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

JUNE 2017

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

The goal of this program is to help motivate people to become physically fit to combat the symptoms of Parkinson's disease. We hope to encourage people to continue a regular exercise routine following the program. Read about a Step by Step success story here.

Start Date: April – June

Location: Brentwood Bay, Courtenay/Comox, Fernie, Kamloops, Maple Ridge/Pitt Meadows, New Westminster,

Penticton, Prince George, Richmond and Vancouver

Fees: Free

Contact Caroline at cwiggins@parkinson.bc.ca or 1-800-3330 to learn more.

MOVING FORWARD, TOGETHER

Please join us for the *Moving Forward, Together* conference, which will bring together members of the Parkinson's community from across the province in Richmond, BC. The return of this much-anticipated event will feature prominent local, national and international presenters who will speak to <u>topics</u> related to the treatment and management of Parkinson's and its associated challenges. The mission of the conference is to foster an educational and inspirational space for enriching the connection between people with Parkinson's, carepartners, friends and healthcare professionals. All those affected by Parkinson's disease are welcome. Please note that space is limited and that is highly encouraged to register in advance of the conference.

Date: Saturday, June 3, 2017 Time: 9:00am – 3:15pm

Location: Sheraton Vancouver Airport Hotel | 7551 Westminster Highway

Richmond (map)

Fees: Member \$40.00 | Member (Couple/Pair) \$70.00

Non-Member \$60.00 | Non-Member (Couple/Pair) \$100.00

Registration: https://www.parkinson.bc.ca/moving-forward

Registration for this event closes Friday, May 26, 2017. Limited registrations will be available at the door.

ASK THE EXPERT WEBINAR SERIES: IMPULSE DISORDERS & PARKINSON'S

For people with Parkinson's disease, it is usually a tremendous relief to find a drug to treat tremors, stiffness or freezing. But for up to 20 percent of individuals, the class of drugs that is often most effective in controlling these motor symptoms comes with devastating side effects. Synthetic dopamine drugs, called dopamine agonists, can sometime lead to risky behaviour. At the University of British Columbia (UBC), behavioural neuroscientist <u>Dr. Catharine Winstanley</u> uses animal models to investigate the link between a protein called GSK3beta and the impulse control problems some people develop when taking these drugs. Join PSBC for a presentation by Dr. Winstanley on research that offers new hope to halt compulsive behaviours.

Date: Tuesday, June 20, 2017 Time: 10:00am - 11:00am

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

start time.

Fees: Free Capacity: 175

Registration: http://bit.ly/ImpulseDisordersPD

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

Champions FOR PARKINSON'S

- Full Throttle: May 28, 2017 (read more)
- Shakin' the Rock for Parkinson's: June 11 16, 2017 (read more)
- Elk Valley Parkinson's Golf Tournament: July 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 mdzaferovic@parkinson.bc.ca or 1-800-668-3330.

PARKINSON SUPERWALK

Are you ready to become a hero for Parkinson's? Register as an individual or team up with your friends, family or coworkers!

Join us for Parkinson Society British Columbia's largest fundraising event of the year, Parkinson SuperWalk! Beginning on September 9 and 10, incredible British Columbians in over 20 communities throughout the province will walk together to help give hope to the 13,000 people in BC living with Parkinson's.

Funds raised help to provide valuable support services, education, advocacy efforts and contributions to research. Register now!



NEWS & ANNOUNCEMENTS

NEW LEGISLATION ON GENETIC TESTING AND PRIVACY

Significant legislative changes are on the horizon in the field of genetic testing with Parliament's recent passage of Bill S-201: An Act to Prohibit and Prevent Genetic Discrimination. This Act will implement broad protections relating to an individual's right to access their genetic information, as well as to prevent an individual from being required to undergo genetic testing and to disclose the results of their genetic tests. Read more here: http://bit.ly/GeneticTestingPrivacy

DANCE FOR PARKINSON'S DISEASE

Explore movement and music in an enjoyable, safe and creative class for people living with Parkinson's disease. Classes will be taught by Megan Walker Straight, a professional dancer and trained Dance for PD® instructor.

Location: Hastings Studio | SFU School for Contemporary Arts

4th Floor | 149 West Hastings Street, Vancouver (map)

Date: Fridays, May 5 – June 23, 2017

Time: 10:30am - 11:30am

Fee: \$12/class (caregivers/partners are no extra charge)

Registration: Megan Walker Straight | meganwstraight@gmail.com | 604-313-0660

NORTH VANCOUVER SONGSHINE CLASS

Join Joani Bye, certified SongShine Instructor, as she leads a SongShine class for people with Parkinson's who want to strengthen their voices, sing their favourite songs and make new friends.

Date: Mondays, May 1 – June 26, 2017 (no class on Victoria Day)

Time: 1:00pm - 2:00pm

Location: Highlands United Church | 3255 Edgemont Boulevard, North Vancouver (map)

Fee: \$12 per class | \$96 for 8 weeks

Contact: Joani Bye | joanibye@icloud.com | 604-202-9784

THE HUMAN VOICEBANK

May is Speech and Hearing Month. As it comes to a close, consider celebrating by donating your voice! The Human VoiceBank celebrates the diversity and richness of human voice. With over 20,000 members all over the world contributing millions of sentences to their platform, they are building a community that will empower voices everywhere. Those that have lost their voice to Parkinson's may want to reclaim theirs through the outcome of The Human Voicebank project. Add your voice to The Human Voicebank and share the gift of voice today: https://www.vocalid.co/voicebank.

GLOBAL NEWS COVERS TELE-EMPATHY DEVICE

Jim Smerdon, a British Columbian resident with YOPD, has been involved in the testing of the Tele-Empathy Device. Developed by Toronto-based lab Klick Health, this device can allow anyone to experience the symptoms (e.g., tremors) of Parkinson's disease. This could potentially be used as a tool to help connect carepartners with people with PD, as well as improve care and understanding amongst the health care team. Watch the Global News coverage here: http://bit.ly/TeleEmpathyDevice.



ANNUAL GENERAL MEETING

This educational component of this year's Annual General Meeting featured a panel of researchers from the Pacific Parkinson Research Centre (PPRC). We have recorded these sessions so you can learn from the information they share at a time that suits you. Watch videos from the event online!

- Dr. Appel-Cresswell <u>The microbiome in Parkinson's</u>
- Matthew A. Sacheli, PhD Exercise Research: update and new findings
- Stefano Cataldi, Phd <u>Parkinson's disease</u>: From genetics to therapeutics
- All Researchers Q&A



Members gather for the AGM at BCIT's Burnaby Campus on April 22, 2017

LENDING LIBRARY: NEW BOOKS!

- GUT: the inside story of our body's most underrated organ by Giulia Enders (2015) view a video interview with the author
- Living Beautifully with Uncertainty and Change by Pema Chodron (2013) learn more via Goodreads

EXERCISE

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!

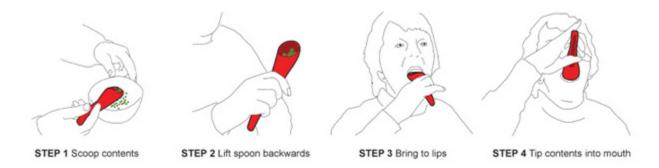
https://www.parkinson.bc.ca/exercise

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

NEWS & ANNOUNCEMENTS

TIP JAR

Do you fumble with your spoon? Do you want to eat your cereal or soup with ease? Try the S'up Spoon for shaky hands!



The S'up Spoon is specially designed for spill proof eating. Unlike a normal spoon, which typically requires your upper lip/teeth to pull content off, this spoon requires you to tip food into your mouth instead. The S'up Spoon was initially designed for one person, but after 18 months in development it is now available to all who may benefit. It can be useful for individuals with cerebral palsy, Parkinson's, essential tremor and shaky hands. Each S'up Spoon is 25g and is dishwasher safe. You can order your very own here: http://www.sup-products.com/.

Note: There is a 0% VAT (valued-added tax). VAT is a tax that consumers pay when purchasing services or goods in the European Union. The standard rate for VAT in the UK is currently 20%. If you are chronically sick or disabled, many items on our website are available VAT free if you are buying them for personal and domestic use and they are relevant to your condition. To claim relief from VAT, customers must have a relevant disability or be purchasing on behalf of someone with a relevant disability. To make it simple when purchasing from this website, you will just need to complete the declaration form in the checkout process.

Do you have any tips or tricks that you would like to share with your 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 Myriame at mlepinelyons@parkinson.bc.ca or 1-800-668-3330.

SUBSCRIBE TO GROUPLINK!

If you wish to receive personal copies of GroupLink please connect with Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 and your name will be added to our GroupLink email distribution list.



DISCUSSION QUESTIONS

- 1. What new exercises have you tried in the last 12 months?
- 2. If you have been exercising, what kind of changes have you noticed in your body?
- 3. What would you tell another person with Parkinson's who is unsure about starting a new exercise plan?

Exercise is very important for people with Parkinson's disease (PD). However, you may wonder, "why bother?" Simply put, for people with PD exercise is not only a means to maintain health, but a vital component to maintaining balance, mobility and activities of daily living. There is increasing evidence that exercise is especially beneficial for people with Parkinson's due to its potential for neuroprotection.

FAST FACTS

- People with Parkinson's who exercise fare better over time than those who are inactive.
- Physical activity should be initiated early and is most effective if it is committed to over a life-time.
- Activities that are aerobic, or that focus on building strength, flexibility and balance improves Parkinson's symptoms (NPF, 2017).

Did you know that the Pacific Parkinson Research Centre at University of British Columbia has recently been declared a National Parkinson Foundation Centre for Excellence? As such, it is joining a network of research centres that research the effects of exercise and Parkinson's while promoting the benefits of physical activity.

The Parkinson's Outcomes Project study conducted by the National Parkinson Foundation in the United States has proven that people with PD who vigorously exercise for 2.5 hours per week were able to maintain their quality of life for longer. The sooner they begin vigorous workouts after diagnosis, the better.

So how does the brain change with exercise? Researchers at the University of Southern California looked at the brains of the mice that had exercised under conditions parallel to a human treadmill study. They found that:

- Exercising changed neither the amount of dopamine nor the amount of neurons in the animals' brains.
- In the mice that had exercised, the brain cells were using dopamine more efficiently.
- These researchers also found that exercise improved efficiency by modifying the areas of the brain where dopamine signals are received the substantia nigra and basal ganglia (ibid).

For more information, you may be interested in one of the following videos:

- Watch Matt Sacheli, UBC PhD Candidate, <u>present his research</u> at PSBC's most recent Annual General Meeting, which involves neuroimaging in Parkinson's disease, specifically investigating dopamine and exercise.
- Naomi Casiro, PT and PWR! Instructor, gives a <u>live exercise demonstration</u> at one of PSBC's regional conferences in 2016.



7

Your loved one will feel better if they stay active, regardless of what stage of the disease they are at. As a carepartner, you can support them in their efforts by becoming an exercise partner and/or a source of motivation. Feeling accountable to another person increases the likelihood of both of you sticking to an exercise routine.

TIPS

- Depending on the stage of the disease, it may be best for people with PD to train in an environment where there are others around, who could offer help if needed.
- People new to exercise programs are generally best off working with a personal trainer or qualified group exercise instructor. If someone' mobility is significantly affected by PD, a physical therapist may be the best choice for helping to start a program.
- Just because you and your loved one are both exercising, does not mean you have to do the same routines. It is important for both of you to have time to yourself and do exercises that are enjoyable and challenging for you. Perhaps a combination of pair and individual activities may be best for you and your loved one.
- Create an activity schedule. Make time for exercise. Write it down, and work it around social activities, meals and adequate rest.
- Vary the type of exercise you both participate in. The body tends to get used to the same exercise routines over and over again. In consultation with a personal trainer or exercise instructor, you can build upon your physical fitness!
 Rock Steady Boxing and Dance for PD are already dynamic, changing forms of activity that are both social and taught by qualified instructors.

ADDITIONAL RESOURCES

- PSBC offers an up-to-date listing of community exercise programs, available at https://www.parkinson.bc.ca/exercise.
- National Parkinson Foundation provides additional information about the benefits of exercise, as well as tips as to
 what activities are best for people with PD at http://www.parkinson.org/understanding-parkinsons/treatment/Exercise.
- The Province of British Columbia has published the BC Seniors' Guide, a compilation of information and resources designed to help seniors live a healthy lifestyle. You can access the book online at http://bit.ly/BCSeniorsGuide. Alternately, you can request a free print copy of the book in English, French, Chinese or Punjabi by contacting the Office of the Seniors Advocate Monday through Friday, between 8:30am 4:30pm at 1-877-952-3181.
- Vary the type of exercise you both participate in. The body tends to get used to the same exercise routines over and
 over again. In consultation with a personal trainer or exercise instructor, you can build upon your physical fitness!
 Rock Steady Boxing and Dance for PD are already dynamic, changing forms of activity that are both social and
 taught by qualified instructors.

Sources

National Parkinson Foundation. (2017). *Neuroprotective Benefits of Exercise*. Retrieved from: http://www.parkinson.org/understanding-parkinsons/treatment/Exercise/Neuroprotective-Benefits-of-Exercise.