

VIEWPOINTS



A quarterly newsletter for the
Parkinson's Community of British Columbia

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**PARKINSON
SUPERWALK**

**Registration
opens April
2nd!**

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OUR MISSION Parkinson Society British Columbia exists to address the personal and social consequences of Parkinson's disease through education, outreach, scientific research, advocacy and public awareness.

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Your support is essential!

PSBC would not exist without the generosity of its members, donors and volunteers since it receives no government support.

The following are some of the ways you can support your society:

Membership—\$25 annual fee

Monthly, Quarterly or Annual Donation

United Way—Remember PSBC when giving through United Way

Special Events—Your participation in our special events makes a difference

Planned Giving and Bequests—Consider PSBC as a beneficiary in your Will

Support 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 Caregivers, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, North Shore Caregivers, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, Richmond, Richmond Carepartner, Shuswap/Salmon Arm, South Sunshine Coast (Sechelt), Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, White Rock, YOPD Online

Editorial Statement

The views and opinions expressed within the pages of *Viewpoints* are not necessarily those of Parkinson Society British Columbia. The intention is to provide the reader with a wide range of material. Parkinson Society British Columbia welcomes submissions for the newsletter. The editor reserves the right to edit material and to withhold material from publication.

Articles contained in *Viewpoints* are for information only. PSBC 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.

Determining the Impact of a Multi-Disciplinary Movement Disorder Clinic on Health Outcomes and Health Care Spending in Parkinson's Disease

At the University of Manitoba, Dr. Anish Kanungo is attempting to change the minds of legislators who've been reluctant to use public dollars to finance dedicated clinics for the care of people with Parkinson's disease.

"The hard thing is that we don't have a cure for this disease... but symptom management and quality of life—that's an important goal," says Kanungo, a neurologist who is spending a year as a clinical movement disorders fellow.

Maintaining a good quality-of-life in people with Parkinson's disease has moved beyond simply prescribing levodopa. Today, caring for these patients requires experienced neurologists with specialized training in movement disorders who are knowledgeable about the explosion of growth in therapies available now and in the near future.

"There are a lot of approaches to the treatment of Parkinson's disease that you don't master in five years of neurology training," Kanungo says. "You need the extra year of fellowship to develop the competency needed to manage the subtle aspects of the disease."

In addition to treating patients, Kanungo is also analyzing Manitoba's population health database to compare outcomes for people with Parkinson's who are being treated at the clinic to outcomes of people with Parkinson's being treated by family doctors and general neurologists in the community.

"Having (specialized care) on one site and under one banner is, we think, the most efficient way to do

PILOT PROJECT GRANT

RESEARCH PROFILE

Dr. Anish Kanungo, Clinical Fellow

INSTITUTE

Movement Disorders Neurology
University of Manitoba



PROJECT GRANT

Parkinson Society British Columbia Pilot Project Grant of \$45,000 over one year through the Parkinson Canada Research Program

this—but nobody has really evaluated it," he says. "As a result, there has been a reluctance to publicly fund such clinics, despite the growing population of patients with Parkinson's across Canada."

Although such clinics have been established in Centres of Excellence, waiting lists are extensive. Frequently, patients with Parkinson's must travel great distances from their home communities to reach such centres. That's why Kanungo hopes to practice in a smaller community outside Manitoba when he finishes his fellowship at the Movement Disorder Clinic at Winnipeg's Deer Lodge Centre.

While undertaking his fellowship, Kanungo will be uniquely situated to perform this analysis.

"Having only one such clinic in Manitoba allows for a more direct comparison of health outcomes and costs between these models of health provision in Parkinson's disease—as opposed to other regions, where two or more movement disorder clinics have been established."

To learn more about other research projects supported by Parkinson Society British Columbia, visit www.parkinson.bc.ca/research.

Reproduced with permission from Parkinson Canada.

Gina Fernandez Explains Occupational Therapy for Parkinson's



Gina is an Occupational Therapist registered with the College of Occupational Therapists in British Columbia and a PWR!Moves Therapist. She graduated from the University of British Columbia with a

Master's Degree in Occupational Therapy in 2008, after finishing her Bachelor's Degree in Psychology from Simon Fraser University.

? What is occupational therapy (OT)?

Occupational therapy (OT) is the art and science of enabling individuals to participate in meaningful activities or occupations by using evidence-based practices and clinical reasoning. Occupational therapists can enable individuals by restoring function, providing equipment, changing the environment, providing strategies or teaching new skills to people to help them to succeed at specific tasks or occupations. We assist individuals in the areas of self-care (feeding or eating, bathing, dressing, toileting or grooming) work, volunteering and leisure (hobbies). An occupation may be different for each person—for example: a child's occupation may include playing on the playground; a young adult's occupation may include attending school or working; a mother's occupation may include looking after the household and her children; and a retiree's occupation may be that of a golfer or grandparent.

? What type of training do occupational therapists (OTs) need?

In Canada, every occupational therapist holds a Bachelor's degree or an entry-level Master's degree in Occupational Therapy. Occupational therapists in British Columbia are legally required to be registered with the College of Occupational Therapists of British Columbia to practice in this province.

If a person with Parkinson's disease (PD) is looking for an OT to improve their physical functioning and provide physical exercises, then they should look for an OT with PWR!Moves Certification. However, all OTs are qualified to provide cognitive exercises and perform home or equipment assessments for people with PD.

? What are some common therapies or routines you might help establish for patients with Parkinson's disease?

We often assist clients in establishing routines to improve their sleep quality and conserve energy, which enables them to participate in the activities that are important to them, such as work, parenting and leisure interests.

? How might the role of an OT change as the disease progresses?

In the early stages of the disease, you may see an OT assessing a client's problem solving, thinking and memory, or providing equipment such as grab bars for the toilet/shower or bathtub seats if a person has

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Is there an expert you know of that you would like Parkinson Society BC to consider for an upcoming feature in *Viewpoints*? Let us know! For comments and suggestions, please contact Amanda McCulley at [1-800-668-3330](tel:1-800-668-3330) or amcculley@parkinson.bc.ca.

decreased balance. Later, if a person with PD finds it challenging to walk long distances, an OT may recommend special wheelchairs to enable clients to still get out of their home and engage in the community. In later stages of disease progression, you may see an OT preventing skin wounds by prescribing special mattresses, or recommending hospital beds or ceiling lifts for transferring clients that can no longer walk on their own. We often perform home safety assessments, provide physical rehabilitation or memory/problem solving exercises, and offer workplace modifications to make a person's job less demanding.

How might someone with Parkinson's disease go about accessing OT services in BC?

Every health authority (Vancouver Coastal Health, Fraser Health, Northern Health Authority, etc.) or geographical area has a community team (home health team) of occupational therapists who can go into homes and perform safety assessments and recommend equipment. These OT services are free to individuals who have a family doctor. Clients do not require a referral to access these OT services (the Home Health Service Line is 1-855-412-2121).

There are also Specialized Senior Clinics that can be accessed if clients are over the age of 65, have complex medical needs and have noticed memory changes. These clinics have OTs working there whose services are free of charge. A doctor's referral is needed for the Seniors' Clinics.

You will also find that most hospitals have outpatient rehabilitation programs with an OT on staff that can provide exercises to clients.

Lastly, Parkinson Society BC maintains a list of health-care providers, and the Parkinson's Wellness Recovery (PWR!) website (www.pwr4life.org/professional-directory) has an up-to-date listing of OTs who have taken the course.

What are some tips you have or resources you would suggest for people with PD who might not have access to occupational therapy?

I would encourage them to reach out to physiotherapists as we have certain areas of overlap, and they can usually recommend some equipment to improve mobility and safety in the home. Individuals can also seek assistance from recreation therapists, as they can often help clients engage in community leisure activities.

For more information about Parkinson's disease management, including tips on daily living and how to access your healthcare team, visit www.parkinson.bc.ca/resources.

April is Parkinson's Awareness Month

This year, in recognition of Parkinson's Awareness Month, and World Parkinson's Day on April 11, we are encouraging individuals affected by the disease to share their experiences through our **#PDANDME** (PD and Me) campaign.

While most people have heard of Parkinson's disease (PD), the breadth of symptoms experienced and ripple effect the disease has on friends, family and the healthcare system is lesser understood. Furthermore, with approximately 13,000 British Columbians diagnosed with the condition, making it the second most common neurological disorder after Alzheimer's, the disease receives considerably less attention.

This year's campaign seeks to expand the public's understanding of Parkinson's disease by highlighting:

- **The complexity of the disease.**

While tremors are a common symptom, people with Parkinson's experience a range of motor and non-motor symptoms.

- **The diversity of the PD community.**

Although PD is slightly more prevalent in men than women, it impacts people regardless of age and ethnicity. The diversity of the disease has been the cornerstone of our *This is Parkinson's disease* campaign in 2016–17.

- **The community impact of the disease.**

We recognize that Parkinson's has an impact on those diagnosed, as well as their family and friends. We also know that the current healthcare system is often ill-equipped and too overburdened to assist patients with timely and effective disease management. With the aging population, the number of people in BC diagnosed with the condition is expected to increase, which will place further financial and social strains on families, institutions and organizations. It is for these reasons that Parkinson Society BC has been advocating for improved care and continuing the search for a cure by investing in promising research.

How You Can Help

Use your voice to help expand the reach of our **#PDANDME** (PD and Me) campaign! You can do this by sharing your experience with Parkinson's disease via Twitter, Facebook and Instagram using the hashtag **#PDANDME**. The more people that participate, the louder we will be heard!

You can share your content and stories with Parkinson Society British Columbia in one or more of the following ways (don't forget to use the hashtag **#PDANDME** where applicable):

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- 1- Like our page on Facebook: www.facebook.com/ParkinsonSocietyBritishColumbia
- 2- Follow us on Twitter: @ParkinsonsBC
- 3- Follow us on Instagram: @ParkinsonsBC
- 4- Send an email to Amanda McCulley at amcculley@parkinson.bc.ca
- 5- Mail can be forwarded to:
Parkinson Society British Columbia
Suite 600 – 890 West Pender Street
Vancouver, BC V6C 1J9

What Is PSBC Doing for April Awareness Month?

WHAT I WISH PEOPLE KNEW ABOUT PARKINSON'S CARDS



Star-shaped cards have been distributed to participating PSBC's support groups and brought to the Society's education events. These postcards have space for individuals to write down what they wish the public knew about PD. The feedback

provided on these cards will help us establish priorities for awareness, as well as direct future campaigns and initiatives.

PARKINSON'S ART EXHIBITION

We're planning an art exhibition featuring work from people with Parkinson's disease. This August, we'll be showcasing the selected pieces at the Vancouver Public Library's Georgia Street branch in "the Moat"!

We'd love to see your artistic side, and are currently seeking submissions for this project until June 1, 2018. Send us your photographs, paintings and/or sketches.

For full details, and submission forms, please visit:
www.parkinson.bc.ca/art-exhibit

SHEDDING LIGHT ON PARKINSON'S DISEASE

Landmarks and monuments light up in PSBC colours in recognition of World Parkinson's Awareness Day on April 11th. If you live, or will be near, one of these landmarks on the evening of April 11th, we encourage you to snap a photo and post it to your social networks using the hashtag **#PDANDME**.

The following landmarks will be participating:

- BC Place
- Canada Place
- Vancouver Lookout
- Telus Science World
- Vancouver City Hall
- Fitzsimmons Bridge (Whistler)

PUBLICITY & MEDIA COVERAGE

We will be continuing our long-standing relationship with Global BC, as well as several other media outlets, including print news and radio stations. As our efforts are extensive, and Viewpoints provides limited space for these details, we invite you to review our plan more in-depth at:

www.parkinson.bc.ca/pdandme





Medical Treatment Options for Parkinson's

Navigating the healthcare system and treatment methods available to people with Parkinson's (PwP) can be challenging. To add to this, some medical professionals lack the knowledge and resources to guide a person with Parkinson's through their options.

Many PwP in the earlier stages of the disease, opt to make use of non-pharmaceutical treatment options; for example, incorporating vigorous exercise, a healthy diet and effective stress management techniques into their daily lives.

As the disease progresses, further treatment may be considered. This article is intended to provide information on some of the medical treatment options available to PwP. It is important to note that this information does not replace consultation with medical professionals. Furthermore, Parkinson Society BC (PSBC) has chosen to identify drugs by their chemical names, as generic and brand names can vary between countries.

Common Pharmaceutical Options

Each individual's experience with Parkinson's disease is unique, and as such, there is no "one-size-fits-all" approach to treatment. As a PwP, it is important to find something that works for you. Remember, two people may have similar symptoms but be pursuing very different medication regimens, and that is alright!

Below is a listing of some common Parkinson's disease (PD) medications and their purposes:

- **Carbidopa-levodopa:** Widely considered to be the most effective Parkinson's disease medication, levodopa is a dopamine precursor that can cross the blood-brain barrier and be converted to dopamine in the brain. Levodopa is broken down rapidly in the body before it crosses the blood-brain barrier, so carbidopa is given concurrently to prevent levodopa from converting to dopamine outside of the brain. This early breakdown could lead to side effects like nausea and dizziness.
- **Dopamine agonists:** Mimic the action of dopamine in the brain by stimulating receptors within the brain. They often aren't as effective as levodopa, but they typically have a longer lasting effect. They are used as a monotherapy in early PD and adjunct therapy with levodopa in advanced PD.
- **Anticholinergic agents:** Believed to correct an imbalance between dopamine and acetylcholine in the brain, which can help control tremor. They have limited efficacy and should not be considered as first choice drugs.
- **Catechol-O-methyltransferase (COMT) inhibitors:** Block an enzyme that breaks down dopamine, which can help prolong levodopa therapy.
- **Monoamine oxidase-B inhibitors, also referred to as MAO-B inhibitors:** Block the MAO-B enzyme, which metabolizes dopamine in the brain. This leads to increased amounts of dopamine in the brain.
- **Amantadine:** Enhances dopamine release by blocking glutamate, a neuro-transmitter. Often used as short-term relief for early-stage or mild Parkinson's symptoms.

(Mayo Clinic, 2018)

Duodopa

Duodopa is a gel form of levodopa and carbidopa drug combination used to treat people with Parkinson's who have responded well to levodopa, but continue to experience severe motor fluctuations.

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It requires surgery where a stoma is placed into the abdomen. A tube is then inserted through the abdomen into the intestine. A pump then delivers a steady release of the drug directly into the intestine, providing a more constant “on” time.

This treatment, which costs approximately \$60,000 a year, was not publicly covered under BC PharmaCare until February 14, 2017, when a dedicated coalition of advocates, supported by Parkinson Society BC, demanded access to better care for PwP. While this was an incredible victory for the Parkinson’s community, it is important to note that there are very few patients in BC who require, and qualify for, this surgery. Selected patients who have private health insurance are required to use up their ‘lifetime’ limit before BC PharmaCare funding is provided.

The Ministry of Health is working with the Pacific Parkinson’s Research Centre, under the direction of Dr. Martin McKeown, to identify and prioritize patients for coverage of Duodopa. Dr. McKeown estimates there are only 10 to 12 patients per year that need to undergo this procedure.

Deep Brain Stimulation

Deep Brain Stimulation (DBS) is a relatively new, but common, surgical procedure whereby wires, called electrodes, are placed into the brain during surgery. The electrodes are then connected by a wire to a “pacemaker” that sits under the skin, usually in the chest. Electrical pulses, produced by the electrodes, reduce motor Parkinson’s symptoms such as stiffness, slowness and tremor. According to Dr. Honey, the DBS neurosurgeon at Vancouver Coastal Health Authority, the fact that the “pacemaker” can be adjusted in intensity to maximize symptom relief and minimize side effects is the greatest strength of this treatment option.

The surgery is best suited to individuals who have had Parkinson’s for several years, still receive benefits from medications, but experience significant “off” times and/or dyskinesia. A thorough assessment process for the surgery is required before an individual is identified as a suitable candidate.

While DBS can provide some relief from motor symptoms, there are some important considerations:

- DBS does not improve non-motor symptoms of Parkinson’s disease, such as dementia, depression, constipation, bladder dysfunction, falling, speech challenges or imbalance.
- There have been reports of cognition in PD patients worsening after DBS if the patient had a pre-existing cognitive impairment, such as dementia or mild to significant cognitive dysfunction.
- People with atypical parkinsonisms, such as Lewy body dementia or progressive supranuclear palsy, typically do not respond well to the surgery.

Advocating for Improved Access to DBS

In British Columbia, there is only one neurosurgeon qualified to perform DBS, Dr. Chris Honey, in Vancouver. Comparatively, Alberta, whose population is smaller than BC’s, is home to three DBS neurosurgeons. This disproportionate level of access has contributed to a growing waitlist for DBS surgery here in BC. Currently, the waitlist is four years in BC and only a number of months in Alberta.

To help improve access to DBS, PSBC is currently advocating for:

- **Outreach DBS clinics in Kelowna, Victoria, Kamloops and Prince George.** Right now, the Vancouver Coastal Health Authority (VCHA) is funding only the procedure itself and not travel costs for patients as they visit Vancouver for assessments before and after surgery. If outreach clinics were established, re-calibration of devices and battery replacements could be completed more locally, helping to manage volume in Vancouver and allow more people to undergo the procedure.
- **Increasing operating room time for Dr. Honey in Vancouver.** At the moment, Dr. Honey is unable to obtain sufficient operating room time to perform surgeries, resulting in an additional delay. Budget increases are needed for additional operating room

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Confessions of a Caregiver



John Murray is a caregiver and member of the Parkinson Society British Columbia (PSBC) community. With a background in business and pastoral ministry, he is now retired but continues to be involved in the pulpit ministry, public speaking and writing. The following is an excerpt from his newest book, *Body Parts and the Invisible You*, also available in PSBC's lending library. To learn more about John and his work, visit jmurray.ca.

My wife, Rita, has had Parkinson's since 2008. Consequently I have become a caregiver. I am not an expert; far from it. I am still learning but let me share a few thoughts on being a caregiver in the hope that it might encourage you if you are in the same situation. Caregiving is not easy. It is not something we seek. We don't ask for it. For the most part it comes upon us quite surreptitiously.

The simplest definition of caregiving is to provide physical and emotional support to those who are unable to care for themselves. But I believe it is more than that. I believe it is to create the very best environment and the best living conditions so that the person cared for enjoys life to the fullest possible extent, in spite of any incapacity.

The care we give develops and grows over time from the normal assistance and help, to ultimately full

time twenty-four hour attention. One begins by doing simple things in the course of a regular day which help and provide support but then as the incapacities grow, so does the need for help. The person cared for slowly becomes incapable of doing most routine daily activities. To me, that has been painful. To see deterioration in the one you love is difficult to handle. One morning, you wake up to realize that anything and everything that is to be done, has to be done by you and that's not just for one day but from here on in, every day! That thought is daunting and disturbing.

If one is caring for a spouse then it comes naturally out of the marriage relationship—it is all part of the commitment. Remember the wedding day and the words, "in sickness and in health." Never did we think it would apply like this. This is where the rubber meets the road. This is where the vows and commitment made take shape and are fulfilled.

If you care for a parent then usually it is because you have accepted the responsibility; maybe because there is no one else to do the job. You recognized the need and have chosen to stand in the gap, strap on the load and commit to being the child again, but this time the roles have reversed and the responsibility for care has fallen on your shoulders.

It may be difficult to imagine but caregiving is not all negative. It brings its own rewards. For the most part, those cared for appreciate the assistance they receive and recognize the effort, and maybe the sacrifice, expended on their behalf. Deep gratitude is never far below the surface even if it is not always verbalized.

What is required of us?

Every situation is different and has its own unique challenges. Those who have to deal with dementia and Alzheimer's have their own set of hurdles. With Parkinson's, I think the slowness and inability of movement, which every patient has to endure, is the cause of much frustration in both the caregiver and those cared for. Everything happens in slow motion.

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Anything that can still be done by the person themselves is painfully slow.

I remember the day when my wife said “Hurry is no longer in my vocabulary!” She was right. There is little point in saying “Hurry up” because that adds frustration to the frustration. Allowing adequate time is the only solution. Leave extra preparation time. Adjust your thinking to accommodate delays. Something often goes wrong and at a time when you least need it to occur. Remember that frustration can easily lead to irritability which is no help to anyone. We as caregivers are especially vulnerable to this when we feel unwell ourselves and we know that we still have to do all the tasks which only we can do.

The great danger with slowness is that the caregiver wants to jump in and do things because they know they can do them much faster. That has to be resisted. We are there to help the cared for to be as independent as possible. It only makes them feel worse if small things which they can do are snatched away from them. As caregivers, we have to be willing to allow things to take place at a snail’s pace if necessary. One has to remember that time is not of the essence in these circumstances but the emotional health of those cared for is. How much better for them to be praised for a small accomplishment than to be ready to go out of the house a couple of minutes earlier.

When does it all end?

Looking squarely at the future is difficult. There is no magic pill that makes all this go away. Hard as it is to

say this but the task will get no easier than it is today. The demands will grow and the responsibilities will grow with them. Individual routine activities will become more difficult. However, the greater difficulty will be knowing when enough is enough and admitting the job is too much. Nobody wants that day to arrive.

I understand that most people go beyond their bearable level of total exhaustion. Pushed by the mindset of “I should be able to do this” or “Who else can do this but me” we are tempted to continue doing what we do and maybe even to the detriment of those for whom we care. The progression of becoming totally exhausted is so slow that it is virtually impossible to recognize. It is not until we find ourselves constantly tired and falling asleep every time we sit down that we might begin to admit that the job just might be getting too much. The justifiable fear is what happens beyond that. None of us want to go there; well I certainly don’t.

So my fellow Caregivers, keep working, keep helping, keep loving and be encouraged. Even if not expressed, your efforts are deeply appreciated. You are important because you play an important role. In fact, you are indispensable. You are the pillar that provides critical support. One day you will have a sense of comfort and satisfaction in the knowledge that you did the best you could. That is all that can be expected of you.

Do you have
Parkinson’s
related legal
issues?

Blakes

Through a partnership with PSBC, the law firm of **Blake, Cassels & Graydon LLP** offers free of charge legal services to people with Parkinson’s in British Columbia.

The Litigation Support Program from Blakes addresses legal issues such as discrimination against individuals with Parkinson’s in the workplace; discrimination in accommodations, services or facilities that are generally available to the public; and, wrongful denial of disability insurance or denial of government services.

If you have a legal problem relating to Parkinson’s disease, please contact **Jean Blake, CEO** at jblake@parkinson.bc.ca for more information.

Education Events

ATTP Community Talks

Organized by the Parkinson's Foundation and the International Parkinson and Movement Disorder Society (MDS), the Allied Team Training for Parkinson's™ (ATTP) comes to Canada for the first time ever! PSBC will be hosting community talks, featuring speakers from the ATTP, in Abbotsford (April 3) and Richmond (April 6). Please visit our website for more details and registration.

Communication and Swallow Workshop, Penticton

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 (PwP). 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:** Friday, April 13, 2018
Time: 10:00 am – 2:30 pm
Location: Days Inn & Conference Centre
152 Riverside Drive, Penticton
Cost: Member \$25.00
Member (Couple) \$40.00
Non-member \$35.00
Non-member (Couple) \$60.00

Communication and Swallow Workshop, Vernon

- Date:** Saturday, April 14, 2018
Time: 10:00 am – 2:30 pm
Location: Vernon Lodge & Conference Centre
3914 32nd Street, Vernon
Cost: Member \$25.00
Member (Couple) \$40.00
Non-member \$35.00
Non-member (Couple) \$60.00

Save the Date: Regional Conference in Kelowna

- Date:** Saturday, June 16, 2018
Location: Ramada Kelowna Hotel & Conference Centre
2170 Harvey Ave, Kelowna



For more information, or to register for these events, please visit www.parkinson.bc.ca/education-events or call Jaclyn Willems at 1-800-668-3330.

Parkinson SuperWalk—Save the Date!

Parkinson SuperWalk will be taking place in communities across BC and Canada starting on the weekend of **Saturday, September 8th**. Stay tuned for a full list of walk locations on our website and in the summer issue of *Viewpoints*.

Parkinson SuperWalk in BC is operated by Parkinson Society British Columbia under license from Parkinson Canada.



Champions for Parkinson's

UPCOMING EVENTS

SHAKE, SHAKE, SHAKE!

Back by popular demand! Join us on Friday, May 25th at The Imperial in Vancouver for an evening of musical entertainment featuring Emily Chambers, Khari Wendell McClelland and Dawn Pemberton. Net proceeds from this concert will benefit Parkinson Society BC (PSBC) and MS Society! To purchase tickets, please visit: www.parkinson.bc.ca/shake2018

FRIDAY
MAY
25

FULL THROTTLE

Start those engines! On Sunday, May 27th, enjoy a relaxed and scenic motorcycle or car ride from Vancouver to Whistler along the Sea to Sky highway while raising funds for PSBC. To register, please visit: www.parkinson.bc.ca/fullthrottle

SUNDAY
MAY
27

PAST EVENTS

Swingin' for Papa

On August 26th, 2017, this friendly baseball game took place in North Vancouver and raised over \$400!

Buy Tom a Beer

Tom Cmajdalka was recently diagnosed with Parkinson's disease so he encouraged his friends to donate to PSBC in lieu of 'buying him a beer'. The fundraiser raised \$1,690 for Parkinson Society BC.

Forever Inked Tattoo & Raffle Fundraiser

Forever Inked Tattoos in Surrey hosted a flash tattoo and raffle fundraiser this past October. Supporters chose from Halloween-themed designs for \$100 each, with proceeds benefiting PSBC. The raffle featured unique collector's items, as well as sports tickets and gift certificates. In total, more than \$4,300 was raised!



Fall Online Auction

Parkinson Society BC hosted an online auction from November 1st to 15th, 2017 with the help of former board member and long-time PSBC supporter, Val Swannell. There were many items up for bid including golf packages, wine and family-friendly activity vouchers. The auction raised \$7,200!

Fall Concert Coquitlam Celebration Choir

The Coquitlam Celebration Choir hosted their annual Fall Concert, featuring the Celtic ensemble Port Na Gael. The choir raised \$500!

The Irish Blessing Poem Card Sales

In September 2017, Avis Muir's husband Douglas, who had lived with Parkinson's disease, passed away. To honour his memory, a dear friend from the choir Douglas sang in created a beautiful calligraphy card featuring Douglas' favourite poem, The Irish Blessing. Reproductions of the card were sold to friends and family, support groups and the choir, raising \$1,100. As a recipient of carepartner services provided by Parkinson Society BC, Avis wants the funds to help provide support and education for people affected by Parkinson's disease.

Thank you to the Rix Family Foundation!

Parkinson Society BC would like to thank the Rix Family Foundation for their generous gift of \$50,000. This commitment to helping improve the lives of those affected by Parkinson's disease is deeply appreciated.

A Comprehensive Guide for Parkinson's Caregivers

NEW!

This April, Parkinson Society British Columbia will be printing and distributing **A Comprehensive Guide for Parkinson's Caregivers**. Kaitlyn Roland, PhD, whose father was diagnosed with Parkinson's in 2002, was the primary contributor for this book. She has completed a Masters in Health and Rehabilitation Sciences, focusing on new ways to measure caregiver burden. Currently, her work at the Institute on Aging and Lifelong Health looks at cognitive changes in Parkinson's disease, associated care needs and caregiver experiences.

This guide contains information about:

- Parkinson's disease
- Living well day-to-day
- Developing a care plan, including planning for the future
- Building a care support team and communicating with healthcare professionals
- Support options
- Self-care

PSBC will be announcing the availability of this guide via email, web and social media.

If you have questions about caring or any of PSBC's resources, please contact Jaclyn Willems at jwillems@parkinson.bc.ca.

MEDICAL TREATMENT OPTIONS FOR PARKINSON'S

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time, staff and equipment that would allow Dr. Honey to travel and perform surgeries elsewhere in the province.

- **Hiring an additional DBS neurosurgeon and additional healthcare staff in BC.** Currently, patients who want to undergo DBS are put on two waiting lists. One waitlist is for a preliminary assessment appointment with Dr. Honey, and another waitlist for the surgery itself. Often, surgeries scheduled for late in the year are rescheduled to the following budget year beginning in April due to annual funding limits. An additional DBS neurosurgeon would ease Dr. Honey's waiting lists and the burden on Parkinson's patients.

PSBC believes in providing the Parkinson's community the tools they need to achieve the best possible quality of life and care. The Society encourages you to discuss your options with a doctor and pharmacist, as applicable.

If you would like to share your Parkinson's treatment story, or how advocating for your rights as a PwP has benefited your care, contact Amanda McCulley at amcculley@parkinson.bc.ca or 1-800-668-3330.

If you have questions about any of the medical treatment options outlined here, contact Jaclyn Willems at jwillems@parkinson.bc.ca or 1-800-668-3330.

If you would like to learn more about advocacy for the Parkinson's community, contact Jean Blake at jblake@parkinson.bc.ca or 1-800-668-3330.

Sources

Mayo Clinic. (2018). *Parkinson's disease: Diagnosis & treatment*. Retrieved from <https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/diagnosis-treatment/drc-20376062>

MediResource Inc. (2018). *Duodopa*. Retrieved from <http://chealth.canoe.com/drug/getdrug/duodopa>.

Parkinson Canada (2017). *Medications to Treat Parkinson's Disease*.

Leaving a Legacy for Parkinson's

We all leave a legacy; some in the hearts of family and friends, some in the next generation we have influenced. Your legacy represents the values meaningful to you during your lifetime.

As an extra way of looking after a community of the people they care about, some people may elect to make a gift to Parkinson Society British Columbia (PSBC) in their will. By considering this type of gift, know that through the generosity of individuals like you, PSBC will continue to bring hope to those affected by Parkinson's disease. The following is a story about Jo Heron, a business management consultant living in the Lower Mainland, who made the thoughtful decision to provide for those affected by Parkinson's disease by designating a portion of her estate for donation to PSBC.

In 2001, Jo Heron's mother, Joan Heron, was diagnosed with Parkinson's disease. For the first 6–7 years, the symptoms were manageable and consisted primarily of tremors. During that time, Joan became involved with one of PSBC's support groups at Vancouver's Marpole Centre. As the disease progressed, Joan moved in with her daughter.

Jo worked full-time during the day and travelled across Canada for her job. Although nurses assisted in caring for her mother during the daytime and while Jo was travelling, eventually Joan's needs exceeded what Jo was able to provide. Together, they made the difficult decision to admit Joan to a long-term care home in Yaletown and eventually to Villa Carital. At both care facilities, Jo was surprised that the staff had limited knowledge of Parkinson's, despite the fact residents in the homes lived with the disease. To assist with the transition, the staff at Parkinson Society BC (PSBC), with whom both Jo and Joan had contact with over the years, offered to come in and conduct an orientation for the staff.

Unfortunately, Joan passed away in 2013 at the age of 88. Four years later, when Jo was revising her own will, she thought long and hard about what to do with her estate. Jo has no children, and only a few extended family members living in the United Kingdom. After deep consideration, she elected to donate part of her

estate to the B.C. Cancer Society—in honour of her father, James Heron who battled cancer—and another part of her estate to PSBC. To Jo, the combination of PSBC's contributions to research and the provision of education for people with Parkinson's, caregivers/carepartners and the public, is important.

Jo says: I wanted to support PSBC in memory of my mom. Through her experiences, I saw how Parkinson's disease robs people of their golden years, both physically and, sometimes, mentally. Over the past 3 or 4 years, due to media coverage, the disease is getting more of a profile in North America. Despite this, it still doesn't receive enough attention. I think every Parkinson's association could do with more funding and, with the aging population, there is going to be so much more need for support. With PD, it's amazing how many people have been impacted. I want to support continued research as well as programs to help inform and educate British Columbians about the disease.



In addition to bequests, PSBC also accepts gifts of life insurance, beneficial interest on RRSPs, RRIFs and securities. To learn more about leaving a legacy gift benefitting BC's Parkinson's community, contact Rav Kambo by phoning 1-800-668-3330 or emailing rkambo@parkinson.bc.ca.

ANNUAL GENERAL MEETING

Saturday, May 5, 2018

9:45 am – 12:00 pm

Broadway Church – Lower Auditorium

2700 East Broadway, Vancouver



Featuring guest speaker **Dr. Martin McKeown** from the Pacific Parkinson Research Centre, who will provide an update on new treatments and research related to Parkinson's disease

➤ To register, please visit: www.parkinson.bc.ca/agm.

The venue will be  wheelchair accessible. | Light refreshments provided.

Please be advised that this is a members-only event and that registration is required for attendance.

If you are currently a non-member interested in attending the AGM and educational session, membership with the Society is offered at an annual fee of \$25. This fee allows you and your household to take advantage of all benefits until December 31, 2018.

For more information, or to become a member, visit our website at  www.parkinson.bc.ca.

THIS EVENT HAS BEEN MADE POSSIBLE THROUGH THE GENEROUS SUPPORT OF

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