigating resources and services available in your community, contact Parkinson Society British Columbia at [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca) or 1-800-668-3330. Our friendly and knowledgeable staff are committed to offering support, sharing reliable information, and providing education.*

## LIVING WELL

### Enhancing neuroplasticity through gaming

Neuroplasticity is the capacity of brain cells to change in response to one's health, environment, lifestyle, and other factors (Shaffer, 2016). Parkinson's disease (PD) is one such factor, causing a degeneration in the cells that produce dopamine.

Dopamine is a neurotransmitter, a chemical released by brain cells (neurons), in order to communicate with other nerve cells. It plays a role in motor function, hormone release, and decision-making. The most common PD drugs target the brain to stimulate dopamine production, while others can be used to repair a variety of impacted functions in the parts of the brain that control non-motor symptoms, mood, and cognition. All of these medications work because of the brain's "plasticity," or in other words, its malleability.

Neuroplasticity allows the brain to mend itself after injury or illness, and return to a healthy, balanced state. While Parkinson's impairs the brain's structure, chemistry, and function, the capacity for malleability allows the brain to adapt and slow the degeneration caused by the disease.

Alongside Parkinson's and the medications that treat it, other factors — such as healthy diet, exercise, and stress management habits — are known to change the brain's chemistry and structure to improve its function. As a result, these lifestyle changes can help slow the progression of the disease. However, incorporating healthy habits can take time, and maximizing their benefit may require a degree of access to resources that may not be possible for everyone.

Some people with Parkinson's may find it difficult to cook, shop for groceries, exercise vigorously, or manage their stress without professional help, making it difficult to adopt brain-healthy habits. However, one surprisingly effective means to improve brain function, with a minimal barrier to access, is gaming.

#### *Games for the brain and body*

Gaming is being introduced in Parkinson's rehabilitation as an accessible means of exercising the brain and

body. Studies have shown that video games, in particular, can increase dopamine levels, making them highly beneficial for PD treatment. Dopamine is linked to reward-motivated behaviour, serving as the chemical pleasure response in the brain. This means that every level beaten, enemy overcome, and problem solved in a video game can boost the brain's dopamine supply.



Video games require users to think critically, problem solve, practice motor sequencing, and utilize memory to complete objectives. Games can mimic traditional exercise, which is known to release endorphins (hormones that inhibit pain signals and produce euphoric emotions), and stimulate the release of dopamine, adrenaline, and serotonin. These chemicals produce a wide range of effects, such as improving one's mood, cognitive ability, and motor function. Further, similarly to exercise, games can stimulate an elevated mood by rewarding players with achievements, and offering opportunities to tackle new, exciting challenges.

Some games can also greatly enhance motor skills when played on consoles like the Nintendo Wii, Xbox Kinect, and virtual reality (VR) headsets. These consoles allow players to perform real-life physical tasks through gaming. For example, Wii Tennis requires participants to use the console's wireless controller as a tennis racket, and encourages players to jump, swing their arms, and move around, mirroring the same actions one would perform in a tennis match on the court.

#### *Gaming to improve daily living*

Reaction time, memory, cognitive functioning, motor control, and multitasking are all important aspects



of performing daily activities that are also developed through video game training. Exercise-based games may be especially suited for people with PD, due to challenges the disease poses in controlling and sequencing movement (Herz et al., 2013). Training on these movement-tracking consoles can help to lower the risk of falls, and improve balance and rigidity, as the games often require large, rapid movements, and quick reactions. Other studies suggest that games which integrate exercise can reduce symptoms of depression and anxiety, as well as increase cognitive abilities and quality of life (McLaughlin et al., 2018).

Virtual reality games have been shown to improve obstacle negotiation, balance, and confidence in individuals living with PD. When using a VR headset, players are immersed in an interactive, 3D virtual world. In one study using this equipment, participants were said to have “enjoyed the experience and thought it was fun, not just exercise. They liked training and challenging themselves without the fear of falling” (Experimental Biology, 2019).

Another good option for people with Parkinson’s is augmented reality, in which the virtual landscape is mapped onto the player’s real surroundings. This type of gaming can allow for greater range of movement than a head-mounted VR display, which does not allow the player to see their surroundings outside of the game’s graphics. Many augmented reality games are available for download on smartphones and tablets.

### Getting started

If you are interested in gaming, and want to know what types of video games are right for you, try playing free games first on your computer,

smartphone, or tablet. You can also visit your local electronics store to learn about console games. There, you can test out new games on display, and talk to staff about the different types of games and consoles available within your budget.

A home therapy routine with a game-based system can be an advantage due to its comfort and convenience. The adrenaline produced by accomplishing a task, gaining points, or upgrading to a higher level in a game can amplify the excitement, joy, and motivation in treating the symptoms of Parkinson’s disease. Consider gaming if you’re looking for a new hobby to not only challenge yourself at beating a high score, but also the progression of PD.

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## ASK THE EXPERT: MINDFULNESS CONT’D

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# APRIL IS PARKINSON'S AWARENESS MONTH



*Pictured: Chris & Harold Olsen*

## THE CAMPAIGN

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

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

Our 2020 campaign highlights:

- Personal **journeys** shared by people with Parkinson's, their families, and carepartners.
- The **ambiguity** of Parkinson's, and the **uniqueness** of each individual's symptoms, experiences, and disease progression.
- **Advocacy** issues affecting the Parkinson's community across British Columbia.

## GET INVOLVED

Let others know that April is Parkinson's Awareness Month, and use the hashtag **#MoreThanATremor** on social media to tell your story.

Be sure to follow the Society online, and tag us in your April Awareness Month posts:

Facebook: @ParkinsonSocietyBritishColumbia

Instagram & Twitter: @ParkinsonsBC

Every journey with PD is unique, and we want to hear about yours. Be an ambassador for our awareness efforts and have your story shared in our newsletters, on our website, or in the media. For more information, contact Jovana Vranic, *Marketing & Communications Senior Coordinator*, at [jvranic@parkinson.bc.ca](mailto:jvranic@parkinson.bc.ca).

# #MoreThanATremor

[WWW.PARKINSON.BC.CA/AWARENESS](http://WWW.PARKINSON.BC.CA/AWARENESS)

## GIVING

### From waiting for Deep Brain Stimulation to funding groundbreaking research: Maureen Hafstein's journey

Maureen Hafstein was diagnosed with Parkinson's disease (PD) just three months short of her 50th birthday, 13 years ago. She was a teacher at the height of her career, but her symptoms progressed quickly, and in just two short years, forced her to step away from the job she loved.

"I went through all the stages of mourning my previous life, spending plenty of time in the denial and anger stages," says Maureen. "My most productive time, however, was during the bargaining stage. I read and researched all I could get my hands on."

*"I joke with my family that my tombstone will read: 'she tried everything!'"*

In 2017, Maureen was one of many hopeful patients on the waitlist to receive Deep Brain Stimulation (DBS) surgery, but her friends and family grew worried about her condition, and frustrated with the wait. "I could see the alarm in their faces when they saw me," she says, "which made the wait that much more excruciating."

With help from her local MLA, Maureen and her loved ones participated in a national letter-writing campaign, alongside Parkinson Society British Columbia, other local MLAs, and policymakers. These efforts inundated the BC Health Minister's office with pleas to increase access to DBS. With only one qualified neurosurgeon – Dr. Christopher Honey – performing DBS in BC, individuals like Maureen were waiting up to three years for a consultation, followed by another two years for their surgery date.

#### *Springing into action*

Deep Brain Stimulation is reserved for people with Parkinson's who have symptoms which cannot be sufficiently managed through medication. At these stages of disease progression, a five-year

wait can pose a significant risk for further decline, sometimes to the point where surgery is no longer a viable option. People with PD seeking DBS must be advanced enough to need the intervention, but well enough to undergo an invasive surgical procedure. For Maureen, waiting was not an option.

"After failing to get the Minister's attention, my family swung into action and organized a fundraising campaign," says Maureen. Led by Maureen's sister, Jane Williams, the campaign sought public support on the popular online crowdfunding platform, GoFundMe (GFM), to help cover the cost of an assessment and potential treatment at the world-renowned Mayo Clinic in Minnesota.

"We were stunned by the response that we received literally from coast to coast," says Maureen. She recalls that, "almost overnight, I went from taking the initial steps for accessing medically-assisted dying to jumping on a plane for my appointment." Her assessment at the Mayo Clinic confirmed that she was, as expected, an excellent candidate for DBS.

At the Mayo Clinic, doctors also addressed Maureen's deteriorating condition by fine-tuning her medication, which made it possible to withstand a wait for DBS. Back home after her assessment, Maureen found herself on the BC DBS surgery waitlist once again. This time, she would receive her long-awaited surgery date: September 17, 2019.

In February 2019, the BC Health Ministry announced an action plan to expand the DBS program, and double operating room time for Dr. Honey. Although the Ministry is currently still working to hire a new neurosurgeon, this first step has shortened the wait for many advanced patients, like Maureen.

Receiving a surgery date meant that Maureen had to find a new use for the thousands of dollars raised by her generous supporters across the country. Along with paying for her trip to the Mayo Clinic, some funds were used to cover the many expenses incurred from receiving DBS in BC. After this, Maureen says "there was a significant amount left over from the campaign to make an impactful donation to a research project of my choice." She chose to donate \$25,000 to a research project by Dr. Michael Schlossmacher at the Ottawa Hospital Research Institute. Her funding is matched by Parkinson Society British Columbia in a one-year



Maureen Hafstein with her grandsons

Pilot Project Grant of \$50,000, awarded through the Parkinson Canada National Research Program.

*“I have always been interested in the fact that, after all of this time, they still don’t know much about the root cause of Parkinson’s disease,” says Maureen. “It did cross my mind that they might be looking in the wrong place.”*

Dr. Schlossmacher’s research is examining the connection between inflammation and genetics in Parkinson’s. The disease is associated with a mutation of the LRRK2 gene, which has been linked to high levels of chemicals called Reactive Oxygen Species (ROS), also known as free radicals. An increase in ROS, caused by inflammation and other immune responses, can result in oxidative stress, which damages cell structure.

“Everything I have read about the direction of Dr. Schlossmacher’s work gives me a feeling of hope for the future,” says Maureen. “I have a strong feeling I could benefit from their work in my lifetime! I can’t think of a better place to put the excess funds from my GFM.”

### **The research project**

Dr. Schlossmacher’s lab recently published research on the pro-inflammatory effects of a specific mutation in LRRK2, called G2019S, during infection. Dr. Bojan Shutinoski, the key co-investigator in Dr. Schlossmacher’s study, says that this “could provide new insights into the understanding of parkinsonism linked to LRRK2 mutations.”

“An important question that remains is the identity of the most responsible cell type that promotes [disease development] in LRRK2-linked parkinsonism,” he says. “Our findings support a growing body of evidence that the LRRK2 protein functions in immune cells both within the brain, and the periphery.”

According to Dr. Shutinoski, this “shift in research perspective” could hold the answer to whether LRRK2 mutations increase the risk of PD through one

main mechanism, such as inflammation, or “multiple distinct mechanisms in more than one cell type, and more than one organ system.” This is the focus of their latest study, funded in part by Maureen.

“The idea that Parkinson’s could be triggered by some other event such as the inflammation response to a previous systemic infection was highly interesting to me,” says Maureen. “My own history of having had rheumatic fever when I was nine years old, along with a family history of rheumatoid arthritis, really got the wheels turning in my head!”

This research may additionally support the popular theory that Parkinson’s originates in the gut. The lab’s previous study showed that LRRK2 can regulate inflammation outside of the brain and central nervous system. This suggests that mutations in LRRK2 that are known to correlate with the risk of developing PD, may confer this risk as a result of imbalanced inflammatory mechanisms in another organ system – particularly in the gut – or elsewhere in the body.

Inflammation has long been tied to the development of disease, but determining the connection to

**CONTINUED ON PAGE 14...**



Dr. Bojan Shutinoski



Researchers at the Schlossmacher lab

brain health is a more recent focus in the scientific community. In relation to what we know thus far, Dr. Shutinoski says that, “for not yet fully understood reasons,” some of the brain cells that make up the neural networks regulating movement are “the most sensitive to increases of [free radicals].”

“Another important process we uncovered is that inflammation driven by [G2019S] can lead to an increase in concentration of a different protein relevant to PD – that is alpha-synuclein,” says Dr. Shutinoski, though further research is needed to better understand this mechanism.

### *The future of Parkinson's treatment*

Support from the Parkinson's community helps researchers like Drs. Schlossmacher and Shutinoski expand the scope of research into the disease, and move closer to finding more effective treatments, potential preventative measures, and a cure.

*“The support from individuals like Maureen Hafstein helps in the diversification of the research on PD,” says Dr. Shutinoski. “And diversity in thinking is what we need if we are to move past [symptom management] and start truly thinking about a cure.”*

One advancement on the horizon is that of a drug therapy that targets the LRRK2 gene. “There is a lot of interest in curbing LRRK2’s enzymatic function,” says Dr. Shutinoski. LRRK2 codes the production of an enzyme (a molecule that serves as a catalyst for biochemical reactions). A mutation like G2019S boosts this enzymatic process, resulting in an increase in inflammation.

Dr. Shutinoski says that the Parkinson's field could also look to cancer as a good treatment model, “where personalized medicine is a step ahead.” He says that, with cancer, “patients are often genetically tested [...] in order to devise the most effective treatment strategy. Perhaps with the advent of cheaper technologies [...] research could bring us closer to predicting who is at the greatest risk for the development of PD, and even finding a cure.”

Maureen is optimistic that such genetic screening will be available in her lifetime. “If I had information about the possibility that I might develop Parkinson's at some point in my life, I would be of two minds,” she says. “I would have time to research all of the things I could either do to stop or slow the onset of disease progression. I would have a fighting chance at least!”

### **MAKE A DIFFERENCE: DONATE TODAY**

Did you know that when you donate to Parkinson Society British Columbia, you have the power to choose where we allocate your funds?

Learn more and donate online today at [www.parkinson.bc.ca/donate](http://www.parkinson.bc.ca/donate).

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## CAREPARTNER'S CORNER

### Ambiguous loss and frozen grief

Many find it challenging to balance their role as a carepartner with being a spouse, family member, or friend. Even more challenging is the transition in their relationship as the disease progresses. Every stage of Parkinson's will require adaptation and acceptance, as carepartners navigate their ever-evolving roles.

As a disease with no cure, and no way to accurately predict its progression, Parkinson's can present a sense of ongoing loss. Carepartners are faced with the knowledge that their loved one will inevitably decline over time, and require increasing levels of care. For many, this uncertainty about the future can be difficult to accept.

#### Ongoing losses

The incremental losses associated with Parkinson's can be a continual presence in the life of a carepartner. These losses may be invisible and difficult to put into words, but they are often related to feelings associated with knowing that the person they care for is no longer the person they used to be. Some of the examples of these losses include:

- the loss of their loved one's abilities, independence, and former roles
- changes in their loved one's identity, interests, and motivations – as well as their own
- decreasing leisure time, and time spent doing shared activities with their loved one
- diminishing opportunities for travel, or spontaneous life changes (eg. moving to a new city, getting a new job, etc.)

It can be difficult to recognize each incremental loss as a carepartner. For example, your loved one being prescribed a new medication may mean additional time spent tracking symptoms and side effects, and more frequent visits to the doctor's office. These new responsibilities can slowly take away from the carepartner's independence and leisure, one hour at a time.

Often, these losses are realized at times of heightened stress, or at the point of burnout. This is why learning to identify ambiguous loss is an important part of managing your role as a carepartner.

#### Ambiguous loss

The term '*ambiguous loss*' was coined by Dr. Pauline Boss, who has studied family stress and grief since the 1970s. As the pioneering theorist in her field, she defined two types of ambiguous loss (*Frequently Asked Questions*, n.d.):

- Type one occurs when there is a physical absence, with a psychological presence.
- Type two occurs when there is a psychological absence, with a physical presence.

Parkinson's may present the challenge of both types of ambiguous loss. For example, the first type may be experienced by carepartners whose loved ones with Parkinson's are hospitalized, in assisted living, or in hospice care. The second type can be experienced in cases where the person with Parkinson's has gone through cognitive changes, has dementia, or whose self-identity or personality has changed significantly as a result of their journey with the disease.

#### The effects of ambiguous loss

A natural response to loss is to grieve, but grief can be complicated when it is not acknowledged or addressed. The grieving process naturally follows a loss of life, and those experiencing the loss can cope by externalizing their grief through mourning. In ambiguous loss, carepartners can be immobilized and face mental health problems as a result of unvalidated, and repressed grief, or grief which has simply not been recognized. Boss (1999) describes this as a state of '*frozen grief*.' Some of the possible manifestations of ambiguous loss and frozen grief include (McGeary et al., 2018):

- anxiety, insecurity, and anxious attachment
- a sense of hopelessness and helplessness
- identity confusion (i.e. wondering "who am I now?")
- ambivalence (i.e. conflicting feelings toward your loved one)

#### Coping with ambiguous loss

Ambiguous loss requires a carepartner to grieve the loss of someone who is still alive. This is considered



a ‘*disenfranchised grief*,’ which is not widely accepted, normalized, or understood (Thelen, 2007). Carepartners can resolve disenfranchised and frozen grief by *recognizing, acknowledging, and validating* their loss (Alzheimer Society, 2013).

### **Recognizing**

To recognize ambiguous loss, it can be helpful to practice introspection (self-observation) during stressful times. If you are experiencing sadness or depression as a result of your caring role, it may be a direct manifestation of your grief.

Although it may be difficult, try taking time to evaluate your relationship with your loved one, and how it makes you feel. Sometimes, changes in your mood, stress, and overall mental wellness can be an indication of an unresolved issue such as frozen grief.

### **Acknowledging**

If you find yourself feeling sad or depressed, it is natural to try making sense of your emotions. Naming the problem of ambiguous loss is the first step in coping with this issue. To acknowledge ambiguous loss, it can help to break it down by naming each individual loss you have experienced.

Consider the changes in your identity, roles, relationships, and responsibilities, and try to acknowledge the individual losses that are associated with these changes. For example, if you spend less leisure time with your loved one, you may look to acknowledge the loss of your previous shared interests and hobbies, and consider the ways this loss has impacted your relationship. No matter how small or insignificant a loss may appear, remember that each is part of the ongoing experience of ambiguous loss.

### **Validating**

Even once you have recognized the feelings of grief and loss, and acknowledged these experiences, it can be difficult to begin the coping process. In order to heal, it is crucial to accept your grief and loss as valid, important, and worthy of attention.

In some cases, carepartners may be conflicted when faced with grief for an ambiguous loss; it can feel wrong to mourn for someone who is still alive. In fact, the process of grieving for such a loss is different from mourning, and should be

acknowledged as such. The means of coping with disenfranchised grief may be more complex, particularly because they often involve the person for whom you are caring.

To validate your grief and loss, it is important to discuss it with others. Sometimes, it may be necessary to consult a healthcare professional. To determine what kind of support you need, try using your emotions as a benchmark. Consider the following:

- If you are experiencing feelings of sadness, you may benefit from peer connections, social support, and shared activities with friends and loved ones. Sadness can be defined by mild grieving and unhappiness which does not significantly impact your functioning.
- If you are experiencing depression, you should consult a clinician, counsellor, psychologist, or family therapist. Depression can be defined as a sadness that is so deep that impairs your own function, and makes it difficult to care for others.

### **Accepting ambiguity**

Another way to validate your grief and loss is to change the way you think about these experiences. Dialectical thinking, also known as “Both-And Thinking,” may be beneficial (McGeary et al.). This type of thinking helps to break the habit of “Either/Or” thinking (which is absolute and binary), and prompts you to consider that you may be dealing with two things at once. For example, rather than “*my partner is still here*,” consider the thought, “*my partner is both gone and here*”. Boss (2011) gives other examples of how to frame your thoughts with Both-And thinking:

- “*I take care of both him and myself.*”
- “*I am both a carepartner and a person with my own needs.*”
- “*I both wish it was over and wish that my loved one keeps on living.*”
- “*I am both sad about my lost hopes and dreams, and happy about some new hopes and dreams.*”

Both-And thinking is a valuable tool for processing the doubt and uncertainty that accompanies ambiguous loss and disenfranchised grief. It allows one to accept contradictions and give up the sense of control over their experiences. By welcoming paradoxical thoughts, it becomes easier to see ambiguity as natural, and develop a trust in the unknown (Boss, 2011).

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# NEWSWORTHY

## UPCOMING EDUCATION EVENTS

### *Communication & Swallow Workshop, Kamloops*

This full-day interactive workshop, led by Registered Speech Language Pathologist Sherri Zelazny, will focus on the communication and swallowing challenges faced by people with Parkinson's.

Date: Saturday, June 13  
Time: 10:00am - 2:30pm  
Location: Coast Kamloops Hotel  
1250 Rogers Way, Kamloops  
Cost: Member \$25 | Pair \$40  
Non-member \$35 | Pair \$60

### *Regional Conference, Kelowna*

Our regional conferences are immersive and interactive opportunities for people affected by the disease to learn from leading experts while connecting with the Parkinson's community.

Topics covered at this conference will include:

- **Symptoms & Progression** | Dr. Daryl Wile, *Movement Disorder Specialist in Kelowna*
- **Fall Prevention** | Shelly Yu, *Neuro-Physiotherapist in Vancouver & Education and Support Services Coordinator at Parkinson Society BC*
- **Speech and Voice Changes** | Meaghan Delay, *Speech Language Pathologist in Kamloops*

Date: Saturday, June 27  
Time: 1:00pm - 4:15pm  
Location: Ramada Hotel & Conference Centre  
2170 Harvey Ave., Kelowna  
Cost: Member \$15 | Pair \$25  
Non-member \$25 | Pair \$45

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

## UPCOMING WEBINARS

### *Six-Week Online Parkinson's Exercise Class*

Due to social distancing efforts during the COVID-19 outbreak, many exercise programs have been cancelled until further notice. We recognize that exercise is a key component to improving and maintaining function in individuals living with Parkinson's. Regular exercise helps to improve balance, strength, mobility, gait, and overall physical function, and can also help combat the depression, fatigue, and apathy associated with the disease.

This series is being offered to allow you to exercise from the comfort and safety of your home while connecting with others.

The first 4 sessions will be geared towards individuals who are able to walk and stand without assistance, as well as have the ability to get up and down off the ground. The last 2 sessions will be done in seated and supported standing positions. These sessions are best suited to those who may have restricted mobility or balance issues and require use of a walker, cane, or wheelchair.

Dates: Tuesdays, starting March 24  
Time: 1:00pm - 2:00pm  
Cost: Free

### *Ask the Expert: Depression & Parkinson's*

When most people think of Parkinson's disease, motor symptoms like tremors and slowness of movement are typically the first to come to mind. However, mental health changes can be a significant aspect of the disease as well, with at least half of all people with Parkinson's experiencing depression and/or anxiety.

Join us on May 12 as Dr. Fidel Vila-Rodriguez, Assistant Professor in the Department of Psychiatry at the UBC Faculty of Medicine, and the Director of the Non-Invasive Neurostimulation Therapies Laboratory and Schizophrenia Program, discusses the symptoms of depression and how to manage them. He will also go over current research on depression and Parkinson's, including an opportunity to participate in a clinical trial for treatment.

Date: Tuesday, May 12  
Time: 10:00am - 11:00am  
Cost: Free

### Ask the Expert: Considerations for Driving with PD

Driving is an important part of daily life for many people. A Parkinson's disease (PD) diagnosis may lead to a number of questions around driving, such as whether people with Parkinson's can continue to drive safely, what a driving evaluation or assessment may look like, and what options for transportation exist for someone who no longer feels safe driving.

On June 8, Kathryn McKall, registered Occupational Therapist, joins Parkinson Society BC to answer these questions, and more, about driving with PD.

Date: Monday, June 8  
Time: 1:00pm - 2:00pm  
Cost: Free

### SAVE THE DATE: MOVING FORWARD, TOGETHER RETURNS SATURDAY, OCTOBER 3!

Our provincial conference, *Moving Forward, Together*, returns this fall. Mark your calendar for a day of learning on Saturday, October 3 at the Radisson Hotel in Richmond!

Join us for expert presentations on Parkinson's symptoms, groundbreaking research, caregiving, and advancements in care.

### Thank you to our fundraisers & donors!

#### Parke Pacific

The Parke Pacific Charity Golf Tournament raised \$12,000 for Parkinson Society BC! This was the tournament's second year running and the third annual tournament will take place on June 26<sup>th</sup>! A big thank you to Stewart Parke for organizing another amazing event!

#### Pull for Parkinson's

This annual Ultimate Frisbee tournament brings together students across high schools in Surrey to raise funds and awareness for Parkinson's. The 2019 tournament raised \$5,825! Thank you to the organizer, Chris Wakelin.

#### Additional thanks to...

- **Donate A Car** for their ongoing support! Over \$7,250 was raised through this program last year.

#### Champions for Parkinson's Raffle

The 2019 Fall Raffle raised \$1,660! The grand prize winner was Shelley Morris, who won a trip for two with WestJet! Congratulations, Shelley, and we hope you enjoy your adventure!

#### Nomad Online Throwdown

This 2019 event showed the power of the CrossFit community - for a good cause. Thank you to Craig White and Kayla Roux for organizing this event and raising \$900!

#### Ultra520k

Nick Hopewell participated in the Ultra520k 2019 and collected \$280 in donations benefitting Parkinson Society BC. Thank you, Nick!

## CAREPARTNER'S CORNER: AMBIGUOUS LOSS CONT'D

### Parkinson Society BC Resources

Counselling | [www.parkinson.bc.ca/counselling](http://www.parkinson.bc.ca/counselling)  
Support Groups | [www.parkinson.bc.ca/groups](http://www.parkinson.bc.ca/groups)  
PD Link Peer Support | [www.parkinson.bc.ca/pdlink](http://www.parkinson.bc.ca/pdlink)

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# SPECIAL NOTICE

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## CORONAVIRUS PRECAUTIONS

In response to the global outbreak of Coronavirus disease (COVID-19), Parkinson Society British Columbia (PSBC) has been taking proactive measures to manage the potential for transmission. It is important that we all actively work to protect vulnerable populations, and as such, we have made the decision to close our office. Staff will be working remotely until further notice.

We remain committed to serving the Parkinson's community as we monitor the situation. While many of us will be practicing social distancing and/or self-isolation, we encourage folks to continue to connect with one another by phone or email to lend a friendly ear of support. It is particularly important in preventing loneliness as in-person social interactions become more limited. PSBC will also be looking at ways to increase contact with our community by phone, particularly for those who are most vulnerable, during this time.

We will continue to offer our programs and services using webinars and other online tools to protect the health and safety of our staff and community. Please visit our website for details on all changes to our programs and services, as well as information on how to stay safe and healthy during the outbreak.

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