# A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC JUNE 2019 ISSUE

#### CELEBRATING 50 YEARS OF SERVICE!



Since 1969, Parkinson Society British Columbia has been proud to empower people with Parkinson's across the province, through education, support services, advocacy, and fundraising. This year, join us as we celebrate the strength of our community, and the many milestones we have reached together. We hope to extend our reach wider and impact stronger than ever before – within the Parkinson's community and beyond.

Throughout the year, we will be sharing inspirational stories from the people with Parkinson's, carepartners, and advocates in our community. If you have a story to share about your life with Parkinson's, we would love to hear it! For more information, email us at <a href="mailto:info@parkinson.bc.ca">info@parkinson.bc.ca</a>.

# **UPCOMING EVENTS**

Parkinson Society British Columbia (PSBC) endeavours to make attendance at events accessible to all who may benefit. The Society may be able to subsidize attendance fees for those who require financial assistance. Please contact us at <a href="mailto:info@parkinson.bc.ca">info@parkinson.bc.ca</a> or 1-800-668-3330 for more details.

#### REGIONAL CONFERENCE | KELOWNA

Our regional conferences are immersive and interactive opportunities for people affected by the disease to learn from leading experts while connecting with the Parkinson's community. The conference does not include a meal, however light refreshments will be provided.

Topics covered at this conference will include:

- New and Advancing Therapies | Dr. Daryl Wile, Movement Disorder Specialist in Kelowna
- Sleep and Parkinson's | Dr. Ron Cridland, MD with the Canadian College of Family Physicians and Fellow at the American Academy of Sleep Medicine
- Living with Purpose & Resilience "I Am Not My Disease" | Debra Coffey, Registered Professional Counsellor

Date: Saturday, June 22

Time: 1:00pm - 4:30pm (check-in begins at 12:30pm)

Location: Ramada Hotel & Conference Centre

2170 Harvey Ave, Kelowna [map]

Cost: Member: \$15 | Member Couple/Pair \$25

Non-member: \$25 | Non-member Couple/Pair \$45

Register: <u>www.parkinson.bc.ca/kelowna-rc</u>

#### ASK THE EXPERT: DEVELOPING TOOLS TO DISCOVER NEW THERAPEUTIC AGENTS I WEBINAR

Join us as Dr. Roger Ashmus from Simon Fraser University presents his research on developing tools to target the protein GCase (glucocerebrosidase). Gene mutations in people with Parkinson's cause a deficiency in GCase, which is one of the key risk factors for disease onset. Studies have shown that treating this deficiency could help prevent the progression of Parkinson's in mice models. Dr. Ashmus uses a combination of organic chemistry, chemical biology, and cell biology in hopes of discovering new therapeutic agents that increase GCase activity.

Instructions on how to access the presentation will be sent out 24 hours before the event's start time.

Date: Tuesday, July 16
Time: 10:00am - 11:00am

Cost: Free

Register: <u>www.parkinson.bc.ca/gcase-research-webinar</u>

## COMMUNICATION & SWALLOW WORKSHOP | KELOWNA

This 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. It is open to those already experiencing communication and swallowing challenges, as well as those who wish to be proactive in their treatment.

Date: Saturday, September 28

Time: 10:00am - 2:30pm (check-in begins at 9:30am)

Location: Ramada Hotel & Conference Centre

2170 Harvey Ave, Kelowna [map]

Cost: Member: \$25 | Member Couple/Pair \$40

Non-member: \$35 | Non-member Couple/Pair \$60

Register: <u>www.parkinson.bc.ca/kelowna-cs</u>

## FOR A LIST OF ALL UPCOMING EDUCATION EVENTS, VISIT WWW.PARKINSON.BC.CA/EVENTS

# **FUNDRAISING EVENTS**



- Champions for Parkinson's Raffle: May 1 September 30 [learn more]
- Elk Valley Golf Tournament: June 15 [learn more]
- Method Tattoo Sales: Ongoing until July 15 [learn more]
- Donate a Car Canada: Ongoing [learn more]
- Naturally Urban Pet Food Delivery Sales: Ongoing [learn more]

We're looking for more Champions! Do you want to help fund research, grow support networks, and improve quality of life for those living with Parkinson's? Become a Champion for Parkinson's and plan your own independent community fundraising event! Please contact Mirela Prime at <a href="mailto:mprime@parkinson.bc.ca">mprime@parkinson.bc.ca</a> or 1-800-668-3330.

# **NEWS & ANNOUNCEMENTS**



WARM WELCOME! NATALIE NUNEZ, BA Counselling Intern (available Thursdays only)

Natalie completed her Bachelor of Science degree at the University of British Columbia in Vancouver, and is currently completing her Master of Counselling Psychology at City University of Seattle. She has had a long-standing interest in health psychology, and understanding how physical disease can impact our mental health and well-being. She has experience providing support for individuals living with chronic medical conditions after spending time working at an obesity medicine clinic, and a prostate cancer supportive care program. Natalie's grandfather had Parkinson's disease, and this personal connection brought her to Parkinson Society BC. She works from a client-centered and strengths-based approach, and believes that every individual has the ability to make positive changes in their lives with the right support and resources. She hopes to provide a warm and empathic space for clients to work towards their goals and live happy and meaningful lives.

Visit <a href="www.parkinson.bc.ca/counselling">www.parkinson.bc.ca/counselling</a> to learn more about our counselling program. Interested in making an appointment? Call us at 1-800-668-3330 or email <a href="mailto:info@parkinson.bc.ca">info@parkinson.bc.ca</a>.

#### SURVEY RESULTS: SINEMET VS. GENERIC LEVODOPA DRUGS

We recently conducted a survey with the intent of better understanding the patient's perspective in achieving symptom control with brand name (Sinemet) vs. generic forms of levodopa. Read our findings and conclusions here: <a href="mailto:bit.ly/2YOMqCz">bit.ly/2YOMqCz</a>.

#### **NEW! NORTH SHORE SUPPORT GROUP**

This group is intended for anyone affected by Parkinson's disease. Carepartners, friends, and family members are welcome. Please note that visitor and street parking is available, but limited. Carpooling is encouraged.

Date: Starting Thursday, May 16

3rd Thursday of each month

Time: 10:00am - 11:00am Location: Amica Lions Gate

701 Keith Rd, West Vancouver [map]

# SAVE THE DATE: PROVINCIAL CONFERENCE

## MOVING FORWARD, TOGETHER | VANCOUVER

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

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

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

Speaker and session information coming soon.

Date: Saturday, October 26

Location: Hilton Vancouver Metrotown

6083 McKay Ave, Burnaby [map]

Registration: Coming Soon!





# TIP JAR



This item is a triple-soap dispenser that can be filled with things like shampoo, conditioner, and body wash. With a gentle pull of the lever, it dispenses products easily into your hand, allowing you to use your other hand to hold on to a grab bar, if needed.

Find the dispensers for purchase here: <u>bit.ly/2LGQLpr</u>.

These covers make it easier to drink from glasses without spilling. They are made of a stretchy, food-grade silicone to fit over multiple cup sizes, and give them a straw top.

Find the glass covers for purchase here: <u>bit.ly/2LLrcDJ</u>.

# DISCUSSION: TRAVELLING WITH PARKINSON'S

## **DISCUSSION QUESTIONS:**

- 1. What are some challenges you face when travelling with Parkinson's?
- 2. How do you prepare for travel?
- 3. What are your travel tips?

Travelling with Parkinson's can be challenging, especially as symptoms progress over time. If you travel each summer, you may notice changes each year. For many, advancing symptoms paired with the usual stressors of planning and packing can lead to increased feelings of anxiety, impeding the desire to travel. However, despite the obstacles, travelling can be fun and rewarding. Planning ahead and staying organized can greatly reduce any stress and anxiety, and allow for a safe and comfortable trip.

It can be helpful to make detailed lists to help you plan out all aspects of your travels, including what to pack, tasks to complete before departure, and accessibility options all along the way. For example, if you are planning a day trip to visit a friend, but are no longer driving, you will need to research your transportation options. In this case, you would need to consider factors such as each option's cost, how comfortable it is, what kind of baggage it will allow you to bring, and how accessible it is for your level of mobility. Similarly, if you are flying somewhere, you might want to compare airlines, secure travel insurance, request extra assistance at the airport, and book an aisle seat on the airplane in order to move around more easily.

Tips for travelling overnight and by airplane include:

- Bring extra medication. Before you travel, make sure you have sufficient supply of all your prescriptions that will last through your entire trip, with extra in case of delays. Visit your pharmacy 1-2 weeks before travel to ensure enough time to organize your medications.
- Make a list, and pack early and efficiently. Start packing at least 2-3 days before your trip to allow enough time to ensure you have all the things you will need. Delegate a bag for your most important items for easy access before and during your flight.
- Arrive to the terminal early. Airports, ferry terminals, and train stations can be crowded and difficult to navigate. Give yourself plenty of time to avoid feeling rushed.
- Pack light. You may need to carry your bags for long periods of time, especially if faced with any delays or detours. Avoid packing too many large or heavy items, like shoes and sweaters, and opt for travel-sized toiletries.

Driving with Parkinson's has its own considerations. If you plan to travel by car, there are several factors that should be taken into account to ensure your safety. Planning ahead, as you would with any other travel, is the key to having a smooth trip.

Tips for driving with PD include:

- **Pre-plan your route, including rest stops.** Determining your route ahead of time can reduce some of the stress and anxiety that come with travelling. You may wish to plan extra rest stops, in case they are needed.
- **Get plenty of rest before driving.** It is important to be alert while driving. Excessive sleepiness and fatigue are common challenges for people with PD. If you feel too tired to drive, either have someone else drive, or pull over to rest.
- **Drive in daylight.** Whenever possible, refrain from driving in the dark. It is safest to drive in daylight, especially if you have a history of fatigue.
- Take regular breaks. Use rest breaks as an opportunity to stretch your muscles, and give your mind a break for a short while.
- **Drive with a companion**. Having a passenger means having someone who can help monitor your driving, give directions, and keep you alert. It is best to travel with someone who can take over the driver's seat if needed, or drive with you in shifts.
- Bring extra medication and water. It is a good habit to keep extra medication stored in the car just in case you need it.
- **Bring snacks.** Whether you are going on a short drive or a long road trip, it is always smart to have quick snacks like nuts, crackers, granola bars, and fruit on hand.
- Check your car insurance. Before departing on a car trip, ensure your insurance plan is up-to-date and includes roadside assistance.

You may find that driving can become more challenging as symptoms of PD progress. If you are a person with PD concerned about your own driving abilities, it is important to be honest with yourself. Retiring your driver's license may be necessary, but it is a sensitive topic, as driving provides a sense of independence and autonomy that can be difficult

to give up. This is also important for carepartners to consider if they are looking to approach the topic of driving with their loved one with PD. It is best to err on the side of caution to ensure your safety, and the safety of your loved ones and others on the road. You may find it beneficial to speak with a trusted healthcare professional, counsellor, or your friends and family. If driving is something you enjoyed, it can also help to replace it with new activities or hobbies.

#### ADDITIONAL RESOURCES

Travelling with Parkinson's | Helpsheet | <u>bit.ly/pdhealthcareteam</u>
Driving with Parkinson's | Helpsheet | <u>bit.ly/paceframework</u>

## SAVE THE DATE: PARKINSON SUPERWALK IN BRITISH COLUMBIA



Parkinson SuperWalk this September!

#### REGISTER TODAY FOR PARKINSON SUPERWALK!

Join us for Parkinson Society British Columbia's largest fundraising event of the year, Parkinson SuperWalk!
Beginning the weekend of September 7 & 8, incredible British Columbians in over 20 communities throughout the province will walk together to help give hope to approximately 13,000 people in BC living with Parkinson's.

Funds raised in BC through this event help to provide valuable support services and education offered by Parkinson Society British Columbia throughout the province, as well as fund research efforts.

Participating communities include:\*

100 Mile House Pitt Meadows/Maple Ridge Burnaby Port Alberni Castlegar **Powell River** Chilliwack Prince George Comox Valley Salmon Arm Cranbrook (Virtual Walk) Terrace Kamloops Vancouver Kelowna Vernon Langley Victoria

Nanaimo Oliver

Don't see your community listed? Sign up to become a Virtual Walker to fundraise and walk in any community outside of the organized walk locations at a time that works for you. Your location can be anywhere in or outside Canada.

White Rock

### PARKINSON.BC.CA/SUPERWALK

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

<sup>\*</sup> Locations are subject to change. Visit our website to learn more.