

VIEWPOINTS



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**Reminder
to Renew
Membership**
BEFORE DECEMBER 31

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

**FALL
2018**

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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

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.

Support Groups

100 Mile House, Abbotsford, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Comox Valley, Cranbrook, Duncan/Cowichan Valley, Kamloops, Kelowna, Kelowna Caregivers, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Caregivers, 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, Sunshine Coast, Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, White Rock, White Rock Caregivers, YOPD Online

Imaging Synaptic Pruning in Parkinsonisms

Although Parkinson’s disease is the broad diagnosis for symptoms that range from tremors to stiffness to problems with gait and cognition, researchers increasingly believe the term may be being applied to a variety of related, but different, neurological conditions.

At the Toronto Western Hospital, Dr. Antonio Strafella, a neurologist and researcher, is using sophisticated imagery technology to develop a new way of diagnosing and potentially differentiating between those different types of Parkinson’s.

Strafella is using a new tracer – a radioactive substance injected into the bloodstream. The tracer will bind to a protein in the brain, allowing it to become visible on PET (Positron Emission Tomography) imaging scans. Those scans will enable researchers to measure the density of the synapses, or connections, between brain cells.

Over time, the density of the synapses declines in people with Parkinson’s, indicating the loss of critical, dopamine-producing brain cells. Lack of dopamine is the key driver of Parkinson’s.

“Until now, there was not a way to measure this directly while people were alive, only at an autopsy after they passed away,” Strafella says. “Now we can quantify... when the disease is at the beginning, the middle stage, and after, so we can measure the progression of this disease.”



RESEARCH GRANT



PROJECT GRANT
\$45,000 over 1 year partially funded (\$14,500) by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCH PROFILE
Antonio Strafella,
Professor

INSTITUTE
University of Toronto and
University Health Network

Strafella hopes this new tool will become a non-invasive way to diagnose Parkinson’s. He also believes it may enable researchers to distinguish between different types of Parkinson’s disease, such as Progressive Supranuclear Palsy and Multiple System Atrophy.

Equally importantly, the imaging may allow doctors and researchers to assess the progress of medication or treatment.

If a drug was working to halt Parkinson’s progression, for example, there should be little change in the density of the synapses seen on the PET scan, rather than a reduction in their density if the drug was not working.

Strafella’s research as a movement disorders specialist is always directed at ways to improve the quality of life of the patients he treats. Giving people with Parkinson’s more answers about the type of disease they have and how it might progress is one way of doing that.

“By improving the quality of life of the patients, you also indirectly affect the quality of life of the family – the caregivers,” he says.

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

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Dr. Kluger Discusses Cannabis Research and Parkinson's Disease



Dr. Benzi Kluger, MD, MS, is an Associate Professor of Neurology and Psychiatry, as well as the Chief and Founder of the Palliative Care Section at the University of Colorado. His research focuses on the

non-motor symptoms of Parkinson's, including fatigue and cognitive dysfunction. Taking a palliative care perspective, Dr. Kluger supports patients with advanced neurological illnesses in exploring novel treatment options like non-invasive brain stimulation and alternative medicine.

Many of Dr. Kluger's patients have turned to cannabis to help treat their non-motor symptoms following legalization in Colorado in January 2014. Depending on the symptoms people wish to address, he helps them find the correct concentrations, doses and sources of cannabis and cannabis-based products.

It is important to note that cannabis cannot be considered a viable overall treatment for Parkinson's. Instead, anecdotal evidence suggests it to be helpful in alleviating some symptoms. Each person will react differently to cannabis-based products, so be sure to consult a physician before trying cannabis as an alternative treatment.



What is cannabis?

Cannabis is the overarching genus of plants that includes sativa, indica and ruderalis. Sativa is a type of cannabis that has higher levels of THC, so people sometimes conflate sativa with THC, but it also contains other chemicals. Indica and ruderalis tend

to have more Cannabidiol (CBD) than Tetrahydrocannabinol (THC).



What are cannabinoids?

Cannabinoids, as the name would suggest, are chemicals that can be derived from a cannabis plant. They act on cannabinoid receptors, which are specialized receptors in the nervous system and immune system. The two most common cannabinoids we talk about are THC and CBD. Now, there are over a hundred psychoactive cannabinoids that have been extracted from the cannabis plant. As you can imagine, it is becoming more and more complicated to try to understand what the effects of cannabis are, since there are so many chemicals in a cannabis plant.



How does cannabis affect the nervous system?

There is a lot of hype around cannabis for Parkinson's disease; however, it is known that if you directly stimulate cannabinoid receptors, you actually decrease the production of dopamine. As a result, it is unlikely that cannabis and cannabis-based treatments are going to replace other medications for Parkinson's. However, there are over a hundred different cannabinoids (chemicals) in cannabis, some of which stimulate cannabinoid receptors and others that block them or work independently of these receptors. How they are going to act also depends on the state of the nervous system. The bottom line is that there is more research needed to understand how best to utilize them in the context of Parkinson's.



Do cannabinoids improve motor symptoms in Parkinson's disease?

In animal models, the published studies are mixed regarding motor improvements. There have been a

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number of studies showing slowed movement in animals, and some that show faster movement. This is because the effect will depend on the type and dose of cannabinoid used.

I published a study in Colorado looking at people with Parkinson's. Only 5% of people in our clinic reported using cannabis and of those, most reported that they found benefits mostly for non-motor symptoms. These would include things like sleep, anxiety, pain, nausea and appetite. The benefits for motor symptoms were much more variable. That being said, I have a few patients who are using cannabis and they feel like it helps smooth out some of their offs and ons and motor fluctuations, but that is really a minority of people I see in my practice.

When people have done other trials with a placebo control group, they have been unable to show that there is a benefit from cannabis. I would say, however, that rather than calling these results negative, they were inconclusive. It is possible that they did not find the right dose of cannabis or the right mix of cannabinoid concentrations in the plant. I think there really is more research to be done.

We are hoping to do a trial at the University of Colorado using high doses of CBD to see if that would help with tremor. I think the dosing is actually very important. If you compare the doses that we extract from the randomized control trials to the doses being used in epilepsy, there is a major difference. These trials use 5–10mg of CBD, compared to 50–100mg used for epilepsy.


Do cannabinoids improve non-motor symptoms in Parkinson's?

There has been some interesting animal research regarding memory and cannabis. It was shown that

Cannabis Legalization in Canada

Medical marijuana is currently legal in Canada, but remains largely unregulated. Recreational cannabis legalization is slated for October 17, 2018. Once legalized, cannabis products will undergo more rigorous testing and labelling to ensure that concentrations of THC and CBD are more precise.

In British Columbia, cannabis will be legal to purchase from regulated dispensaries by anyone of legal age. Adults will be allowed to possess up to 30 grams in a public space, but smoking will be prohibited everywhere tobacco is prohibited, in addition to playgrounds, recreational areas and other places where children commonly gather.

 To learn more about the Cannabis Control and Licensing Act, visit www2.gov.bc.ca. To learn more about federal legalization, visit Canada.ca.

CBD may actually improve memory and increase neuronal function and THC may improve memory in older mice, but not younger. If you look at the research on people, however, the oldest subject in any cannabis trial was 30 years old. So we have almost no idea what cannabis does in people over 30 despite the fact that this is now the largest growing population in terms of medical cannabis use.

There have been some case series which suggest there may be a benefit for REM behaviour disorder and for psychotic symptoms like hallucinations, delusions and agitation in people with either Lewy Body dementia or Parkinson's disease dementia. Both of those were with CBD.

What is your advice to people interested in using cannabis to treat their symptoms?

When it comes to alternative medicines, there is no regulation on products. One thing I advise people is to find a dispensary that they know and trust, and to

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Managing Gut & Bladder Problems

Some of the most common non-motor symptoms of Parkinson's are issues with digestion and elimination. Constipation is experienced by at least half of all people with Parkinson's, sometimes decades before the onset of motor symptoms, or later as a side effect to drugs like levodopa. Additionally, about one third of people with Parkinson's will develop incontinence. Although these issues are often considered mere nuisances, they can cause significant pain, discomfort and complications if left unmanaged.

The best way to treat elimination issues is by maintaining healthy everyday habits. As with any other symptoms of Parkinson's, digestion and continence issues may not be experienced by everyone and can differ greatly between individuals. Regardless of whether or not you have encountered these issues, it is important to recognize warning signs and be prepared to treat any new symptoms accordingly. Below is a guide to some of the simple lifestyle changes you can adopt to prevent and treat constipation and incontinence.

Constipation

A healthy gut can pass stool anywhere from three times per day to three times per week, while each meal can take anywhere from 12–72 hours to digest. Constipation is diagnosed when fewer than three bowel movements occur weekly, at which point stool remains in the intestines long enough that it becomes too dry and lumpy to pass comfortably. Other signs of constipation include sensations of rectal obstruction and fullness, or incomplete passing of stool during bowel movements (GI Society, 2017).

Bowel pattern changes occur in people with Parkinson's as a result of improper nerve functioning in the gut, which can slow the passing of stool. These issues can also worsen due to the presence of other common

PD symptoms, including dehydration, lack of exercise, poor diet and stress. In order to alleviate constipation, it is important to treat these symptoms first.

Constipation can most effectively be managed by adopting a high-fibre diet, along with maintaining adequate fluid intake and exercise levels. Fibre helps to bulk and soften stool, making it easier to pass. Health Canada recommends eating 25–38 grams of fibre daily, but reports that most Canadians eat only half that much (Health Canada, 2012). This is likely due to the favouring of quick, easy food products packed with sugar and fats. Adding more fibre to your diet can be as simple as using alternatives to some of these everyday foods, including:

- whole wheat and bran to replace refined grains in breads and crackers
- brown rice or quinoa to replace white rice
- whole grain pastas to replace white pasta
- oatmeal to replace sugary cereals

Along with these grain products, you should increase your intake of legumes, nuts, seeds and fruits and vegetables with skin. Some more fibre-rich foods you can add to your grocery list include: apples, avocados, bananas, berries, broccoli, cauliflower, corn, oranges, pears, peas, potatoes, raisins and spinach. Keep in mind the rule that the darker and richer the colour, the higher in fibre the food.

Dietary fibre should be increased slowly to reduce bloating, cramping and gas. Exercise can help lessen these side effects and promote bowel movements. An adequate fluid intake is also important to ensure proper digestion of fibre and regularity. People with Parkinson's should look to drink six to eight 250mL glasses of water daily. To help with constipation, warm liquids like herbal teas can help with bowel movements, especially in the morning (Dolhun, 2017). However, caffeinated beverages, alcohol and hot liquids can lead to dehydration and should be limited.

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If problems persist beyond these dietary changes, speak to your doctor about fibre supplements and aids for constipation. Do not turn to laxatives without doctor's supervision, as these may damage the lining of the colon, which only serves to worsen constipation (Parkinson's Disease Clinic and Research Center).

Incontinence

Many people with Parkinson's will develop incontinence, which can cause sensations of urgency commonly occurring during the night. This nighttime hyperactivity, referred to as Nocturia, is among the most common non-motor symptoms reported by people with Parkinson's. Nocturia not only disrupts sleep, but increases risk of falls and injury in navigating trips to the restroom in the dark. Other incontinence problems include increased frequency of urination, leakages and the inability to completely empty the bladder.

Though many Parkinson's medications can lead to constipation, they are also known to help with incontinence. Control of the bladder is linked to the body's dopamine levels, so many people experience the worst of their incontinence symptoms during the times of day when medication wears off between doses. Taking medication on time every time can help continence significantly (Continence Foundation Australia, 2014).

Many people with incontinence may look to decrease their fluid intake in order to control symptoms, but this is counterproductive as it can lead to dehydration. Instead, incontinence is best managed by drinking enough water while decreasing intake of bladder irritants such as: caffeine, coffee (even decaffeinated), alcohol, artificial sweeteners, dairy products, citrus juices, carbonated beverages, chocolate, honey and spicy foods (NAFC, 2017). No diet can guarantee a cure for incontinence, but healthy eating can help regulate the body's elimination patterns and schedule.

Constipation and incontinence can often occur at the same time, but the maintenance of healthy habits such as drinking enough water and "honouring the urge" to pass stool or urinate can have a profound effect on both conditions. If these smaller, everyday changes are not enough to help your bowel or bladder problems, consult a physician before attempting further treatments.

For more resources on identifying and treating bladder and bowel conditions:

Bowel Management Program helpsheet:

<https://www.parkinson.bc.ca/media/31455/bowel-management-program.pdf>



Bladder Dysfunction helpsheet:

<https://www.parkinson.bc.ca/media/72340/bladder-dysfunction.pdf>



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Making the Most Out of Your Doctor's Appointments



When living with a chronic condition like Parkinson's disease (PD), it is important to keep track of the symptoms you encounter as well as any changes in your lifestyle and mood. The information that you provide to your healthcare team serves as the basis for recommendations they may give you.

Many of your medical appointments will be short, so it is important to practice effective communication and build a strong relationship with your healthcare team. Parkinson Society British Columbia has resources available to help you make the most of your care by being prepared for every doctor's visit. To guide your conversations with healthcare providers, or help with self-management, you can download our new Comprehensive Care Plan Checklist at <http://bit.ly/PDCarePlan>.

Changes & concerns to reflect on when preparing for an appointment

1. Note your general health and wellbeing, as well as recent stress levels and mood.

Always trust your gut when discussing your overall wellbeing with healthcare professionals. Elevated stress levels can be a significant indicator that

something is wrong, or that your treatment is not working. In some cases, it can be difficult to pinpoint specific symptoms and you may simply be feeling unlike yourself. Rather than taking guesses as to what may be causing you to feel unwell, bring your concerns to a healthcare professional who can help you identify new symptoms and conditions.

Along with physical symptoms, issues to note about your mental wellbeing include changes in your sleep pattern, excessive sleepiness, vivid dreams, sadness/depression, apathy, anxiety, euphoria and loss of motivation or pleasure from activities. Also, be candid about any instances in which you may have experienced hearing things that were not there or believing that certain things were happening that other people say were not.

2. Track your physical symptoms, both motor and non-motor.

When discussing your symptoms, note when new symptoms appear and when old ones are no longer present. There are four key points to cover whenever you talk to your healthcare team about any new concerns:

- Where on your body do you have the problem?
- What does it feel like? Is it constant or fluctuating?
- How long has it been going on? Has it changed over time?
- How intense, uncomfortable or inconvenient is it?

Be as specific and detailed as you can with this information, and consider using the Comprehensive Care Plan Checklist as a guide in these discussions. Covering these four points can help your healthcare team identify whether your new issues may be linked to pre-existing symptoms, your medication schedule or your lifestyle and everyday habits.

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3. Track your medications, including schedules, doses and side effects.

Every individual with Parkinson's will have a unique set of symptoms and side effects to medication, so keeping your healthcare team informed about your medication experience is crucial. When visiting your doctor, ask about refills and bring any new medications you are taking, including new vitamins or supplements. The effectiveness of some Parkinson's drugs can be reduced when combined with drugs for other health conditions.

How to practice effective communication with your healthcare team

Dr. Donald Cegala at the University of Ohio developed the P.A.C.E. framework to help patients make the most of their communication with doctors and healthcare professionals. Effective patient communication involves:

- P – presenting** detailed information about how you are feeling
- A – asking** questions if desired information is not provided
- C – checking** your understanding of information that is given to you
- E – expressing** any concerns about the recommended treatment

Patients do not typically ask many questions, despite wanting as much information as possible. Consider asking your healthcare team questions that will confirm your understanding of the information you have been given. Do not hesitate to ask for further details if needed, or to make requests such as “Could you refer me to a specialist?”




Another crucial but often missed step in communicating with healthcare professionals is to express your concerns, fears and hesitations about any particular treatment or medication. Do not assume that the treatment plan given to you is your only



option. Feel free to discuss alternative treatments, therapies and medications with your doctor. Doing so can help you avoid misinformation from unscientific sources on the internet or elsewhere.

For more resources, including checklists to help track your symptoms and medications, visit www.parkinson.bc.ca. To learn more about our education and support services, contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

Additional resources:

- Comprehensive Care Plan checklist: https://www.parkinson.bc.ca/media/134128/parkinsons-disease-checklist-for-comprehensive-care-plan_final.pdf 
- Preparing for a medical appointment helpsheet: <https://www.parkinson.bc.ca/media/31542/preparing-for-a-medical-appt.pdf> 
- P.A.C.E. Framework helpsheet: <https://www.parkinson.bc.ca/media/48895/how-to-talk-to-your-health-care-professional.pdf> 

Out of the Frying Pan and into the Fire

Donna McRae is a carepartner for her husband, John, and an active member of the Parkinson's community. Below she shares what she has learned on her carepartner journey and her advice to others.

The route to diagnosis and becoming a caregiver

As is the case with many people with Parkinson's disease (PD), ours was a long and twisted route to diagnosis – over two years. First, it was restless legs syndrome, and then “Parkinson's-like”. Once we were able to visit the Movement Disorder Clinic at UBC, my husband, John, received an immediate diagnosis of Parkinson's disease. I had a strong feeling that this was the case just from the physical signs that he was displaying. Even with prior suspicion, the pronouncement of PD was hard to accept and for a good deal of time I was in denial. That was back in 2010, but the movement disorder specialist felt that he had been misdiagnosed for about 7 years. From speaking to others with PD, I know this is a common occurrence.

In the beginning, I really didn't have much of a carepartner role, mostly just reminding him of his medications. Over the past eight years, we have evolved the carepartner role to include any physical help he might need, including ADLs (activities of daily living). As a carepartner, you try to make your loved one's environment as accommodating as possible so they can be independent for as long as possible. Remaining conscious of their limitations and rearranging whatever is necessary, as well as providing a safe environment, becomes second nature as you try to keep them active and involved in daily life. Being a carepartner is a 24/7 job and people do not realize how much effort goes into everything!

Adapting to change and living well

Accepting the little things and rewarding accomplishments are part of never giving up to the disease. A simple “thank you” for any information or assistance you have given or received goes a long way. Just being grateful for another day and trying to have as good and as long of a life as possible is important.

Be open with each other and discuss what is happening, and above all else, **look after yourself**. This is not an easy journey and stress can become a constant in your home. Stay on top of it and try to find a way to destress and develop a thick skin so that you can deflect hurtful actions or statements by reminding yourself that these are by and large unintentional. My best advice is to continue a normal life as much as possible. If you have activities that you have participated in, keep them up. I have curled for over 30 years and still do it twice weekly during the season. If you have ever really wanted to do or accomplish anything, do it now – don't wait! Travelling is a good thing and you would be surprised how it helps the stress levels as well. Work as long as you feel comfortable doing so, as the social aspect helps to keep you level headed at home. I retired this year and am now looking for volunteer positions, as well as spending more time with our grandsons.

We also participate in SuperWalk, although John may have to use a scooter to cover the distance this year – oh, well. We need to be grateful for what we have and not dwell on what could have been. This is another hard concept for me to absorb and put into practice but I am constantly working on it.

How others can help

Social isolation is something that happens to both the caregiver and the person with Parkinson's. Friends and acquaintances tend to fade out of contact and you soon learn who is a true friend. Cherish these

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friends! And please do not be those people who leave. We all have busy lives, but take the time to call and ask how it's going or offer a coffee date or to go for a walk. Ignoring the PD family and leaving contact up to them can cause resentment and an ever-increasing sense of isolation. Slowed speech and softening of the voice also occur in people with PD. When they are searching for a word, please do not interject! Let them indicate if and when they might like assistance. Likewise, in a group, don't talk around them – that just furthers their feelings of isolation.

Advice for your journey with Parkinson's

Do your research and keep abreast of new developments but be sure to seek out reputable sources. Attend as many events and webinars as possible, even if for the simple reason of reminding yourself that **you are not alone**. Voice your concerns and try very hard to attend doctor's appointments with your partner. Two sets of ears are

always better as someone always misses something or misinterprets what is said.

Being given a diagnosis such as PD initiates the grieving process. There are many steps prior to acceptance. I know that I was in denial for quite a while and refused to attend support group meetings. Friends became my sounding board and gradually I accepted the diagnosis and started participating in PD-related events. John and I have now co-lead our support group for several years and I find it rewarding. Trying to help someone through a difficult time – even if just by calling them – just seems right. Be strong, but also be vocal and try to initiate change so that someday soon we will find a cure for Parkinson's!

Parkinson Society British Columbia offers a breadth of educational resources and support services for carepartners. Learn more at www.parkinson.bc.ca/resources or contact Caroline Wiggins at cwiggins@parkinson.bc.ca.

DR. KLUGER DISCUSSES CANNABIS RESEARCH AND PARKINSON'S DISEASE

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stick with that dispensary and their products. The second thing is to start with a low dose and go up slowly. A third thing is to try and tailor your use of cannabis to the symptoms you wish to treat. For example, in people who are having pain, often what we will do is start with a cream or a patch, which can be helpful for pain and tends to have less of the systemic side effects compared to oral or smoking products. THC seems to be best for nausea and appetite; so if those are the target symptoms, having a product with more THC than CBD would be helpful. On the flip side of that, for things like sleep, CBD might be more helpful than THC.

We generally recommend oral products such as drops or candies to avoid smoking, which can have effects

on the lungs and vocal cords. The disadvantage of oral products is that a lot of the time, absorption is harder to predict in terms of timing as well as dosage. I do have some patients that will use a vape pen to get targeted hits to smooth out certain symptoms. We really want to make sure we are using the right product for the right symptom, and also that we have a target.

This Ask an Expert feature was adapted from Dr. Kluger's presentation at **Moving Forward, Together**, a Provincial Conference hosted by Parkinson Society British Columbia in June 2017. Recordings from this event are still available at www.parkinson.bc.ca/movingforward.

Thank you to our fundraisers and donors

Shaken, Not Stirred

On April 28, members of the Prince George Parkinson's community attended Shaken, Not Stirred, a dinner-dance fundraiser in support of PSBC and the Prince George Parkinson's Support Group. The evening featured exciting door prizes, two 50/50 draws and a silent auction, raising \$6,835 for PSBC!

Pull for Parkinson's

On May 4, high school students from throughout the Lower Mainland and Fraser Valley participated in the fifth annual Pull for Parkinson's, an Ultimate Frisbee tournament in support of PSBC. Players raised a record-setting \$5,294! PSBC would like to thank tournament organizers Thomas, Nigel, Lambert and Mariam for their ongoing support!

Shake, Shake, Shake

Shake, Shake, Shake was back for its third year on May 25! Organized by Emily Chambers, the concert featured performances by herself, Khari Wendell McClelland and Dawn Pemberton, as well as a special acoustic performance by Paul Pigat for VIP attendees. This year's concert raised over \$21,000, with 60% benefitting PSBC, and the remainder going to the MS Society of Canada – BC & Yukon Division!

Elk Valley Parkinson's Golf Tournament

Parkinson Society BC extends our deepest gratitude to Merl Shelley and Adam Toner for hosting the third annual Elk Valley Parkinson's Golf Tournament on June 2 at the Sparwood Golf Course, raising a record-breaking \$7,268!

EDUCATION EVENTS

Workshops

Communication and Swallow Workshops

These full-day interactive and participatory workshops, led by Registered Speech Language Pathologist Sherri Zelazny, will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP).

- Richmond – Saturday, September 22, 2018
- Langley – Saturday, November 3, 2018

Time Out for Carepartners Workshops

Join us for a day of education, socializing and relaxation. Expert speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease (PD).

- Kelowna – Saturday, October 20, 2018

Additional Thanks To:

- Simon Fraser University's Students for Humanity club bake sale raising \$200
- Simon Fraser University's Pre-Dental Society's "Spring Manual Dexterity Night" raising \$61
- Aya Hirabayashi of Orca Henna's fundraiser at "Car Free Day" in Vancouver raising \$95
- The North Vancouver Host Lions Club for their \$1,000 gift
- AbbVie for their generous \$10,000 sponsorship in support of the Kelowna Regional Conference and our Annual General Meeting
- Sunovion Pharmaceuticals for providing partial support for our Allied Team Training Program (ATTP) scholarships with a \$5000 contribution
- UCB Canada for their \$3,500 gift to help us produce information & resource folders

Community Talks

- **Emotional and Mental Health**, Prince George – Saturday, September 29, 2018
- **Research at Pacific Parkinson's Research Centre**, Parksville – Friday, October 12, 2018

Save the Date!

- **Regional Conference**, Vancouver – Saturday, November 24, 2018



UPCOMING EVENT

PARKINSON SUPERWALK®

Join us for Parkinson SuperWalk!

Everyday Heroes. Extraordinary Hope.

Heroes come in all forms – register today to bring extraordinary hope to British Columbians affected by Parkinson's disease. Visit www.parkinson.bc.ca/superwalk to register online or donate.

THANK YOU TO OUR SPONSOR 

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

Ask the Expert Webinars

- **Cognitive Health Influences on Fall Risks** – Tuesday, October 23, 2018
- **How to Stay Safe and in Your Home for Longer** – Tuesday, November 20, 2018
- **Understanding Palliative Care** – Tuesday, December 11, 2018



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

Leaving a Legacy

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.

For most people, their will is a way of looking after the people they care about. Making a will and planning for end of life are important steps in supporting your family and carepartner(s) by alleviating some of the stress and burden of decision making.

Writing and reviewing your will on a regular basis is an important task. To ensure that you have a valid will, we strongly recommend enlisting the services of a professional.

Why should I prepare a will?

Your will outlines how you wish to distribute your assets after you pass, whether it be to your children, spouse, friends and/or charitable causes. It allows you to specify where your money, investments, real estate and other property will go, including cherished belongings like jewelry or artwork. As part of your will, you can also set-up trusts for minor children, and appoint them a legal guardian.

What happens if I die without a will?

Under provincial law, the government distributes your assets for you if you have not prepared a valid will. In this case, your estate can only be administered to family, and any dependent children will be appointed a guardian by the court.

If you have a spouse and no children, your estate would go to your spouse. If you do have children, then the distribution of your estate would depend on whether you have children in common with your spouse, or if they are your descendants only. If your children are minors, their share is held in a government trust until they reach 19. If you have no spouse or children, your estate is distributed to

your family in the following order: parents, siblings, nieces and nephews. If no relation is found following this, your assets go to the government.

What is probate?

Every will names an executor, who is the individual or company responsible for submitting an application to the court to determine the validity of your will. This process is called probate. All estates over \$25,000 generally need to be probated. Whether or not a will must be probated also depends on the financial institutions that hold assets within an estate. Some agencies require a will to be probated before allowing the funds or property they hold for the deceased to be distributed.

Certain fees may be charged depending on the size of the estate, up to a rate of 0.14% for large estates.

Preparing a will

There are certain formalities you need to follow when making your will. Although legal advice is not required, you may want to consult a lawyer, estate planning professional and/or a notary public to ensure that you have drawn up your will correctly. A well-prepared will ensures lower costs, fewer mistakes and deficiencies, and minimized taxation. If you want to leave a gift to charity, legal aid is especially important.

The formalities:

- wills must be in writing
- wills must be signed and dated at the end by the will-maker, in the presence of two witnesses
- witnesses must not be beneficiaries or spouses of beneficiaries, and must be of legal age
- will-makers must be of sound mind
- will-makers must not sign under duress, coercion or undue influence

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Lawyers generally recommend reviewing your will every five years, or with any new change in the family or beneficiaries. It is also recommended to sign your initials on every page of your will.

Other methods of administering your estate

If you wish to reduce taxes and probate fees, you may want to consider distributing your property in other ways. Many holdings can be assigned a beneficiary, such as life insurance, tax-free savings accounts and retirement savings plans. This money cannot be disposed of by means of a will.

Other property may be held in joint tenancy, including homes, bank accounts and motor vehicles, which are signed over to the co-owner in the event of your death. Many couples will hold all of their assets jointly and designate each other as beneficiaries so that on the death of one spouse, all assets go to the other, even if they have children together.

You may also consider establishing a trust before your death. Property held in a living trust is not considered a portion of your estate, and is not

subject to probate fees. However, other fees may be involved with setting up and managing a trust.

Planned giving

You can benefit from tax minimization by including charitable gifts in your estate planning to organizations like Parkinson Society British Columbia (PSBC). By considering a gift to PSBC, you are providing for our programs, services and research contributions. Whether your estate is large or small, a gift to PSBC in your will can make a lasting impact on individuals with Parkinson's disease, caregivers and families.

Options for planned giving:

- Bequests
- Gifts of life insurance
- Gifts of registered plans
- Charitable remainder trusts and annuities
- Gifts of real estate
- Gifts of securities

For more information on leaving legacy gifts to Parkinson Society British Columbia, visit www.parkinson.bc.ca/donate/estate-planning.

This article was adapted from a webinar on wills and estate planning, presented by lawyer Mary-Jane Wilson for Parkinson Society British Columbia. A recording of this webinar is available at bit.ly/EstatePlanningWebinar.

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.

Stay connected to the Parkinson's community!

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

For only \$25, you will receive an annual membership for you and your household valid until December 31, 2019.

Reasons to renew your membership:

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

▶ Visit www.parkinson.bc.ca or return the insert inside this issue of *Viewpoints*.



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

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