

## UPCOMING EVENTS

*Parkinson Society British Columbia endeavors 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 Stacey at 1-800-668-3330 or [sdawes@parkinson.bc.ca](mailto:sdawes@parkinson.bc.ca) for more details.*

### STEP BY STEP

Step by Step has started! Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps. The goal of this program is to help motivate people to become physically fit to combat the symptoms of Parkinson's disease.

Interested in the Step by Step program? Contact Caroline at [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330.

Communities currently participating in Step by Step include: Chilliwack, Courtenay/Comox, Kamloops, Maple Ridge/Pitt Meadows, New Westminster, Penticton, Prince George, Saanich Peninsula and Victoria.

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### ELDER ABUSE WEBINAR: WHAT IS IT? HOW DO WE DEAL WITH IT?

This workshop addresses the correlation between social isolation and abuse of older adults, types of abuse and people involved, and strategies to deal with abuse. We discuss the importance of staying connected to others through brainstorming community resources, and viewing a short video depicting a fictional story of social isolation and elder abuse.

We welcome all individuals with Parkinson's to this webinar as well as their spouses and/or carepartners/caregivers as they may benefit from learning more about the topic to assist in supporting their loved one.

Date: Wednesday, May 25, 2016  
 Time: 10:00 am – 11:00 am  
 Location: Via webinar. Instructions on how to access the presentation will be sent out 24 hours before the webinar start time.  
 Cost: Free  
 Registration: <http://bit.ly/1UYOSBE>

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### REGIONAL CONFERENCE, PRINCE GEORGE

Parkinson's is a journey with different stages and associated challenges. Our regional conferences provide attendees the opportunity to learn from experts and connect with others who have been affected by Parkinson's disease. To ensure the best learning experience, a minimum of 50 participants will be required 14 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.

Date: Saturday, May 28, 2016  
 Time: 10:00 am – 4:00 pm (registration opens at 9:30 am)  
 Location: Westwood Church  
 2658 Ospika Blvd S, Prince George ([map](#))  
 Cost: Member \$30.00 | Member (Couple/Pair) \$50.00  
 Non-Member \$40.00 | Non-Member (Couple/Pair) \$70.00  
 Registration: Members: <http://bit.ly/1Utzm0D>  
 Non-Members: <http://bit.ly/1Y4bdf5>  
 Registration Deadline: Monday, May 9, 2016

**COMMUNICATION AND SWALLOW WORKSHOP, CASTLEGAR**

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practice treatment techniques and gain insight from a registered speech-language pathologist. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment. A catered lunch will be provided.

To ensure the best learning experience, a minimum of 25 participants will be required 7 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.

Date: Friday, June 3, 2016  
 Time: 9:00 am – 4:00 pm (registration opens at 8:30 am)  
 Location: Sandman Hotel Castlegar | 1944 Columbia Ave, Castlegar ([map](#))  
 Cost: Member \$40.00 | Member (Couple/Pair) \$70.00  
 Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00  
 Facilitator: Sherri K. Zelazny, MA RSLP  
 Registration: Members: <http://bit.ly/1Utzm0D>  
 Non-Members: <http://bit.ly/1Y4bdf5>

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**ABBOTSFORD COMMUNITY TALK WITH DR. ERIC AHLKOG**

Professor of Neurology at the Mayo Medical School, and Chair of the Mayo Section of Movement Disorders, Mayo Clinic, Rochester, Minnesota, Dr. Eric Ahlskog is widely considered to be a leading authority on Parkinson's disease.

Topic: The Nuts and Bolts Approach to the Treatment of Parkinson's Disease  
 Date: Thursday, June 9, 2016  
 Time: 3:00 pm – 4:30 pm (registration opens at 2:30 pm)  
 Location: Garden Park Tower | 101-2825 Clearbrook Road, Abbotsford ([map](#))  
 Cost: Free  
 Registration: <http://bit.ly/1UYOSBE>

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**VICTORIA COMMUNITY TALK WITH DR. ERIC AHLKOG**

Professor of Neurology at the Mayo Medical School, and Chair of the Mayo Section of Movement Disorders, Mayo Clinic, Rochester, Minnesota, Dr. Eric Ahlskog is widely considered to be a leading authority on Parkinson's disease.

Topic: The Nuts and Bolts Approach to the Treatment of Parkinson's Disease  
 Date: Friday, June 10, 2016  
 Time: 2:00 pm – 3:30 pm (registration opens at 1:30 pm)  
 Location: The Salvation Army Victoria Citadel | 4030 Douglas Street, Victoria ([map](#))  
 Cost: Free  
 Registration: <http://bit.ly/1UYOSBE>

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**ANNUAL GENERAL MEETING**

On Saturday, June 11th, PSBC will hold its Annual General Meeting featuring keynote speaker Dr. J. Eric Ahlskog, PhD, MD of the Mayo Clinic, Minnesota. This is a members only event.

Date: Saturday, June 11, 2016  
 Time: 9:45 am – 12:00 pm (registration opens at 9:00 am)  
 Location: Vancouver Public Library, Alice MacKay Room | 350 West Georgia, Vancouver BC, V6B 6B1 ([map](#))  
 Cost: Free for 2016 members  
 Registration: <http://bit.ly/1UYOSBE>

## NIDUS - REPRESENTATION AGREEMENTS PRESENTATION

British Columbia has excellent legislation for personal planning to ensure people's wishes are carried out if they are incapable or cannot communicate. Representation Agreements are a legally enforceable document to cover health care as well as personal care decisions in the event of incapacity, at end-of-life and for other support needs. Individuals in Vancouver have an opportunity to attend an in-person presentation by Nidus.

Date: Friday, June 10, 2016  
 Time: 1:00 pm – 3:00 pm  
 Location: South Granville Seniors Centre | 1420 West 12th Ave. ([map](#))  
 Cost: Free  
 Registration: No registration required

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## REGIONAL CONFERENCE, KELOWNA

Parkinson's is a journey with different stages and associated challenges. Our regional conferences provide attendees the opportunity to learn from experts and connect with others who have been affected by Parkinson's disease.

Date: Saturday, June 25, 2016  
 Time: 10:00 am – 4:00 pm (registration opens at 9:30 am)  
 Location: Ramada Kelowna Hotel & Conference Centre  
 2170 Harvey Avenue, Kelowna ([map](#))  
 Cost: Member \$30.00 | Member (Couple/Pair) \$50.00  
 Non-Member \$40.00 | Non-Member (Couple/Pair) \$70.00  
 Registration: Members: <http://bit.ly/1Utzm0D>  
 Non-Members: <http://bit.ly/1Y4bdf5>

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## COMMUNICATION AND SWALLOW WORKSHOP, PARKSVILLE

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practice treatment techniques and gain insight from a registered speech-language pathologist. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment. A catered lunch will be provided.

To ensure the best learning experience, a minimum of 25 participants will be required 7 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.

Date: Friday, July 22, 2016  
 Time: 9:00 am – 4:00 pm (registration opens at 8:30 am)  
 Location: Parksville Community and Conference Centre | 132 Jensen Ave E, Parksville ([map](#))  
 Cost: Member \$40.00 | Member (Couple/Pair) \$70.00  
 Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00  
 Facilitator: Sherri K. Zelazny, MA RSLP  
 Registration: Members: <http://bit.ly/1Utzm0D>  
 Non-Members: <http://bit.ly/1Y4bdf5>

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## WORLD PARKINSON CONGRESS

Date: September 20 – September 23, 2016  
 Location: Oregon Convention Center | 777 NE Martin Luther King Jr Blvd, Portland, OR ([map](#))

put on your capes...  
it's time to become a hero for parkinson's!



**register now**

help bring hope to those living with parkinson's.  
over 20 walk locations across BC!

<http://bit.ly/SuperWalkBC>

**EVERYDAY HEROES.  
EXTRAORDINARY  
HOPE.**

## UPCOMING EVENTS

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### UPCOMING FUNDRAISING EVENTS

- Me-n-Ed's Charity Golf Classic: Tuesday, May 24, 2016 ([read more](#))
- 4 Peaks 4 PD: Sunday, June 5, 2016 ([read more](#))
- Paddle for PD: begins Tuesday, June 7, 2016 ([read more](#))
- Sparwood Golf Tournament: Saturday, July 23, 2016 ([read more](#))

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 Lucy at 1-800-668-3330 or [lishamturner@parkinson.bc.ca](mailto:lishamturner@parkinson.bc.ca).

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

## NEWS & ANNOUNCEMENTS

### OUR NEW LOOK

Following dissolution of the Parkinson Canada Federation, Parkinson Society British Columbia has implemented our new look in 2016. This look has been applied to our newsletters and emails, website as well as many of our other resources. We welcome any questions or feedback you may have on our new appearance.

For more information: [Rebranding Announcement](#)

### FEATURED BOOKS FROM OUR LENDING LIBRARY

1. **Parkinson's: Stepping Forward. By Dr. David Grimes (2004).** This book explains in straightforward language what we know and don't know about Parkinson's, and how its various stages can be identified and treated. It offers a wealth of practical, hands-on tips for adapting homes and lifestyles to the needs of those affected.
2. **Parkinson's Treatment: 10 Secrets to a Happier Life. By Dr. Michael Okun (2013).** A guide to living with Parkinson's and finding hope and happiness. The book aims to inspire those with Parkinson's to discover their core values, and shares 'secrets' that will improve their lives.
3. **If Only I'd Had This Caregiving Book. By Maya Hennessey (2006).** Whether you are a caregiver for a loved one or a professional caregiver trying to help caregivers, Maya's Model is for you! Using a workshop format, the reader will move through self-discovery exercises to honor his/her unique personality and preferences, developing an individualized network to support, regardless of the loved ones condition or resources.

View all resources available in our lending library: <http://www.parkinson.bc.ca/resources-services/library/>.

### RESEARCH STUDIES SEEK VOLUNTEERS

#### Brain Research (Pacific Parkinson's Research Centre)

The Pacific Parkinson's Research Centre, Faculty of Medicine is looking for healthy men between the ages of 19 & 85, and healthy women between the ages of 30 & 85 who are interested in participating in research using P.E.T. (Positron Emission Tomography) brain scanning.

Potential candidates should not have Parkinson's disease, depression, or other memory or mood disorders; should not be on regular doses of ASA/Aspirin (81 mg/day is allowed), anti-inflammatories (Advil, Ibuprophen etc), or treatment for Gout; nor have a first degree relative with Parkinson's disease. Female candidates cannot participate if they are pregnant or breastfeeding.

If you are interested in becoming involved, or would like more information, please contact Valarie O'Neill at the Pacific Parkinson's Research Centre | 604.822.869.

#### Caregiver Burden (University of British Columbia)

Researchers from the University of British Columbia are looking for volunteers to participate in a study examining caregiver burden and caregiver technologies.

[Download information poster](#)

[Download information brochure](#)

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**WEBINAR RECORDINGS**

The Pharmacists Clinic at the UBC Faculty of Pharmaceutical Sciences is Canada's first university-affiliated, licensed, pharmacist-led patient care clinic. They provide the highest possible standard of health consultation services to patients, research opportunities for the health care community and learning opportunities for health professionals and students alike.

This one hour webinar briefly discusses Parkinson's disease, medication and treatment options: <http://bit.ly/1YJzPKo>.

**SUBSCRIBE TO GROUPLINK!**

If you wish to receive personal copies of GroupLink please connect with Caroline Wiggins, [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca), and your name will be added to our GroupLink email distribution list.

**DISCUSSION TOPIC****MEDICATION ABSORPTION CONCERNS: LEVODOPA (SINEMET) AND PROTEIN**

Levodopa continues to be the gold standard for the treatment of Parkinson's disease (PD), and nearly everyone diagnosed with PD is prescribed this medication. Levodopa is found in a variety of formulations including:

- Levodopa plus carbidopa, referred to as levocarb or levodopa/carbidopa (brand name Sinemet and Sinemet CR)
- Levodopa plus benserazide (brand name Prolopa)
- Levodopa/carbidopa/entacapone (brand name Stalevo)

Some people taking levodopa notice a decrease in the effectiveness of their medication if it is taken at, or close to, the same time as a high protein meal or snack (e.g., steak, chicken breast, peanut butter). Not everyone with PD has this problem. However, for those

who do, they find that eating a protein-rich food at the same time as taking their levodopa can interrupt the absorption and effectiveness of the medication.

**Why does protein sometimes interfere with the absorption of levodopa?**

When any kind of protein is being digested, it is broken down into its core components, which are amino acids. The lining of the digestive tract contains many receptors designed to absorb the amino acids and to transfer them into the blood stream to be carried to the brain.

There are only so many receptors in the digestive tract and for some people food-based amino acids may be absorbed first, leaving medication sitting in the gut. This means that the medication does not start working and providing symptom relief until the protein is out of the system.

**What does this mean for me?**

A decrease in medication effectiveness can be different for everyone. For some, it may seem as though it is taking a very long time for your medication to "kick in" or you may be spending more time than you usually do in an "off" state. In some instances, you may experience "dose failures", defined as when your medication does not work at all.

If you are concerned about your ability to absorb levodopa, we recommend that you discuss this with your healthcare team. Prior to your appointment, it is useful if you can make notes about the effectiveness of your medication.

When you take your medication please note:

- If you have food with your medication and what was in your main meal and/or your snack
- How close your medication was to a main meal
- Effectiveness of your medication around the time you are eating

Even if you suspect that protein is getting in the way of adequate absorption of levodopa, **you must not make adjustments to your medication schedule without talking to your doctor.** Effective management of Parkinson's medications requires following a strict schedule.

**Adjust your meals and snacks, not your medication.**

#### **Should I have a snack along with my levodopa?**

Opinions differ on this question, but it is generally considered wise to have a light, non-protein snack along with your levodopa to assist with digestion. Foods to consider include:

- Fruit
- Crackers
- Apple sauce

Protein is essential to good nutrition and good health. If you find that protein does interfere with the absorption of levodopa, do not cease eating protein unless directed to do so by your doctor. Rather, reschedule your meals and snacks around your medication schedule. Regular amounts of these protein-rich foods may be taken 1 hour before or after your scheduled medication time.

#### **If I notice an absorption problem relating to protein, what foods should I avoid when I am taking my scheduled dose of levodopa?**

Foods that are high in protein and should be avoided in large servings include:

- High protein milk products (including yogurt, ice cream, butter, cheese, and cottage cheese) - a little in coffee or tea, or on cereal is usually OK
- Almond milk, soy milk, hemp milk and rice milk
- Eggs and egg substitutes – an egg maybe OK but not with bacon and sausages
- Meats, poultry and fish of all types
- Nuts (including spreads like peanut butter)
- Sunflower seeds and all other seeds such as pumpkin, flax, and sesame
- Beans, peas
- Soybeans (including tofu and tempeh)
- Puddings and custards
- Dietary supplements (Ensure and other similar products have a high percentage of protein) as do whey and protein powders

Adapted from Dr. J. Eric Ahlskog's book "The Parkinson's Disease Treatment Book: Partnering with your doctor to get the most from your medications" and; [http://www.pdf.org/pdf/fs\\_understanding\\_medications\\_15.pdf](http://www.pdf.org/pdf/fs_understanding_medications_15.pdf).

## BE A MEDICATION ADVOCATE!

People with Parkinson's (PwP) have unique care needs while in the hospital. It is more likely that your loved one will be hospitalized for medical problems other than Parkinson's. As a result, you and your family must be prepared to alert the medical staff to the needs of a person with Parkinson's.

It is not uncommon for healthcare professionals to be unfamiliar with these needs. Not all medical staff have had experience treating patients with Parkinson's. Therefore sharing your knowledge is important! Use the Hospitalization and Parkinson's brochure from the Society as a tool to help you direct your care as effectively as possible in a hospital setting - <http://bit.ly/1No0N9S>.

### Making Needs Known

To help your medical team understand the care needs of someone with PD, mention the following important points:

- **On/off fluctuations** are NOT intentional and can be unpredictable.
- **Physical and mental slowness** can be associated with PD and may worsen in the hospital.
- **Speech problems** may affect the ability to use the intercom.
- **Hand dexterity** may affect eating, hygiene and intercom use.
- **Lack of facial expression** is a symptom of PD and may make it difficult for the clinicians to understand what the PwP is experiencing and that they may need attention.
- Hospitalization increases the risk of **falling and fractures** for individuals with PD.
- Advise the nurses if PwP has had **Deep Brain Stimulation surgery**.

**Note:** Visits to the hospital emergency department for concerns about increased dyskinesia or prolonged "off" periods are best avoided. These symptoms, while distressing, will eventually diminish and it is strongly recommended that you and your loved one stay at home in a calm and quiet environment.

### Medication Timing

It is unlikely that the medication schedule will coincide with the hospital's schedule; however, PD medications **MUST** be given on time, every time. You will need to help the staff understand why the PwP needs to take their medications at specific times of the day. Delayed drug delivery can aggravate PD, slowing recovery and delaying discharge.

Ask your family doctor to attach the drug regimen and schedule to the hospital admitting orders and discuss with him/her the possibility of obtaining authorization to self-administer your loved one's medication.

**Tip:** Speak up when medication is wearing off!





Bring with you and share with the nurses:

- “PD Medication: Timing is Everything” folder (available from Parkinson Society British Columbia - <http://www.parkinson.bc.ca/resources-services/resources/>). Ask that one of the post-it notes be placed in your file.
- PD medication in original bottles.
- A list of all known allergies.
- Several copies of your list of daily PD medications and the specific schedules for each.
- Any experimental drugs that the PwP is taking as part of a research study and a letter explaining the clinical trial and the contact phone number of the study coordinator.

**Tip:** Give the nursing staff a copy of the PSBC medication card (Note: it includes a list of contraindicated medications).

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**April was a big month for PSBC.** Along with the launch of the April Awareness Campaign, PSBC was involved in many advocacy causes. Specifically, on April 11, 2016, World Parkinson's Awareness Day, the Society visited the BC Legislature in Victoria, BC. The purpose of the meetings was to build awareness of the impact of Parkinson's disease (PD) on those diagnosed and their families, and to ask for support in the development of a provincial strategy for the management of PD. This strategy would increase access to allied health professionals and movement disorder specialists, as well as call for a more integrated system that worked to improve knowledge of PD among health professionals. PSBC is calling for a pilot project to be funded that would address these issues and assist in forming a provincial strategy.

[\(View Full News Item\)](#)

Parkinson's disease (PD) is a progressive neurodegenerative disorder causing a gradual loss of motor control. Currently, 13,300 (2014/2015) British Columbians, and approximately 12% of Canada's population over the age of 80, are living with the disease. Although treatment is complex, it is one of the most treatable neurological conditions. Yet, according to the BC Ministry of Health, in 2012/2013, \$112 million was spent in BC on direct care related to PD. Through better education and the development of a provincial strategy, we believe patient outcomes can be improved.

Parkinson Society British Columbia aims to be an effective advocate for issues important to the Parkinson's community. To be successful, we need the grassroots support of our community.

If you are interested in joining our provincial and/or national advocacy networks, please contact: [Jean Blake](#), Chief Executive Officer.

[\(Advocacy Ambassador Recruitment Poster\)](#)