

PARKINSON'S AWARENESS MONTH



April is internationally recognized as Parkinson's Awareness Month, and with every year that passes, the need to draw attention to the incidence and prevalence of the disease grows. There are over 12,500 British Columbians living with Parkinson's disease (PD), a number that is expected to increase 65% by 2031.

One of the first illustrations of Parkinson's disease was published in 1886, and since then, it has been widely recognized as a disease that only affects the senior population, primarily characterized by shaking. Parkinson Society British Columbia is committed to changing that perception. The truth is that Parkinson's doesn't discriminate based on age, gender, ethnicity, religion or sexual orientation. It affects people from all walks of life, and at PSBC, we are firm believers that the diversity of our community strengthens us. We're in this together.

This year, we are proud to launch This is Parkinson's disease, a campaign aimed at reshaping the public's understanding of PD. A campaign that will bring together individuals across the province, country and internationally, in an effort to better the lives of those affected by Parkinson's disease. To do this, we're sharing real-life stories from members of BC's Parkinson's community.

"Every individual of the Parkinson's community has a unique experience with the disease" says Jean Blake, CEO of Parkinson Society British Columbia. "It is our belief that our differences will unite us rather than divide. Unique perspectives contribute to our overall understanding of the disease, and rather than face a life-changing diagnosis on your own, you can find comfort and support in the collective."

Parkinson Society British Columbia has connected with public transportation companies in Kelowna, Prince George, Vancouver and Victoria to help promote this message. For the month of April, in these communities, you may see some of the photos shown here on this page, in transit ads (buses & skytrains). We have also worked with community centres, seniors centres, clinics, physiotherapists, fitness professionals, businesses and support group facilitators across the province to help promote the campaign.

You can help! We've developed posters available digitally via PDF that you can share with your contacts. Don't have a printer? If you're interested in helping canvas your community, we have a limited number of print posters available. Please contact Amanda McCulley, Marketing & Community Engagement Specialist at amcculley@parkinson.bc.ca or 1 800 668 3330. Don't forget to join in the conversation via social media! Follow us on Facebook & Twitter (@ParkinsonsBC) for details! For more information on this campaign, the individuals involved and how to help, visit our website at:

<http://www.parkinson.bc.ca/this-is-parkinsons>

Photography: Noah Asanias (www.noahasanias.com)

Production Support: The Artistry Collective (www.theartistrycollective.com)

Special thank you to Norwegian photographer/videographer Mr. Anders Leines whose exhibit, This is Parkinson's, provided inspiration for our campaign.

[▶BACK TO TOP](#)

UPCOMING EVENTS

ART EXHIBITION BY ALAN JACQUES, PERSON WITH PARKINSON'S

As part of Capture Photography Festival 2016, Alan Jacques will be featuring 30 black and white photographs. Even though Jacques has had Parkinson's disease for 27 years, he continues to find innovative ways to thrive as an active photographer. Many of his photographs are characterized by a low camera angle combined with a prominent wide angle lens, challenging conventional perceptions of our every day world.

Date: Friday, April 1, 2016 (open reception)

Time: 6:00 pm - 9:00 pm

Location: Via webinar. Instructions on how to access the presentation will be sent out 24 hours before the webinar start time.

Cost: Free

Website: www.alanjacques.com

STEP BY STEP

Starting Monday April 11, 2016 PSBC is bringing back the Step by Step program! 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 participating in the Step by Step program? Contact Caroline 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.



PHARMACIST WEBINAR

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 leading opportunities for health professionals and students alike. On April 11, the Pharmacists Clinic will be offering a one hour webinar that will briefly discuss Parkinson's disease, medication and treatment options.

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 disease to assist in supporting their loved one.

Date: Monday, April 11, 2016

Time: 2:30 pm - 4:00 pm

Location: Via webinar. Instructions on how to access the presentation will be sent out 24 hours before the webinar start time.

Cost: Free

Capacity: 95

Registration: This webinar has now reached capacity. Due to popular demand, Parkinson Society British Columbia intends to record this session and have it available as a resource in coming weeks.



BRAIN HEALTH FAIR

The Brain Health Fair is a free, daylong event connecting hundreds of neurology patients, families, and caregivers affected by a brain disease, as well as students interested in brain science and the general public interested in brain health. The program is designed and executed by neurologists, with local and national experts, who are on hand to answer questions about the wonders of the brain and the latest research advances.

Date: Friday, April 15, 2015
 Time: 10:00 am – 4:00 pm
 Location: Vancouver Convention Centre, Ballroom ABCD ([map](#))
 Cost: Free
 Registration: <https://patients.aan.com/brainhealthfair/>

THE VICTORY SUMMIT® BY DAVIS PHINNEY FOUNDATION

The Victory Summit® Parkinson's symposium is a free national educational event of information and inspiration, featuring dynamic presentations from leading movement disorder neurologists and therapists from across Canada and the US. It's an upbeat, fast-paced event of community and connection, filled with laughter and conversation. You will leave feeling motivated and armed with tools to help you be more involved in your own treatment and to improve your quality of life.

As one attendee said, "I left this event with the knowledge and hope of how to live well with my Parkinson's."



Date: Saturday, April 30, 2016
 Time: 8:30 am - 4:00 pm
 Location: Sheraton Vancouver Airport Hotel, 7551 Westminster Hwy, Richmond, BC ([map](#))
 Cost: Free
 Registration: <http://bit.ly/DavisPhinneyVancouver>

SONGSHINE INSTRUCTOR TRAINING

In partnership with PSBC, *SongShine* Foundation is offering an Instructor Training, May 12-14 2016 (2.5 days). Participants will be trained to teach an integrated voice strengthening method for those with Parkinson's. The method combines singing, drama therapy techniques, creative expression, improvisation, imagination, and speech. Additional components include breath support, physical awareness, and relaxation, all designed for reviving the speaking voice. *SongShine* Foundation is seeking those with experience and/or education in voice, music education, choral music, speech pathology, music or drama therapy, theater arts or arts in healthcare.

More information on the *SongShine* method, *SongShine* classes and learning about their passion for restoring voices can be found at their website www.SongShineforParkinsons.org.

Date: May 12-14, 2016
 Time: 9:00 am – 3:00 pm (Thursday & Friday), 9:00 am – 12:00 pm (Saturday)
 Location: Broadway Church | 2700 E. Broadway, Vancouver, BC ([map](#))
 Cost: \$300.00
 Registration: Registration for this event is now full, if you would like to be added to the waitlist, please fill out this online application. <http://goo.gl/forms/sNkr8esJUB>

Contact Myriame, mlepinelyons@parkinson.bc.ca or 1-800-668-3330 for more information about the training, accommodations, and scholarship opportunities.

ELDER ABUSE AND SUPPORT WEBINAR WITH LIN CHEN, BC CENTRE FOR ELDER ADVOCACY & SUPPORT

This webinar will address the correlation between social isolation and abuse of older adults, types of abuse and people involved and strategies to deal with abuse.

Date: Wednesday, May 25, 2016
 Time: 10 - 11 am

Contact Myriame, mlepinelyons@parkinson.bc.ca or 1-800-668-3330 for more information or to register.

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.

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: <https://parkinson15273.thankyou4caring.org/event-registration-members>
 Non-Members: <https://parkinson15273.thankyou4caring.org/event-registration-nmem>

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 practise 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: <https://parkinson15273.thankyou4caring.org/event-registration-members>

ANNUAL GENERAL MEETING

Save the date! On Saturday, June 11, 2016, PSBC will hold its Annual General Meeting featuring keynote speaker Dr. J. Eric Ahlskog, PhD, MD of the Mayo Clinic, Minnesota.

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: <https://parkinson15273.thankyou4caring.org/event-registration-no-charge>

COMMUNITY TALKS

Dr. Eric Ahlskog will speak on The Nuts and Bolts Approach to the Treatment of Parkinson's Disease in the following communities:

Abbotsford (Location TBD): Thursday June 9th 2016. 3:00 pm - 4:30 pm.

Victoria (location TBD): Friday June 10th 2016. 2:00 pm - 3:30 pm.

Visit <http://www.parkinson.bc.ca/events/education-events/> for the most up-to-date education and events information!

UPCOMING EVENTS

5

WORLD PARKINSON CONGRESS

Date: September 20 – September 23, 2016

Location: Oregon Convention Center | 777 NE Martin Luther King Jr Blvd, Portland, OR ([map](#))

Parkinson Society British Columbia's WPC Scholarship Program: We are proud to offer scholarships to those with financial limitations that may prevent them from attending the 2016 World Parkinson Congress. In providing these scholarships, our hope is to increase the diversity of leadership in BC's Parkinson's community. Completed applications are due Sunday, April 3, 2016. For more information, please visit: <http://bit.ly/1UKtVtP>

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

NEWS & ANNOUNCEMENTS

FEATURED BOOKS FROM OUR LENDING LIBRARY

1. **Making the Connection Between Brain & Behavior: Coping with Parkinson's Disease. Joseph H. Friedman, MD. (2013).** When people think about PD they usually picture tremor, shuffling and other physical changes. But as many as 90% of all Parkinson's patients also live with behavioural symptoms that few families are prepared to handle. In his 2nd edition, Dr. Friedman, a leading expert in PD, explains the most common behavioural issues in down-to-earth, straightforward language, offers the most current research on available therapies and medications and provides guidance on ways to communicate with your healthcare team for effective treatment.
2. **Surviving Adversity: Living with Parkinson's disease. Gord Carley. (2007).** This book contains 28 profiles of individuals who share their inspiring stories of how they have adjusted to Parkinson's disease. Carley provides readers with perspective and hope. These stories will surely inspire you.

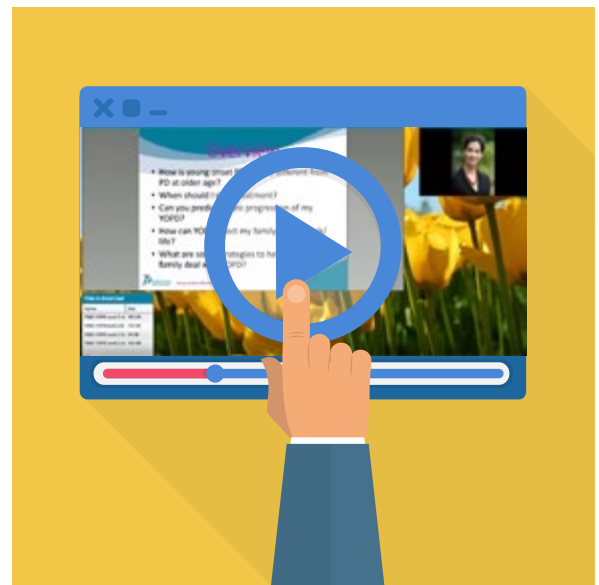
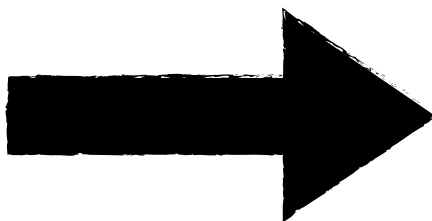
WEBINAR RECORDINGS

Young Onset Parkinson's Disease recordings are available online at:

<https://www.youtube.com/playlist?list=PLTORB8dL-B6L-FrPC7Htnv2VR0MY8KF2bM>

Nanaimo Regional Conference recordings are available online at:

<https://vimeo.com/album/3819434>



SUBSCRIBE TO GROUPLINK!



If you wish to receive personal copies of GroupLink, our monthly newsletter, to your email inbox, please connect with Caroline, cwiggins@parkinson.bc.ca. Going forward, you will receive an email which will bring you to this newsletter at the beginning of every month.

[▶ BACK TO TOP](#)



Spring is upon us and that can only mean one thing...Well perhaps it means several, but one that may be more evident when looking around is Spring Cleaning! Some of us may dread this time of year, while others may rejoice in the mindfulness of it all. Either way, the time has come. What is on your cleaning bucket list this year? Have you considered doing an in home safety check for yourself and your family? In-home safety checks are an easy way of making your home more secure, helping you reduce your risks of falling. If you have balance difficulties, it may be time to consider de-cluttering for both your physical safety and...sanity.

THINGS YOU CAN DO TO REDUCE YOUR RISK OF FALLING

Review the following questions carefully. For best results, correct the items you have checked off. Helpful hints designed to reduce your risk of falling are included. Always remember - falls are preventable!

DO YOU HAVE:

- Unsafe stairs? Broken or worn steps?
Repair broken or worn steps. Keep them free of clutter.
- Broken or missing railings?
Repair or install handrails on stairs, if possible.
- Poor lighting?
Good lighting on stairs can reduce your chance of falling. Add bright strips of tape to the edge of each stair where you do not step. They can help you see the stairs better.
Consider adding night-lights where overhead lighting is lacking.
A night-light in the bathroom can also may night trips to the bathroom easier.
Always keep a charged flashlight near your bed for emergencies.
- Throw rugs?
They are a tripping hazard. If you do not wish to remove them, they should be securely fastened with an adhesive, double-stick tape.
- Clutter?
Shoes, electrical cords and magazines can be hazardous in walkways. Always keep walkways clear.
- Regularly used items out of reach?
Put regularly used items on shelves within easy reach between hip and eye level.
A long-handled grabber can be used to reach objects that are on high shelves or on the floor.
- Spills that go un-wiped?
Spills on the floor can be dangerous. It is best to wipe up spills as soon as they happen.
If you bathe in the shower, consider installing a non-skid shower chair and hand-held shower head so you can sit while bathing.
Avoid pulling up on the sink to get up from the toilet or bathtub. Bathroom sinks are generally not securely fastened to the wall or floor, and are not intended to support your weight.
Install grab bars or handrails in the shower, on the walls around the bathtub, and alongside the toilet, where necessary.
- Furniture that is difficult to get in and out of?
Try to sit on furniture with good back support that you can get into and out of easily. Firm chairs with arm rests are easier to get out of. Add pillows to the back of the chair so your feet can touch the floor.
- A phone that is not accessible?
In case you trip and fall, help is only a phone call away. Keep emergency numbers readily available.

SAFETY TIP

Change the batteries in your smoke detector when you change your clock for daylight savings time.

PLEASE NOTE

This article does not include all potential causes of falls. It is a starting point. Contact your doctor or health provider if you have further questions, or need help with making changes.

For more information on falls prevention, please contact PSBC for a copy of the booklet "*Stay on Your Feet: Understanding and reducing the risk of falling for people with Parkinson's.*"

Source: *S.A.F.E. (Students Against Falls in the Elderly), Roberta Newton Ph.D., Temple University and Pacific Parkinson's Research Centre, University of British Columbia.*

CAREPARTNER'S CORNER

CONSIDERING ASSISTIVE DEVICES & HOME ADAPTATIONS FOR YOUR LOVED ONE?

With Spring cleaning well underway, you may need to reconfigure some of your household items in order to ease mobility for your loved one with Parkinson's. Consider assistive device and home adaptations if you feel your loved one may benefit from the extra home support.

Question: I need an assistive device (walker, bed rails, bath lift, wheelchair, etc.). How do I go about finding the one that is right for me?

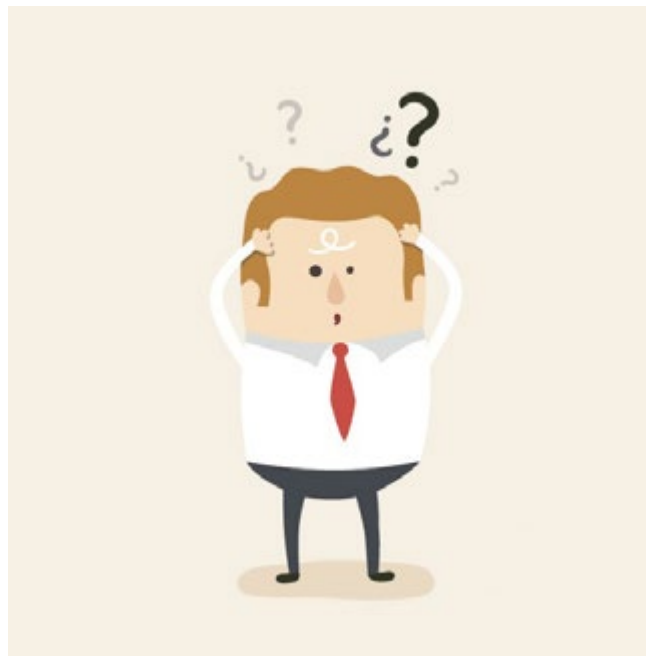
Question: I want to make some adaptations to my home to make things safer for me. Who should I approach and is there any government funding?

First step – Request a home safety assessment

An important first step in addressing both of the above questions is to contact your **local health unit** to request a home safety assessment. The phone number for local health units can be obtained from **Service BC (1-800-663-7867)**. When you call your health unit, have this information handy:

- Your address
- B.C. Carecard number
- Name and phone number of the doctor who manages your Parkinson's

This home safety assessment is usually done by an **Occupational Therapist (OT) or Physiotherapist (PT)** who will determine if you would benefit from an assistive device and/or any home adaptations. The OT/PT can give instructions and advice on **adaptive equipment, safety awareness, energy conservation, renovations and mobility issues.**



Requests for reimbursement for equipment or home adaptations purchased and paid for prior to approval can be rejected. Parkinson Society British Columbia does not provide funding towards these devices and adaptations, nor are we able to coordinate an equipment exchange.

It is important to obtain the opinion of an OT/PT prior to the purchase of any equipment and prior to beginning any renovations in order to select the most appropriate equipment for your individual needs. In addition, most funding agencies require a **letter of medical justification** from an OT/PT or other medical professional prior to approving requests for assistance.

Second Step – Resources for information on assistive devices, home adaptations and funding

- **Your local Health Unit** (see above)
- **The BC government Personal Supports Information Line:** (Toll free 1-888-818-1211). Information about government programs providing equipment and assistive aids.
- **Extended medical insurance companies:** Insurance benefits available through an employer may be an option for reimbursement of associated costs.
- **Local service clubs:** May be approached for assistance with the purchase of equipment or home adaptations.
- **Red Cross Medical Equipment Loan Service:** (Toll free 1-800-278-7177 www.redcross.ca). Short term equipment loan may be available in your community.
- **Ministry of Housing and Social Development:** (Toll-free: 1-866-866-0800 or Personal Supports Information Line 1-888-818-1211). Health supplements may be provided to eligible income assistance recipients. Health supplements include medically essential equipment and devices to meet individuals' basic mobility, hearing, positioning and breathing needs.
- **Veterans Affairs Canada (VAC):** (Toll-free: 1-866-522-2122 <http://www.veterans.gc.ca/eng/services/health>) VAC offers health benefits for veterans, including medical, surgical and dental care, prescription drugs, and hearing and vision aids. The ability to access health benefits may depend on your eligibility, your health needs and whether these services are available through your province.
- **Technology for Independent Living:** (Phone: 1-604-326-0175 www.tilbcits.org) Technology for Independent Living (TIL) provides services in two main areas: Augmentative Communication Systems (ACS), for those who cannot speak or write to communicate with others, and Environmental Control Systems (ECS), for those who need assistance with their environment such as telephones, light switches, door and entry access, entertainment systems.
- **Tetra Society:** (Toll-free Phone: 1-877-688-8762 www.tetrasociety.org). The Tetra Society of North America is an independent non-profit that recruits skilled technical volunteers to design and fabricate custom assistive devices for people with disabilities. Tetra volunteers create innovative solutions for people with needs that cannot be met by commercially available products. Clients are asked to pay just for their volunteer's mileage and materials costs, when possible.
- **MEDChair:** (<http://www.medichair.com/index.php/locations/british-columbia>). A rehab equipment supply company with an extensive on line catalogue that can be used to research ideas for assistive devices or just to see what is commercially available.
- **Canada Mortgage and Housing Corporation:** (Toll free: 1-800-668-2642 www.cmhc.ca) HASI (Home Adaptations for Seniors Independence) and RRAP-D (Residential Rehabilitation Assistance Program for People with Disabilities) provide forgivable loans to low income owners or renters to adapt their homes for safety and accessibility.
- **Use of personal savings is sometimes required**, but explore the other options first!