GROUPLINK V Parkinson Society British Columbia Société Parkinson Colombie-Britannique

May 2015

Upcoming Events News **NEW!** Counselling Services4 The Parkinson's Movement: Highlights SuperWalk 2015 **Discussion Topic:** Medication7 **Research Profile:** Paul Cocker Carepartner's Corner

UPCOMING EVENTS

Regional Conference - Kelowna

Saturday, May 23, 2015 - 10:00am - 4:00pm Ramada Hotel and Conference Centre | 2170 Harvey Avenue, Kelowna

This May, join us in Kelowna to learn from leading experts in the field helping you to live well at every stage. Speakers include: Dr. Daryl Wile, Matthew Sacheli, Kaylee Larocque, Kim Froom and Joanne Taylor.

Registration available at: www.parkinson.bc.ca/kelowna-conference

Regional Conference - Vancouver

Thursday, June 11, 2015 - 10:00am - 4:00pm Italian Cultural Centre | 3075 Slocan Street, Vancouver

This June, join us in Kelowna to learn from leading experts in the field helping you to live well at every stage. Speakers include: Dr. Claire Hinnell, Matthew Sacheli, Erin Reeds and Joanne Taylor.

Registration available at: www.parkinson.bc.ca/vancouver-conference

Voice & Swallow Seminar - Burnaby

Wednesday, June 17, 2015 & Wednesday, June 24, 2015 10:00am - 3:00pm Accent Inns | 3777 Henning Drive, Burnaby

Facilitated by Sherri Zelazny, Registered Speech Language Pathologist and Certified LSVT Practitioner, this two-day seminar will focus on the voice and swallowing challenges faced by people living with Parkinson's. It will be an interactive and participatory format, and all levels of voice and swallow disorder are welcome, including those who currently do not experience voice or swallow symptoms but wish to be proactive with their treatment.

Registration available at: www.parkinson.bc.ca/Burnaby-Voice-and-Swallow

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





Have you seen Parkinson Society British Columbia's new website?

In light of the growing number of individuals seeking Parkinson's related information and referrals online, in April we announced the launch of a brand new website. If you've not yet had a chance to visit it, we encourage you to do so. <u>www.parkinson.bc.ca</u>

Online tool trains doctors to diagnose and treat Parkinson's.

Parkinson Society Canada has launched its first online learning module accredited by the College of Family Physicians of Canada and available at <u>http://www.parkinson.bc.ca/healthcare-professionals</u>. The module, offered at no cost, enables healthcare professionals to work through practical case scenarios. Family doctors will gain insight into key clinical challenges that can be applied to their own patient management. The content is based on the 84 recommendations from the Canadian Guidelines on Parkinson's Disease.

Professionals from a variety of health disciplines can take advantage of the module's transferable content to further their continuing professional education and training. Although the module is geared towards healthcare professionals, anyone with an interest is welcome to use the resource to become better informed about Parkinson's. Participants can access the online course through a secure login and registration process.

Volunteers needed for Speaker's Bureau

Parkinson Society British Columbia (PSBC) is starting a volunteer Speaker's Bureau! We're looking for individuals who are passionate, educated and experienced with Parkinson's disease and would be interested in sharing their knowledge with the public.

Parkinson Society British Columbia's Volunteer Speakers Bureau will help to:

- Offer presentations about PSBC and Parkinson's disease.
- Raise awareness and spread education about Parkinson's disease.
- Increase PSBC's outreach to communities.
- Increase public understanding of the Society and what our purpose, goals and services provide.

Qualifications: Experienced with or knowledgeable about Parkinson's disease; comfortable presenting to large groups of people; retired healthcare professional, teacher or public speaker; ability to communicate effectively both verbally and in writing; proficient computer skills: Word, PowerPoint and email; and ability to work independently.

For more information contact: Caroline Wiggins, Education and Support Services Coordinator cwiggins@parkinson.bc.ca or 604 662 3240 | Toll-Free: 1 800 668 3330

Pharmacists Clinic at UBC

The Pharmacists Clinic at UBC is the first of its kind in North America, offering a unique health care environment that integrates a commitment to the best in patient care with academic and research programs. It is a free service and does not require a doctor's referral. Generally, you can be seen within 2 weeks.

The clinic provides a 1 hour consultation for a first visit with follow-up visits based on each patient's needs. A pharmacist will go over everything a patient is taking including medication, food/diet, supplements, herbs/ spices, etc. They do not prescribe medication or dispense any medications but instead send a write-up to the patient's doctor and/or neurologists with recommendations.

For more information visit: www.pharmsci.ubc.ca/pharmacists-clinic



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NEWS (continued)

Volunteers Needed: UBC Health Mentors Program

UBC is currently looking to recruit 2-3 people through Parkinson Society British Columbia to be a part of a unique educational program in which teams of students from different health and human service programs learn together from / with a mentor (patient / client / caregiver). The program will run from September 2015 to December 2016.

Beginning in Fall 2015, student teams (4 students per team) will meet with their mentor six times (twice per term) over the course of 16 months, each visit focusing on specific topics. The Health Mentors program will help students learn about chronic disease and about the range of work involved in chronic disease self-management from the perspective of the patient and family.

If you know someone with a chronic health condition who would be a good mentor and would like to share their expertise with students, please pass along this information and encourage them to apply. In addition, please feel free to share this call out on social media, or in newsletters, you can include this video: <u>https://www.youtube.com/watch?v=MsoPmSECgss</u>.

Applications will be reviewed until July 31st for a September orientation. For more information and to apply, visit <u>http://www.dhcc.chd.ubc.ca/healthmentors</u>. If you are interested in hosting an information session for potential applicants, please contact Coordinator, <u>cckline@mail.ubc.ca</u>.

Further information:

Health Mentor Program Information [Download] Health Mentor Program Brochure [Download] Health Mentor Program Application Form (Caregiver) [Download] Health Mentor Program Application Form (Mentor) [Download]



UNDERSTANDING. ACCEPTANCE. GROWTH. WE'RE HERE TO HELP. M

Need an understanding ear or someone to talk to? Parkinson Society British Columbia offers free, short-term, confidential and non-judgmental counselling services for people touched by Parkinson's disease. Counselling will provide you with a safe and structured environment to discuss challenges, process emotions and provide you with the extra support you and your loved one(s) may need.

Our Registered Clinical Counsellor, Courtney Hanna, has experience working with people living with Parkinson's and their loved ones. She is able to help in dealing with any combination of issues including:

- Coping with a diagnosis
- Life transitions
- Grief/loss
- Depression
- Anxiety

This service is available province-wide in-person, by telephone and online via Skype.

About Courtney Hanna, MCP, RCC

Born and raised in Ottawa, ON, Courtney completed her B.A. in Halifax, NS at Dalhousie University. After her undergraduate degree, and a little soul searching, she decided to follow her dream of becoming a counsellor and moved to Vancouver, BC to pursue a Masters of Counselling Psychology at Adler University (formerly Adler School of Professional Psychology). Now a Registered Clinical Counsellor (RCC) with the British Columbia Association of Clinical Counsellors (BCACC), her personal connection to Parkinson's disease (PD) brought her to Parkinson Society British Columbia (PSBC).

Courtney's father was diagnosed with PD over 10 years ago, and recently underwent Deep Brain Stimulation surgery, which has been a successful form of treatment for him.

Believing that every individual has the potential to lead a happy and fulfilling life regardless of challenges faced, she brings a unique perspective and skill set to PSBC.

Schedule an appointment

Not sure if counselling is right for you? Call or e-mail Courtney for a 15 minute consultation at 604 662 3240, Toll Free 1 800 668 3330 or <u>channa@parkinson.bc.ca</u>.

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THANK YOU FOR SUPPORTING THE PARKINSON'S MOVEMENT!

There's still time to support The Parkinson's Movement

Although Parkinson's Awarness Month has come to a close, that doesn't mean The Movement has ended. Let's keep the momentum going! There's still time to join the movement to improve your well-being and help raise funds for critical programming and services. Donations to The Parkinson's Movement will be accepted until the end of the year, and many participants have taken it upon themselves to continue with an exercise commitment.

We are so proud of the Parkinson's community's efforts this year and wanted to share some great stories with you that made the headlines!



NEW WESTMINSTER STEP BY STEP
 read more



PARKSVILLE STEP BY STEP
read more



Thank you to our sponsors:







EVERYDAY HEROES. EXTRAORDINARY HOPE. PARKINSON SUPERWALK



This year marks the **25th Anniversary of Parkinson SuperWalk** nationally. Thank you to everyone who has made this event such a huge success over the years and we hope that we can count on your continued support.

It takes a community to fight Parkinson's! Gather your family members, friends and colleagues and form a fundraising team. Together, we can support critical research and provide essential programs to help the 12,500 individuals living with Parkinson's in BC.

You are the everyday heroes of Parkinson's disease. You have the power to build extraordinary hope.

There are several ways that you can get involved in Parkinson SuperWalk taking place in over 20 communities across British Columbia:

- 1. Register as a walker and/or start a team
- 2. <u>Sponsor a walker</u>
- 3. <u>Volunteer</u>

Burnaby Chase Chilliwack Cranbrook Duncan Elk Valley / Sparwood Fraser Valley / Fort Langley Invermere

- Kamloops Kelowna Nelson Oliver Parksville Pitt Meadows / Maple Ridge Prince George
- Quadra Island Richmond Salmon Arm Surrey Vancouver Vernon Victoria

For information, help or to organize a SuperWalk in your community, please contact: Cecilia Tupper | <u>ctupper@parkinson.bc.ca</u> | 604 662 3240 | 1 800 668 3330.



DISCUSSION TOPIC: MEDICATION

Introduce the topic by asking these questions:

- 1. What issues have you had with your medication? Have you found it to wear off?
- 2. Do you know the best way to take your medication?

The purpose of treating Parkinson's is to reduce the effect of symptoms on your daily life. Without treatment, you will eventually find that the symptoms make it hard to perform daily activities. Symptoms, such as shaking and stiffness, may cause discomfort; the risk of injury from falls may increase, and swallowing may become more difficult.

Medication will help you function, but may cause side effects. It is important to find the right balance between the medication's benefits and side effects. Everyone with Parkinson's is unique and will experience different symptoms, which means the treatment you receive will be geared to your specific needs. Drugs for Parkinson's work on the brain's complex chemistry and may need to be taken several times a day. Use them as prescribed and do not alter your doses without consulting your doctor. Current treatment neither cures Parkinson's nor stops it from advancing.

When should I start taking medication?

If you have been diagnosed with Parkinson's, you may be wondering when you should start treatment and with what medication. There is no single strategy that applies to everyone. The timing will differ from person to person. It depends on a variety of factors, such as:

- your age
- the nature of your symptom(s)
- your lifestyle (e.g., if you are working or retired and the kind of leisure activities you enjoy)
- your overall physical health
- whether you experience balance problems with walking
- changes in intellectual abilities, and
- your own attitude toward taking medication

What about medications for other health conditions?

The effectiveness of some Parkinson's drugs can be reduced when combined with drugs for other health conditions. It is important to seek advice from your doctor or pharmacist regarding any new drug prescription.

How can I get the most benefit from my Parkinson's medications?

- The timing of medications is an important way to control your symptoms. Follow the guidelines provided by your healthcare professional.
- Use a timer to remind you to take your medication on time to avoid "double-dosing".
- Take each dose with a full glass of water to aid absorption.
- Do not break, crush or chew controlled-release tablets, unless instructed by your doctor.
- For nausea, take the drug after meals or with a cracker or fruit.
- Keep an accurate list of all medications, including over-the-counter products, herbal remedies, vitamins or supplements.



DISCUSSION TOPIC: MEDICATION (continued)

What are the side effects of Parkinson's drugs?

The most common reactions (which occur within the first several days of a new treatment) include nausea, vomiting, dizziness (drop in blood pressure), sleepiness and visual hallucinations.

In the last few years, levodopa and dopamine agonists in particular (ropinirole [ReQuip], pramipexole [Mirapex]) have been associated with the emergence of behavioral changes such as impulse control disorders. These are characterized by failure to resist an impulse to perform certain actions.

Impulse control disorders include a range of behaviors such as compulsive gambling (up to 5% of treated patients) or shopping, hypersexuality, binge eating, addiction to the Internet or to other recreational activities. These activities are often pleasant in the moment, but over time may become harmful to you or to others. If you are experiencing these behaviours, tell your neurologist/doctor. Often the medication can be adjusted which can reduce or control the behaviour.

Care partners can play an important role in helping to identify when these behaviours occur. If you are a care partner, tell the person if you have noticed a change in his/her behaviour or personality and encourage him/ him/her to speak with the doctor immediately so medication can be adjusted.

What questions might I ask about treating Parkinson's?

You might find it helpful to write down any questions you have before your next appointment. This can help your visit be more efficient. Here are a few questions you may wish to ask:

- 1. What are the benefits of each kind of medication?
- 2. What are the side effects and how can I manage them?
- 3. When do I take the medication relative to meal time to get the best result?
- 4. How soon can I expect the treatment to start working?
- 5. How will treatment affect my daily activities?
- 6. How often do I need to follow up with my doctor about my medications?
- 7. Do drugs lose their effectiveness over time if I start treatment early on?
- 8. Should I be concerned about behaviours related to taking drugs, such as confusion or compulsive activities (e.g., shopping or gambling)?
- 9. Are my medications covered by the provincial drug plan?
- 10. Would a clinical trial be appropriate for me? Can you help me find one?

Look on our website or contact our office for the following help sheets & resources:

- <u>Preparing for your medical appointment</u>
- Parkinson's Medication: Timing is Everything
- Medication Card
- Levodopa (Sinamet) and Protein: Medication Absorption Concerns

Source: Parkinson Society Canada, Medication. www.parkinson.ca



RESEARCH

RESEARCH DISCLAIMER

Our monthly updates are a collection of recent articles that we have found on the Internet and in publications. They are offered solely on an informational basis. PSBC does not research or investigate the articles further and we do not provide additional follow up to verify that they are anything other than interesting. We urge you to do your own follow up on any of the information found in the articles presented. *If you have any questions or concerns about the information contained in the articles ALWAYS check with your doctor.*

Research Profile: Paul Cocker Grappling with Gambling: The receptor that could hold the key

Research Project: Investigating the potential efficacy of Dopamine D4 receptors in alleviating compulsive gambling in Parkinson's disease.

Pilot Project Grant: \$30,000 over two years

Project Description:

"We want to develop a model of problem gambling, and then see if we can tailor treatments so we can stop these pathological forms of gambling."

For a small percentage of people with Parkinson's disease, taking dopamine-replacement drugs to treat their stiffness, tremors or rigidity can cause side effects such as impulse control problems resulting in compulsive shopping, gambling or hyper-sexuality. So far, those behaviours have been tough to treat without taking people off medication to control their other symptoms.

At the University of British Columbia, graduate student Paul Cocker investigates the possibility that blocking a particular set of receptors – the portion of a cell that receives signals from chemicals like dopamine – in brain cells might alleviate these troubling behaviours. Cocker, a student in Dr. Catharine Winstanley's lab, uses a rodent slot machine to investigate compulsive gambling. Initially, Cocker and his colleagues administered a medication that mimics the effects of the dopamine-replacement drugs that people with Parkinson's take. When rats are under the influence of that medication, they can't distinguish between winning and losing outcomes.

Cocker now plans to give the rats a different kind of compound that blocks dopamine D4 receptors, the receptors that may cause these impulse control problems. If they can alleviate the rats' compulsive gambling behaviour, their data could help other researchers redesign dopamine-replacement drugs to make sure they don't activate the D4 receptors. Alternatively, pharmacologists who design drugs could develop an additional drug to block those receptors and prevent the problem behaviour.

"If we were able to show that problem gambling in this animal model was contingent on this one receptor, that might present a relatively easy fix," says Cocker.

Receptors, which sit on the surface of cells, are like the locks that brain chemicals like dopamine fit into. Once the receptors receive a signal from dopamine, they initiate activity, which is the reason blocking the D4 receptor might halt the gambling, shopping or hypersexuality. Cocker, who has devoted most of his research to decision-making and impulsivity, is fascinated by the role dopamine plays in this behaviour.

"If this works, I would want to see dopamine D4 receptor drugs explored as a treatment option," he says.



RESEARCH (continued)



Biography:

Paul Cocker completed his undergraduate degree at the University of Sussex in the UK and following a brief stint with a 'real job', returned to academia. He began a Master's in Neuroscience in Dr. Catharine Winstanley's lab at the University of British Columbia in 2012, before transferring into the PhD program in 2013.

Cocker's primary research interests lie in the neurobiological basis of pathological gambling. Specifically, he is interested in the iatrogenic gambling that occurs in a small but significant sub-population of individuals with Parkinson's disease. Using animal models of gambling he aims to mimic this particularly compulsive form of gambling and thereby potentially inform novel treatment options.



CAREPARTNER'S CORNER

FAMILY CAREGIVER WEEK

MAY 4-10, 2015

Join Parkinson Society British Columbia in celebrating those who provide care and support to their loved ones during Family Caregiver Week in British Columbia.

Parkinson Society British Columbia Société Parkinson Colombie-Britannique



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CAREPARTNER NEWS & RESOURCES

UPCOMING WEBINARS FOR CAREPARTNERS

Hosted by Family Caregivers' Network Society British Columbia



What don't I know that I need to know? Effective decision making in caregiving.

Tuesday, May 5, 2015 | 6:30pm - 8:00pm Facilitator: Maureen Grant, Social Worker

Are you new to caregiving or feeling at a loss as to what needs to be done? Not sure where to start or how to decide what to do next? Are you worried that you might be missing something important? This practical and informative webinar will outline the various aspects of providing care to your family member. A checklist of decisions that need to be made and problem solving options starting with the basics and then moving into more complex situations will be discussed.

Registration: Call the Care-ring Voice Network at 1 866 396 2433 or register online at <u>www.thecaregivernetwork.ca</u>

Creating an unhealthy environment for caregiver burnout.

Thursday, May 7, 2015 | 6:30pm - 8:00pm Facilitator: Allison Reeves, Registered Clinical Counsellor

Knowing how to create an unhealthy environment for caregiver burnout is invaluable. Why? Because treating caregiver burnout like a disease helps you to "starve it out" so to speak. In this valuable webinar, Allison will outline how you can increase your resiliency and hardiness and be proactive in living your life in a way that will not allow caregiver burnout to take root.

Registration: Call the Care-ring Voice Network at 1 866 396 2433 or register online at <u>www.thecaregivernetwork.ca</u>



Carepartner vs. Caregiver

Caregiver is the traditional term used to describe an individual who is providing support and coordinating care for another person or persons. More recently, you may have heard the term carepartner used in place of, or interchangeably with, caregiver. The term carepartner was introduced to provide inclusion to, and in recognition of, family members and friends who are playing an active role in providing support to someone they know and care for. A carepartner is not usually the sole decision maker in terms of an individual's care, but rather assists where necessary. As a result, the relationship is considered more of a partnership. Most often the term 'carepartner' is used during the earlier stages of a disease or ailment; however, its usage in place of caregiver is also based on personal preference.

The term caregiver has since evolved and may refer to: an individual who is a medical professional and/or is paid for their services; and/or an individual who is responsible for the bulk of decision making regarding the care of someone they know – most often as a disease or ailment has progressed to where decision-making is difficult.

When using either of these terms, the most important consideration is how the individual who is providing care wishes to be addressed and recognized.

This publication is written and distributed by: Parkinson Society British Columbia Suite 600 - 890 West Pender Street, Vancouver, BC V6C 1J9 Telephone: 604 662 3240 | Toll Free: 1 800 668 3330 | Fax: 604 687 1327 www.parkinson.bc.ca

Information relating to Parkinson's disease contained in the Parkinson Society British Columbia website (<u>www.parkinson.bc.ca</u>) and information provided in other formats such as printed materials is intended to be used for general information only and should not replace consultation with healthcare professionals. Consult with a qualified healthcare professional before making medical decisions or if you have questions about your individual medical situation.

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