# VIEWPOINTS

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SUMMER 2020 A QUARTERLY NEWSLETTER BY PARKINSON SOCIETY BRITISH COLUMBIA

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Suite 600 - 890 West Pender Street, Vancouver, BC V6C 1J9 *Phone* 604-662-3240 | *Toll Free* 1-800-668-3330 | *Fax* 604-687-1327

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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.

#### 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.

#### SUPPORT GROUPS

Our network of over 50 volunteerled 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, 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, Osoyoos/Oliver, Parksville/Qualicum, Parksville/ Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, Richmond Carepartners, Shuswap/Salmon Arm, Sunshine Coast (Sechelt), Surrey, Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, West Vancouver, West Vancouver Carepartners, White Rock, White Rock Carepartners, YOPD Online

## RESEARCH

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

When researchers design a clinical trial to evaluate the effectiveness of a new drug or therapy, one of the tools they use to assess the treatment's impact on a patient's quality of life is a generic questionnaire, called a preference-based measure.

At McMaster University, Assistant Professor Ayse Kuspinar thinks researchers, clinicians, and policymakers would get better information on how well a treatment works for people with Parkinson's disease if they could use a questionnaire designed specifically for that purpose.

That's why Kuspinar, a rehabilitation scientist, is conducting interviews and gathering feedback from people with Parkinson's about just what quality of life means to them.

"We're going to ask them, 'What areas of your life are most affected by your Parkinson's disease?'," Kuspinar says. "It might be social participation, like being able to spend time with grandchildren – or it might be specific symptoms, like tremors."

Once she has enough information from a pool of people with Parkinson's, Kuspinar will be able to incorporate their values and preferences into a new questionnaire that can be scored to produce a single numerical value. That questionnaire will eventually help doctors, researchers, and even policymakers decide which Parkinson's drugs and treatments to approve, administer, and pay for, as well as help clinicians assess whether a treatment is working.

"If we have a questionnaire that's developed for people with Parkinson's...it should allow us to capture the benefits of these treatments more precisely. Even more importantly, it allows us to assess these benefits from the patient's perspective."

"The challenge is that different types of treatments can have benefits on the health and quality of life of



#### **PROJECT GRANT**

\$89,249.51 over 2 years, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCHER Dr. Ayse Kuspinar INSTITUTE McMaster University

people with Parkinson's, but it's difficult to decide which treatment should be offered or approved, and at what cost," Kuspinar says.

Scoring the questionnaire can help doctors and researchers decide if a treatment is effective if it produces an improvement in only one domain – such as physical symptoms – versus all the domains people with Parkinson's consider important.

As a physical therapist, Kuspinar always valued even the incremental improvements she saw in her patients, whether it was better walking or their ability to get out of bed. That's why she wants to measure those improvements objectively and factor them into decision-making about how well a therapy is working.

"We have an important role and impact in improving the lives of people who are struggling," says Kuspinar. "We can make a big difference... that has been my reason to pursue this path."

Reproduced with permission from Parkinson Canada.

#### DID YOU KNOW...

You can volunteer to participate in leading Parkinson's research right here in BC. Learn more about current opportunities at www.parkinson.bc.ca/research-recruitment.

## **ASK AN EXPERT**



Matthew Sacheli, PhD, discusses his research on exercise for Parkinson's

Matthew Sacheli, PhD, is a Research Program Specialist at the Weston Brain Institute. Dr. Sacheli completed a PhD at the Pacific Parkinson's Research Centre (PPRC)

and the Djavad Mowafaghian Centre for Brain Health, University of British Columbia, under the supervision of Dr. A. Jon Stoessl. His research looked at the therapeutic mechanisms of exercise in Parkinson's disease using PET and fMRI neuroimaging. During his graduate studies, he also studied sensory-based exercise interventions for the treatment of Parkinson's disease at the Sun Life Financial Movement Disorders Research and Rehabilitation Centre.

#### Please tell us a bit about your research.

We used functional magnetic resonance imaging (fMRI) and positron emission tomography (PET) brain imaging techniques to show how exercise can change the brain.

fMRI allows us to measure the brain activity of an individual while they are doing a task. fMRIs measure changes in blood flow to different parts of the brain, allowing us to see which parts of the brain are most active during a specific task.

PET imaging uses radioactive drugs called tracers. These tracers group together in areas of your body with higher levels of chemical activity, showing up as bright, glowing spots in the final image. PET imaging can provide insight into the chemical activity of the brain.

We used both types of neuroimaging to show that people with Parkinson's who exercise regularly have more dopamine released in their brains. We also found that regular exercise increased the amount of activity found in the region of the brain that is regulated by dopamine when compared to people with Parkinson's who don't regularly exercise. We then enrolled people with Parkinson's who did not regularly exercise, in a three month, three times a week cycling program. After three months, people who took part in the cycling program had more dopamine

> release and more activity in the region of the brain regulated by dopamine than people who only stretched for three months.

## What are the benefits of exercise for people with Parkinson's disease?

Exercise helps to enhance neuroplasticity and promote healthy brain function. Neuroplasticity refers to our brain's ongoing ability to form and reorganize connections between brain cells, also called neurons. It is the process at the heart of how we learn, adapt, and function daily.

Our research showed that exercise increases dopamine release, which is an essential chemical in the brain involved in movement, mood, pleasure, and motivation. This mechanism occurs in an area of the brain called the basal ganglia, which is heavily involved in the brain's control of movement. We also showed

that exercise increases activity in an area of the brain that is related to motivation and reward.

An increase in dopamine and activity in these regions of the brain means exercise may improve some of the motor symptoms associated with Parkinson's disease. Exercise may also help with some non-motor symptoms, such as feelings of apathy and depression.

# How can research like yours help in the development of future treatments for Parkinson's?

By understanding how exercise can change the brain, we can create exercise routines for people with Parkinson's that maximize the benefits. By showing the effects of exercise are specifically beneficial to people with Parkinson's, we hope that exercise will become commonly added to the treatment plan for Parkinson's disease.

# What future research is needed to expand our understanding of exercise for Parkinson's?

There are a number of routes that can stem from this work. Primarily, this work should be replicated in other studies with more participants spread across multiple sites. This will ensure the results are accurate and repeatable.

Additionally, it would be very interesting to look at different types of exercise and how they affect or improve symptoms of Parkinson's disease. Exercise in the context of other lifestyle approaches, such as diet and sleep, could also be explored.

# How do diet, sleep, and exercise all interact with Parkinson's?

Our group is currently conducting a longitudinal study, a longer-term project where we observe many factors in our participants throughout the study. This longitudinal study is investigating the long-term effects of exercise on disease progression. Some previous research suggests exercise may slow the progression of Parkinson's disease, but this has not been proven, so we are hoping to test that idea.

# What do you want the community to know about the role of research in Parkinson's?

Research plays an incredibly important role in Parkinson's disease, and people with Parkinson's play an incredibly important role in research. We certainly could not have done any of our studies without the generous financial support and the selfless dedication of all of our participants and their families.

Research projects like this one allow us to gain insight into the complexity of Parkinson's disease, help begin to unravel the disease, and bring us closer to a cure. Many researchers all over the world, and especially in British Columbia, have dedicated their lives to improving care, and hopefully finding a cure for Parkinson's disease. We appreciate all of your support.

#### Anything else you would like to add?

This was an incredibly complex study with many moving parts. I want to thank all of our study participants and their caregivers that dedicated their time and effort to this study. I also want to thank the entire team at the Pacific Parkinson's Research Centre and the generous donors at the Pacific Parkinson's Research Institute, Parkinson Canada, and Parkinson Society BC.

The Parkinson's disease community in BC has fully embraced me, and it is truly an honour to be able to share these results and give back to the community that has helped me so much. Thank you!

#### EXERCISE RESOURCES

To help support our community in staying healthy and active during the COVID-19 outbreak, Parkinson Society BC is offering a variety of exercise programs that you can follow along with from the comfort of home.

10 Day Exercise Challenge www.parkinson.bc.ca/10-day-challenge

#### Exercise Classes with Naomi Casiro http://bit.ly/psbc-neurofit

Exercise with Nordic Poles http://bit.ly/exercise-with-poles

Morning Pilates with Shelly Level 1: Seated/Modified http://bit.ly/pilates-with-shelly-1

Level 2: Standing http://bit.ly/pilates-with-shelly-2

Move with Shelly http://bit.ly/move-with-shelly

#### Rock Steady Boxing with Allie Saks http://bit.ly/psbc-rsb

For listings of our upcoming exercise programs, please visit <u>www.parkinson.bc.ca/events</u>.

#### Sources

Sacheli, M. A. (2019). Exercise increases caudate dopamine release and ventral striatal activation in Parkinson's disease. *Movement Disorders*, 34(12). Retrieved from: <u>https://doi.org/10.1002/mds.27865</u>

# PARKINSON SUPERWALK

Parkinson SuperWalk is Parkinson Society British Columbia's largest annual fundraising event. Funds raised through SuperWalk help us provide life-changing programs and services to our community. During the COVID-19 pandemic, we have made strides to ensure that the people with Parkinson's, carepartners, and families we serve all get the support and resources they need in this difficult time.

Here are just some of the efforts we've made to support you during the outbreak:

- We have tripled our educational event offerings this year, in order to better support our community with online resources during COVID-19. Our staff are working hard to bring you new webinars every week, featuring expert speakers on topics like social distancing, mindfulness, and self-management — all free for participants. We want to make sure you continue to stay informed and engaged in your Parkinson's care while we practice social distancing.
- To help you better navigate the support services and resources available to you, we have increased our availability for information and referral consultations via phone and email. We have also expanded our counselling service to accommodate more clients, with phone sessions now available 5 days per week, almost doubling our usual availability.
- We are **keeping our community socially connected** by helping our support groups transition to phone and video chat meetings, and through new initiatives like our weekly online support group, online improv workshops, and other online events.
- To help you stay active, we are offering a range of new exercise programs, including classes run by neuro physiotherapist and PSBC staff member, Shelly Yu, and through partnerships with Parkinson's exercise experts from NeuroFit BC, Rock Steady Boxing, Urban Poling Inc., Dance for PD<sup>®</sup>, and others.

Fundraising through Parkinson SuperWalk is crucial to the Society as we move forward with adapting to the new normal. So gather your teammates, register online, and donate today!





# NO MATTER WHAT

At Parkinson Society British Columbia, we are inspired every day by the strength and resilience of our community. Together, we are united in our commitment to the advocacy, research, and fundraising efforts that are bringing us closer to a future without Parkinson's disease. We invite you to join us and champion the cause again this year for the 30<sup>th</sup> annual Parkinson SuperWalk.

We are adapting to the new normal this year by bringing you an engaging virtual SuperWalk experience, with walk weekend taking place September 12<sup>th</sup> and 13<sup>th</sup>. As we continue to practice physical distancing for the health and safety of our communities, the event will help us carry on providing the programs, support services, educational resources, and advocacy that people with Parkinson's, their families, and carepartners rely on.

This August, take part in our exercise and fundraising challenges leading up to SuperWalk's opening ceremonies, which will be held online, on Saturday, September 12<sup>th</sup> at 10:00am.



## Annual Report

2019

CHRIS & HAROLD, MAPLE RIDGE CHRIS WAS DIAGNOSED WITH PARKINSON'S DISEASE IN 2002

## What is Parkinson's Disease?

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

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

#### **Our Mission**

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

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# PARKINSON SUPERWALK

## Save the Date!

Parkinson SuperWalk will return to British Columbia

September 12 & 13, 2020

For more information and to register, visit: www.parkinson.bc.ca/superwalk

Charitable Registration Number 11880 1240 RR0001

# Executive Message

In 2019, we celebrated the 50<sup>th</sup> anniversary of the Society. With your help, we achieved many successes. In February, The Ministry of Health announced the doubling of Deep Brain Stimulation procedures from 36 to 72 annually, and the provision of budget for hiring a second neurosurgeon. We celebrated the announcement with the Honorable Adrian Dix (*BC's Minister of Health*), 29 members of the BC Legislature, Drs. Christopher Honey and Tara Rastin, and advocacy volunteers.

We engaged in conversations to increase our impact and reach with Interior Health and Island Health authorities. Contract negotiation continues into 2020; however, there has been positive progress in discussions to add allied healthcare staff, including, speech-language pathologists and physiotherapists, to existing movement disorder clinics. These positions will initially be funded by PSBC to help provide more holistic care to people living with Parkinson's disease.

# Our Progress in Empowering the Parkinson's Community:

Bringing together support group facilitators for a day-long training to expand knowledge of the disease, as well as provide tools for more effective group management

Launching a weekly information kiosk staffed by PSBC at the Pacific Parkinson's Research Centre (PPRC)

Hosting Moving Forward, Together, a provincial conference which offered a stream for healthcare professionals Successfully piloting an online exercise program aimed at reaching people in communities who have limited access to Parkinson's-specific exercise programming and/ or who are homebound

Awarding travel scholarships to people affected by Parkinson's disease and healthcare professionals to attend the World Parkinson Congress in Kyoto, Japan

Funding leading-edge research through the Michael Smith Foundation for Health Research, and the Parkinson Canada Research Program to improve understanding, treatment options, and search for a cure

We continued to inform our decisions by listening to feedback from those that rely on us – including carepartners, families, people with Parkinson's disease, and healthcare professionals.

Again, we reflect on the many accomplishments that have been made possible by you. Thank you for putting your trust in us to serve the needs of the Parkinson's community for over 50 years.

Signed,



ean Blake CEO ean Blake



Andrew Davenport CHAIR Comolos Aft

# Message from Finance Committee

The Statement of Financial Position for the year ended December 31, 2019 presents healthy working capital with current assets significantly exceeding current liabilities. The Society's investment portfolio with a market value of \$1,666,462 (2018 - \$1,417,549) continues to generate modest returns.

Overall, the 2019 Statement of Revenue and Expenses presents an excess of revenue over expenses of \$125,074 compared to the 2019 budget that was approved with a planned deficit of \$259,035. This excess reflects the receipt of an unanticipated bequest of \$200,000 and a foundation gift of \$75,000. Fundraising revenue, excluding bequests, also increased in 2019 to \$1,122,551 from \$1,042,728 in 2018, and continues to be an important part of PSBC's financial well-being. We are grateful for the continued commitment and support of our event participants, volunteers, donors, and sponsors.

During 2019, the Board invested in additional education and support services to extend our reach, increase our impact, and improve quality of life for people affected by Parkinson's disease in BC. This included hosting a number of Communication & Swallow Workshops across the province, which continue to assist people with Parkinson's in managing communication and swallowing challenges in the absence of qualified speech-language pathologists.

Notably, we have already committed to investing a minimum of \$394,208 in research from 2020 through 2023, in addition to \$142,823 in 2019. While we continue to fund research through the Parkinson Canada Research Program, we also partner with the Michael Smith Foundation for Health Research (MSFHR), which matches our research contributions.

The Society enters 2020 with reserves equal to 13 months of its historical expenses, which provides the Board with further opportunity to actualize our strategic priorities. An innovative initiative is the funding of additional allied health staff for the Kelowna movement disorder clinic and the Victoria movement disorder clinic beginning in 2020. The Board continues to review opportunities to further increase the Society's impact and reach throughout BC including conversations with Northern Health and Fraser Health authorities to implement visiting clinics.

## Our Picture of Financial Accountability

REVENUE 2019		٠	BEQUESTS	\$513,225	(31%)
	REVENUE	•	SPECIAL EVENTS	\$537,007	(33%)
		•	DONATIONS	\$506,555	(31%)
			INVESTMENTS & OTHER INCOME	\$78,989	(5%)
		•	SUPPORT SERVICES	\$683,347	(45%)
EXPENSES 2019		•	FUNDRAISING	\$417,919	(28%)
	•	PUBLIC AWARENESS, COMMUNICATION, & ADVOCACY	\$199,982	(13%)	
	2019	•	RESEARCH	\$142,823	(9.5%)
		•	GOVERNANCE & ADMINISTRATION	\$66,631	(4.5%)

To view a copy of our audited 2019 Financial Statements, please visit www.parkinson.bc.ca

# **Our Year** in Review

To our volunteers who contributed over 7,850 hours to assist with the Society's programs, services, advocacy, and fundraising...



education events





hours for advocacy



Parkinson SuperWalk

administration

hours volunteered for





**5513,225** given from the estates of 8 individuals



techniques at our **Communication &** Swallow Workshops



referrals through our PD Connect program



people attended our Moving Forward, Together

766

information and

referral connections



our Moving Forward, Together



people attended our online webinars



presentations



# Special Thanks to Our Supporters

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  - · David Christopher
  - Donald Chunn
  - Les Consenheim
  - · David and Debbie Couling

· Dick and Pamela Cowan

• Doug and Donna Dalquist

• Tony and Glenys Dawson

• Paul and Karen Degraaf

Gavin Dirom

David Evans

Joseph Donnelly

• Mrs. Sharon Dyball

Murray and Carol Firth

Norm and Pat Francis

• Gerald and Margo Gartner

• Robert Gauthier and Dorothy Read

Meredith Folkestad

Marion George

• Barbara Cox and William Reed

Nancy Coutts

## LIVING WELL

# Understanding disease progression and advanced Parkinson's disease

When it comes to determining the best treatment options for their patients with Parkinson's, healthcare professionals rely on knowledge of disease progression. Parkinson's is degenerative, so many people living with the disease will require a different approach to care at each stage. These stages are determined by consensus among Parkinson's experts, and are based on research observations of patients' commonly-shared symptoms.

For people with Parkinson's, it is important to discuss disease progression with your healthcare team in order to better understand your treatment, therapy, self-management, and medication options. By being familiar with the different stages of Parkinson's disease (PD), you can also become better equipped to recognize the symptom changes that may indicate disease progression into a later stage.

#### Parkinson's disease progression

Parkinson's starts in what is classified as the "premotor stage," when symptoms, mostly non-motor, begin to occur. The onset of early symptoms often begins 5 or more years before motor symptoms develop. These symptoms start off mild, and may go undetected for many years. In this stage, symptoms can include depression, sleep disturbances, constipation and bowel changes, autonomic nervous system dysfunction (which impacts the control of unconscious body functions), and a reduced sense of smell.

The disease then progresses into early-stage Parkinson's, in which rigidity, dyskinesia (tremors), bradykinesia (slowed movement), and akinesia (freezing) may develop. With further progression, some people with PD may also experience vision impairment and mild cognitive impairment. In the advanced stages, frequent falls are common, as is the onset of dementia or psychosis.

One of the most commonly-cited systems measuring the progression of Parkinson's, called the Hoehn and

Yahr scale, classifies the disease into the following five stages, based on motor symptom progression and personal independence (Hoehn and Yahr, 1967):

- Stage One: mild symptoms like tremors on one side of your body, and changes in posture, walking, and facial expressions
- *Stage Two:* symptoms worsen to tremors and rigidity on both sides of the body; walking issues and poor posture may be noticeable to others
- Stage Three: loss of balance and slowness; falling becomes more common, and it may be difficult to dress and feed oneself
- Stage Four: movement may require a walker or other assistive device, and it becomes increasingly difficult to perform daily tasks unassisted
- Stage Five: it may become impossible to stand or walk, and a wheelchair is required; hallucinations and delusions may also occur

#### Evaluating disease progression and healthcare options

Parkinson's is difficult to predict, and its progression can be a vastly different journey for each person with the disease. In order to get the best healthcare possible, it is important for people with PD to self-report their symptoms and experiences, and work with their healthcare teams to build personalized care plans.

When healthcare professionals evaluate people with Parkinson's, they may rely on a few different classifications of disease progression. The most commonly referenced evaluation system in Parkinson's research, the unified Parkinson's disease rating scale (UPDRS), groups together different patient evaluation techniques and disease progression scales, in order to build a holistic clinical rating scale. This scale is formulated in four parts, which include questionnaires for guiding healthcare professionals' assessment of patients with Parkinson's, as well as for patients to self-report their symptoms and experiences (Goetz et al., 2008).

Evaluations like the UPDRS help healthcare professionals map the progression of their patients' Parkinson's, in order to determine the efficacy of treatments, therapies, and interventions, as well as inform new treatment options. Clinical studies often evaluate the condition of their research participants using the same scale, which makes it easier for healthcare professionals to compare research findings with potential healthcare outcomes for their own patients. For example, if a certain medication is clinically proven to help improve motor function in people with Parkinson's evaluated to be in a certain stage of disease progression based on the UPDRS, healthcare professionals may prescribe such a medication to their patients with a similar UPDRS evaluation to that of the research participants.

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

Symptom management in the later stages of Parkinson's can be challenging without specialized care and multi-drug regimens. Sometimes, deviceaided therapies like Duodopa® (levodopa-carbidopa intestinal gel) or Deep Brain Stimulation (DBS) are also necessary for people with PD to maintain their quality of life. These types of advanced Parkinson's care are best provided by movement disorder specialists, who are experts in treating people with PD and other neurodegenerative conditions like Huntington's disease, dystonia, and essential tremor. A clear and concise definition of advanced Parkinson's disease helps primary care physicians know when it is time for their patients to see a movement disorder specialist.

#### Advanced Parkinson's

While there is still some debate among professionals on what exactly classifies as advanced Parkinson's disease (APD), leading movement disorder specialists from 10 European Union countries came together in a recent study to reach a consensus about its classification. They came up with a simple definition, called Five-Two-One, which determines someone to have APD if they:

- take 5, or more, oral levodopa doses per day,
- · have 2, or more, hours a day of "off" symptoms, and
- have 1, or more, hour(s) of moderate troublesome motor dyskinesia (Antonini et al., 2018).

There are, of course, exceptions to this definition, and every case of APD is unique. However, this definition provides a good rule of thumb for neurologists and patients, and allows them to plan their care accordingly. When a patient fits the Five-Two-One definition, it may be time for their primary care physician or general neurologist to refer them to a movement disorder specialist.

#### Planning for advanced stages

Throughout all stages of life with PD, it is important to prepare for what may come next. While these can be difficult conversations to have, being prepared for the future can make a huge impact on improving your quality of life and the lives of your loved ones.

As a degenerative condition, Parkinson's requires a palliative approach to care from the point of diagnosis. Palliative care refers to a holistic care strategy, involving your whole healthcare team, that takes into account the progressive and lifealtering nature of your condition. It means that your healthcare team is focused on maintaining your quality of life, beyond meeting your basic medical needs. As a person receiving palliative care, you are empowered to make informed decisions on the types of treatment and support services you prefer.

There are many ways you can plan for APD, including:

*Symptom Tracking:* A crucial part of PD care involves tracking your symptoms and reporting them openly and accurately to your healthcare team. Any changes in your condition should be shared with your primary care physician and neurologist, no matter how big or small. A worsening symptom could be a sign of disease progression, medication side effects, or ineffective treatment. By catching these changes as early as possible, your healthcare team can respond accordingly, and support you in maintaining your quality of life.

- Talking to Your Healthcare Professionals
  <u>http://bit.ly/paceframework</u>
- Comprehensive Care Plan Checklist <u>http://bit.ly/pdsymptomchecklist</u>

*Mental health & independence:* It can be difficult to cope with losing your independence as Parkinson's progresses. Many people with PD also find themselves losing their sense of identity, and their interest in hobbies and leisure, as the disease progresses. Speaking to a

mental health professional can help you gain a positive outlook and learn healthy coping strategies. Accepting help, especially from loved ones, may be challenging, but is necessary in order to stay safe and protected from unnecessary harm and injury. A counsellor or therapist can work with you and your family to ensure you feel comfortable and supported in all aspects of your life.

Mental Health & PD
 <u>http://bit.ly/pdmentalhealth</u>

*Work:* For those diagnosed with Parkinson's before the age of retirement, it is important to discuss potential workplace adaptations and accommodations with your employer, such as allowing adaptive technology, flexible scheduling, or a reduced workload. Parkinson's is considered a disability by law, so your employer is obligated to make a reasonable effort to accommodate your needs, and they cannot treat you differently because of your PD. If you do decide to discuss your PD with your employer, you may also find it helpful to connect them with a member of your healthcare team who can provide information on suitable accommodations, and advocate for your needs.

- Disclosing Parkinson's to Employers
  <u>https://bit.ly/pdemployers</u>
- Making Changes in the Workplace
  <u>http://bit.ly/pdworkplaceadapt</u>

*Finances:* Depending on your situation, you and your family may be eligible for certain tax credits, benefits, and deductions. Speak to your healthcare team, as well as your accountant or financial advisor, about your eligibility. If you do not have one already, you should also explore your options for a comprehensive insurance plan to cover medical expenses and support services. It is never too early to begin planning and saving money for the future, and as your PD progresses, you can revisit your financial plans to ensure you are prepared for any next steps.

- Tax Tips for People with Parkinson's <u>http://bit.ly/taxtipsforpwp</u>
- Disability Tax Credit
  <u>http://bit.ly/pddisabilitytax</u>
- Assistive Devices, Home Adaptations, & Funding <u>http://bit.ly/pdhomeadaptation</u>

*Legal:* Discuss advance care planning with your family as soon as you feel comfortable to do so. As PD progresses, it may cause cognitive changes that

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

- Power of Attorney
  <u>http://bit.ly/pdpowerofattorney</u>
- Healthcare Decision Making
  <u>http://bit.ly/pdadvancecareplan</u>

#### **Additional Resources**

For help navigating resources and services available in your community, contact Parkinson Society BC at <u>info@parkinson.bc.ca</u> or 1-800-668-3330. Our friendly and knowledgeable staff are committed to offering support, sharing reliable information, and providing education.

#### **Helpsheets & Articles**

- Advanced Parkinson's | <u>http://bit.ly/advancedpdmgmt</u>
- Kathleen Yue Discusses Palliative Care for Parkinson's | <u>http://bit.ly/vptspalliativecare</u>
- Progression of Parkinson's | http://bit.ly/pdprogression

#### Videos

- Advanced Stages: Cognitive Changes & Palliative Care - Dr. Keiran Tuck | <u>https://vimeo.com/376226744</u>
- Advanced Symptoms Dr. Martin McKeown | https://vimeo.com/album/4639252/video/221358336

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Antonini, A. et al. (2018). Developing consensus among movement disorder specialists on clinical indicators for identification and management of advanced Parkinson's disease: a multi-country Delphi-panel approach. *Current Medical Research and Opinion*, 34(12). Retrieved from: <u>https://doi.org/10.1080/030079</u> 95.2018.1502165

Goetz, C. et al. (2008). Movement Disorder Societysponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale presentation and clinimetric testing results. *Movement Disorders*, 23(15). Retrieved from: <u>https://doi.org/10.1002/mds.22340</u>

Hoehn, M., Yahr, M. (1967). Parkinsonism: onset, progression, and mortality. *Neurology*, 17(1). Retrieved from <u>https://doi.org/10.1212/WNL.17.5.427</u>

## **GIVING**

#### BC Fraternal Order of Eagles gifts \$500,000 to Parkinson Society BC from sale of Vancouver chapter building

The Fraternal Order of Eagles (FOE) is an international service club dedicated to uniting fraternally in the spirit of liberty, truth, justice, and equality. Each year, the FOE donates over \$10 million worldwide to charities, fundraisers, and community projects. Their motto is *People Helping People*.

The Eagles name their chapters after the nests of birds of prey, called aeries. There are several Aeries across British Columbia, all raising money and donating funds to support local organizations. In the last year, the Provincial President of the FOE in BC, Joseph Millette, chose to raise money for Parkinson Society British Columbia (PSBC) during his term. Donald Chunn has been a member of the Vancouver Eagles since 1980. Six years ago, he also became involved with PSBC when he visited with his sister, Debbie, who has Parkinson's. PSBC provided them with resources to learn more about the disease, and referred Debbie to her local support group in Burnaby.

Donald and his other sister, Brenda, wanted to continue supporting Debbie and her group, so together, they became involved in Parkinson SuperWalk. For two years, they coordinated the Burnaby SuperWalk, and they continue to support PSBC every year.

This past winter, Donald's Aerie of the Fraternal Order of Eagles made the difficult decision to shut down their club. In the spirit of their organization's enduring philanthropy, Donald and his fellow Eagles gifted PSBC with a donation of \$500,000 from the sale of their Aerie's building in Vancouver.

Parkinson Society British Columbia is grateful for this incredibly generous donation, which will support us in growing our support services, educational resources, advocacy efforts, and research contributions, and continuing to empower people touched by Parkinson's like Debbie, Donald, and Brenda.



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

## LIVING WELL

# Telehealth for Parkinson's: Accessing healthcare from home

Having access to timely and convenient healthcare is crucial for people living with Parkinson's. Modern technology has allowed for the growth of telehealth – medical care and services provided over the phone, internet, or remote devices – which is helping to make high-quality care more accessible.

There are many kinds of telehealth available, all of which serve to remotely connect patients to their healthcare providers. Some popular examples include:

- Phone or video chat appointments with your healthcare team
- Assessments, referrals, and prescriptions via internet or smartphone applications
- Medical information and advice phone lines and websites, such as HealthLink BC
- Medical alert systems, including smartphone applications, wearable sensors, or smart home systems for remote patient monitoring (telemonitoring)

The COVID-19 pandemic has led many healthcare professionals to turn to telehealth, in order to better practice physical distancing and protect their immunocompromised patients.

#### The benefits of telehealth

Telehealth enables people to quickly and easily connect with doctors, nurses, and other healthcare professionals from the comfort of their home. It also allows those living in smaller communities or rural areas to gain access to advice and assessment from busy specialists, who often have offices only in large urban centres.

One recent study (Beck et al., 2017), which had 195 people with Parkinson's receive their usual care through virtual appointments, evaluated telehealth to be an equally effective alternative to in-person visits. These virtual house calls saved the study's participants an average of 169 minutes of travel time, and roughly 150km of driving. Across British Columbia, access to movement disorder specialists and allied healthcare professionals can be extremely limited, and telehealth may be a way for many more people with PD to access their care, no matter where they live.

For people with PD, telehealth can also replace many in-person appointments with primary care providers. Healthcare professionals can perform visual assessments, and hear patients' self-reported symptoms over video chat. For many people, these types of appointments could even result in more accurate assessments, since patients are likely to feel more comfortable in their home environment than in a clinic or doctor's office, resulting in a more honest and candid conversation (Bloem et al., 2020).

Telehealth further allows people to connect with healthcare professionals during times when their guidance is most urgently needed, such as during freezing episodes, "off" periods, or other instances of severe symptom fluctuations. Bloem et al. (2020), note that assessments in a clinical environment may be unrealistic for some patients, who may appear to have little difficulty with their mobility during appointments, but who experience disabling symptoms at home. This discrepancy may come as a result of medication timing, as many people with Parkinson's will adjust their dosing in order to avoid symptoms that will affect their mobility and communication during appointments, and travel to and from them.

Bloem et al. (2020) also note that some patients, especially those who require visits to hospitals or mental health clinics, may feel ashamed or embarrassed in these environments. Virtual care from the comfort of home can eliminate this discomfort, and help patients focus on making the most of their healthcare appointments.

#### Accessing telehealth

If you are interested in accessing telehealth services, it is important to discuss this with your healthcare team, so they may refer you to services they know and use, or services proven useful for other people with Parkinson's. You may ask your healthcare team about setting up appointments through video conferencing platforms like Skype or Zoom to get started. For general health advice and guidance, you can also access telehealth through services like HealthLink BC (healthlinkbc.ca or 8-1-1) or through smartphone applications like Babylon by TELUS Health.

## NEWSWORTHY

#### **UPCOMING WEBINARS**

#### Time Out for Carepartners Webinar Series

Parkinson Society British Columbia recognizes the daily efforts made by carepartners and caregivers. This August, we invite all carepartners and caregivers to join us for this webinar series on education, health, and wellness.

The first two sessions will be hosted by Parkinson Society BC's own Tricia Wallace, Registered Clinical Counsellor, and Shelly Yu, neuro physiotherapist. These sessions focus on exploring mindfulness for mental and physical wellness.

The final two sessions, centred on education, will be hosted by Connie Jorsvik, Founder and Senior Healthcare Navigator/Advocate at Patient Pathways. Connie will provide guidance and practical information on how to navigate BC's healthcare system, with a focus on all aspects of the transition process from acute care to long-term and home care. General guidance, applications, and navigation tools that can be utilized by carepartners provincewide, will also be discussed.

Separate registration is required for each session.

Dates:	Tuesdays, August 4, 11, 18, & 25
Time:	11:30am - 12:30pm
Cost:	Free

#### Laughter Yoga for Parkinson's

Led by certified Laughter Yoga Leader, Marg McLaughlin, this workshop combines the breathing elements of yoga with laughter exercise to nurture inner joy. Different games and activities will be used to stimulate laughter in participants.

No equipment is required to participate.

Date:	Friday, August 14
Time:	2:00pm - 3:00pm
Cost:	Free

Thank you to our fundraisers & donors!

#### Me-n-Ed's Sweetheart Pizza Sales

This Valentine's Day, Me-n-Ed's generously donated \$2 from the sale of every heart-shaped Sweetheart Pizza at their parlors. They raised a total of \$720! Thank you to Me-n-Ed's for their ongoing support!

#### **IMPACT Parkinson's**

Thank you to IMPACT for their donation of \$376.75 from the sale of raffle tickets this spring!

#### Chocolate & Beer

The Annual Chocolate & Beer Tasting fundraiser returned for its 7<sup>th</sup> year this March, raising a record \$4,250! Thank you to Sherri and Julian Zelazny for organizing, and to Moody Ales and Take a Fancy Chocolates for providing the delicious brews and treats!

#### RBC & Parke Pacific Golf Tournament

Although the annual Parke Pacific Tournament was unfortunately cancelled due to COVID-19, RBC donated \$2000 to the event. Thank you, RBC!

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

#### LIVING WELL: TELEHEALTH CONT'D

As with any other method of healthcare service delivery, telehealth must adhere to high standards of security, privacy, and confidentiality between patients and their doctors. Before accessing telehealth, be sure that the services you choose are ones which are recommended by qualified healthcare professionals. For support in navigating services available to you, speak with your healthcare team, or connect with the friendly and knowledgeable staff at Parkinson Society BC.

#### Sources

Beck, Christopher A., et al. (2017). National randomized controlled trial of virtual house calls for Parkinson's disease. *Neurology*, 89(22). Retrieved from: <u>https://n.neurology.org/content/89/11/1152</u>

Bloem, Bastiaan R., Dorsey, E., and Okun, M.S. (2020). The Coronavirus Disease 2019 Crisis as Catalyst for Telemedicine for Chronic Neurological Disorders. *JAMA Neurol*. Retrieved from: <u>https://bit.ly/32KeGeP</u>

# SAVE THE DATE

#### MOVING FORWARD, TOGETHER SATURDAY, OCTOBER 17<sup>тн</sup>

Our provincial conference is moving online! Featuring presentations from prominent Parkinson's specialists and researchers across the country, this year's *Moving Forward, Together* will be a fully virtual experience.

The half-day event will offer three plenary talks, with opportunities for participants to ask their questions of our expert speakers. Just like our in-person event, we will also offer guided exercise breaks, and host a virtual exhibition hall. Register early, and you will be entered into a prize draw, with winners announced at the end of the conference. Mark your calendars, and stay tuned! Plenary speakers include:



#### **Dr. Anthony E. Lang**, Professor & Jack Clark Chair for Parkinson's Disease Research at the University of Toronto

Dr. Lang is the Director of the Edmond J. Safra Program in Parkinson's Disease and the Morton and Gloria Shulman Movement Disorders Clinic. He also holds the Lily Safra Chair in Movement Disorders at the Toronto Western Hospital, University Health Network. He has published over 700 peerreviewed papers and more than 100 book chapters, and is one of the most highly cited investigators in the field of movement disorders. In 2010, he was appointed as an Officer of the Order of Canada.

## **Dr. Matthew Sacheli**, Research Program Specialist at the Weston Brain Institute

Dr. Sacheli completed his PhD at the Pacific Parkinson's Research Center (PPRC) and the Djavad Mowafaghian Centre for Brain Health, University of British Columbia, under the supervision of Dr. A. Jon Stoessl. His research looked at the therapeutic mechanisms of exercise in Parkinson's disease using PET and fMRI neuroimaging. During his graduate studies, he also studied sensory-based exercise interventions for the treatment of Parkinson's disease at the Sun Life Financial Movement Disorders Research and Rehabilitation Centre.

#### **Dr. Jon Stoessl**, Professor & Head of Neurology at the University of British Columbia

Dr. Stoessl previously served as the Director of the Pacific Parkinson's Research Centre, and is now the Director of the Djavad Mowafaghian Centre for Brain Health at UBC. He holds a Tier 1 Canada Research Chair in Parkinson's, and is Editor in Chief of the Movement Disorders Journal. Dr. Stoessl uses positron emission tomography to study Parkinson's, including imaging biomarkers, the basis for complications of treatment, and mechanisms of the placebo effect.

### **REGISTRATION COMING SOON! STAY TUNED AT WWW.PARKINSON.BC.CA.**



600—890 West Pender Stree Vancouver, BC V6C 1J9

