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If you wish to personally receive GroupLink please connect with Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 and you will be added to the GroupLink e-mail distribution list.

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 Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 for more details.

COMMUNICATION AND SWALLOW WORKSHOPS, RICHMOND & LANGLEY

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

Cost: PSBC Member \$25.00 | PSBC Members (Pair) \$40.00
Non-member \$35.00 | Non-members (Pair) \$60.00

	Richmond	Langley
Date:	Saturday, September 22	Saturday, November 3
Time:	10:00am – 2:30pm (registration opens at 9:30am)	10:00am – 2:30pm (registration opens at 9:30am)
Location:	Executive Hotel Vancouver Airport 7311 Westminster Hwy, Richmond (map)	Holiday Inn Express & Suites Langley 8750 204th Street, Langley (map)
Registration:	https://www.parkinson.bc.ca/richmond-communication-workshop	https://www.parkinson.bc.ca/langley-communication-workshop

COMMUNITY TALK, PRINCE GEORGE

Join PSBC for an afternoon of education with Clinical Counsellor, Myriame Lépine Lyons. Myriame will discuss emotional and mental health for those affected by Parkinson's disease. This talk is for both people with Parkinson's and their carepartners/caregivers. A light lunch will be provided and the education session will begin at 1:00pm.

Date: Saturday, September 29
Time: 12:00pm – 3:30pm (registration opens at 11:30am)
Location: Spruce Capital Senior's Recreation Centre
3701 Rainbow Drive, Prince George ([map](#))
Cost: PSBC Member \$10.00
Non-member \$15.00
Registration: <https://www.parkinson.bc.ca/prince-george-community-talk>

COMMUNITY TALK, PARKSVILLE

On October 12, join Parkinson Society British Columbia (PSBC) for an afternoon of education at the Parksville Community Centre. Research Assistant Emma Kiss and Research Coordinator Christy Jones will provide an overview of past and ongoing research studies taking place at Pacific Parkinson's Research Centre (PPRC).

UPCOMING EVENTS



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Date: Friday, October 12
Time: 1:00pm – 2:30pm (registration opens at 12:30pm)
Location: Parksville Community Centre
132 E Jensen Ave, Parksville ([map](#))
Cost: \$5.00 per person
Registration: <https://www.parkinson.bc.ca/parksville-community-talk>

TIME OUT FOR CAREPARTNERS WORKSHOP, KELOWNA

Join us for a day of education, socialization and relaxation. Expert speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease. Lunch and light refreshments will be provided.

Special Notice: *An adjacent room will be available for people with Parkinson's (PwP) to partake in activities, while their carepartner participates in discussions with other carepartners. We ask that those PwP coming to the October 20 event respect this room divide, and not attend sessions unintended for them. This room will be managed by volunteers. The volunteers will not be medical professionals.*

Date: Saturday, October 20
Time: 10:00am – 2:30pm (registration opens at 9:30am)
Location: Ramada Kelowna Hotel & Conference Center
2170 Harvey Avenue, Kelowna ([map](#))
Cost: PSBC Member \$30.00 | PSBC Members (Pair) \$45.00
Non-member \$40.00 | Non-members (Pair) \$55.00
Registration: <https://www.parkinson.bc.ca/time-out-for-carepartners-kelowna>

ASK THE EXPERT WEBINAR: HOW COGNITIVE HEALTH INFLUENCES FALL RISKS

Barbara Adams, Physiotherapist and Clinical Director for PhysioCare At Home, graduated from Dalhousie School of Physiotherapy in 1984 and gained experience working in cardiac rehabilitation, intensive care, neurology and geriatrics. After 18 years with the Capital District Health Authority in Nova Scotia, Barbara transitioned into the private practice world. Barbara works actively in falls prevention for the elderly. In March she participated in a [CBC radio interview](#) on preventing falls for seniors, and now on October 23, the Society will have her speak on this very topic.

Date: Tuesday, October 23
Time: 10:00am – 11:00am
Location: Via webinar. *Instructions on how to access the presentation will be sent out 24 hours before the event's start time.*
Capacity: 200
Cost: Free
Registration: <https://www.parkinson.bc.ca/cognitive-health-webinar>

ASK THE EXPERT WEBINAR: HOW TO STAY SAFE AND IN YOUR HOME FOR LONGER

By the age of 85, one in three seniors will live in a care facility. What can we do to keep our elderly family members safe and in their homes longer? For the first time on November 20, Dr. Roger Wong joins the Society for a presentation on staying safe and in your home for longer.

As Executive Associate Dean, Education at UBC, and Clinical Professor in the Division of Geriatric Medicine in the Department of Medicine, Dr. Wong works tirelessly to advance academic and clinical health sciences related to geriatrics. His work has significant impact on the care for older people in Canada and beyond. He was President of the Canadian Geriatrics Society and founded the state-of-the-art Acute Care for Elders Units (ACE) in Vancouver. His clinical research focuses on hospital medicine in vulnerable older adults, including quality improvement in acute care geriatrics.

UPCOMING EVENTS



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Date: Tuesday, November 20
Time: 10:00am – 11:00am
Location: Via webinar. *Instructions on how to access the presentation will be sent out 24 hours before the event's start time.*
Capacity: 200
Cost: Free
Registration: <https://www.parkinson.bc.ca/home-safety-webinar>

REGIONAL CONFERENCE, VANCOUVER

Parkinson's disease is a unique and complex condition. To assist in expanding your knowledge of the disease, on November 24th, Parkinson Society British Columbia (PSBC) will host an afternoon of learning in Vancouver.

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:

- **Parkinson's Disease 101:** Nancy Polyhronopoulos, Registered Nurse (RN) at the Deep Brain Stimulation (DBS) Clinic
- **Speech and Swallow:** Jamie Russell, MScA, Registered Speech-Language Pathologist (RSLP), Certified by Speech Language & Audiology Canada (SLP(C))
- **Finding Stability:** Gina Fernandez, Occupational Therapist (OT) in Richmond

Date: Saturday, November 24
Time: 1:00pm – 4:15pm (registration opens at 12:30pm)
Location: Library Square Conference Centre | Alice MacKay Room
350 West Georgia Street, Vancouver ([map](#))
Cost: PSBC Member \$15.00 | PSBC Members (Pair) \$25.00
Non-member \$25.00 | Non-members (Pair) \$45.00
Registration: <https://www.parkinson.bc.ca/vancouver-conference-2018>

ASK THE EXPERT WEBINAR: UNDERSTANDING PALLIATIVE CARE

Palliative care is provided by a team of health professionals who work together with primary care physicians, referred specialists and other hospital or hospice staff to provide additional support. Although most people think of palliative care as an important component of end-of-life care, it is appropriate at all stages of an illness.

For the very first time, [BC Centre for Palliative Care](#) will be joining Parkinson Society British Columbia (PSBC) for a presentation on how palliative care can play a role in symptom management and improving the quality of life.

Date: Tuesday, December 11
Time: 10:00am – 11:00am
Location: Via webinar. *Instructions on how to access the presentation will be sent out 24 hours before the event's start time.*
Capacity: 200
Cost: Free
Registration: <https://www.parkinson.bc.ca/palliative-care-webinar>

For a listing of all upcoming education events, visit our [education events calendar](#).

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Champions FOR PARKINSON'S

- Shifting Gears for Parkinson's: Continuing until October 31 [\[read more\]](#)
- Donate a Car Canada: Ongoing [\[read more\]](#)
- Naturally Urban Pet Food Delivery Sales: Ongoing [\[read more\]](#)
- Tea Parky: In this ongoing fundraiser, 35% of proceeds from every sale on TeaParky.com will go to Parkinson Society BC. *Special: Use promo code PSBC at checkout for 10% off your purchase.*

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 mprime@parkinson.bc.ca or 1-800-668-3330.



**PARKINSON
SUPERWALK®**

Join Parkinson Society BC for the largest fundraising event of the year, Parkinson SuperWalk!

Beginning the weekend of September 8th, everyday heroes in communities across the province will walk together to inspire hope for over 13,000 British Columbians living with Parkinson's. Funds raised through SuperWalk will help provide valuable support services and education offered by PSBC as well as assist in funding research efforts across Canada.

To learn more, visit www.parkinson.bc.ca/superwalk or call 1-800-668-3330.

NEWS & ANNOUNCEMENTS

GIVE BACK: SUPPORT GROUP FACILITATORS NEEDED

Due to the increasing demand for peer support groups, PSBC is actively recruiting a volunteer Support Group Facilitator to assist in strengthening the Parkinson's community in **Richmond, Vancouver (Arbutus) and Surrey.**

The responsibilities of Support Group Facilitators include:

- Working to create an environment that is safe and respectful, and where participants feel comfortable sharing their experiences, insight and knowledge with others.
- Assisting with the delivery of information, education and resources for people with Parkinson's and their carepartners/families.
- Leading support group meetings once a month, for a couple of hours, from September to June.

Facilitators are supported by Parkinson Society British Columbia through access to information and resources, teleconference calls, bi-annual one-on-one follow-ups, advocacy/awareness campaigns and educational opportunities. Please contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330 for more details.

SAVE THE DATE: WORLD PARKINSON CONGRESS 2019, KYOTO

The 5th [World Parkinson Congress](#) (WPC) will be held in Kyoto, Japan from June 4th – 7th, 2019. Are you interested in attending? Most travel agencies can begin booking a year prior to the travel date. If you have a connection with a local travel agency that you have used for past trips, you may want to inquire with them. The following is an example of what a travel agent could provide for your trip to WPC 2019. This particular travel package example was produced by Expedia CruiseShipCenters:

Sample Itinerary:

- Depart Vancouver May 29, 2019 > Depart Tokyo June 8, 2019
- Airfare = \$1,339/person including taxes*

Land Only Package:

- 10-14 passengers: \$2,850/person
- 15-19 passengers: \$2,531/person
- Single Supplement: +\$540

This would include:

- First class hotel accommodation as per itinerary based on double occupancy
- All transfers and transportation is by private, air conditioned coach with driver/guide
- Arrival & departure guide assistance
- Sightseeing and admissions as per the itinerary
- Bullet/express trains
- Meals as indicated on the itinerary



For more information on this particular travel package and to see a detailed itinerary, please contact Pat Thompson at pthompson@cruiseshipcenters.com or 250-763-2900.

A few additional suggestions on travel agencies are below:

- [Intrepid Travel](#): 1-855-299-1211
- [Marlin Travel](#): 604-681-0117 (West Georgia, Vancouver Location)

* Airfare based on May 2018 rates, subject to change

Registration for the 5th World Parkinson Congress opens on September 10th. Early registrants benefit from a discount until February 27, 2019. Full information on registration categories is available at www.wpc2019.org/page/RegFees.

	People with Parkinson's & Caregivers (attending alone)	Caregivers (attending with a PwP)
Early Fees:	\$300	\$200
Standard Fees:	\$350	\$250

For general questions about WPC and travel arrangements, contact us at info@parkinson.bc.ca or call 1-800-668-3330.

A COMPREHENSIVE GUIDE FOR PARKINSON'S CAREGIVERS IS AVAILABLE

Parkinson Society British Columbia (PSBC) is pleased to announce a new resource: A Comprehensive Guide for Parkinson's Caregivers. The primary contributor of this guide is Kaitlyn Roland, PhD, whose grandfather was diagnosed with Parkinson's. She holds a Masters in Health and Rehabilitation Sciences that focused on new ways to measure caregiver burden. Access the digital version of the guide here: <http://bit.ly/PDCaregiverGuide>.

This booklet has been made possible thanks to the support of PSBC's Title Sponsor, The Tenaquip Foundation, and grants from UCB and The Hamber Foundation.

Print versions of the guide are available upon request. To order your complimentary copy, please contact our Education and Support Services staff at info@parkinson.bc.ca or 1-800-668-3330.

WATCH NOW

**Annual General Meeting Recording**

Dr. Martin McKeown shared a Parkinson's disease and Pacific Parkinson's Research Centre Update at our 2017 Annual General Meeting. This presentation is now available to view online:

<https://vimeo.com/269260319>

**How to Cope as a Family Caregiver Webinar**

Eleanor Silverberg, social worker, author, speaker and grief specialist, shared her expertise in caregiving as a part of Parkinson Society British Columbia's Ask the Expert Webinar Series. This webinar is now available to view online:

<https://youtu.be/GJZIVaJJ8H8>

**Naturopathic Medicine Research Update Webinar**

Dr. Laurie Mischley, Naturopathic Doctor from Seattle, WA, presented her newest research findings involving naturopathic medicine for people with Parkinson's. This webinar is now available to view online:

<https://youtu.be/FHb2b-joVko>

Note: Any listings above should not be considered an endorsement of the third-party event(s). As such, the Society cannot be held responsible or liable for any loss or damage suffered as a result of participation.

Do you have any tips or tricks that you would like to share with the PD community? These can be tips from something that works well, to eating and dressing, to getting out of bed or travelling! All tips and tricks are welcome! Please share your ideas with us at info@parkinson.bc.ca or 1-800-668-3330.

DISCUSSION QUESTIONS:

1. Do you know the difference between dystonia and dyskinesia?
2. What have you found helpful to manage dystonia?
3. How have you managed your dyskinesia?

DIFFERENTIATING DYSTONIA FROM DYSKINESIA

You may have heard the words dystonia and dyskinesia thrown around during your medical appointments or perhaps with your exercise professional. Hearing about these two conditions is different than experiencing them. Like the symptoms of Parkinson's disease (PD) not all people living with PD will experience dystonia and dyskinesia. However, some might and learning about them can be a stepping stone to getting relief from these symptoms.

DYSTONIA

- Painful abnormal muscle contractions
- Abnormal posture
- Rigid twisting
- Turning/clenching

Dystonia

Primary dystonia affects an estimated 300,000 people in the United States and Canada; secondary dystonia is caused by a number of diseases and traumas and is much more prevalent than the primary forms (Dystonia Canada, 2015). When we look at the dozens of diseases that can cause dystonia, Parkinson's is one of them.

Dystonia in Parkinson's occurs as a result of painful abnormal muscle contractions related to a dysfunction in the region of the brain called the basal ganglia. It is characterized by abnormal postures, rigid twisting, turning and/or clenching (e.g., toe curling or leg cramps). People may experience these symptoms in their neck, shoulders, arms, hands, feet, face, jaw and vocal folds.

Dystonia may occur as an early symptom of PD or as a complication of treatment. For instance, "off" dystonia may occur during "off" periods, when the efficacy of levodopa treatment begins to wear off. In contrast, "on" dystonia may also occur during periods when levodopa has recently been taken and muscle spasms occur as a result of too much dopamine in the brain at one time. In some circumstances, dystonia may simply be a symptom of PD, however this is rare.

DYSKINESIA

- Abnormal, involuntary wriggling movements
- Dance-like motions
- Can be side effect of medications

Dyskinesia

The meaning of dyskinesia comes from dys, referring to "not correct", and kinesia referring to "movement". Dyskinesia is characterized by abnormal, involuntary wriggling movements that some describe as random dance-like motions. These movements are different from the common PD tremor. Dyskinesia can affect part of the body or the entire body, including the legs, arms, trunk, head, face, mouth and tongue.

It is important to note that not all people living with PD will experience dyskinesia. It can be a side effect of medication prescribed to treat PD. As PD progresses, there are changes in how the brain is able to store and release dopamine. This means that over time, people with PD are more likely to experience dyskinesia no matter how long they have been on treatment.

TREATING DYSTONIA

Knowing what is causing your dystonia is the first step in treating it. If your dystonia is affected by your PD medications, your doctor may be able to work with you to minimize these side effects by modifying doses of levodopa. The purpose of treatment for dystonia is to help lessen the symptoms of muscle spasms, pain and awkward postures (Dystonia Canada, 2015). Additional treatment options may include:

- Yoga, tai chi, qi gong and meditation
- Physical therapy
- Muscle relaxants or antispastic agents
- Botulinum toxin injections (i.e. Botox, Xeomin, Dysport) may be effective for some patients
- Deep Brain Stimulation surgery

(D. Wile, personal communication, February 20, 2018)

MANAGING DYSKINESIA

It is best to discuss the options for managing dyskinesia with your medical team. PD doctors will work to minimize your movement problems to get the most “on” time without dyskinesia. It can be a lengthy process to determine the correct dose, timing and type of medication as each individual is different and treatment needs can change over time. Some people with PD choose to live with mild dyskinesia as they are not bothered by it and feel that treating it may be more disruptive to the treatment of other, more serious symptoms.

(D. Wile, personal communication, February 20, 2018)

ADDITIONAL RESOURCES

- Dystonia Canada (website): <https://dystoniacanada.org/home>
- Dystonia (helpsheet): <http://bit.ly/PSBCDystonia>
- Dyskinesia (helpsheet): <http://bit.ly/PSBCDyskinesia>
- Deep Brain Stimulation (helpsheet): <http://bit.ly/PSBCDBS>
- Preparing for a Medical Appointment (helpsheet): <http://bit.ly/PDAppointments>
- Physical Activity (helpsheet): <http://bit.ly/PDPhysicalActivity>
- Treatment (helpsheet): <http://bit.ly/PSBCTreatment>

Sources:

Ahlskog, J. E. (2015). *The New Parkinson's Treatment Book: Partnering with Your Doctor to Get the Most from Your Medications, Second Edition*. New York, NY: Oxford University Press.

Christensen, Jackie Hunt. (2005). *The First Year Parkinson's Disease: An Essential Guide for the Newly Diagnosed*. New York, NY: Marlowe & Company

Dystonia Canada. (2015). *What is Dystonia?* Retrieved from: <https://dystoniacanada.org/whatisdystonia>

Okun M. S. & Fernandez, H. H. (2010). *Ask the doctor about Parkinson's disease*. New York, NY: Demos Medical Publishing.

Parkinson's Disease Foundation. *Dystonia*. Retrieved from <http://www.pdf.org/Dystonia>

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