



# Grouplink

January 2015

This publication is written and distributed by Parkinson Society British Columbia.  
For more information please email [info@parkinson.bc.ca](mailto:info@parkinson.bc.ca) or call 1 800 668 3330.

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## Upcoming Events

### Carepartner Support Series

Date: January 20 – February 24, 2015 (six week series)

Time: 2:00 – 4:00 pm

Location: Amica at West Vancouver

Details: The Carepartner Series involves six weeks of support meetings driven by participants' needs. A facilitator will present topics and manage discussions, but the series will focus on the personal experiences of group members.

Registration: Contact Caroline Wiggins | 604 662 3240 | [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca)

### Voice and Swallow Seminar

Date: February 19 – February 20, 2015 (two days)

Time: 10:00 am – 4:00 pm

Location: Victoria

Details: This two-day event 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 will be included.

Registration: Opens in January - check [www.parkinson.bc.ca](http://www.parkinson.bc.ca) for details.

### Regional Conference

Date: March 28, 2015

Time: 10:00 am – 4:00 pm

Location: Surrey

Details: Parkinson's is a journey of different stages and challenges. Learn from leading experts in the field to help you live well at every stage.

Registration: Opens in January - check [www.parkinson.bc.ca](http://www.parkinson.bc.ca) for details.



## Discussion Topic: Apathy and Motivation

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### Manage apathy and gain motivation

#### Introduce the topic by asking the group these questions:

1. How has apathy affected your life?
2. What do you do to manage feelings of apathy?

#### What is apathy?

About 40-45% of people with Parkinson's have unusually high levels of apathy. Individuals with apathy demonstrate a reduction in self-initiation and/or motivation.

Here are some examples of apathy as it presents in Parkinson's:

- Difficulty with initiating activity, low activity levels and motivation
- Lack of interest in socializing and reduced productivity
- Lack of concern for issues that would have been important to you in the past
- Needing someone else to remind you or prompt you to do things

#### Why does apathy matter?

Apathy is associated with many undesirable things and can even result in negative consequences for people with PD or for their spouses, family members, or caregivers.

Some of the things that apathy has been associated with include:

- Cognitive decline, impairment in occupational functioning and daily functioning
- Reduced community and social participation
- Treatment compliance, poor illness outcome and poor general health

#### How to fight against apathy and gain motivation:

- Create or get help creating a daily schedule of activities and set times to get things done.
- Create small weekly goals for leisure activities.
- Establish a reward system for successful completion of activities.
- Exercise: Daily exercise not only can slow down the progression of Parkinson's, but also releases chemicals in the brain that elevates mood and increases motivation.
- Sleep: Try to get a good night sleep every night. Sleep affects motivation for everyone, not just those with Parkinson's. Medication management may be necessary.
- Get out of the house and be social: Being around others and engaging in interesting conversations and experiences can boost mood and enhance motivation.

#### Conclude the topic with the following activity:

1. Ask each person to identify two tips that they will resolve to do to fight apathy.
2. In small groups, ask people to share their experience with apathy and discuss ideas to reduce apathy and increase motivation. Share their ideas with the whole group.

Source: Adapted from Movement Disorders Clinic (University of Florida) <http://bit.ly/1zXxl0W>

## Research Update

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### 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.**

### Study Links Parkinson's Disease to Gut Bacteria

**Compared to healthy controls, people with Parkinson's appear to have different gut bacteria.**

The study, led by the University of Helsinki Institute of Biotechnology, is published in the journal *Movement Disorders*. It involved 72 patients with Parkinson's and an equal number of matched, healthy controls.

More and more studies are discovering the huge influence that our gut bacteria - which vastly outnumber the cells of our body - have on our health: when they get sick, we get sick.

Some clues already exist about the links between Parkinson's and gut problems. For example, as the study authors say in their paper, "gastrointestinal dysfunction, in particular constipation, is an important non-motor symptom" in Parkinson's disease, and "often precedes the onset of motor symptoms by years."

They also mention that recent research shows gut bacteria interact with parts of the nervous system via various pathways, including the enteric nervous system - the so-called "brain in the gut" - and the vagal nerve.

Highlighting their findings, lead author of the new study, Dr. Filip Scheperjans, a neurologist in the Neurology Clinic of Helsinki University Hospital, says:

"Our most important observation was that patients with Parkinson's have much less bacteria from the *Prevotellaceae* family; unlike the control group, practically no one in the patient group had a large quantity of bacteria from this family."



The team did not find out what an absence of *Prevotellaceae* might mean in Parkinson's. But they have many questions. For example, does this family of bacteria protect against the disease? Or does the disease wipe them out?

The team also found that levels of another family of bacteria called *Enterobacteriaceae* appear to be linked to severity of Parkinson's symptoms. They observed patients who had more difficulty with balance and walking tended to have higher levels of these bacteria.

Dr. Sheperjans and his colleagues are already planning further research to explore the connection between Parkinson's disease and gut bacteria.

**They hope eventually that their findings will lead to new tests for Parkinson's and perhaps even new treatments to stop, slow or even prevent the disease by focusing on gut bacteria.**

Source: Adapted from Medical News Today: <http://bit.ly/1J9hD3>

## News & Events

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### NEW! PSBC Introduces Step by Step Program

Do you want to...  
Improve your Parkinson's symptoms?  
Exercise, but need motivation?  
Be more social?

**Our new, 12 week *Step by Step Program* is just for you!**

Date: Saturday, April 11, 2015 (World Parkinson's Day) to Saturday, July 4, 2015

Details :

- You will record your steps on a daily basis with a pedometer (provided by PSBC).
- In the first week, you will determine a baseline of your average steps, and then you will be encouraged to increase your steps each week.
- There will be a group walk in each community that meets once or twice a week, led by the group leader.
- The program will conclude with a celebratory luncheon.

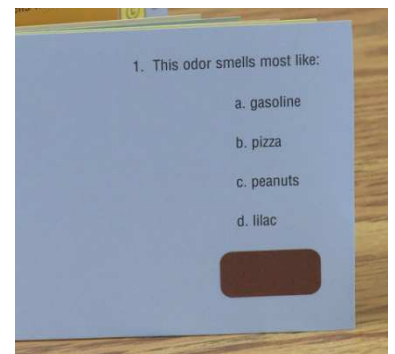
**We are currently looking for individuals who would be interested in leading this program in their local community.**

Contact: Caroline Wiggins at [cwiggins@parkinson.bc.ca](mailto:cwiggins@parkinson.bc.ca) | 604-662-3240 | 1 800 668 33330

### Research Update: Sniff Test for Parkinson's

A study underway in Halifax is looking at the sense of smell and using a scratch and sniff test to see what role it could play in the early diagnosis of PD.

"What we're interested in doing is try and find ways to identify people who are in the early stages of Parkinson's disease, even before they have the motor symptoms that you typically association with Parkinson's," said Kim Good, co-principal investigator of Predict Parkinson's and an associate professor in the Dalhousie Department of Psychiatry.



How participants answer the scratch and sniff tests will allow researchers to pinpoint biomarkers to then identify who may be at risk of the degenerative disease.

The test has been used for years in Parkinson's research. But this is believed to be the first time the test is being used for early diagnosis of pre-clinical Parkinson's. The study, which began in 2007, is expected to be completed by 2017.

Source: Global News <http://bit.ly/1rdtyLG>

## Google Acquires Spoon that Steadies Tremors

Google is throwing its money, brain power and technology at the humble spoon. But these spoons are a bit more than your basic utensil: Using hundreds of algorithms, they allow people with essential tremors and Parkinson's disease to eat without spilling.

The technology senses how a hand is shaking and makes instant adjustments to stay balanced. In clinical trials, the Liftware spoons reduced shaking of the spoon bowl by an average of 76 per cent.



Source: Global News <http://bit.ly/1vblqZ7> Liftware Spoon [www.liftlabdesign.com](http://www.liftlabdesign.com)

## Research Participants Needed

### Do you use a mobility scooter?

At the GF Strong Research Centre Dr. Ben Mortenson and his research team are conducting a study on the reliability of several new measures and tools related to scooter use. This study involves answering questions about your scooter use and daily life as well as completing a scooter mobility test. From the information gathered from this study they hope to conduct larger intervention studies on how training programs can help increase community participation.

(You must have owned your scooter for at least 3 months. You must also have the ability to read, write and speak in English.)

The study requires two visits and a stipend will provided for each visit. The studies can be done at the GF Strong Rehabilitation Centre **OR** Blusson Spinal Cord Centre.



If you are interested, contact Mary-Ellen Johnson| [maryellen.johnson@ubc.ca](mailto:maryellen.johnson@ubc.ca) | 604-714-4108

## Funding Available – Assistive Devices and Vehicle Retrofits

The March of Dimes Canada Istvan and Barbara Haas Fund will provide \$15,000 to a successful candidate(s) for vehicle modification. The application deadline is February 16, 2015.

The funding is intended to provide vehicle modifications for an eligible individual or family to enable a person with disabilities that restrict mobility to participate in his/her community. Eligible applicants will be residents of British Columbia, with a physical disability that impedes mobility and substantially restricts the activities of daily living and participation in the community. They must also have limited financial resources to cover the expense of the vehicle modifications they require.

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Vehicle modifications will allow drivers with a limited range of physical movement to safely enter; exit and operate their vehicle. They include:

- Installation of ramps and lifts to assist entry and exit.
- Specialized seating and related accessories.
- Raising the vehicle's roof and lowering the vehicle's floor.

Modified vehicles will:

- Remove or minimize a life safety risk (reducing impact on caregivers)
- Remove or prevent long-term hospitalization by assisting the individual to continue living safely in their own home and accessing services in the community.
- Maintain/gain full employment or pursue their education.

For more information and the application, please go to [www.marchofdimes.ca](http://www.marchofdimes.ca) or contact:

**Istvan and Barbara Haas Vehicle Retrofit Initiative**

Phone: 1-855-660-6632    Email: [haasretrofit@marchofdimes.ca](mailto:haasretrofit@marchofdimes.ca)

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## Caregiver Corner

### How to identify and cope with apathy

Apathy is a symptom that typically has a greater negative impact on caregivers than on a person with Parkinson's. Many caregivers report feeling frustrated with the person they care for and it is not uncommon for caregivers to feel they are working harder than the person with Parkinson's.

Without an understanding of the nature of apathy in PD, a caregiver may start to see the person they care for as lazy, defiant, bored, difficult to motivate and generally unwilling to help themselves. This can become a highly stressful situation resulting in significant strain on the relationship.

Here are some things you can do to identify and cope with apathy:

- **Ask:** Ask the person with Parkinson's how they are feeling. What looks like apathy may be a symptom of another condition that could benefit from medical attention, or it may be related to Parkinson's.
- **Activity:** Regular physical activity and exercise are important for enhancing energy levels and for social interaction. A pre-arranged schedule, involving other people or an exercise class, can help.
- **Support:** Participate in a support group for people with PD and for caregivers.
- **Help:** Let family and friends know when help is needed. Do not let yourself become isolated.
- **Patience:** After being gently encouraged to take part in an activity, a person experiencing apathy may say afterwards that they were glad they did participate. Getting started is often the hardest part.

Source: *Parkinson Society BC help sheet – Apathy & Parkinson's* [www.parkinson.bc.ca](http://www.parkinson.bc.ca)

## Advocacy Campaign

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**Join us as we raise our voice for Parkinson's!**

### Parkinson's Disease – The Issue and How You Can Help

**Parkinson's disease (PD) is one of the most treatable of all neurological conditions.** Medical treatment increases longevity and allows most people with PD to remain active and productive for many years.

**The medical treatment of PD, unfortunately, is not always simple** and the need for specialist care increases with the advancing disease. Currently, people with PD in British Columbia are facing a very lengthy waitlist – 18 to 24 months - to see a Movement Disorder specialist.

People with PD need to receive care from a Movement Disorder Specialist and they need it sooner than 18 to 24 months.

**Contact Jean Blake [jblake@parkinson.bc.ca](mailto:jblake@parkinson.bc.ca) or 604-662-3240 if you are willing to add your voice, meet with your MLA, and become an Advocacy Ambassador for Parkinson's.**



Information relating to Parkinson's disease contained in the Parkinson Society British Columbia website ([www.parkinson.bc.ca](http://www.parkinson.bc.ca)) 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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