

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC JANUARY 2020 ISSUE

UPCOMING EVENTS

Parkinson Society British Columbia 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 us at info@parkinson.bc.ca or 1-800-668-3330 for more details.

COMMUNICATION & SWALLOW WORKSHOP | NANAIMO & ABBOTSFORD

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

Nanaimo:Saturday, January 25Abbotsford:Saturday, March 14Time:10:00am - 2:30pmTime:10:00am - 2:30pm

Location: Vancouver Island Conference Centre Location: Quality Hotel & Conference Centre

Dodd Narrows Room A/B Pinnacle 1

101 Gordon Ave, Nanaimo [map] 36035 Parallel Rd, Abbotsford [map]

Cost: Members: \$25 | Pair \$40 Cost: Members: \$25 | Pair \$40

Non-members: \$35 | Pair \$60 Non-members: \$35 | Pair \$60

Registration: www.parkinson.bc.ca/nanaimo-cs Registration: www.parkinson.bc.ca/abbotsford-cs

ASK THE EXPERT: MINDFULNESS | WEBINAR

What does it mean to be mindful? How does one practice mindfulness, and why is it beneficial?

Join us on Wednesday, January 29, as Parkinson Society British Columbia's own clinical counsellor, Judy Zhu, discusses mindfulness, and leads a meditation practice via webinar. Judy is a registered doctor of Traditional Chinese Medicine and has been practicing Zen meditation for over 10 years. In this webinar, she will share the researched benefits of mindfulness on our body and mind, from reducing anxieties, stress, and pain, to improving cognitive function, emotional regulation, and overall quality of life. She will also talk about how mindfulness can be applied to daily life to help manage the many stressors that people with Parkinson's disease, their families, and carepartners face.

Instructions on how to access the presentation will be sent with your registration confirmation email, and a reminder sent approximately 24 hours before the event's start time.

Date: Wednesday, January 29 Time: 10:00am - 11:00am

Cost: Free

Registration: www.parkinson.bc.ca/mindfulness-webinar

ASK THE EXPERT: INTIMACY & PARKINSON'S | WEBINAR

Approximately half of all men and women with Parkinson's disease will experience problems with intimacy and sexual functioning. These symptoms can be difficult to talk about, but are important to address. The sexual functioning and wellbeing of people with Parkinson's and their partners can be affected by many factors, including motor symptoms, non-motor symptoms, medication effects, and relationship issues.

This webinar, led by Elaine Book, Social Worker at the Pacific Parkinson's Research Centre, and Tricia Wallace, Clinical Counsellor at Parkinson Society BC, will discuss challenges with sexual intimacy and will explore options to address emotional distance influenced by physical limitations and role transitions brought on by Parkinson's disease.

We strongly encourage couples to participate in this webinar together. The content is focused on relationships, sharing, and communication, so the exercises in the webinar are geared toward couples. Registration is required by all participants to access the event, however, registrants will have the opportunity to be anonymous during the webinar presentation.

Instructions on how to access the presentation will be sent with your registration confirmation email, and a reminder sent approximately 24 hours before the event's start time.

Date: Thursday, February 13 Time: 7:00pm — 8:30pm

Cost: Free

Registration: <u>www.parkinson.bc.ca/intimacy-webinar</u>

NEW DIAGNOSIS WORKSHOP | VANCOUVER

Have you been diagnosed with Parkinson's disease in the past year? Join us for our New Diagnosis Workshop this February.

Movement Disorder Neurologists, Dr. Jonathan Squires and Dr. Tara Rastin, and Joanna Davis, the Nurse Practitioner from the Movement Disorders Clinic at the UBC Centre for Brain Health, will lend their knowledge to provide an overview of the disease, treatment options, and tips on staying active to help slow the progression of symptoms. You will also hear from Parkinson Society BC about the programs and services available to support you on your journey.

This workshop will provide you with the opportunity to ask our presenters questions you may have about Parkinson's management, treatment, and support.

Date: Saturday, February 22

Time: 10:00am - 12:30pm (check-in begins at 9:30am)

Location: Vancouver General Hospital | Paetzold Multipurpose Room

Jim Pattison Pavilion Room #1888 899 W 12th Ave, Vancouver [map]

Cost: Free

Registration: <u>www.parkinson.bc.ca/new-dx-workshop</u>

SAVE THE DATE: REGIONAL CONFERENCE | VICTORIA

Parkinson's disease is a unique and complex condition. To assist in expanding your knowledge of the disease, on March 7, Parkinson Society BC will host 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.

Speaker and topic information coming soon.

Date: Saturday, March 7

Time: 1:00pm – 4:30pm (check-in begins at 12:30pm)

Location: Sandman Hotel

2852 Douglas St, Victoria [map]

Cost: Member: \$15 | Member Couple/Pair \$25

Non-member: \$25 | Non-member Couple/Pair \$45

Registration: www.parkinson.bc.ca/victoria-conference

FOR A LIST OF ALL UPCOMING EDUCATION EVENTS, VISIT <u>WWW.PARKINSON.BC.CA/EVENTS</u>



- Chocolate & Beer Tasting: March 8 [buy tickets]
- Donate a Car Canada: Ongoing [learn more]
- Naturally Urban Pet Food Delivery Sales: Ongoing [learn more]

We're looking for more Champions! Do you want to help fund research, grow support networks, and improve quality of life for those living with Parkinson's? Become a Champion for Parkinson's and plan your own independent community fundraising event! Please contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

NEWS & ANNOUNCEMENTS

WELCOME! ALANA DHILLON & SHELLY YU ARE JOINING OUR SUPPORT SERVICES TEAM

Alana and Shelly are our newest Education and Support Services Coordinators, joining us starting on January 6th, 2020. Welcome to the team!

Alana, who will be with us in a full-time role, brings a diversity of skills and experience to the team, including education delivery, counselling/advising, and social work. Most recently, she has eight years of experience teaching social work at a private institution to a multicultural student body. She also has training in public relations and event management. Alana will be supporting the Society in planning and executing our education events.

Shelly, who will join us three days a week, has been a practicing physiotherapist since 2015. She has experience working with the Parkinson's community, and training in the PD Warrior exercise program. She is also currently completing her Dance for PD certification. With her wealth of knowledge and experience, Shelly will be assisting with information and referrals, webinars, and education events.

CONGRATULATIONS! CAROLINE WIGGINS IS OUR NEW SPECIAL EVENTS & FUNDRAISING OFFICER

After 5 years with Parkinson Society BC's Education and Support Services team, Caroline has now transitioned into a new role supporting our Resource Development team in organizing and facilitating fundraising events. She will also be helping to coordinate Parkinson SuperWalk. Congratulations to Caroline on her new position!

WE'RE LOOKING FOR A NEW BOARD TREASURER

We're seeking a new Board member for the role of Treasurer to join us in our mission of empowering the Parkinson's community in BC. The right candidate will be well versed in understanding financial statements and best practices.

For more information: bit.ly/PSBC-Treasurer.

CONTINUING EDUCATION SCHOLARSHIPS

Parkinson Society British Columbia aims to provide opportunities for individuals who wish to pursue a career involving Parkinson's disease (PD) 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.

The program is open to any professional interested in working with this population. Scholarships will be awarded to applicants who demonstrate a strong commitment to supporting those with PD through long-term community engagement and programming. Special consideration will be given to applicants living in communities with limited resources for people with Parkinson's.

Six scholarships up to \$1000.00 will be awarded in 2020.

For more information: www.parkinson.bc.ca/continuing-education-scholarships

MOVAPO (APOMORPHINE) NOW AVAILABLE UNDER THE LIMITED DRUG COVERAGE PROGRAM

As of November 26, 2019, Movapo has been made available under BC PharmaCare's Limited Drug Coverage Program. For more information, visit: bit.ly/Movapo-Announcement.

DISCUSSION: MENTAL WELLNESS & PARKINSON'S STIGMA

DISCUSSION QUESTIONS:

- 1. Do you think Parkinson's is stigmatized? What about dementia, or mental illness?
- 2. Do you feel uncomfortable talking about cognitive decline?
- 3. What does mindfulness meant to you? Have you ever practiced it, and if so, how?

January is Alzheimer's Awareness Month and January 29th, 2020, marks the 10th annual Bell Let's Talk Day. These events have been established to raise awareness and fight the stigma, prejudice, and discrimination linked to mental health challenges.

Mental illnesses can affect people with Parkinson's disease (PD), due to changes in the brain resulting from disease progression and/or medications. Some people with PD and their carepartners may find it challenging to openly discuss cognitive decline, and may be hesitant to learn more. Understanding these disorders, and knowing how to recognize their onset, is crucial for effective self-management and caregiving.

DEMENTIA

Parkinson's disease dementia is a serious cognitive decline, which can cause forgetfulness, sleep disturbances, depression, hallucinations, and slow thought process. It is also associated with difficulty concentrating, problem-solving, word-finding, planning, and decision-making.

Alzheimer's and PD dementia can share many symptoms, like memory loss, confusion, speech issues, and difficulty finishing tasks. While PD dementia is a result of Parkinson's-related brain changes, Alzheimer's is caused by the development of toxic substances in the brain (plagues and tangles), which interfere with vital processes.

Dementia is commonly misunderstood, and there is little public awareness of its different forms. The Alzheimer Society of Canada notes that "stigma is one of the biggest barriers for people with dementia to live fully with dignity and respect" (2019). People with dementia and PD can both lead full and happy lives, and increasing public understanding can help them do so.

The stigma surrounding cognitive decline often causes those affected to hide, deny, or ignore their symptoms. In a survey of over 1,500 Canadians, the Alzheimer Society of Canada (2017) found that roughly half of respondents would feel uncomfortable disclosing their dementia to family and friends, and 68% would be uncomfortable telling coworkers and acquaintances. Over half of respondents also admitted to using stigmatizing language, such as telling dementia-related jokes, referring to someone as "senile," "crazy," or "demented."

MENTAL ILLNESS

Parkinson's can cause depression, apathy, anxiety, and behavioural disorders, as a result of symptoms, challenges in coping with the disease, and medication side effects. The stigma surrounding mental health concerns is a barrier to early diagnosis and treatment, as many may feel embarrassed about their experiences, and thus reluctant to seek help.

Early intervention for mental health challenges can be life-changing, whether or not you live with PD. According to the Mental Health Education Resource Centre of Manitoba, benefits include:

- · less stressful assessment and treatment
- reduced need for hospitalization
- · reduced family disruption and distress
- · improved recovery and better attitudes to treatment
- · reduced risk of suicide, self-harm, or harm to others

For people with PD, early mental health intervention can also be beneficial in managing the progression of other symptoms. Apathy, depression, and anxiety, for example, can decrease motivation and interest in hobbies, causing people with PD to avoid important activities like exercise and socialization.

WELLNESS DESPITE STIGMA

By opening up about cognitive and mental health changes, people with Parkinson's can greatly improve their wellbeing. Although these concerns may be difficult to disclose, people with PD and their carepartners should feel empowered to advocate for their needs, and seek help just as they may do for physical health concerns.

DISCUSSION: MENTAL WELLNESS & PARKINSON'S STIGMA

Parkinson's symptoms, including fatigue, slowness, speech issues, and a lack of facial expression, can mirror the effects of dementia and declining mental health. This can make it difficult for healthcare professionals to diagnose and treat these concerns without their patient's cooperation and candour.

One way to cope with these concerns, and avoid denial and isolation, is to practice mindfulness. This involves being present, aware, and accepting of your circumstances in any given moment. The goal of mindfulness is to feel secure, and free from defensiveness and fear, in order to observe rather than react to ourselves and our worlds. By taking this objective approach to self-assessment, you may be better equipped to relay your observations and seek help.

ADDITIONAL RESOURCES

Parkinson's and Dementia | Helpsheet | bit.ly/pddementia

Mental Health and PD | Helpsheet | bit.ly/pdmentalhealth

Bell Let's Talk | letstalk.bell.ca

Alzheimer's Awareness Month | ilivewithdementia.ca

SOURCES

Alzheimer Society of Canada (2017). 2017 Awareness Survey Executive Summary. Retrieved from: https://ilivewithdementia.ca/wp-content/uploads/2018/01/2017_AWARENESS-SURVEY_EXECUTIVE_SUMMARY.pdf

Alzheimer Society of Canada (2019). Alzheimer's Awareness Month. Retrieved from:

https://alzheimer.ca/en/Home/News-and-Events/Media-centre/alzheimers-awareness-month

Mental Health Education Resource Centre of Manitoba (n.d.). Early Intervention. Retrieved from: http://www.mherc.mb.ca/page.php?id=13

PARKINSON'S AWARENESS MONTH



BE A PART OF OUR APRIL AWARENESS CAMPAIGN!

Every April, Parkinson Society British Columbia launches a provincial campaign for Parkinson's Awareness Month. Last year, we used the slogan "more than a tremor" to remind the public that there's far more to Parkinson's disease (PD) than meets the eye.

In 2020, we are inviting members of the Parkinson's community to take part in our campaign by sharing their stories, and helping spread awareness of the realities of life with PD. This an opportunity to promote education and compassion, and advocate for the needs of our community on a large scale. We will be sharing your stories in advertisements, in the media, and online.

We are currently searching for individuals to participate in photo and video shoots in late January and early February.

Are you interested in taking part, or have any questions? Contact Jovana Vranic, Marketing & Communications Senior Coordinator, at ivranic@parkinson.bc.ca.