



VIEWPOINTS

FALL 2019

A QUARTERLY MAGAZINE
BY PARKINSON SOCIETY
BRITISH COLUMBIA

3

50TH ANNIVERSARY
HISTORICAL
TIMELINE

6

MANAGING FALL
RISKS WITH
EXERCISE

14

WORLD PARKINSON
CONGRESS: RECAP
& HIGHLIGHTS

Suite 600 - 890 West Pender Street, Vancouver, BC V6C 1J9
Phone 604-662-3240 | **Toll Free** 1-800-668-3330 | **Fax** 604-687-1327
Charitable Registration Number: 11880 1240 RR0001
www.parkinson.bc.ca | info@parkinson.bc.ca

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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.

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.

100 Mile House, Abbotsford, Advanced Carepartner Online, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, 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, North Shore, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Princeton, Quadra Island, Quesnel, Richmond, Richmond Carepartners, Shuswap/Salmon Arm, Sunshine Coast (Sechelt), Surrey, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, West Vancouver Carepartners, Williams Lake, White Rock, White Rock Carepartners, YOPD 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.

Celebrating 50 years of community.

50TH ANNIVERSARY

Parkinson Society British Columbia

1969

The BC Parkinson's Disease Association is incorporated on November 14, 1969.

In late 2018, Parkinson Society British Columbia (PSBC) made the decision to amend its mission statement to better align with the needs of the Parkinson's community and more accurately reflect the desire for those affected by the disease to be active participants in symptom management.

As our bylaws state, the Society is required to have a minimum of two people with Parkinson's disease as active members on the Board of Directors. This is to ensure that the Society remains focused on priorities important to the community it serves, as well as provide a greater diversity of opinions.

The change in the Society's mission statement was guided by those living with Parkinson's disease who sit on the Board.

Our old mission statement:

Parkinson Society British Columbia is the voice of British Columbians living with Parkinson's. Our purpose is to ease the burden and find a cure for Parkinson's disease through advocacy, education, research, and support services.

Our new mission statement:

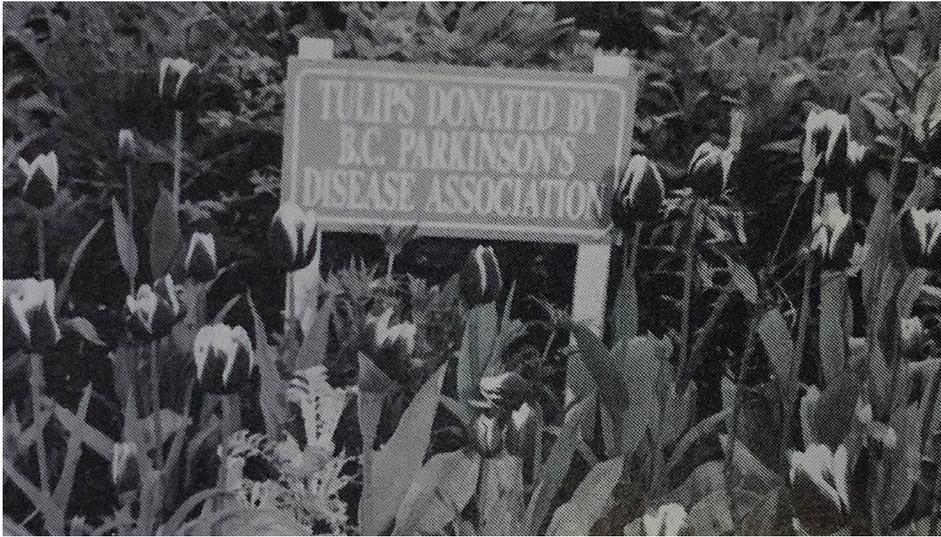
Empower the Parkinson's community in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

Parkinson Society British Columbia considers itself a service-based organization. Our priority is to help people affected by Parkinson's disease improve their quality of life and live well.

Our change in mission does not mean that we will stop providing programs, services, advocacy efforts, and research contributions. Rather, it highlights a shift in approach to empowering and enabling individuals to take control of their health.

While Parkinson's can cause disabling symptoms, we recognize that each person's experience with the disease is different. In recent years, there has been a greater effort to improve awareness of disabilities, with focus being placed on what adaptations can be made to help people live well, recognizing each person's strengths, and presenting a more realistic picture of what it means to live with a chronic condition.

We see our change in mission to align with the shift in social awareness, in that it acknowledges that each individual can use informed decision making to manage their health. The resources and services provided by PSBC will allow people to choose what fits their needs at any given point in time.



1984

The BC Parkinson's Disease Association establishes its own Board of Directors. Before this, we shared a Board with the Vancouver Neurological Centre.

1987

At this time, we had a network of seven support groups across the province.

1989

An Executive Director, Ellen LeFevre, was hired to advance the Association's goals.

1990

The BCPDA selects their first logo from community design submissions.

1992

Our first community needs survey was conducted, and we hired our first part-time support services staff member.

2002

We changed our name to Parkinson Society British Columbia.

2006

At this time, we employed six staff members to serve the BC Parkinson's community.

2007

We held our first conference, *Parkinson's: The Journey*, on October 26 - 28, and launched our partnership with Blakes, bringing pro bono legal services to the Parkinson's community.

2009

We funded new equipment for Deep Brain Stimulation surgery at Vancouver General Hospital.

A VERY SPECIAL HELLO!

I am delighted to have been appointed Executive Director of the B.C. Parkinson's Disease Association. As of 15 August, I am working three days a week on your behalf to promote the growth and development of our Association. There is lots to be done, and it looks like good work -- by that I mean it looks both challenging, as well as do-able.

Several areas are high priority, and I will be working to:

- 1) increase public and professional awareness of Parkinson's Disease, and of our Association's purpose and activities;
- 2) support and link existing self-help groups in B.C., and encourage development of new groups and new volunteers;
- 3) increase financial support to the Association.

I will be relying on the skills and knowledge of the Board and

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Best wishes,

Ellen
ELLEN (LeFevre)





Moving forward, Parkinson Society BC will be working to address the needs of all those affected by Parkinson's disease across the province, informed by the results of our recent Community Needs survey.

Based on the survey's key findings, we will work to incorporate more education on topics such as cognitive health changes, disease progression, and navigating the healthcare system.v

We will also continue to provide scholarships for PD-specific training to allied healthcare professionals (AHCP), and strengthen our collaboration with local health authorities. Approximately one-fifth of our survey respondents expressed that access to AHCP was an issue in their communities. That is why we are actively working to support PD-specific services across BC. These include exercise, physiotherapy, occupational therapy, and speech-language pathology programs, among others.

To support carepartners, we will be circulating a second survey to our networks, so that we may better define problems and work towards solutions.

A full report of our survey findings will be available soon.

2013

We produced *Understanding and Moving Forward*, a booklet providing an introduction to Parkinson's disease.

2015

Our free counseling program was launched to support people with Parkinson's disease and their loved ones.

2017

The BC Ministry of Health began funding DUODOPA® therapy, thanks to advocacy efforts led by Parkinson Society BC. We also brought *Aware in Care Kits* to BC through a partnership with the Parkinson's Foundation, and launched our Continuing Education Scholarship Program to provide opportunities to allied healthcare professionals to get Parkinson's-specific training.

2018

We published *A Comprehensive Guide for Parkinson's Caregivers*, and introduced PD Connect, giving healthcare professionals the tools to refer their patients to our support services.

2019

Our advocacy campaign led to the BC Health Ministry's announcement of an action plan to expand the Deep Brain Stimulation Program.

On Thursday, November 14th we are celebrating 50 years of service. Thank you for your ongoing support.

We look forward to growing our programs and services to ensure that every person touched by Parkinson's disease across the province knows that they are not alone in their journey.

Visit www.parkinson.bc.ca/50 to learn more about our 50th anniversary, watch videos about our community, and see clippings from our archives.



ASK AN EXPERT



Naomi Casiro Discusses Balance & Falling in Parkinson's

Naomi Casiro, BSc, MPT is a PWR! Certified Therapist, and the founder of NeuroFit BC. She started her career working as a personal trainer and lifestyle bootcamp instructor, and developed a passion for

motivating people to get the most out of life through active, healthy lifestyles.

After completing a Master's degree in physiotherapy, Naomi became focused on neurological rehabilitation, and over time, treating people with Parkinson's disease (PD) became the focus of her work. Now, she runs NeuroFit BC, where she teaches classes, treats clients, and offers courses for other health professionals to learn about the positive impact of exercise on neuroplasticity for those living with PD. Naomi is also an adjunct professor at the University of British Columbia.

What are some balance issues commonly experienced by people with Parkinson's?

People with Parkinson's disease often experience balance issues related to four specific challenges. These include:

- Freezing of gait (e.g. your feet not following when you are trying to turn)
- Retropulsion (the increased risk of falling backwards that comes with PD)
- Postural hypotension (a sudden drop in blood pressure when you stand up)
- Postural and gait issues (e.g. your affected foot catching when you step up a curb, or over an obstacle on the ground)

How is fall risk evaluated?

Fall risk is evaluated based on a thorough assessment that takes into consideration medical history, falls history, neurological assessment, and a gait/postural assessment.

Some of the tasks which we often look at in a balance assessment are someone's ability or inability to do the following:

- multi-task, especially while walking
- get up and down from the floor
- maintain their balance when nudged in various directions
- turn in a small space
- pick-up objects from the floor
- step backwards safely

What are some strategies for self-managing balance problems? What about helpful assistive devices or exercises?

One of the most important self-management tools people with Parkinson's can use is to stop and think about *when, where, and why* they are falling. Are you falling when trying to turn in the kitchen? Are you falling when trying to pick up an object? Are you getting dizzy when standing up, and then falling? Are you falling backwards?

Determining why falls are happening will allow you to problem solve much more effectively to improve balance and reduce fall risk. The second and very effective

management strategy is exercise, including functional movement challenges.

Assistive devices can be helpful or harmful depending on their use. A walker set too low can actually increase freezing and fall risk, and canes can worsen a forward leaning posture. However, using assistive devices properly can be extremely beneficial for balance. Walking poles are often a great tool to help improve posture and gait, and are a common assistive device we prescribe and use in the clinic.

How can people with Parkinson's minimize their risk of falling?

Balance exercises should be completed under the guidance of a healthcare professional. Please do not try the following at home without having had your balance assessed or a professional to guide you as you begin adding new challenges to your routine.

Practice your balance! When it comes to Parkinson's, it is truly a "use it or lose it" phenomenon. If you practice

your balance, it is much more likely to be there for you when you need it. This does not mean standing on one leg and counting to ten; it means including dynamic balance challenges. Some examples you can work on building into your fitness routine include:

- Stepping over and around objects
- Turning in various directions
- Getting up and down off the ground
- Getting up and down from kneeling
- Turning your head slowly while walking
- Practicing tall posture and dynamic arm swings while walking and standing still

How can physiotherapy help people with Parkinson's who have difficulties with balance, or a high risk of falling?

Every person diagnosed with PD should get a detailed physiotherapy assessment as early as possible. A qualified physiotherapist can assess posture, gait, balance, strength, and coordination. They can also help design a PD-specific exercise and treatment plan which will assist in achieving your goals and improving in areas you may be struggling. It is important to remember that our brains are neuroplastic, and can change. Healthcare professionals are trained to see things through a detailed biomechanical lens, and can help pinpoint what needs to be worked on in order to optimize your function, both now and for the future.

Specific functional exercise is key! Feeling off balance can be scary, but there are things you can do to take action and optimize your function. The time to get moving is now!

Additional Resources

Visit Naomi at NeuroFit BC for Parkinson's-specific group classes and one-on-one physiotherapy.

neurofitbc.com | info@neurofitbc.com | 604-345-9318

Naomi also offers many helpful videos on YouTube:

5 Tips To Better Posture | youtu.be/oCciCqYmYn8

Parkinson's Exercise Series | youtu.be/TCIUh9KshDs

To learn more about balance, fall risk, freezing, and other related topics, read some of our helpsheets:

Balance and Falls | bit.ly/pdbalanceandfalling

Walking Problems | bit.ly/pdwalkingproblems

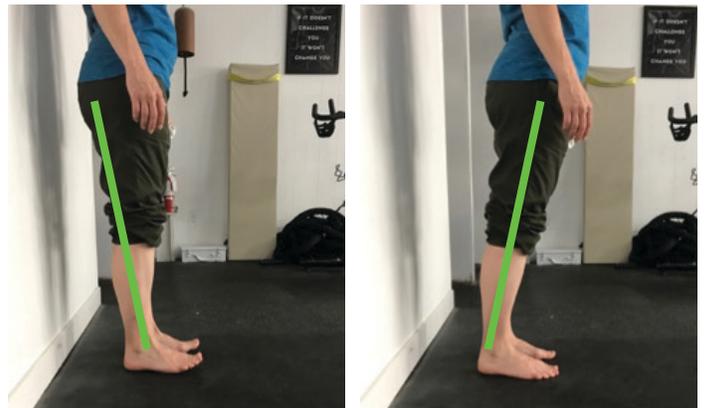
Freezing | bit.ly/pdfreezing

This article outlines a few common balance issues and potential solutions. Please consult your healthcare provider before attempting these at home.

Helpful Exercises

Problem: You tip backwards when standing still

Solution: Stand with a wall behind you. Imagine you have a triangle on the bottom of your foot with three points: one under your heel, one under your big toe, and one under your pinky toe. Practice keeping your body straight like a board, and leaning your weight back onto the heels, then forward to the toes. The movement should be small and come from your ankle. Next, try practicing a stable backwards step by sticking your bottom back to the wall and leaning your trunk forward.



Ankle weight shifts x 10 each direction



Stable backwards step x 10 repetitions each side

CONTINUED ON PAGE 11...

FREQUENTLY ASKED

Answering Your Questions

Every day, our friendly and knowledgeable staff are proud to offer information, resources, and referrals to people with Parkinson's disease (PD) and their loved ones across the province. To help you better understand how Parkinson Society BC (PSBC) can help you, we have compiled answers to some of the most common questions we receive.

What programs and services are offered by Parkinson Society British Columbia?

As a service-based organization, PSBC is proud to offer information, education, support, and advocacy to the Parkinson's community across the province.

Information

Individuals with Parkinson's, their carepartners, and family often find it helpful to talk with someone about their challenges. When you call, email, or visit PSBC at our Vancouver office, our compassionate staff can provide you with information and resources, help you understand the healthcare system, and offer guidance in problem-solving and planning. We are available during business hours through our toll-free line (1-800-668-3330) and via email, at info@parkinson.bc.ca.

Parkinson Society BC also provides information and support from the point of diagnosis, through our PD Connect program. PD Connect gives healthcare professionals the tools to refer their patients directly to our Society for support and education.

Education

The Society collaborates with leading Parkinson's experts in research, treatment, and supportive care in order to provide high-quality, credible educational resources. Our printed materials include helpsheets and booklets produced or purchased by PSBC, as well as a lending library of books on Parkinson's-related topics. Many presentations from our webinars and conferences are also posted online. We are constantly working to update and expand our available materials, and welcome topic suggestions from our community.

To connect our community directly to support and learning opportunities, we offer educational events across the province. These events allow participants to ask questions and meet our expert presenters. Throughout the year, our educational events include:

- Community Talks, facilitated by researchers, healthcare professionals, counsellors, and other Parkinson's experts
- Communication & Swallow Workshops, which offer an introduction into speech-language pathology, and the treatment of voice and swallowing difficulties
- Webinars, presented online by Parkinson's experts
- Carepartner workshops, tailored to educate caregivers and family, and provide respite
- Regional Conferences, bringing communities together for a full day of learning
- *Moving Forward, Together*, our provincial conference, featuring notable international, national, and local speakers

Support

At PSBC, we believe all people with Parkinson's deserve to know that they are not alone. People with PD can experience a wide range of unique symptoms, and disease progression is difficult to predict; the uncertainty of PD can feel overwhelming and isolating. That is why we offer services dedicated to helping those touched by the disease manage their wellbeing. These include:

- over 50 support groups for people with Parkinson's and carepartners, facilitated by members of the Parkinson's community with guidance from PSBC
- free, short-term counselling services, available in person or over the phone
- PDLink, a peer-to-peer support program, in which PSBC matches participants with peers who have similar experiences with PD

Advocacy

Parkinson Society BC aims to be an effective lobbyist for issues important to the Parkinson's community. With the grassroots support of our advocacy networks, we have helped put pressure on the Ministry of Health to increase funding and access to crucial PD treatments, like DUODOPA® therapy and Deep Brain Stimulation surgery.

Through a partnership with Blake, Cassels & Graydon LLP, PSBC members are also eligible to receive pro

bono legal services for issues such as workplace discrimination, wrongful denial of disability insurance or government services, and discrimination in public accommodations, services, or facilities.

Who runs Parkinson Society BC?

The Society is governed by a volunteer Board of Directors, and employs 10 full-time staff members. Our staff coordinate support services, education events, fundraising, publications, and advocacy efforts. The Society operates independently, and is not managed by any other external authority.

Support groups and fundraising events are facilitated largely by volunteers. Without the support of our hundreds-strong volunteer network, none of the Society's work would be possible.

How is Parkinson Society BC funded?

Parkinson Society BC relies on the generosity of our members and donors.

We are funded in large part by bequests, monthly gifts, and other donations. Last year, these gifts made up 66% of our income. Another large portion of our revenue comes from special events, like Parkinson SuperWalk, PSBC auctions and raffles, and fundraisers put on by members of our community. The remainder of our funding comes from investments and other income. More information is available in our annual reports.

I don't live in Vancouver. Can I still access the Society's services?

Parkinson Society BC strives to make all of our resources and services accessible across the province. Our educational materials are available for download on our website, and members may borrow books from our lending library that can be mailed to your home address. Consultations, counselling services, and referrals can be accessed over the phone. Education events are held province-wide, and webinars can be accessed from your home computer.

We are actively collaborating with local healthcare authorities to expand our reach, and bring our in-person support services to more locations across BC.

How much do the Society's services cost?

The majority of resources and services provided by Parkinson Society BC are completely free of charge. Our educational materials are readily available to

download online, and there is no fee to attend most of our webinars. Consultations, information, referrals, and counselling services are also free to access.

For many of our education events, we charge small fees to help us cover costs such as venue bookings, presenter honorariums, and printing of materials. Discounts are available to the Society's members, who pay a \$25 annual fee per household. Annual membership is not required to attend our events or access services.

We are always happy to subsidize these costs for those who show a financial need. The Society also offers travel scholarships for certain major events, like our provincial conference.

What are support groups, and how can they benefit me?

Support groups provide people with Parkinson's, carepartners, and family an opportunity to meet their peers in a friendly, supportive setting. Participants have the opportunity to share with others who are experiencing similar difficulties. There is comfort in knowing you are not alone, and learning from your peers.

Groups are led by volunteers with guidance from PSBC, but each group varies in how they choose to run their meetings. Some groups will go around the room and give all attendees a chance to provide an update on how things are going for them each meeting. Facilitators will relay timely resources and information from PSBC, and for some meetings, they may organize guest speakers for their group. Some support groups also offer exercise sessions.

All of the Society's groups operate on a drop-in basis. Typically, meetings take place once a month.

How does Parkinson Society BC support carepartners and families?

Our mission states that we serve to empower all those affected by Parkinson's disease — this includes the loved ones and carepartners of people with PD. PSBC's programs and services are available to anyone touched by PD, and we proudly offer resources tailored specifically to those who help manage the care of their loved one with the disease. Recently, we also released our *Comprehensive Guide for Parkinson's Caregivers*, which covers many topics necessary to support those

CONTINUED ON NEXT PAGE...

caring for a person with PD. Here are some of the other ways we support carepartners and families:

- workshops, community talks, webinars, and conference sessions geared towards carepartner education and respite care
- peer-to-peer support for carepartners through PDLink
- counselling with focus on caregiver burnout, respite, healthy relationships, and other topics important for carepartners
- educational resources for families, including guides on discussing the diagnosis with children and teens

Why does the Society use the term “carepartner”, and what does it mean?

Although it is possible to live a full life with Parkinson’s, most people with the disease greatly benefit from the support of their loved ones. We believe it is important to recognize the efforts of all those who support people with PD in managing their care, in any capacity.

Carepartner is an inclusive term we use to describe anyone in a caring role. More specifically, it implies a cooperative relationship (i.e., a partnership) between the individual giving care and the one receiving it. Most people with Parkinson’s are able to manage their own care, and make their own decisions about how to handle their personal affairs. In this case, the carepartner has a supportive role, helping the person with PD who can manage their own care. This term offers flexibility to those who do not identify as caregivers, especially if they identify more strongly with their primary relationship to their loved one with PD (i.e., spouse, partner, child, friend, etc.).

However, when someone is unable to self-manage, their carepartner may need to advocate for them more fully, sometimes through a legal representation agreement. In this case, the term caregiver may be more appropriate, and is often preferred.

What is Parkinson Society BC’s advocacy plan?

1. **Add specialized staff to existing PD programs**
PD-specific treatment programs need more physicians and allied healthcare professionals on staff to allow for additional and timely assessment.
2. **Fund PD training for allied healthcare professionals**
Professionals like physiotherapists, speech-language pathologists, and occupational therapists need specialized education to better treat PD.

3. Continue to Expand Access to the Deep Brain Stimulation (DBS) Program and DUODOPA®

Patients are often on the DBS waitlist for up to five years, while DUODOPA® has a cap of five procedures per year.

4. Expand medication coverage

More funding is needed to cover the cost of medications, and reduce out-of-pocket expenses for people with PD and their families.

5. Support for carepartners

Most carepartners are the spouses or family members of people with PD. Greater access to home care and respite is necessary to support carepartners, and improve outcomes for them and their loved ones.

What is Parkinson Society BC doing to educate healthcare professionals?

In order to bring more specialized PD care to communities across the province, PSBC offers a continuing education scholarship program. Each year, the Society offers \$6,000 in scholarships to healthcare professionals and exercise instructors who are seeking specialized training to better serve their clients with PD.

We also offer direct education through in-service presentations to healthcare professionals to help them learn more about the disease, as well as training programs for PWR!, SongShine, and Dance for PD.

How does Parkinson Society BC support research?

Parkinson Society BC funds research projects through partnerships with the Parkinson Canada Research Program (PCRP) and the Michael Smith Foundation for Health Research (MSFHR). The Society contributes to the PCRP, where money is distributed to promising Canadian research projects. The MSFHR matches our contribution of funds to research projects based in BC. *Read about new projects we’re funding on page 19.*

Additional Resources

Resources & Services | www.parkinson.bc.ca/resources
Counselling | www.parkinson.bc.ca/counselling
Advocacy | www.parkinson.bc.ca/advocacy
Annual Reports | www.parkinson.bc.ca/annualreport
Education Events | www.parkinson.bc.ca/events
Support Groups | www.parkinson.bc.ca/groups
Scholarships | www.parkinson.bc.ca/hcpscholarships
Research | www.parkinson.bc.ca/research

ASK THE EXPERT: BALANCE & FALLING CONT'D

Problem: You get dizzy when bending over or going from sitting to standing

Solution: Let your doctor or another healthcare professional know. Before you stand up, point and flex your toes up and down 20 times, pumping your ankles vigorously to get the blood flowing up towards your heart. When you stand up, before you step forward away from the chair or couch, march in the spot and count five "Mississippis". If you feel dizzy, sit down, pump your heels again, and re-try in about 30 seconds to one minute.



Point and flex toes x20 at a rapid rate

Problem: You fall or lose your balance when trying to turn in smaller spaces (i.e., the kitchen, closet, etc.)

Solution: Try taping a line to the floor that you can step over as you turn. This will help your feet move and reduce the chance of freezing. Always think "feet move first". For example, if you want to turn to the left, your feet need to point to the left before anything else goes.



Correct!
Foot first,
shoulders stay tall

Incorrect.
Feet fall behind,
shoulders move

REMINDER...

Please consult your healthcare provider before attempting these at home.

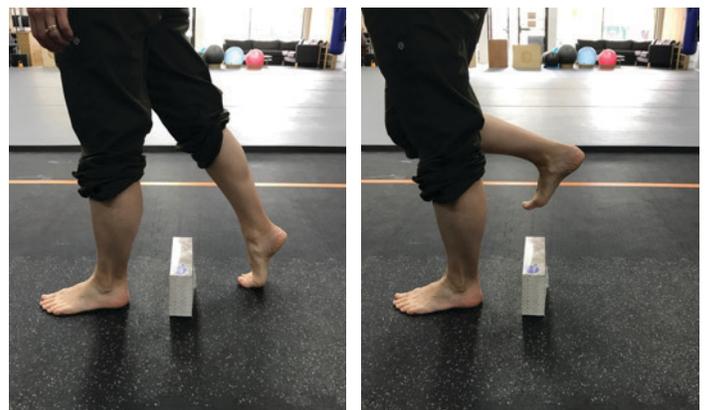
Problem: You catch your foot when walking (i.e. on a crack in the pavement, going up the curb, etc.)

Solution: follow the steps below to work on an exaggerated foot lift and ankle mobility, to reduce foot-catching and improve your walking mechanics. Repeat 10 steps for each foot. *Have a wall or chair beside you for safety.*



Stand tall with a tissue box in front of you

Lift one foot up and take a big high step over the box, exaggerating the toes-up posture



Land your front foot flat on the floor. Shift weight to the front foot, and practice the "toe-down, heel-up" position of the back foot

Push off the toes of the back foot and exaggerate the step height and toes-up position as you step over the box



MOVING FORWARD

together

Saturday, October 26

Hilton Vancouver Metrotown

Crystal Ballroom | 6083 McKay Ave, Burnaby

www.parkinson.bc.ca/movingforward

Parkinson Society British Columbia (PSBC) invites all members of the Parkinson's community in BC to join us for an exciting opportunity to learn about recent scientific breakthroughs and disease management techniques.

Moving Forward, Together will foster an educational and inspirational space for enriching the connection between people with Parkinson's, carepartners, friends, and healthcare professionals. The return of this much-anticipated event will feature prominent local, national, and international presenters who will speak to topics related to the treatment and management of Parkinson's and its associated challenges. The conference will include two morning plenaries and eight afternoon breakout sessions, which aim to offer a diversified itinerary for all attendees.

This year, we are offering a new breakout stream specifically for healthcare professionals to attend and expand their knowledge of Parkinson's disease.

Supported in part by

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AGENDA AT-A-GLANCE

- 8:00am *Registration Opens*
- 9:00am *Welcome* – Jean Blake, CEO of PSBC
- 9:10am *Motivational Speaker* – Doug Dalquist
- 9:25am *Plenary 1*
 - Non-Motor Symptoms* – Dr. Mark Mapstone
- 10:25am *Movement Break* – Marilyn Araujo
- 10:35am *Break | Exhibit Hall*
- 11:05am *Plenary 2*
 - Motor Symptoms* – Dr. Alex Rajput
- 12:05pm *Movement Break* – Megan Walker-Straight
- 12:15pm *Lunch | Exhibit Hall*
- 1:30pm *Breakout Session 1*
 - Advanced Stages: Cognitive Changes & Palliative Care* – Dr. Keiran Tuck
 - Fatigue & Sleep Problems* – Dr. Daryl Wile
 - Mental Health Changes* – Dr. Andrew Howard
 - Upright & Walking Light: How to Prevent Falls* – Naomi Casiro
 - Beyond the Tremor: Treating Motor & Non-Motor Symptoms ** – Dr. Anish Kanungo
- 2:30pm *Break | Exhibit Hall*
- 2:45pm *Breakout Session 2*
 - Ambiguous Loss *** – Kathryn Brosseau
 - Medication Management* – Dr. Claire Hinnell
 - Nutrition* – Dr. Pamela Hutchinson
 - What Can Allied Healthcare Professionals Do For You?* – Panel
 - New Canadian Guidelines on Parkinson's Disease ** – Parkinson Canada
- 3:45pm *Conference Ends*

* Healthcare professional session

** Carepartner session

PLENARY SPEAKERS



Dr. Mark Mapstone is a translational neuroscientist, and professor of neurology at the University of California, Irvine School of Medicine. He is a member of the UCI Institute for Memory Impairments and Neurological Disorders and a Fellow

of the UCI Center for Neurobiology of Learning and Memory. His research focuses on pre-clinical detection of neurological disease using cognitive tests and biomarkers obtained from blood. He has a special interest in developing strategies to maintain successful cognitive aging. In the clinic, he specializes in cognitive assessment of older adults with suspected brain disease.

Dr. Mapstone earned a PhD in Clinical Psychology at Northwestern University and completed fellowship training in Neuropsychology and Experimental Therapeutics at the University of Rochester. He received a Career Development Award from the National Institute on Aging and his research has been funded by the National Institutes of Health, the Michael J. Fox Foundation, and the Department of Defense.



Dr. Alex Rajput is Head of the Division of Neurology at the University of Saskatchewan. His primary interests are Parkinson's disease and other parkinsonian conditions, essential tremor, and dystonia. He is a member of the Parkinson Study Group, the

International Essential Tremor Medical Advisory Group, Tremor Research Group, and the Canadian Movement Disorders Group. He has been a member of the editorial review boards of Parkinsonism and Related Disorders and The Canadian Journal of Neurological Sciences in addition to reviewing for other journals.

Dr. Rajput is the director of the Saskatchewan Movement Disorders Program and the Frozen Brain Studies Laboratory. He is involved in both clinical and basic science research with local, national, and international collaborators. He has authored or co-authored 16 book chapters, and authored or contributed to more than 140 peer-reviewed publications. Dr. Rajput is a co-author of the first Canadian Guidelines on Parkinson's Disease published in the Canadian Journal of Neurological Sciences in 2012.

Celebrating 50 Years of Education

Since its inception in 1969, Parkinson Society BC has been bringing people with Parkinson's, carepartners, and healthcare professionals together to collaborate and inspire hope. As our largest education event, *Moving Forward, Together* is an opportunity to celebrate 50 years of empowering our community.

Our very first provincial conference was held on October 26-28, 2007, exactly 12 years before *Moving Forward, Together* this fall. With your support, we hope to make this conference an annual event.

Questions? Contact us!

Phone: 604-662-3240

Toll-Free: 1-800-668-3330

Email: info@parkinson.bc.ca

EXHIBITORS:

- *CDI College Massage*
- *Dance for PD*
- *Family Caregivers of BC*
- *NeuroFit BC*
- *Physiotherapy Association of BC*
- *Pacific Parkinson's Research Centre*
- *Rock Steady Boxing New West*
- *Rock Steady Boxing Vancouver*
- *Route 65 - EngAge BC*
- *Telus Health*

WPC 2019

World Parkinson Congress Highlights 2019

This June, the 5th World Parkinson Congress (WPC) took place in Kyoto, Japan. The Congress unites the global Parkinson's community to inspire hope and share knowledge, self-management tools, and research findings.

Our staff in attendance were thrilled to see so many members of the BC Parkinson's community in Kyoto. The Society proudly funded scholarships for 10 attendees, including people with Parkinson's, carepartners, and healthcare professionals, and we were happy to meet a number of attendees who travelled from BC independently.

Travel to a foreign country was certainly part of the attraction of this year's WPC, but what stood out most to our delegates was the passion and positivity at the event. The sheer volume of people working to study Parkinson's disease (PD) and improve patient outcomes leads us to believe in a brighter future.

A few session highlights from this year's World Parkinson Congress include:

- Dr. Shinya Yamanaka, 2012 Nobel Laureate in Physiology Medicine, discussed human trials in cell reprogramming. Recent studies have shown that stem cells may be injected into the brain to replace dopamine-producing neurons. Drs. Jun and Masayo Takahashi have performed studies on monkey models, in which subjects showed significant improvements lasting two years following human stem cell injection.
- Angelo Antonini introduced a new definition of advanced PD, determined by consensus among leading Parkinson's experts. A person is said to have advanced PD if they are taking at least five doses of levodopa per day, with two hours or more of "off" periods, and one hour or more of troublesome dyskinesia. This is referred to as the "Five-Two-One" definition.
- Jeffrey Kordower presented on the connection between Parkinson's and gut health. Given that

clinical and pathological evidence support the notion that PD may begin in the intestinal wall, and that symptoms of intestinal disease may precede PD diagnosis by over a decade, it may be possible to one day use colonic tissue biopsy to predict the onset of PD. Research suggests that treating inflammatory bowel disease may also lower the risk of developing PD.

Soaring with Hope for PD

Traditionally, in Japan, the crane is a symbol of peace and hope. It is believed that if one folds 1,000 cranes, their wish will come true.

Famously, a young girl by the name of Sadako Sasaki, decided to fold cranes hoping that her wish to live would be granted. As an infant, Sadako was exposed to radiation from the atomic bomb that was dropped on Hiroshima, and later diagnosed with leukemia. Unfortunately, she was unable to finish the project before she passed, but her classmates continued to fold cranes in her honour.

At WPC, this tradition was continued to help inspire hope for the international Parkinson's community.



Three individuals, Naomi, Clara, and Amy, were brought together by Young Onset Parkinson's disease (YOPD), and a love for juicy pork dumplings. They decided to undertake a project called "Soaring with Hope for PD", where they coordinated volunteers from around the world to help fold over 16,000 origami cranes, each carrying a message of hope. Individuals from 39 countries participated in the project. These cranes were then strung from traditional Asian umbrellas, and placed on display at the Congress.

Following the Congress, the cranes were presented to a number of people and organizations. Parkinson Society BC was fortunate to have been selected as a recipient. To carry forth this message of hope and continue to raise awareness, the umbrella will be on display at our upcoming provincial conference, *Moving Forward, Together*.



Topic Highlight: Wearable Devices and Applications for Parkinson's Disease

In recent years, there has been an increased interest in the use of wearable devices for Parkinson's disease. The primary reason to have people wear sensors is to capture data, and the reasons for capturing this data are multi-fold:

- To improve disease diagnosis – PD is diagnosed mainly through clinical examination. When symptoms are subtle, healthcare professionals may not be able to firmly diagnose PD. Some wearable technology research efforts are focused on developing an algorithm to help make a clearer diagnosis of PD by tracking the patient's symptoms and daily functioning.
- To improve symptom monitoring – Patients tend to see their doctors for relatively brief periods, and currently, doctors adjust medication doses based on anecdotal patient and carepartner reports. More information about how a patient is actually doing at home, in the form of reliable information gleaned from a wearable sensor, may allow for more accurate and timely medication adjustments.

- To encourage increased activity or track compliance with an exercise program – This is the rationale behind personal fitness tracking devices, which are used by the general population, and can be effective in the PD population as well.
- To improve clinical trial data – Currently, the way clinical trials determine whether a medication is helpful is by performing rating scales at various points in the trial, such as the United Parkinson's Disease Rating Scale (UPDRS). This is a very crude way of determining medication effectiveness, since the scale shows imperfect inter-rater reliability (i.e. different examiners can come up with a different UPDRS score for the same patient). In addition, patients tend to perform well for their physician when they may not be doing as well at home. Trials sometimes ask patients to keep diaries at home to gather more information; however, like other methods of self-reporting, these can also be inaccurate. Supplementing the current rating scales and patient diaries with data gathered from wearable sensors could help determine whether a clinical trial medication is effective. This effort explains why pharmaceutical companies are very interested in wearables, and some are working to develop their own devices.

Wearable sensors can be placed on the wrist, ankle, or trunk, and data captured by these sensors can detail the patient's typical daily activities and symptoms. Sometimes, the sensors are too complicated or large to be used at home, and the patient needs to come to a neurophysiology lab for the data collection. However, recent technological advancements mean that wearable sensors are not only getting smaller and lighter, but also becoming increasingly more accessible, affordable, and user-friendly.

Many everyday devices are already equipped with sensors that can track patient data. For example, typing data can be collected by installing software on a patient's computer, with the patient continuing to interact with the keyboard as they normally would. Typing data can include how long a patient spends touching a key, and how long it takes between touching one key and the next. These details can provide information on the patient's dexterity, for example. Similarly, most smartphones and wearable fitness trackers (e.g. pedometers, smart

CONTINUED ON PAGE 18...

NEWSWORTHY

UPCOMING EDUCATION EVENTS

Time Out for Carepartners Workshop, Parksville

Parkinson Society BC recognizes the efforts made by carepartners and caregivers every day. On October 18, we invite all carepartners/caregivers to join us for an afternoon of education, socialization, and relaxation. Guest speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease. Light refreshments will be provided.

Special notice: An adjacent room will be available for people with Parkinson's (PwP) to partake in activities (e.g., light exercise, tai chi, meditation), while their carepartner/caregiver participates in the sessions. We ask that PwP coming to the event respect this room divide, and not attend sessions unintended for them. This room will be managed by volunteers who will provide companionship and light exercise activities. The volunteers will not be medical professionals.

Date: Friday, October 18
Time: 1:00pm - 4:30pm
Location: Parksville Community Centre
132 Jensen Ave E, Parksville
Cost: Member \$30 | Pair \$45
Non-member \$40 | Pair \$55

Communication & Swallow Workshop, White Rock

This full-day interactive and participatory workshop, led by Registered Speech Language Pathologist Sherri Zelazny, will focus on the communication and swallowing challenges faced by people with Parkinson's. This event is open to those already experiencing communication and swallowing challenges, as well as those who wish to be proactive in their treatment.

Date: Saturday, November 16
Time: 10:00am - 2:30pm
Location: Hazelmere Golf & Tennis Club
18150 8th Ave, Surrey
Cost: Member \$25 | Pair \$40
Non-member \$35 | Pair \$60

UPCOMING WEBINARS

Young Onset Parkinson's Disease Series

Young Onset Parkinson's Disease (YOPD) is generally defined as a diagnosis of Parkinson's before the age of 60. Because of the age of diagnosis, the needs of those with YOPD will differ from those with later-onset Parkinson's. Elaine Book, social worker at Pacific Parkinson's Research Centre, joins Parkinson Society BC for this webinar series aimed at addressing some of the specific issues faced by people affected by YOPD. Each session will allow time for a Q&A and discussion. All webinars in this series are free to participants.

Self-Management

Self-management refers to the tasks that an individual must undertake to live well with one or more chronic conditions. It is particularly important for people with YOPD as Parkinson's is a lifelong progressive neurological illness. This session will go over self-management techniques to help you live well and thrive.

Date: Thursday, November 7
Time: 7:00pm - 8:00pm

Coping as a Carepartner

This session will be co-facilitated by a carepartner of a YOPD individual and will cover some of the feelings and challenges that a carepartner of someone with YOPD may experience. Methods for coping will also be discussed.

Date: Thursday, November 14
Time: 7:00pm - 8:00pm

Parenting

One of the unique challenges of YOPD is that those diagnosed are often parents to young or adolescent children. In this session, co-facilitated by a YOPD parent, we will discuss how children may be affected by a Parkinson's diagnosis in the family and how parents are able to support their children in this journey.

Date: Thursday, November 21
Time: 7:00pm - 8:00pm

TO VIEW OUR FULL EDUCATION EVENT LISTINGS & REGISTER ONLINE, VISIT WWW.PARKINSON.BC.CA/EVENTS



Parkinson Superwalk is accepting online donations until December 31st!

Thank you to everyone who joined us at their local SuperWalk this September, as well as all those who participated in Virtual Walks! Funds raised at SuperWalk help Parkinson Society British Columbia continue to provide and grow our resources, support services, and educational events across the province. Your support also allow us to grow our awareness and advocacy efforts, and contribute funding to groundbreaking research.

Donations will be accepted online through the end of the year at www.parkinson.bc.ca/superwalk.

Ask the Expert: Hospitalization & Parkinson's

People with Parkinson's disease (PD) have unique needs and considerations while in the hospital, and it is not uncommon for healthcare professionals to be unfamiliar with these needs. It is important for people with Parkinson's to be prepared for both planned and unplanned hospital visits, and to know how to self-advocate for their care.

Debra Mayer will join Parkinson Society BC for the first time to discuss hospitalization and PD, share tips for how to best self-advocate in the hospital setting, and how you can make the most out of your Aware in Care kit. Debra is a member of the Aware in Care advisory committee at the Parkinson's Foundation, and is a registered nurse specializing in critical care and emergency nursing. Her areas of practice include chronic and acute care nursing, clinical experiences, and simulation. She also teaches nursing full-time.

Date: Tuesday, November 19
Time: 11:30am - 12:30m
Cost: Free

Thank you to our fundraisers & donors!

Full Throttle

On May 26th, participants took a car and motorcycle ride along the scenic Sea to Sky Highway, ending with a delicious lunch in Whistler. This year's ride raised \$13,145! Thank you to organizer Jim Smerdon and his family for another amazing event.

Shaken, Not Stirred

The Prince George Parkinson's support group held their annual dinner-dance fundraiser, Shaken, Not Stirred, on April 28th. The evening featured door prizes, a silent auction, 50/50 draws, and much more. The event raised nearly \$9,000, with 25% of proceeds benefitting the support group directly!

Elk Valley Parkinson's Golf Tournament

The 4th annual tournament at Sparwood Golf Course raised \$8,173 in benefit of the Society! Thank you to organizers Merl Shelley and Adam Toner.

Additional thanks to...

- **Laura Fey** organized a 30-day yoga challenge in Nanaimo, and raised \$460!
- **Michael Cheung** raised \$400 from his final year of Tea Parky sales. We look forward to his future fundraisers!
- **Storm City Coffee** donated \$1 from each purchase of their delicious Butterfly Tea Lemonade this April, raising a total of \$60.
- **Emily Chambers**, musician and long-time supporter of the Society, donated 50% of her merchandise sales for the month of April, totalling \$50.

Me-n-Ed's Pizza Parlors Charity Golf Classic

Thank you to Me-n-Ed's and organizer Chris Florian for an amazing \$7,000 raised for the Society at their 12th annual Charity Golf Classic this summer! The event featured a silent auction, raffle, and contests for golfers.

Spring Online Auction

Our Champions for Parkinson's Spring Online Auction included a variety of exciting items, like hotel getaways, passes to local attractions, dining experiences, and gift packages. Thank you to all the generous bidders who helped raise over \$1,600!

Anh and Chi at Main Street Car Free Day

Award-winning Vancouver restaurant, Anh and Chi, sold out at this year's Car Free Day festival on Main Street, and donated a portion of their proceeds to the Society! Thank you to the restaurant's sibling co-owners, Vincent and Amelie Nguyen, for their generous \$1,000 donation to the Society!

ASK THE EXPERT: WORLD PARKINSON CONGRESS HIGHLIGHTS

watches) come equipped with accelerometers and gyroscopes, which track movement and orientation, vibration, and tilt. The values generated by these sensors can detail the patient's movements, like walking, running, biking, and climbing stairs.

One system, which is already cleared by the US Food and Drug Administration (FDA), and is available on the market for monitoring of PD patients between visits to the doctor's office, is known as the Personal KinetiGraph® (PKG®). A patient wears this watch-like sensor for 6-10 days in anticipation of an office visit. The sensor collects data which is then interpreted through the PKG® algorithms to measure bradykinesia and dyskinesia throughout the time period that the watch is worn. The PKG® also has the ability to alert a patient to take a medication dose, and allows the patient to record whether the dose was taken. After the data is collected, the patient mails the watch in, and the data is downloaded and sent to the patient's physician to inform their next appointment. This data can then complement what the patient and carepartner say about their medication responses at home. A poster at WPC demonstrated that when PKG® is in use, it often influences and informs the decision to change medications.

Also presented at WPC was a smartphone-based system developed by the pharmaceutical company Roche. The data gleaned from their algorithm directly correlated with traditional scales and testing performed at movement disorder clinics, and in clinical trials.

In addition to wearable technologies that track patient symptoms, new devices are being developed to improve symptoms, too. In 2017, a Microsoft watch prototype was revealed that uses vibrating motors to dampen tremor. The device is known as Emma Watch, named after Emma Lawton, a British graphic designer with Young Onset PD. Lawton was the inspiration and first user of the invention, which dramatically improved her writing. This product is still under development, and not yet available on the market. Another similar technology is the Lifeware adaptive spoon. These vibrating and self-leveling spoons are designed to stabilize a trembling hand, making it easier bring food to the mouth. These spoons are specifically meant to help tremors that occur with action, which can be a symptom of Parkinson's, although less common than resting tremors.

Submitted by Andrew Davenport, PSBC Board Chair

WPC from the Perspective of an Attendee

Learning & Sharing

The choice of lectures at WPC seemed endless, with lots of great topics based in both research and practical aspects. There were also demonstrations, health rooms, and theatre presentations to watch. Caregivers had their own space for learning and conversing, which my daughter found very helpful. There really was something for everyone.

One of the most surprising lectures I attended examined the link between music and Parkinson's. The presenters explained that music and movement can change the brain. Even those with late stage PD benefit from singing, dancing, or swaying to the music. The type of music or dancing doesn't matter; they all work and improve the health and wellness of those living with PD.

I also had an opportunity to observe the Young Onset group discussing their problems, as I was early for the next lecture. It was interesting listening to them and hearing their passion for self-advocacy, and continuing the conversation beyond the discussion of the day. Their enthusiasm was contagious, and I felt positive and empowered after hearing them.

Making Connections

The learning and sharing at the Congress are key reasons for going; however, it is the people that I meet that keep me coming back. Those attending come from all walks of life and bring such unique perspectives and ideas. The Congress provides a chance to meet with those walking a similar path to your own.

Submitted by Diane Daignault

Additional Resources

Personal KinetiGraph® | bit.ly/pkgsystem

Roche Digital Biomarker App | bit.ly/rochepdapp

Microsoft Emma Watch | bit.ly/projectemma

Lifeware Assistive Spoons | lifeware.com

SAVE THE DATE: WPC 2022

The 6th triennial World Parkinson Congress will be held in Barcelona, Spain on June 7-10, 2022. To learn more, visit wpc2022.org

NEW RESEARCH

Through our partnership with Parkinson Canada, Parkinson Society BC is funding four new research projects starting this October, through July 2021.

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

RESEARCHER

Dr. Michael Schlossmacher

AWARD TYPE

Pilot Project Grant

AWARD AMOUNT

\$50,000

INSTITUTE

University of Ottawa

DESCRIPTION

Inflammation is the immune system's response to either an infection, a poison, or an injury, meant to help the body heal and return to normal. In mice, these inflammatory responses include elevated oxygen in several organs which help to limit the spread of infection or injury. Exploring a causal association between environmental exposure history to the development of typical Parkinson's is of great interest to researchers.

A new dopaminergic therapeutic target for gait dysfunction in Parkinson's disease

RESEARCHER

Ms. Linda Kim

AWARD TYPE

Graduate Student Award

AWARD AMOUNT

\$20,000

INSTITUTE

Hotchkiss Brain Institute

DESCRIPTION

Gait disturbance in advanced Parkinson's can profoundly institutionalize. This study's key question is whether the activation of alternative dopamine-producing neural pathways can provide a better therapeutic target for gait abnormalities that are otherwise difficult to manage using current treatments. The characterization of other pathways will help explain the mechanisms of gait control, and assist with the development of new therapeutic interventions for gait dysfunction in PD.

Development of a new health-related quality of life measure for Parkinson's disease

RESEARCHER

Dr. Ayse Kuspinar

AWARD TYPE

New Investigator Award

AWARD AMOUNT

\$89,249.51

INSTITUTE

McMaster University

DESCRIPTION

It is often difficult to make decisions about which new Parkinson's therapies should be approved, and at what cost. Current health-related quality of life (HRQL) measures that are used to measure cost-effectiveness are too general. At present, there are no HRQL questionnaires that have been co-designed alongside people with PD. This project will develop a new questionnaire directly with people with PD, incorporating the patient's voice into the outcome of clinical trials.

Validation and calibration of the PREDIGT score to predict the incidence of Parkinson's in healthy subjects

RESEARCHER

Dr. Juan Li

AWARD TYPE

Basic Research Fellowship

AWARD AMOUNT

\$100,000

INSTITUTE

University of Ottawa

DESCRIPTION

The use of inexpensive, validated tools to calculate the risk of developing Parkinson's disease in neurologically healthy individuals, and to forecast the course of advancing stages, remains an unmet need with potential for prevention and interventional studies. This lab has recently created a non-invasive, mathematical score, i.e., the PREDIGT Score, as a new prediction tool. The validation of the hypothesis-driven PREDIGT score in (inter)national cohorts would further advance understanding of disease causation, and the reliable identification of at-risk populations and persons in early stages would impact clinical trial design and recruitment. This study would produce an online tool using the PREDIGT model to assist clinicians and nurses in identifying, counselling, and caring for at-risk individuals.

STAY CONNECTED TO THE PARKINSON'S COMMUNITY

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

For only \$25, you will receive an annual membership for you and your household, valid until December 31, 2020. Reasons to renew your membership:

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

Get an annual membership for only

\$25

Questions? Call or email Susan Atkinson, Donor & Member Services Coordinator
604-662-3240 | 1-800-668-3330 | satkinson@parkinson.bc.ca



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