UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | FAMILY CAREGIVERS MONTH | CAREPARTNER'S CORNER | DISCUSSION

NOVEMBER 2016

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 for more details.

CAREPARTNER CONNECT

Carepartner Connect is a 4-week webinar series for carepartners of people with Parkinson's. Join our conversation with PD experts on caregiver wellness & autonomy, navigating health care and cultivating intimacy.

Date: Thursdays for 4 weeks beginning November 3rd 2016

Time: 11:00am - 12:30pm

Location: Via webinar.

Capacity: 95 Cost: Free

Registration: Contact Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330 to register.

COMMUNITY TALKS WITH DR. LAURIE MISCHLEY - FOOD FOR THOUGHT: DIET & NUTRITION IN PD

Does it matter what I eat? How do I know if I'm getting enough? Should I take supplements? If you or someone you know with Parkinson's disease has been asking these questions, you may benefit from our upcoming community talks with Dr. Laurie Mischley.

ABBOTSFORD

Date: Friday, November 4, 2016

Time: 9:30am – 11:00am (Registration opens at 9:00am)
Location: Quality Hotel & Conference Centre, Pinnacle Room 2

36035 North Parallel Road, Abbotsford (map)

Cost: Free

Registration: http://bit.ly/DietNutritionInPD

BURNABY

Date: Friday, November 4, 2016

Time: 2:30pm – 4:00pm (Registration opens at 2:00pm)
Location: Executive Hotel & Conference Centre Burnaby,

Centennial Room

4201 Lougheed Hwy, Burnaby (map)

Cost: Free

Registration: http://bit.ly/DietNutritionInPD



UPCOMING EVENTS 2

REGIONAL CONFERENCE, VICTORIA

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, November 5, 2016

Time: 10:00am – 4:00pm (registration opens at 9:30 am)

Location: Sandman Hotel Victoria - Orchid Room 2852 Douglas Street, Victoria (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/PSBCMemReg

Non-Members: http://bit.ly/PSBCNonMemReg

ROADSAFETYBC WEBINAR: GETTING INFORMED ABOUT DRIVING WITH PD - WAITLIST AVAILABLE

Catherine Douglas and Kevin Murray, RN's from RoadSafetyBC, join us in an engaging presentation about driving and Parkinson's disease. They will speak to the processes involved in assessing fitness to drive (disclosing a diagnosis to ICBC, the measures taken to assess fitness to drive, if someone is deemed unfit to drive, timelines) and much more.

Date: Tuesday, November 22, 2016

Time: 11:00am - 12:00pm

Facilitators: Catherine Douglas, BA, RN, BSnN, a Nurse Case Manager

Kevin Murray, RN, BScN, ENC, a Program Manager from the Driver Medical Fitness Program.

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

event's start time.

Cost: Free

Registration: Please contact Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330 to be added to the

waitlist.

For a listing of all upcoming education events, visit our events calendar.

PSBC FALL ONLINE AUCTION

You can support PSBC programs, services and contributions to research by participating in our Fall Online Auction! The auction closes at 5pm, November 2, through Able Auctions. Bid on a tantalizing array of over 35 luxury, sport and travel items including a seven day cruise through Holland America and a two night stay at Hilton Whistler Resort & Spa. Further details about the auction are available on our website and Able Auctions page.

CHAMPIONS FOR PARKINSON'S

- Holt Renfrew Shopping Night for Parkinson's (Vancouver): Wednesday, November 16, 6:00pm 9:00pm (read more)
- Shake, Shake!: Friday, January 27, 2017 (<u>read more</u>)
- Cotswolds Walking Holiday: August 31 September 8, 2017 (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 Mirela at 1-800-668-3330 or mdzaferovic@parkinson.bc.ca.

VOLUNTEER OPPORTUNITIES: TRI-CITIES CAREPARTNER SUPPORT GROUP FACILITATOR

PSBC is actively recruiting a volunteer Support Group Facilitator for the Tri-Cities Carepartner Support Group. This support group is for individuals who care for someone with Parkinson's. Those involved meet on the second Thursday of each month between 10:00am and 12:00pm at 750 Delestre Avenue in Coquitlam.

SURREY SUPPORT GROUP FACILITATOR

PSBC is actively recruiting a volunteer Support Group Facilitator to start a Surrey Support Group. This support group is for individuals affected by Parkinson's, such as people with Parkinson's, family members and friends.

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.

For more information, please contact Stacey Dawes at sdawes@parkinson.bc.ca or 1-800-668-3330.

CAREGIVER SUMMIT SESSION RECORDINGS

The National Parkinson Foundation (NPF) Caregiver Summit took place Monday, September 19 in Portland, Oregon. The daylong event brought together caregivers from all over the world to share experiences and everyday strategies for coping with the complex problems that arise as a result of PD. Now you can view the session recordings online at: http://www.parkinson.yourbrandlive.com/c/summit

ONLINE LEARNING MODULE FOR PHARMACISTS BY PARKINSON CANADA

Parkinson Canada is launching an online learning module that is designed to help pharmacists understand Parkinson's medications and advise their patients living with the disease. We encourage people living with Parkinson's and their carepartners to share this news with their own pharmacist and other members of their health care team.

Registration: http://pc.discoverycampus.com/en/index.html

AVAILABLE NOW! BALANCE TRAINING RESEARCH PROGRAMME RECORDING

Irene Wong, a PhD Candidate in Rehabilitation Sciences at The Hong Kong Polytechnic University, presented her findings on the effects of a multi-system balance training programme for enhancing comprehensive balance and fall-prone functional performance in people with Parkinson's. View her presentation at this link: https://youtu.be/rgzNMrUw_lw

NEW! Support Group - Kootenay Lake East Shore

Date(s): 1st Wednesday of each month

Time: 2:00pm - 3:30pm

Location: 857 Riondel Road, Riondel (map)

NEWS & ANNOUNCEMENTS

NEW! Support Group - Langley Young Onset PD (YOPD) & Young at Heart

Date: 3rd Sunday of each month

Time: 10:00am - 12:00pm

Location: Willoughby Community Centre at Langley Events Centre

7888 200 St, Langley (map)

NEW! YOPD Online Support Group

Parkinson Society British Columbia is piloting an online support group for those with Young Onset Parkinson's disease facilitated by Myriame Lépine Lyons.

Date: 2nd Tuesday of each month

Time: 7:00pm - 8:00pm

Location: Online. A valid internet connection will be required to participate.

Registration: You must register to attend this support group by contacting Myriame Lépine Lyons at

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

Our website includes an up to date list of all of the Parkinson's specific Community Exercise programs across the province, there may be one near you! http://www.parkinson.bc.ca/exercise



Note: Any listing in the aforementioned documentation should not be considered an endorsement of the third party event(s). As such, the Society cannote be held responsible or liable for any loss or damage suffered as a result of participation.

SUBSCRIBE TO GROUPLINK!

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



Also referred to as caregiver or family caregiver, carer is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness







ages of 45-65 their peak earning years



CARERS MAKE A DIFFERENCE

CONTRIBUTE 5 in unpaid labour to our health care system



SUSTAINABILITY OF THE LABOUR MARKET

BILLION

in saving from a loss of productivity through their continued participation

PROVIDE of community care for older adults

PROVIDING WIDE ARRAY OF ACTIVITIES:



Personal and medical care



Housekeeping



Financial management



Social/emotional support



Advocate

HOW CARING IMPACTS THEIR LIVES

CAREER

















HEALTH & WELL-BEING

Carers can experience an array of negative emotional and health outcomes



In honour of National Family Caregivers Month, Parkinson Society British Columbia (PSBC) wanted to share with you some fast facts about the people that love and care for you every day: your family caregivers or carepartners.

When someone who is known to be looking after or helping someone is asked, "Are you a family caregiver?" several are quick to reply, "No." When the question is reframed as, "Do you look after a sick, disabled, aging parent or friend without payment?" the answer often changes to "Yes!"

Many family caregivers/carepartners simply don't self-identify as caregivers/carepartners. However, they provide between 70-80% of all community care for the people they are helping. They do everything: daily check-in or telephone support, personal care, household management, transportation, case management, care co-ordination, advocacy and end-of-life care.

Did you know?

- 1 in 4 Canadians are caregivers/carepartners (that's 8.1 million!)
- 50% of caregivers/carepartners are between 45 and 65 years old
- 54% of caregivers/carepartners are women
- Caregivers/carepartners contribute \$25 billion in unpaid labour in our health care system

The guiding principles of the Canadian Caregiver Strategy are:

- Family caregivers are acknowledged, respected and valued for their caregiving work.
- Family caregivers have a choice to become partners in care and have the right to choose the degree of their involvement at every point on the continuum of care.
- Family caregivers have the right to express their needs and receive support.

Staff here at PSBC appreciate all you do so thank you for being a family caregiver/carepartner! If you or someone you know is an unpaid caregiver/carepartner for someone, we thank you. Not everyone plans to be a family caregiver/carepartner; it is often a full-time job that can be both challenging and rewarding, so thank you for being there and for your support!

PSBC offers support for those carepartners and caregivers helping individuals with Parkinson's.

NATIONAL FAMILY CAREGIVERS MONTH

We invite you to learn with us! The more informed you are as a caregiver/carepartner, the better you can support the one you love. This upcoming year we are holding multiple events just for you, the caregiver/carepartner. Starting with a <u>Carepartner Connect webinar</u> this month followed by a Carepartner Day in the New Year, and much more. We want you to know that we are here for you! See our events at: http://www.parkinson.bc.ca/events/education-events/.

We want you to feel supported. Whether it's a walk with a friend to vent, a caregiver/carepartner support group, counselling or simply time away to rejuvenate, caregivers/carepartners who feel supported are able to care better. Don't expect others to know what type of support or help you need; it's up to you to take the initiative. Access PSBC's free counselling services by calling 1-800-668-3330 or emailing counselling@parkinson.bc.ca.

Adapted from: http://www.familycaregiversbc.ca/communication-skills/blog-do-you-know-a-family-caregiver/

CAREPARTNER'S CORNER

CAREGIVER SPECIFIC RESOURCES

In efforts to provide you, the carepartner/caregiver, with resources to alleviate the challenges faced when caring for someone with Parkinson's, PSBC wishes to share with you some specific resources to you that have recently been made available and that we find invaluable.

Educational Materials

The National Parkinson Foundation (NPF) Caregiver Summit took place Monday, September 19, 2016, in Portland, Oregon. The daylong event brought together caregivers from all over the world to share experiences and everyday strategies for coping with the complex problems that arise as a result of PD. There are two distinct but complementary aspects to caregiving – caring for the person with Parkinson's and caring for yourself. The Caregiver Summit addressed this dual role, focusing particular attention on strategies that can be used to cope in the moment. You can view session recordings of the Caregiver Summit here - http://www.parkinson.yourbrandlive.com/c/summit. More sessions will be made available soon, so make sure to revisit this site: http://www.parkinson.org/Caregiver-Summit.

National Parkinson Foundation has developed a new guide called <u>Caring and Coping</u>. This guide contains tips and tools to make the caring journey as productive as possible with the least amount of stress. The book focuses on your dual role as a caregiver/carepartner: caring for someone with Parkinson's disease and taking care of yourself.

Support Groups

Parkinson Society British Columbia offers caregiver/carepartner specific support groups in a number of communities across British Columbia. To view a list, visit our <u>support groups page on our website</u>. If you cannot find one in your area, Family Caregivers of British Columbia (<u>www.familycaregiversbc.ca</u>) offers family caregiver support groups across the province. Search their listing to find one near you: http://www.familycaregiversbc.ca/support/family-caregiver-groups/.

HealthLink BC

• Call 811 24/7 to speak to a nurse. On weekdays, you can speak to a dietitian about nutrition and healthy eating. At night there are pharmacists available to answer your medication questions: www.healthlinkbc.ca/.

BC Ministry of Health website

• Information and resources for "Caring for Seniors" and "Caring for the Caregiver". Includes self-assessment tools, financial information and tips for communicating with healthcare professionals: www.gov.bc.ca/health. Visit www.gov.bc.ca/health. Visit www.gov.bc.ca/healthlinkb

CAREPARTNER'S CORNER

BC Ministry of Health website

Information and resources for "Caring for Seniors" and "Caring for the Caregiver". Includes self-assessment tools, financial information and tips for communicating with healthcare professionals: www.gov.bc.ca/health. Visit www.healthlinkbc.ca/healthtopics and put in the search term "Caregiver."

BC Seniors Guide (BRAND NEW!)

 Provincial resources. Free hard copy or digital file. Available in English, Chinese, French & Punjabi. There is also a First Nations Guide: www.gov.bc.ca/seniors-guide or 1-800-663-7867.

Family Caregivers of BC

- Registered charity that supports family caregivers with support groups, educational webinars; quarterly newsletter; presentations; online resources; involvement in health system improvement: www.familycaregiversbc.ca.
- Caregiver Support Line: 1-877-520-3267.

Source: Family Caregivers of BC, http://www.familycaregiversbc.ca/.

DISCUSSION TOPIC

REDUCING YOUR RISK OF FALLS

Discussion questions:

If at on the floor.

- 1) What changes have you seen in your balance? Have you had any issues with falling as the disease has progressed?
- 2) Do you experience concerns with balance and falling more often during the fall and winter months? What are your concerns? How have you dealt with them?

trying to move.



and legs, move your

bottom around.

November is an important month for British Columbians; not only is it National Family Caregivers Month, the BC government also proclaims this month as Seniors' Fall Prevention Awareness Month. The latter's goal is to raise awareness about preventing falls and injuries among older adults, and to encourage leadership and collaboration between health authorities across the province.

Falls are the leading cause of injury for seniors. One in three British Columbians over the age of 65 will fall once every year, and falls are the main reason why older adults lose their independence. Since Parkinson's disease (PD) affects the parts of the brain controlling balance and coordination, people with Parkinson's (PwP) are at a greater risk for falling and fractures.

In her webinar presentation on the effects of a balance training programme for PwP, Irene Wong explained that it is especially important for PwP to engage in exercises that are diverse and involve as many different muscle groups as possible. Diversification of exercise helps to strengthen the whole body, which helps reduce balance issues and the risk of falling. View her presentation here - https://youtu.be/rgzNMrUw_lw.

While exercise may not be everyone's "go-to", Hilary, a woman with YOPD from BC, wrote in her blog that "you climb a little at a time." Establishing new habits can be difficult – it means changing our behaviour and our mindset. This is easier said than done, especially if a PwP has already fallen and is scared of falling again. However, she writes that conquering our fears is to "do it consistently, to raise your level step by step like climbing a staircase". One way to raise your level is to understand how to properly get up from a fall or call for help if needed. This can be especially important with the changing of seasons.

As winter approaches, weather conditions fluctuate and can make it more dangerous to go on a walk, bike and even drive. If you are having balance and coordination issues, we encourage you to seek support from a healthcare professional, such as an occupational therapist or physiotherapist, to help you develop the skills to protect yourself from serious injuries. In the meantime, here are some steps you can take if you fall and *CAN* get up or if you fall and *CANNOT* get up.

What to Do You if You Fall:

If you CAN Get Up

- · Stay calm and assess your situation.
- Turn onto your side, bend the leg that is on top and lift yourself onto your elbows or hands.
- Crawl on your hands and knees toward a chair or other sturdy piece of furniture, then kneel while placing both hands on the stairs or furniture.
- Place your stronger leg in front, holding on to the furniture for support.

If you CANNOT Get Up

If you think you are injured, or you are feeling dizzy, do not try to get up. Instead, try to get help and do the following:

- Stay calm and assess your situation.
- If you have an emergency call device or telephone at hand, use it.
- If you don't, call out for help if you think you can be heard or try to slide or crawl towards a telephone or a place where you will be heard.
- Make noise with a cane or any object at hand to attract attention.
- Wait for help in the most comfortable position for you.
- If you can, use anything that is accessible to help you stay comfortable and warm.
- Try to move your joints to ease circulation and prevent stiffness.

Fall Prevention Resources:

- Centre for Hip Health and Mobility
- Province of British Columbia, Fall Prevention Resources
- <u>The Physical Activity Line</u> there to gain free advice from a qualified exercise professional on how to prepare for physical activity.

Sources:

Pacific Parkinson's Research Centre, University of British Columbia and National Parkinson Foundation, Balance Checklist.

BC Injury Research and Prevention Unit, http://www.injuryresearch.bc.ca/events/seniors-fall-prevention-awareness-month/

BC Ministry of Health: Fall Prevention, http://www2.gov.bc.ca/gov/content/family-social-supports/se niors/health-safety/disease-and-injury-care-and-prevention/fall-prevention