UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | DISCUSSION TOPIC | CAREPARTNER'S CORNER

MARCH 2018

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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.

STEP BY STEP

Starting Tuesday, April 11th, Parkinson Society British Columbia is bringing back the Step by Step program for a fourth consecutive year! Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps taken by an individual. The first week will determine each walker's baseline, and then each subsequent week they will be challenged to increase their steps based on a personal goal. While participants are encouraged to walk and track their own steps, a community group leader will organize a weekly walk allowing walkers to meet, socialize and support one another.

The goal of this program is to help motivate people to become physically fit to combat the symptoms of Parkinson's disease. It is designed to encourage people to continue exercising regularly following the program.

Interested in becoming a Step by Step leader in your community? As a team leader you would be responsible for organizing a weekly walk, selecting walking locations and motivating your team! Contact Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 to learn more.

COMMUNITY TALK: MEDICATION MANAGEMENT, VANCOUVER

On March 7th, join Parkinson Society British Columbia (PSBC) as we host an afternoon of education at the Italian Cultural Centre. Movement Disorder Specialist Dr. Jonathan Squires from Pacific Parkinson's Research Centre at UBC will provide an overview of Parkinson's disease, treatment options and tips for medication management.

Date: Wednesday, March 7, 2018

Time: 1:30pm - 3:30pm (registration opens at 1:00pm)

Location: Trattoria Hall at Italian Cultural Centre

3075 Slocan Street, Vancouver (map)

Cost: PSBC Member \$5.00

PSBC Non-member \$10.00

Registration: This event is now full.

To join the waitlist, please contact Jaclyn at jwillems@parkinson.bc.ca or 1-800-668-3330.



UPCOMING EVENTS 2

REGIONAL CONFERENCE, VICTORIA

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

Topics covered at this conference will include:

Keynote Address: Dr. Jon A. Stoessl, Co-Director of Djavad Mowafaghian Centre for Brain Health at UBC

Emergency Preparedness and Risk Management: Karen Martin, Disability Alliance

• Enhancing Communications - Taking Care of Your Voice: Sue Decker, Registered Speech-Language Pathologist

Date: Saturday, March 24, 2018

Time: 1:00pm - 4:30pm (registration opens at 12:30pm)

Location: Sandman Victoria

2852 Douglas Street, Victoria (map)

Cost: PSBC Member \$15 / PSBC Members (couple/pair) \$25

PSBC Non-member \$25 / PSBC Non-members (couple/pair) \$45

Registration: <u>www.parkinson.bc.ca/victoria-conference</u>

ALLIED TEAM TRAINING FOR PARKINSON'S (ATTP)™ COMMUNITY TALKS

Designed by the Parkinson's Foundation and the International Parkinson and Movement Disorder Society (MDS), the Allied Team Training for Parkinson's (ATTP)™ comes to Vancouver, BC April 4 − 6, 2018. This three day on-site course was developed to increase the knowledge of Parkinson's disease and build capacity for comprehensive interprofessional care in the treatment of Parkinson's disease.

For the first time in Canada, the ATTP™ is coming to Vancouver and Parkinson Society British Columbia (PSBC) has access to world renowned Parkinson's experts. Join PSBC and the ATTP™ faculty at upcoming ATTP™ Community Talks.



ATTP™COMMUNITY TALK: MILD COGNITIVE IMPAIRMENTS AND NON-MOTOR SYMPTOMS, ABBOTSFORD

Lucie Lachance, RN, is one of the leaders of the Movement Disorders Program at the McGill University Health Centre as well as a lecturer at McGill University. She has been involved as a director on the board for Parkinson Canada from 2004 – 2010 and 2011 – 2014. Additionally, she was involved as faculty on the program for the World Parkinson Congress in 2013 in Montreal and 2016 in Portland Oregon. Currently, she acts as the Program Director of the Neurology Residency Training at McGill University. In this community talk, she will be speaking about mild cognitive impairments and non-motor symptoms of Parkinson's disease.

Date: Tuesday, April 3, 2018

Time: 1:30pm – 3:00pm (registration opens at 1:00pm)

Location: TBD

Cost: PSBC Member \$5.00

PSBC Non-member \$10.00

Registration: Coming soon!

UPCOMING EVENTS

ATTP™ COMMUNITY TALK: INNOVATIVE PROGRAMS TO IMPROVE LIVES OF PATIENTS AND FAMILIES, VANCOUVER

Julie Carter (MN, ANP) is the co-founder and past co-director of the Oregon Health & Science University (OHSU) Parkinson Center of Oregon (PCO) and Movement Disorders Program. She joined the OHSU movement disorders faculty in 1979 and is currently a professor of neurology. As past director of education and outreach for the PCO, she has developed many innovative programs to improve the lives of patients and families who live with Parkinson's disease. She is a popular speaker locally and nationally on a variety of topics related to the care of people and their families who have Parkinson's disease.

Date: Wednesday, April 4, 2018

Time: 6:00pm - 7:30pm (registration opens at 5:30pm)

Location: Trattoria Hall at Italian Cultural Centre 3075 Slocan Street, Vancouver (map)

Cost: PSBC Member \$5.00

PSBC Non-member \$10.00

Registration: Coming soon!

ATTP™ COMMUNITY TALK: LIVING WELL WITH PD AND PREVENTING FALLS, RICHMOND

Julia Wood, MOT, OTR/L received her Bachelor of Science in Exercise Science and Wellness from Ball State University and her Masters in Occupational Therapy from the University of Minnesota. As an outpatient occupational therapist, Julia specializes in treating neurological movement disorders and neurodegenerative diseases.

Heather Cianci, PT, MS, GCS is a Geriatric Clinical Specialist and founding therapist at the Dan Aaron Parkinson's Rehabilitation Center (Good Shepherd/Penn Partners) at Pennsylvania Hospital in Philadelphia, PA – part of the University of Penn Health System. She has been a physical therapist since 1994, with the majority of those years

Date: Friday, April 6, 2018

Time: 6:30pm – 8:00pm (registration opens at 6:00pm)

Location: City Centre Community Centre

5900 Minoru Boulevard, Unit #105, Richmond (map)

Cost: PSBC Member \$5.00

PSBC Non-member \$10.00

Registration: Coming soon!

ATTP™ COMMUNITY TALK: SWALLOWING AND PARKINSON'S DISEASE, TRI-CITIES

Darla Freeman is a licensed Speech-Language Pathologist, certified by the American Speech-Language-Hearing Association. While in the Ohio State University (OSU) master's program, she developed a special interest in voice disorders and their management, and she was selected for a clinical internship in the Department of Otolaryngology at OSU. During the internship, she gained valuable experience and advanced training in the evaluation, diagnosis and management of a wide variety of laryngeal disorders in a multidisciplinary centre.

Date: Saturday, April 7, 2018

Time: TBD Location: TBD

Cost: PSBC Member \$5.00

PSBC Non-member \$10.00

Registration: Coming soon!



UPCOMING EVENTS 4

COMMUNICATION AND SWALLOW WORKSHOP, PENTICTON

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.

Date: Friday, April 13, 2018 Time: 10:00pm – 2:30pm

Location: Days Inn & Conference Centre

152 Riverside Drive, Penticton (map)

Cost: PSBC Member \$25.00 / PSBC Members (couple/pair) \$40.00

PSBC Non-member \$35.00 / PSBC Non-members (Couple/Pair) \$60.00

Registration: www.parkinson.bc.ca/penticton-communication-workshop

COMMUNICATION AND SWALLOW WORKSHOP, VERNON

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.

Date: Saturday, April 14, 2018 Time: 10:00pm – 2:30pm

Location: Vernon Lodge & Conference Centre

3914 32 Street, Vernon (map)

Cost: PSBC Member \$25.00 / PSBC Members (couple/pair) \$40.00

PSBC Non-member \$35.00 / PSBC Non-members (Couple/Pair) \$60.00

Registration: <u>www.parkinson.bc.ca/vernon-communication-workshop</u>

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



- Shake, Shake, Shake: May 25 (read more)
- Full Throttle: May 27 (registration available in March)
- Shifting Gears for Parkinson's: Continuing until October 31 (read more)
- Donate a Car Canada: Ongoing (<u>read more</u>)
- Naturally Urban Pet Food Delivery Sales: Ongoing (<u>read more</u>)
- Tea Parky: 35% from every sale on <u>TeaParky.com</u> will go to PSBC, ongoing. Special: Use promo code PSBC at check-out for 10% off your purchase.

WE'RE LOOKING FOR MORE CHAMPIONS THIS YEAR!

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

GROUPLINK SURVEY

In January, we sent each support group facilitator paper copies of a GroupLink survey to distribute to support group participants. Support group feedback is extremely valuable and will help us make improvements to the publication in the future. Please take the time to fill out the survey and return it to your facilitator. Surveys are due back at Parkinson Society BC's office the week of March 5th, 2018.



CONTINUING EDUCATION SCHOLARSHIP PROGRAM FOR EXERCISE INSTRUCTORS & HEALTHCARE PROFESSIONALS

Parkinson Society British Columbia (PSBC) aims to provide opportunities for individuals who wish to pursue a career involving Parkinson's disease (PD) specific training through our Continuing Education Scholarship Program for exercise instructors & healthcare professionals. This scholarship was established to assist people who have a passion to gain PD specific training and bring these benefits to the BC PD community. Scholarships are open to any professional interested in working with this population. The panel will choose applicants who demonstrate a strong commitment to supporting those with PD through long-term community engagement and programming.

Six scholarships, valued up to \$1000, will be awarded in 2018. Three applicants will be chosen for each deadline. Deadlines for the scholarship program are:

- March 31, 2018
- September 30, 2018

For more information, please visit www.parkinson.bc.ca/continuing-education-scholarships or contact Caroline at cwiqqins@parkinson.bc.ca or 1-800-668-3330.

COMPREHENSIVE CARE PLAN CHECKLIST

In collaboration with Vancouver Coastal Health, Providence Health, and Fraser Health Authority PSBC developed a checklist to help people with Parkinson's and carepartners monitor symptoms and request specific health services. This self-management tool enables you and your healthcare professionals work together to obtain the best care possible. Access a draft of the checklist here.

MEDICAL PLAN			
I have a confirmed diagnosis (of Parkinson's disease or other Movement Disorders)		ves [l no
I have access to a Neurologist or doctor with a focus on Movement Disorders	=	yes [no
I have appropriate medications for my Parkinson's disease symptoms	=	yes [no
I know when/how to take my medications, such as timing or with certain foods	-	yes [700
I have access to healthcare professionals (Social Worker, Physiotherapist, Occupational Therapist,	-	yes [no
Speech Language Pathologist, Nurse, Clinical Counsellor, Naturopath, Dietitian, Ramily Physician, Pharmacist)	Lives		
For the questions below, check the box if the health issue is new, is currently being managed, or if you need more information.	New	Issue is being Managed	Need more info
EVERDAY ACTIVITIES			
Dressing, washing, bathing, using the toilet			
Preparing food or meals (planning, shopping, or cooking)			
Adapting to my home, leisure activities, or place of work			
Taking my medications			
Driving a vehicle			
MOVEMENT AND EXERCISE	•		
Difficulty with moving around, stability, or balance (with or without a walking aid)			
"Freezing" of movement or falling when walking			
Getting outside, accessing transit, or getting into/out of cars			
Exercises and fall prevention			
General weakness, such as difficulty turning over in bed or getting out of a chair			
Physical activity plan to achieve my 'daily dose' of exercise (prescription for exercise)			
COMMUNICATION AND SWALLOWING	•		
Communication challenges, such as voice, speech problems, and/or word-finding			
Swallowing challenges, such as eating food or drinking; problems with drooling or choking			
Loss or changes in my ability to taste or smell			
TREMOR, RIGIDITY, AND UNCONTROLLED MOVEMENTS			
Rigidity, slowness, and stiffness (may be medications or learning new strategies)			
Dyskinesia (uncontrolled movements)			
Tremor or uncontrolled movements (shaky, clumsy)			
Twisting postures (dystonia)			
PAIN	V		
Pain and muscle/joint soreness			
Medications, education, or strategies to help me live better with the pain	П		

NEWS & ANNOUNCEMENTS

COMING SOON: CAREGIVER BOOKLET

This year, Parkinson Society British Columbia will be printing and distributing A Comprehensive Guide for Parkinson's Caregivers. The book was written by Kaitlyn Roland, PhD, with support from other members of the PD community. Her father was diagnosed with Parkinson's in 2002. Since then, she has completed a Masters in Health and Rehabilitation Sciences, focusing on new ways to measure caregiver burden. Currently, her work at the Institute on Aging and Lifelong Health looks at cognitive changes in Parkinson's disease, associated care needs and caregiver experiences.

This book includes information about:

- Parkinson's disease
- · Living well day-to-day
- Developing a care plan, including planning for the future
- Building a care support team and communicating with healthcare professionals
- · Support options
- Self-care

PSBC will be announcing the publication of this guide via email, web and social media. If you have questions about caring or any of PSBC's resources, please contact Jaclyn Willems at jwillems@parkinson.bc.ca or 1-800-668-3330.

PILOT! KAMLOOPS CAREGIVER SUPPORT GROUP

PSBC and MS Society of Canada – BC & Yukon division are partnering to offer a special Kamloops Caregiver Support Group. This monthly volunteer-led support group is intended for individuals caring for a loved one with Parkinson's disease or Multiple Sclerosis. If you or someone you know may be interested in joining this group, please contact PSBC at info@parkinson.bc.ca.

Note: Any listing 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.

TIP JAR

Have you ever considered how a service dog could help a person with Parkinson's? Renée Le Verrier, author of Travels with Tommy: Stories of Life with a Service Dog, sure did! Renée started using a cane to help her balance issues, but soon traded it in for Tommy, a Great Dane and service dog.

A number of breeds can act as service dogs. Each person has different needs, so the size, strength, type of working dog and the animal's temperament will all factor in to matching a dog with a person. Some guide dogs are trained specifically to help those with visual impairments or diabetes and seizures. A person with Parkinson's would require a service dog trained specifically in assisting with mobility and balance.

This book includes information about:

- Service dogs in BC: www.asdbc.org
- · Lions Foundation of Canada Dog Guides: www.dogguides.com/index.html
- You can also learn how to get a dog certified on the BC government website: www2.gov.bc.ca/gov/content/justice/human-rights/guide-and-service-dog



Source

Le Verrier, Renée. (2017). Service Dogs Aid Increased Independence in Carees. Retrieved from www.ecarediary.com/Blog2824/Service-Dogs-Aid-Increased-Independence-in-Carees.aspx.

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 Jaclyn at jwillems@parkinson.bc.ca or 1-800-668-3330.



NUTRITION TIPS

- 1. What kind of diet works best for you?
- 2. Have you noticed any foods you respond to particularly strongly, in either a positive or negative way?
- 3. What are some steps you have taken to eat well? Is there anything you would like to try? (examples: grocery delivery service, meal planning, meal prepping, etc.)

WHAT ARE THE BASICS OF A BALANCED DIET?

Good nutrition plays a particularly critical role for individuals with Parkinson's disease. A balanced diet helps to maintain your energy, contributes to brain health, maximizes the potential of medications and promotes well-being (American Parkinson's Disease Association, 2009). Each individual's needs for nutritional intake will vary, so it is prudent to consult with a healthcare professional to determine what is best. Generally, a balanced diet involves eating regularly and not skipping meals, eating from a variety of food groups and eating to maintain a healthy weight (Traviss, 2007). Following the guidelines provided in Eating Well with Canada's Food Guide will ensure that you are getting the recommended daily servings you need from each of the four food groups.

While this may seem like simple advice, some people with Parkinson's may find it challenging to ensure they are eating a balanced diet due to their lifestyle or symptoms, which may affect the ability to shop, prepare food and eat. You may find it helpful to seek assistance from others for shopping and meal preparation (Traviss, 2007).



IS THERE A SPECIFIC DIET TO FOLLOW FOR PARKINSON'S?

Research has provided some evidence on the possible benefits of certain foods; currently, no singular diet has been shown to treat Parkinson's disease or its symptoms, but a healthy and balanced diet can improve general wellbeing (Michael J. Fox Foundation, n.d.). So what can you eat as a part of an informed diet? Look for foods that are neuroprotective, anti-inflammatory and rich in antioxidants.

- Neuroprotective foods have been studied for their potential to improve brain health. Nuts have shown the most promise; however, they are high in calories, so your intake should be limited to a handful per day. Consider making a healthy granola for breakfast with chopped nuts and dried fruit, but skip the oatmeal and grains. If you have trouble swallowing, you can incorporate a nut butter into your diet instead. In addition to nuts, some herbs and spices have been shown to keep the brain healthy such as turmeric, ceylon cinnamon and rosemary. Please remember that nuts are a good source of protein and need to be worked into your medication schedule. Taking protein with levodopa may make it less effective.
- Anti-inflammatory foods may be useful in keeping the brain healthy. The types of fat you consume are important
 in reducing inflammation. One type of oil that appears to have positive benefits is coconut oil, and you can cook
 with it as you would with olive oil. Other foods that are considered to have anti-inflammatory properties are dark
 leafy greens such as kale, spinach and collard greens; soy products; and oily fishes like salmon, tuna and mackerel
 (Zwickey, 2016).
- Antioxidants, according to the Mayo Clinic, are "substances that may protect your cells against the effects of free radicals molecules produced when your body breaks down food or is exposed to tobacco smoke and radiation." (n.d.). Essentially, free radicals are toxic substances formed from stressors. When you have too many free radicals, the body is said to be under oxidative stress. A diet high in antioxidants may offset cellular damage and oxidative stress (Michael J. Fox Foundation, n.d.). Look for fruits that are purple and red, like blueberries and raspberries. These berries contain pigments called anthocyanins, which are well-known antioxidants (Zwickey, 2016).

WHAT IMPACT MAY DIET HAVE ON MY MEDICATIONS?

Your mealtimes may affect how quickly medications are absorbed into your body. For example, some individuals who take carbidopa-levodopa, or Sinemet®, may find that protein-rich foods increase the time it takes for their medication to kick in, or make it less effective (Zwickey, 2016). If you find that this is an issue for you, try taking your carbidopa-levodopa (Sinemet®) 30 minutes before your meal with a carbohydrate food such as a cracker or biscuit (Parkinson's UK, 2012).

Pyridoxine, or Vitamin B6, has also been found to reduce the effects of levodopa when levodopa is taken on its own. It is recommended that if you are taking levodopa by itself, you avoid taking vitamin products containing B6 unless specifically discussed and prescribed by your doctor. Foods such as bananas, egg yolks, lima beans, meats, peanuts and whole grain cereals contain large amounts of pyridoxine (B6). Check with your doctor as to how much of these foods should be in your diet while taking levodopa (Mayo Clinic, 2015).

If you feel inspired to better manage PD symptoms through your diet and nutrition, feel free to try one (or several) of the recipes on Cookspiration®: www.cookspiration.com

Read more in PSBC's Nutrition helpsheet: www.parkinson.bc.ca/media/31506/nutrition-and-parkinsons.pdf Watch Food for Thought: www.parkinson.bc.ca/media/31506/nutrition-and-parkinsons.pdf Watch Food for Thought: www.parkinson.bc.ca/media/31506/nutrition-and-parkinsons.pdf Watch Food for Thought: www.parkinsons.pdf Watch Food fo



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CAREPARTNER'S CORNER: NUTRITION TIPS & SWALLOWING CHALLENGES

NUTRITION TIPS

As a carepartner, it might be useful for you to review the information in the above discussion topic or the nutrition help sheet to establish a knowledge baseline about nutrition and Parkinson's disease. Even if you're already aware of the information, a review never hurt anyone! In addition to the discussion topic, below are some additional tips and resources for carepartners, as well as some other symptoms to look out for.

- Constipation is a common Parkinson's related symptom. To ease constipation, it is important to slowly incorporate more fibre into one's diet. High fibre foods include whole grains, bran cereals, fruits and vegetables.
- Serving calcium-rich food at least three times a day helps keep bones strong.
- If your loved one is taking levodopa, remember that it is easier to absorb on an empty stomach and that protein affects its efficacy (Pathak, 2017).
- If your loved one has trouble swallowing, try to serve moist, soft foods or thick drinks like protein shakes. Avoid foods that crumble easily, like crackers.
- Fruits like mangos and bananas can be made into smoothies or mashed.
- Try incorporating nut milk, such as almond milk, into smoothies. Remember, nuts are a source of protein and may affect levodopa efficacy.
- Depending on your loved one's circumstances, you'll likely want to limit fried and spicy foods, as well as sugar intake (Saraswat, 2014).

SWALLOWING AND PARKINSON'S DISEASE

Half of all people with Parkinson's disease develop difficulty swallowing. It is more common with advanced Parkinson's, but may also appear in the early stages of the disease. Difficulty swallowing can result in food, liquid or saliva entering the lungs, a process called aspiration. Repeated episodes of aspiration can lead to aspiration pneumonia, a condition that is a primary cause of death for people with PD. Some symptoms of swallowing challenges in Parkinson's include:

- Choking
- · Coughing or throat clearing during meals
- Difficulty moving food or liquid from the front of the mouth to be swallowed
- · Loss of liquid or food from the mouth
- Drooling
- Slowed chewing
- Increased time required to eat a meal
- Feeling food or liquid sticking in the throat
- · Increased difficulty swallowing pills
- Weakened cough or changes in voice

It is important that any eating and swallowing difficulties in people with Parkinson's are discussed with their family doctor.

Swallowing difficulty should be evaluated and treated by an experienced Speech-Language Pathologist (SLP). Contact Parkinson Society British Columbia at 1-800-668-3330 or info@parkinson.bc.ca or speak with a physician to obtain

Sources

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