

VIEWPOINTS



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

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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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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.

Support Groups

100 Mile House, Abbotsford, Burnaby, Campbell River, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Delta/Ladner, Duncan/Cowichan Valley, Elk Valley (formerly Sparwood), Fort St. John, Kamloops, Kelowna, Kelowna Caregivers, Kootenay Lake East Shore, Ladner, Langley, Langley YOPD, Lion's Bay, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Mission, Nanaimo, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, North Shore, 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

The fungal microbiome of the gut in Parkinson's

For researchers who study Parkinson's disease, a new frontier of investigation is emerging: the micro-organisms, including viruses, bacteria and fungi, that live in and on us.

At the University of British Columbia, Dr. Silke Appel-Cresswell, a neurologist and assistant professor, is concentrating on changes to the olfactory system and the gut that occur long before the tremor, stiffness and trouble walking that are the classic motor symptoms of Parkinson's.

Loss of the sense of smell, insomnia and constipation are all symptoms that people with Parkinson's may experience years or even decades before their movement difficulties emerge – but often, clinicians don't link the issues.

"If you look at the pathology, you can see pathological changes in the nervous system of the gut very early on," Appel-Cresswell says.

Appel-Cresswell and her colleagues know that the internal surface of the nose and the entire gut are heavily populated by microbes that co-exist there and serve as the interface between the environment and the human body.

"It turns out that the microbes outnumber the number of cells that are human by a factor of 100," she says. "We have more microbes in our system than human cells."

Appel-Cresswell now wonders if the fungi in the gut influence the development of Parkinson's disease. Using fecal and nasal samples from people who have Parkinson's and people who do not, she is assessing those samples to see if changes in the fungi could be related to Parkinson's and its symptoms ranging

RESEARCH PROJECT



The fungal microbiome of the gut in Parkinson's

RESEARCH PROFILE
Dr. Silke Appel-Cresswell

INSTITUTE
University of British Columbia

PILOT PROJECT GRANT
\$44,996 over one year

from tremor and rigidity to constipation, depression and impaired judgment and reasoning.

If Appel-Cresswell can establish a relationship between fungi and the symptoms of Parkinson's disease, her work would open the door for follow-up studies to examine the mechanisms by which fungi might influence the development of Parkinson's disease. This line of research might eventually lead to treating the fungi with antifungal medications, for example, to see if eliminating the fungus or reducing the amount of it in the body also eliminates Parkinson's.

Alternatively, it might also be possible to boost other microbes in the body, such as with probiotics.

"The really exciting thing would be if in the future, we could look at people at high risk of Parkinson's and treat them early," she says. Identifying what role the human microbiome plays in disease is truly a new frontier for medicine, Appel-Cresswell says.

"It is something that is easily accessible and modifiable, so it holds promise for treatment."

THIS IS PARKINSON'S DISEASE

April is Parkinson's Awareness Month

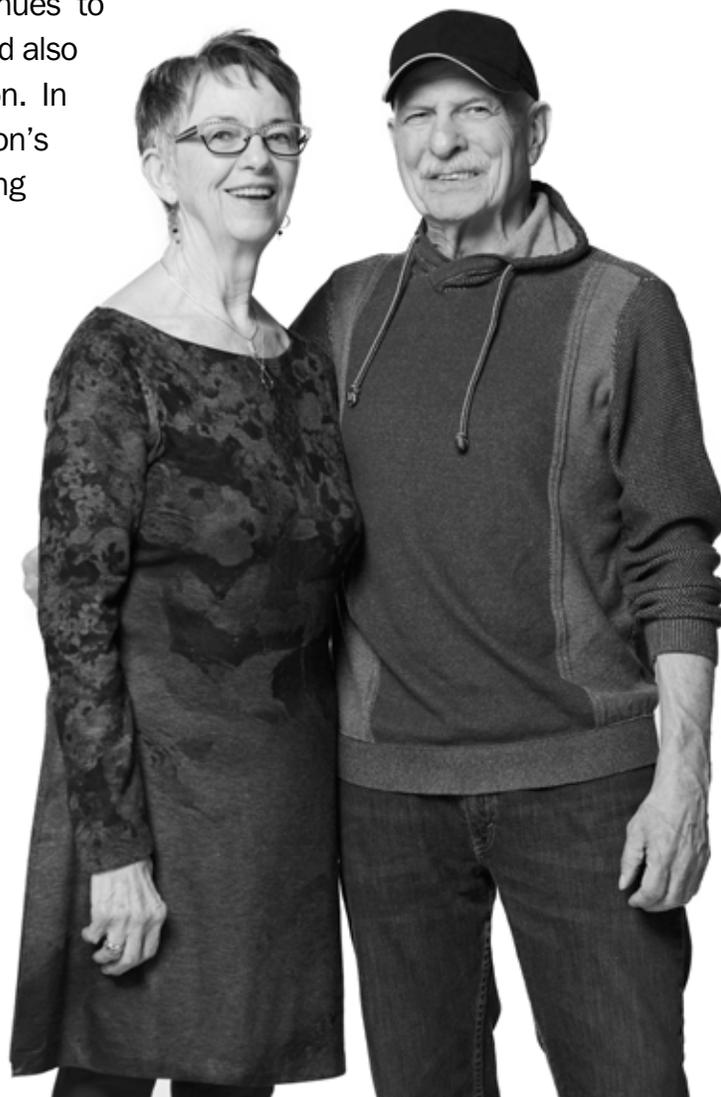
This year marks the 200th anniversary of the publication titled *An Essay on the Shaking Palsy* by British physician James Parkinson. It broke ground by being the first paper to describe in detail the symptoms of Parkinson's disease (PD), potential causes, treatment and means to a cure. Now, in 2017, the Parkinson's community is looking back at the 200 years of research that has gone into treatment, and ultimately, a search for the cure. Parkinson Society British Columbia (PSBC) continues to build awareness of the disease and its treatment and also to change out-of-date perceptions of the condition. In this issue, we highlight the diversity of the Parkinson's community and draw attention to the issues affecting people with Parkinson's here and now.

'This is Parkinson's disease'

Last year, five active members of the Parkinson's community agreed to participate in a campaign aimed at increasing awareness and educating the public about PD. Their images and stories were shared on posters at community and health centres around the province, print and radio media in select communities and online. The awareness initiative was inspired by and adapted with permission from a Norwegian video journalist named Mr. Anders Leines, who also lives with PD.

While the five individuals who participated in our *This is Parkinson's disease* campaign reflected the diversity of those affected by PD, we recognize that there are many more stories to tell.

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In 2014/2015, the BC Ministry of Health released statistics that estimated approximately 13,300 British Columbians are living with the condition. That number is expected to rise as the population ages. As a result, we know there is still much progress to be made in terms of education about the disease and improving quality of care for Parkinson's patients.

Wayne and Elaine

Wayne and Elaine are part of a team of Parkinson's support group co-facilitators in Courtenay/Comox Valley. They have been married for 52 years, and were diagnosed with Parkinson's within two years of each other. Elaine worked with Revenue Canada, and Wayne had a career in the Alberta oilfields before his Parkinson's symptoms forced him to retire. The couple are now both active retirees with two adult children and six grandchildren.

Richard

Richard is a 49 year old Vancouver resident. He serves on PSBC's board of directors and is a regular participant in Parkinson SuperWalk. Like many others in the Parkinson's community, he has committed himself to staying active in order to combat the symptoms and progression of the disease. Rather than exercise at a gym, he prefers to play a variety of sports to help maintain his quality of life. He is a digital designer who also enjoys videography and photography. As his upbringing and values rooted in Buddhism have taught him, he strongly believes in the power of positive thought.



Hilary

Hilary is 25 years old and lives in Langley with her husband Justin. She began experiencing Parkinson's symptoms at the age of 14 and, after almost a decade, was diagnosed with PD. She credits her faith in God and her strong family support system as her source of strength. Currently, she is nourishing her creative side by working as a freelance graphic designer and website developer. In Hilary's spare time, she takes part in the rigorous exercise program CrossFit and runs her own website and blog. Recently, her neurologist recommended her as a candidate for Deep Brain Stimulation (DBS) surgery and she has since been placed on a three year waitlist for an assessment with Dr. Honey, the only neurosurgeon who specializes in DBS in British Columbia.



Deep Brain Stimulation

Currently, British Columbians with Parkinson's may wait for as long as five years for DBS treatment. DBS is a surgical procedure used to treat numerous debilitating symptoms of PD, including tremor, rigidity, stiffness, slowed movement and walking problems. A neurostimulator – similar to a pacemaker – delivers electrical stimulation to specific areas in the brain that control movement, effectively blocking the abnormal nerve signals that cause PD symptoms. Most patients experience significant reduction of

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Changing Attitudes Towards Healthcare

In September 2016, the World Parkinson Congress (WPC) was held in Portland, Oregon. This international forum provided attendees with the opportunity to learn about the latest scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. One of the themes that emerged at the conference was the shifting attitudes in public health towards a more preventative, rather than treatment-based, approach. This approach, and some of the tools that have been developed as a result of this shift, may be useful for people with Parkinson's disease (PD).

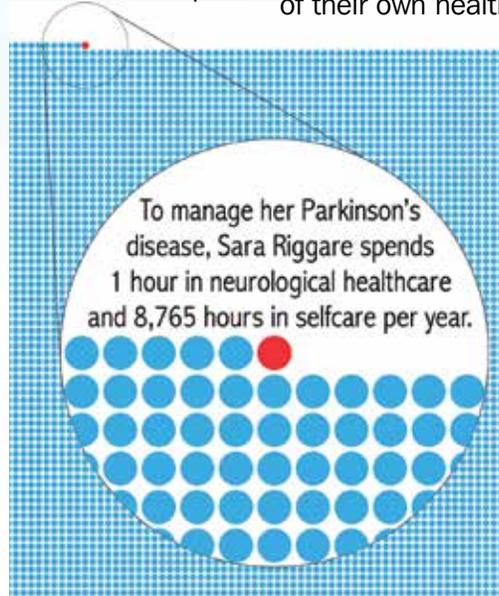
Patient-driven care

Preventative healthcare often places greater responsibilities on the patient; however, this need not be burdensome. American research associate Melanie Swan summarizes patient-driven healthcare as the process of the patient collecting information about variations in their health and analyzing and sharing this information with their healthcare providers (Swan, 2009, p. 492). According to Swan, both technology and self-tracking are major components of this type of care.

Interactive online platforms provide tools where people can track their own symptoms, share information and provide emotional support for one another (ibid). The number of virtual health services has expanded making it easier than ever to connect with a physician in Canada. Activity trackers, such as Fitbit, allow individuals to track their exercise, diet and sleep patterns. It is a logical progression that physicians, innovators and the average individual are beginning to turn attention to how technology can assist with healthcare for conditions such as PD.

Self-Tracking

Self-tracking includes measuring many different types of information, from biological to behavioural (ibid). Monitoring one's own health can lead to earlier diagnosis of conditions, as well as the identification of more effective treatments in consultation with one's physician. Focusing on prevention and alternative methods of symptom management is one way in which individuals can take more control of their own health.



Sara Riggare is a Parkinson's advocate and PD patient who is working on a PhD in self-care at Karolinksa Institute in Stockholm, Sweden. She presented at WPC regarding her approach to self-tracking for Parkinson's. Riggare defines self-tracking as measurement or monitoring to learn about yourself. While tracking can be facilitated through the use of technology, she also promotes a 'low-tech' method – pen and paper. Riggare explains that self-tracking

“can be a very powerful tool to find answers to your own questions about Parkinson's... [it can help] improve your situation and optimize the effects of your medications”. She encourages people with Parkinson's to track medication intake, stress and other factors. To Riggare, self-tracking is a way of life because, “I see my neurologist twice a year, about half an hour every time. That's one hour per year in healthcare for my Parkinson's disease. During the same year I spend 8,765 hours in self-care, applying my knowledge and experience together with what I get from my neurologist to manage a difficult disease the best I can” (Riggare, 2014).

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Tracking for long-term studies

Researchers have caught on to patient tracking, and a number of studies based on the principle have been executed or are currently taking place around the world. Here in British Columbia, Dr. Martin McKeown of Pacific Parkinson's Research Centre at UBC and Kathy O'Donoghue, a former video game designer, had the idea for a mobile game – also known as an app – that can help monitor patient cognition. The app, CognitiaPD, was first tested at WPC and is currently being used as part of a large Parkinson's research study that will collect data through mobile games. The app includes two games, one is called Animal Snap and it monitors response time by requiring players to tap a screen when animals appear. The other game, Gift Shop, tests memory. Two items appear on the screen, and then the game asks the user in which order the items appeared. As the game goes on, it becomes more complex, with more items appearing on screen. Afterwards, it assesses how correct your responses were.

If users play these games regularly, it can allow physicians to better track and assess motor and cognitive changes. Ideally, better data can improve medication recommendations and dosages, and help minimize the frequency at which Parkinson's patients are hospitalized with severe symptoms.

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Voice Box – Speaking up with Technology

Are you experiencing voice changes? Parkinson Society British Columbia (PSBC) strongly encourages you to seek treatment from a Registered Speech-Language Pathologist (SLP) and to participate in a formal speech therapy program. Sherri Zelazny, PSBC board member and Registered Speech-Language Pathologist, recommends a number of apps that can supplement patient progress:

- **Sandcastle's Speak Up for Parkinson's:** This app is free but is available for iPhones only. Created by the Northwest Parkinson's Foundation, it supports daily voice exercises. It can be accessed online at: <https://nwpf.org/wellness-center/resources/speak-up-for-parkinsons/>
- **Decibel 10th:** Compatible with iPhone and Android platforms. This app turns your smart phone into a professional sound meter that can help you monitor your loudness targets.

Delayed Auditory Feedback (a method that modifies the speech signal and then sends it back to the speaker through their own ear) has been effective in improving communication for some people with Parkinson's disease. The following are some apps you may consider utilizing:

- **Parkinson's Speech Aid:** This app is free but is available for iPhones only. It allows you to speak in unison with yourself, with a slight delay and change in pitch.
- **DAF Professional:** This app is available for a small fee for both iPhone and Android platforms. It is an easy and convenient tool to help people speak more slowly when hearing their own speech in an altered manner.

These are just a few of the apps available to help with communication difficulties. They are not for everyone and require different levels of ability to use effectively. A qualified SLP can help you find the best app for your needs.

The Mind-Gut Connection in Parkinson's Disease

You may have heard the expression “listen to your gut” when faced with an important decision; but this is no longer just a metaphor. Some researchers have elected to explore the complexity of Parkinson's disease (PD) by investigating its relationship to the gastrointestinal system (GI) system. Based in part by the prevalence of constipation in Parkinson's patients, a growing number of researchers and neurologists, including Vancouver-based Movement Disorder Specialist Dr. Silke Appel-Cresswell, conduct research under the hypothesis that PD may have its origins in the gut under the influence of microbiota. While this theory remains to be definitively proven, it has become part of the discourse around the cause of the disease. Researchers are optimistic that further exploration into the Parkinson's-gut connection could lead to improved treatment methods and, potentially, a cure.

What is Microbiota?

American molecular biologist Joshua Lederberg coined the term microbiota. It is defined as “the ecological community of commensal, symbiotic and pathogenic microorganisms that literally share your body space” (Lederberg & McCray, 2001). The human gut contains over 100 trillion of these microbial cells that can influence human physiology, metabolism, nutrition and immune function. Disruption of the gut's microbiota has been linked to gastrointestinal conditions such as inflammatory bowel disease and obesity. Further understanding of microbiota, including what constitutes a ‘healthy gut microbiota’, may provide the key to unlocking the mysteries of other diseases (Guinane & Cotter, 2013).

Gut Bacteria and Parkinson's disease

H. Pylori

One of the most important observations in modern GI medicine was the discovery that a bacteria in the gut called *H. pylori* (*Helicobacter pylori*), could underpin GI infections and lead to ulcers. If left untreated, *H. pylori* may affect the absorption of Parkinson's medications and negatively affect overall treatment responses. In 2008, Lee and colleagues from Samsung Medical Center in Korea reinforced existing research by Pierantozzi et al who concluded that levodopa medication was more effective in patients who had been treated for *H. pylori* infection (National Parkinson Foundation, 2016).

Alpha-Synuclein

Alpha-synuclein, a protein that collects in the brains of all people with Parkinson's, has been found in several locations outside the brain, including the nerves controlling the intestines. Researchers question whether alpha-synuclein could develop in the gut first, causing non-motor symptoms, and spread to the brain later, causing motor symptoms (Michael J. Fox Foundation, 2014).

Prevotella

Lower levels of the bacteria *Prevotella* have been observed in the intestines of people with Parkinson's when compared with health control groups. This bacterium helps create the vitamins thiamine and folate, maintaining the intestinal barrier, which protects against environmental toxins. This finding could potentially lead to earlier diagnosis, as well as treatment through dietary adjustments and vitamin intake.

Nutrition as Treatment

In recent years, healthcare professionals, including neurologists, general physicians and naturopaths, have encouraged their patients with PD to cultivate intestinal health to improve ‘healthy gut microbiota’.

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In November 2016, Parkinson Society British Columbia (PSBC) hosted a Regional Conference in Victoria where Dr. Laurie Mischley, ND, PhD, MPH shared her thoughts on food, diet and nutrition in PD. Her presentation included several tips for people with Parkinson's who would like to improve health and balance in their gut. Some of her primary suggestions were:

- **Avoid fried foods**, as there is strong evidence that they lead to proteins misfolding (proteins that fail to fold into their normal configuration can become toxic or disrupt the function of the cells, tissues and organs)
- **Limit eating beef**, as the increased levels of iron can cause damage of the substantia nigra through oxidation
- **Avoid canned fruits and veggies**, as they were found to accelerate disease progression
- **Limit diet soft drinks**, as the artificial sweeteners can affect the healthy bugs growing in the gut
- **Consider probiotic supplements**, as they can help treat constipation, and
- **Eat more plants**, including nutrient-dense foods such as kale, spinach, beets, broccoli, berries and cherries, nuts (Mischley, 2016)



Since diet can alter the composition and activity of gut microbes, proper nutrition is important to maintain good overall health, and is vital in the management of Parkinson's symptoms.

Remember, useful tips about daily living with Parkinson's, including nutrition information, can be found on the PSBC website at www.parkinson.bc.ca.

👉 If you would like more information or resources about managing Parkinson's symptoms, please reach out to Myriame, Education & Support Services Coordinator at 1-800-668-3330 or mlepinelyons@parkinson.bc.ca.

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Young Onset Parkinson's Disease

Parkinson's disease (PD) is typically understood as a condition that affects seniors. Although this perception is generally accurate, it does not account for the 35% of cases that have been identified as Young Onset Parkinson's disease (YOPD). YOPD is defined as a diagnosis of Parkinson's disease between the ages of 21 and 40, although some studies include patients diagnosed up to the age of 50. Some research has suggested that a small percentage of individuals with YOPD may be genetically predisposed to developing the condition (Lister Hill National Center for Biomedical Communications, 2012).

Due to the age of the population living with YOPD, individuals with the condition face a different set of challenges than more mature populations. Individuals with YOPD are more likely to experience dyskinesia, due to the length of exposure to levodopa over time (Ahlskog, 2016). This is in addition to the challenge of maintaining career goals and family life with young children. It is important to understand that while the percentage of British Columbians living with YOPD is smaller than people living with PD, the experience can be drastically different, and resources and support systems

need to be in place to help individuals with YOPD manage their specific set of conditions.

Stigma

In a recent American study that compared the experiences of people with YOPD and patients above the age of 50 diagnosed with PD, patients' perceptions of disease severity were identical. However, the younger patients reported a higher rate of depression and indicated that they experienced a lower quality of life. It is suspected that these differences are, in part, due to social stigma around YOPD, strain on marital relationships and higher rates of unemployment in people with YOPD (Parkinson Foundation Western Pennsylvania, 2017). It can be difficult for employers, the general public and family members to understand how someone who is seemingly young and fit could have a disease of this type.

It can also be difficult to diagnose Parkinson's in youth, or individuals on the cusp of middle age. Gina Lupino, a professional lawyer who was diagnosed with Parkinson's at the age of 38, explains that the Parkinson's diagnosis actually helped alleviate some stress because there was finally an explanation for the symptoms she was experiencing. She immediately told her family and a number of friends about her Parkinson's diagnosis. She explains, "Their response was overwhelmingly supportive. I did feel conflicted about telling people who I was intimate with and who I worked with. Then I said to myself, screw it – I wouldn't want to date anyone who cared about my brain's ability to produce dopamine. It didn't adversely affect my work. It did make me do a 180 and take exceptional care of my health, which ironically made me better at my job and feel and look the happiest and healthiest I've ever felt in my entire life. The only way to change the public's perception of people with disabilities is to be open and out about it. If people like me don't open up, public perception will stagnate and negative stereotypes will remain in place."

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Disclosing the disease

Many individuals with Parkinson's grapple with the decision of whether or not to disclose their condition. However, as the disease progresses, it may become necessary for the person with PD or YOPD to disclose their condition to their employer. According to human rights law, it is illegal for an employer – current or prospective – to discriminate against an employee with a disability. Legally, Parkinson's is defined as a disability (Parkinson Society British Columbia, 2013). For Gina, she began to experience extreme fatigue, loss of mobility on the right side of her body and tremor in her right hand. The tremor affected her ability to type, write and shake hands with colleagues. This disease forced her to begin to prioritize self-care – she gets plenty of sleep, sticks to a healthy diet, gets rest and focuses on her emotional wellness.

Gina sometimes uses dictation software to help her type documents and emails, has opted for phone calls rather than email exchanges with colleagues and clients and takes medication to help regulate her dopamine levels. Interestingly, she is positive that all the steps she has taken to manage her Parkinson's and continuation with a high-stress career has made her a better lawyer. However, she is concerned about long-term effects of the disease, especially the effect that Parkinson's may have on her cognition, ability to work, play percussion or be physically active.

Family

When a family member is diagnosed with Parkinson's disease, it may be difficult for family to process. They may react emotionally, and be scared for the future. In Gina's experience, her family members who actively learn about the disease have many of their fears alleviated. While it may be difficult for family to fully comprehend a disease like Parkinson's, family and social networks can also be a major source of support for the person diagnosed.



Finding tools to cope

There are numerous ways for people with YOPD to find the support systems they need. There are YOPD-specific or YOPD accepting support groups across British Columbia. Conferences such as those hosted by Parkinson Society British Columbia (PSBC) and the World Parkinson Congress can help bring people with Parkinson's together. Many people with YOPD also turn to the Internet to find information and help. PSBC runs its own online YOPD support group, facilitated by staff member and clinical counsellor Myriame Lépine Lyons. Many PSBC members mention that Ben Stecher's blog, My PD Journey, is a useful source of information and inspiration; you can view it at: <https://tmrwedition.com/my-pd-journey/>. National Parkinson Foundation (www.parkinson.org) has numerous helpful resources, including information on YOPD and an online YOPD forum. Coping mechanisms and support systems can vary widely – in addition to online and offline support systems. Gina lists her percussion band, improv classes, yoga, ballet, hiking, nutritional counselling and even infrared sauna treatment as activities that help her manage YOPD.

PSBC is constantly trying to improve programs and services for people with Parkinson's disease and the public. There are informative help sheets with tips for people with YOPD available on our website's resource page: <http://www.parkinson.bc.ca/resources-services/resources/#yopd>. If you have any questions about YOPD, or have feedback about our services, please contact Myriame at 1-800-668-3330 or mlepinelyons@parkinson.bc.ca.

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THIS IS PARKINSON'S DISEASE

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PD symptoms after DBS and can reduce the amount of oral medications they take as a result (Lazarus, 2017). Expansion of the DBS program in BC would significantly improve the quality of life of patients with Parkinson's. Parkinson Society BC will continue to advocate for improvements to the availability of the treatment. To learn more about PSBC's four point advocacy plan, including how to get involved, please visit www.parkinson.bc.ca/advocacy.

You can help! We have developed posters available digitally via PDF that you can share with your contacts. Don't have a printer? If you're interested in helping canvas your community, we have a limited number of letter sized posters available. Please contact Amanda McCulley, Marketing & Community Engagement Specialist at amcculley@parkinson.bc.ca or 1-800-668-3330.

For the most up-to-date information about Parkinson's Awareness month, including where you might see advertisements and promotions, please visit www.parkinson.bc.ca/this-is-parkinsons.

The following landmarks will light up in PSBC colours to recognize International Parkinson's Awareness Day on Tuesday, April 11, 2017:

- Sails of Light at Canada Place, Vancouver, BC
- Science World, Vancouver, BC

Thank you to communities and organizations that are acknowledging Parkinson's Awareness this April!

Don't forget to join in the conversation through social media! Follow us on Facebook, Twitter and Instagram (@ParkinsonsBC).

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YOUNG ONSET PARKINSON'S DISEASE

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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.



MOVING FORWARD together

Moving Forward, Together Conference
Saturday, June 3, 2017
Sheraton Vancouver Airport Hotel
7551 Westminster Hwy, Richmond

- ▶ Travel grants available for those who may qualify
- ▶ Nominate an outstanding member of the Parkinson's community for the Above and Beyond awards

Parkinson Society British Columbia (PSBC) invites all members of the Parkinson 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, from research to different journey points of Parkinson's.

▶ PLENARY SPEAKERS

Beate Ritz, M.D., Ph.D.

Dr. Ritz is a Professor of Epidemiology and Environmental Health Sciences at the UCLA Fielding School of Public Health and of Neurology at the UCLA Geffen School of Medicine. Dr. Ritz will be discussing the relationship between genetics and the environment and Parkinson's disease.

Benzi Kluger, M.D., M.S.

Dr. Kluger is an Associate Professor of Neurology and Psychiatry and Director of the Movement Disorders Center and Neurology Supportive and Palliative Care Programs at the University of Colorado. Dr. Kluger will be presenting on apathy and non-motor symptoms of Parkinson's disease.

WWW.PARKINSON.BC.CA/MOVINGFORWARD

▶ For more information or to register, please connect with PSBC's Education and Support Services Department in one of the following ways:

Phone: 604-662-3240 | 1-800-668-3330

Email: Caroline Wiggins – cwiggins@parkinson.bc.ca

Myriame Lépine Lyons – mlepinelyons@parkinson.bc.ca

WITH BREAKOUT SESSIONS COVERING:

- ▶ PAIN
- ▶ SEX AND PD
- ▶ COMPLEMENTARY CARE
- ▶ AUTONOMIC DYSFUNCTION
- ▶ MEDICATION MANAGEMENT AND DYSKINESIA
- ▶ YOUNG ONSET PARKINSON'S DISEASE
- ▶ CAREGIVING

Fundraising Events

SHAKE, SHAKE, SHAKE!

Shake, Shake, Shake brought together over 200 people for an extraordinary night of music, featuring talented artists Jesse Roper, Emily Chambers, Dutch Robinson and IMUR at The Imperial in Vancouver. Concert-goers raised over \$16,500 in support of PSBC. We would like to extend a special thank you to Emily Chambers for spearheading this fantastic event!

#TWOLIPS4PD

On Valentine's Day, supporters of the Parkinson's community came together online and offline to support loved ones with Parkinson's disease. On social media, people used the #TwoLips4PD hashtag to help spread awareness about the disease and encourage people to donate online. In Vancouver, PSBC staff and volunteers distributed candy and hot chocolate in front of CF Pacific Centre while encouraging the public to participate in a

photobooth. Special thanks to the Daily Hive, CF Pacific Centre, Safeway Robson and Starbucks for their generous support.

SKATE AND SIP

This fundraiser at Robson Square Ice Rink in Vancouver brought together skaters of all levels as they laced up their skates and enjoyed hot chocolate by donation, with all the funds benefitting Parkinson Society BC.

HOLT RENFREW SHOPPING NIGHT

On November 16, 2016 fashion-conscious individuals gathered together for our charity shopping night in partnership with Holt Renfrew, Pacific Centre in Vancouver. The attendees were treated to a scrumptious reception followed by some fantastic wardrobe upgrades. With 10% of the evening's sales generously donated to the Society by Holt Renfrew, we raised an incredible \$12,736.94!

CHANGING ATTITUDES TOWARDS HEALTHCARE

continued from page 7...

Conclusion

Whether you choose to communicate the details of your condition with healthcare professionals, or keep your data to yourself, self-tracking can be a useful tool for people of all ages and health conditions. Chances are, you are probably already tracking your health in one way or another! While technology is at a point where it can help facilitate the process, there are low to no-tech ways to track and better understand your symptoms. Self-tracking will never replace the advice and care of professionals, however it can help you identify simple ways to manage the disease and take charge of your own health. On a

larger scale, it has strong potential for assisting with Parkinson's research.

References

- Rigarre, Sara. (2014). 1 vs 8,765 [Blog post]. Retrieved from <http://www.riggare.se/1-vs-8765/>
- Swan, Melanie. (2009, Feb). Emerging Patient-Driven Health Care Models: An Examination of Health Social Networks, Consumer Personalized Medicine and Quantified Self-Tracking. *Int. J Environ Res. Public Health*, 6(2), 492-555. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2672358/>

▶ If you would like to speak with someone about tools to manage Parkinson's disease or health resources available to you, please refer to Myriame Lépine Lyons, Education & Support Services Coordinator by calling 1-800-668-3330 or emailing mlepinelyons@parkinson.bc.ca.

We would like to thank Desert Hills Estate Winery for kindly providing the beverages for the exclusive reception.



FALLS PREVENTION WORKSHOP FOR PEOPLE WITH PARKINSON'S

This workshop presented by ZHOOSH Fitness Garage aimed to teach individuals essential safety skills to prevent injury. Attendees raised \$265 for the Society!

OSCARS GALA

Parkinson Society BC and The Morrissey Pub joined forces to present the 2017 Oscars in style on Sunday, February 26. Oscars fans were treated to a dinner of their choice and raised over \$225 in support of PSBC.

SAVE THE DATE

PARKINSON SUPERWALK 2017

will take place
September 9 & 10, 2017.



EDUCATION AND SUPPORT SERVICES EVENTS

MAY
13

COMMUNICATION AND SWALLOW WORKSHOP – VICTORIA

- Date:** Saturday, May 13, 2017
Time: 10:00am – 2:30pm
Place: Sandman Hotel Victoria | 2852 Douglas St, Victoria, BC
Cost: \$40.00 Member / \$70.00 Member (Couple)
\$50.00 Non-Member / \$90.00 Non-Member (Couple)

Further information and registration for our Education Events can be found on our website at www.parkinson.bc.ca/education-events

APRIL
11

STEP BY STEP

Starting Tuesday, April 11, PSBC is bringing back the Step by Step program for a third consecutive year! Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps taken by an individual. The first week will determine each walker's baseline, and then each week they will be encouraged to increase their steps based on a personal goal. While participants are encouraged to walk and track their own steps, a community group leader will organize a weekly walk allowing walkers to meet, socialize and help support one another.

The goal of this program is to help motivate people to become physically fit to combat the symptoms of Parkinson's disease. We hope to encourage people to continue a regular exercise routine following the program.

Interested in becoming a community group leader or a participant? As a team leader you would be responsible for organizing a weekly walk, selecting walking locations and motivating your team!

Contact Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 to learn more.

Notice of Annual General Meeting

Saturday, April 22, 2017
9:45am – 12:00pm

BCIT Burnaby Campus – Great Hall
3700 Willingdon Avenue, Burnaby

With guest speakers Dr. Silke Appel-Cresswell and others.



➤ Go to our website at www.parkinson.bc.ca/education-events for more information, or to become a member

Please be advised that this is a members only event and that registration is required for attendance. If you are 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, 2017.

The venue will be wheelchair accessible. \$5.25 day parking is available in Lots P5 & P7.



Light refreshments provided.

 Parkinson Society
British Columbia
600—890 West Pender Street
Vancouver, BC V6C 1J9



RETURN POSTAGE GUARANTEED
PORT DE RETOUR GARANTI