

## UPCOMING EVENTS

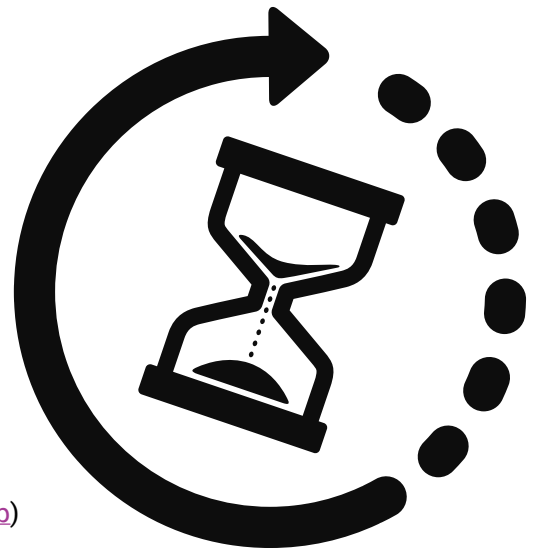
*Parkinson Society British Columbia (PSBC) endeavours to make attendance at events accessible to all who may benefit. The Society may be able to subsidize attendance fees for those who require financial assistance. Please contact Stacey at [sdawes@parkinson.bc.ca](mailto:sdawes@parkinson.bc.ca) or 1-800-668-3330 for more details.*

### TIME OUT FOR CAREPARTNERS

PSBC recognizes the efforts made by carepartners and caregivers every day. On February 25, 2017, we invite carepartners across the province to join us for a day of education, socialization and relaxation. Guest speakers will share experiences and everyday strategies for coping with the complexities that arise as a result of Parkinson's disease (PD). Lunch and light refreshments will be provided.

**SPECIAL NOTICE:** An adjacent room will be available for people with Parkinson's (PwP) to partake in activities (e.g., light exercising, games, socializing), while their carepartner participates in discussions with other carepartners. We ask that PwP coming to the February 25th event respect this room divide. Please note that this room will be managed by volunteers; volunteers will not be medical professionals.

Date: Saturday, February 25, 2017  
 Time: 10:00am – 2:30pm  
 Location: Burnaby Executive Suites | 4201 Lougheed Hwy, Burnaby ([map](#))  
 Fees: PSBC Member \$30.00 | PSBC Members (Couple/Pair) \$45.00  
 PSBC Non-Member \$40.00 | PSBC Non-Member (Couple/Pair) \$55.00  
 Registration: Members: <http://bit.ly/PSBCMReg>  
 Non-Members: <http://bit.ly/PSBCNonMemReg>



### REGIONAL CONFERENCE - KELOWNA

Parkinson's disease is a unique and complex condition. 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. A catered lunch will be provided.

Special speakers at this conference will include:

- Dr. Silke Appel-Cresswell is a neurologist and researcher from the Pacific Parkinson's Research Centre and will speaking on current research relating to microbiota and its connection with Parkinson's disease.
- Sun Nee Tan is a researcher at Pacific Parkinson's Research Centre and will be presenting on the effects of exercise and music on brain plasticity.
- Cheryl Daniels is a nurse from the Kelowna MS and Movement Disorders Clinic who will be providing an update on the clinic, community resources and hospitalization.
- Mary de Souza is a PWR! Certified Instructor and member of PSBC's speakers bureau. She will be leading an exercise component and speaking on the importance of exercise for managing symptoms of Parkinson's disease.

Date: Saturday, March 4, 2017  
 Time: 10:00am – 4:00pm (registration opens at 9:30am)  
 Location: Kelowna Ramada Hotel & Conference Centre | 2170 Harvey Avenue, Kelowna, BC ([map](#))  
 Fees: PSBC Member \$30.00 | PSBC Members (Couple/Pair) \$50.00  
 PSBC Non-Member \$40.00 | PSBC Non-Member (Couple/Pair) \$70.00  
 Registration: Members: <http://bit.ly/PSBCMReg>  
 Non-Members: <http://bit.ly/PSBCNonMemReg>

## UPCOMING EVENTS

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### STEP BY STEP



Starting Tuesday, April 11, PSBC is bringing back the Step by Step program for a third 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 week they will be encouraged 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 help 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. We hope to encourage people to continue a regular exercise routine following the program. Read about a Step by Step success story [here](#).

Interested in becoming a community group leader? 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](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330 to learn more.

**SAVE THE DATE:** Moving Forward Together, PSBC's provincial conference, will take place on Saturday, June 3, 2017.

For a listing of all upcoming education events, visit our [events calendar](#).

## UPCOMING FUNDRAISING EVENTS

### TWOLIPS4PD

On Tuesday, February 14, we encourage you and your loved ones to pucker up for Parkinson's. Show your support for the 13,300 British Columbians, and their families, affected by Parkinson's by taking a photo "puckering up" and making a donation to Parkinson Society British Columbia!

Do you live in Vancouver? Drop by our photobooth at Pacific Centre CF (corner of Georgia St. & Howe St.) from 11:00am to 6:00pm on Tuesday, February 14 to participate and make a donation!

#### *Why TwoLips4PD?*

The campaign's title is a play on the word 'tulip', which is internationally recognized as the symbol for the Parkinson's community, while incorporating the theme of love, through the use of 'lips', for Valentine's Day.

#### *How do I participate?*

1. Take a selfie "puckering up" and show your support for the Parkinson's community
2. Post and tag your picture on social media with the hashtag #TwoLips4PD
3. Make a donation to PSBC (under the "designation" dropdown menu, select "TwoLips4PD")
4. Spread awareness by challenging others to participate

Be sure to 'like' or follow PSBC on [Facebook](#), [Twitter](#), and [Instagram](#)!

### CHAMPIONS FOR PARKINSON'S

- Skate and Sip: Join us at the Robson Square Ice Rink and enjoy a day of fun for a good cause. Parkinson Society British Columbia will be present accepting donations and providing information on our programs and services to all those in attendance. Donors will be offered a voucher for a free warm beverage of their choice at the rink's café. Access to the ice rink is free, and skate rentals are available for a nominal fee. 3:00pm – 9:00pm, Saturday, February 4 ([read more about Robson Square Ice Rink](#))
- 4th Annual Chocolate and Beer Tasting: Sunday, March 5 ([read more](#))
- Cotswolds Walking Holiday: August 31 – September 8 ([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](mailto:mdzaferovic@parkinson.bc.ca) or 1-800-668-3330.

# Champions FOR PARKINSON'S

## NEWS & ANNOUNCEMENTS

### AWARE IN CARE KITS

Sales of Aware in Care kits have begun! Other than the cost of shipping & handling, kits will be free to members. As a member, you should have received a special discount code to be entered during checkout via email earlier in January. If you did not receive this code, please contact the PSBC office and ask for Myriame or Caroline. The kits are available for online purchase at <http://parkinson.bc.ca/awareincare> or by phoning 1-800-668-3330.



## AWARE IN CARE KITS NOW AVAILABLE

Your doctor wants you to get your medications on time. 3 out of 4 people with Parkinson's don't.

Get AWARE IN CARE today.

### NEW! SCHOLARSHIP PROGRAM FOR HEALTH CARE PROFESSIONALS AND EXERCISE INSTRUCTORS

PSBC aims to provide opportunities for individuals who wish to pursue a career involving 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 Parkinson's community in BC.

Please see our website for criteria and eligibility: <http://www.parkinson.bc.ca/continuing-education-scholarships>

## VOLUNTEERING WITH PSBC

PSBC is always looking for dedicated and enthusiastic volunteers. We are currently recruiting:

- **Support Group Facilitators** – A support group facilitator works to create an environment that is safe and respectful, and where participants feel comfortable sharing their experiences, insight and knowledge with others.
- **Speakers Bureau** – Are you a health care professional, teacher or public speaker, active or retired? Would you like to help spread awareness to communities about Parkinson's disease? PSBC is looking for individuals who are passionate, educated and experienced with Parkinson's disease who are interested in sharing their knowledge with the public through presentations.

To learn more about becoming a support group facilitator or speakers bureau volunteer, please contact Stacey at [sdawes@parkinson.bc.ca](mailto:sdawes@parkinson.bc.ca) or 1-800-668-3330.

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## NEW! SONGSHINE DELTA

Vocal exercises and group singing to strengthen voices that includes body awareness, relaxation and breath exercises; drama activities to spark imagination and encourage emotional expression; and opportunities to build community, create connection and lift spirits.

Date: Thursdays, January 12 – February 23  
Time: 1:00pm – 2:15pm  
Location: Kennedy Seniors Recreation Centre | 11760 88 Avenue, Delta ([map](#))  
Fees: \$7 (for the 7-week session)  
Registration: Contact Margaret Chorbajian (SongShine Certified Instructor) | 604-584-5597



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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! <http://www.parkinson.bc.ca/exercise>

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**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.

## TIP JAR



Are you struggling to walk safely with all the ice? Do you have the proper footwear? Try some traction devices that fit over a boot or shoe! They can help a lot with walking in winter conditions. [Mountain Equipment Coop \(MEC\)](#) or your local sporting store may be able to rent you a pair at low-cost.

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 Caroline at [cwiggins@parkinson.bc.ca](mailto:cwiggins@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](mailto:cwiggins@parkinson.bc.ca) or 1-800-668-3330 and your name will be added to our GroupLink email distribution list.

## DISCUSSION TOPIC

## SEXUAL HEALTH

Discussion questions:

1. What is the difference between intimacy and sexuality? Is one more important than the other?
2. How do you cultivate and maintain intimacy in your relationship?

Sexuality is an essential part of all of us no matter how old we are or what our physical abilities may be. The desire to love, be loved and to experience sexual pleasure is an integral part of the human experience. Sexual health depends on the physical and psychological health of each individual and the state of a couple's relationship. The most significant ingredient to being sexual with a partner is open communication.

In Parkinson's disease (PD), sexual dysfunction can arise from the changes in dopamine levels and the autonomic nervous system (the system that controls our blood pressure, heart rate, erections, swelling of the clitoris, etc.). PD symptoms cause difficulty with fine movements, coordination and moving freely in bed. Couples may need to be willing to experiment with different positions to find the most comfortable satisfying positions during sexual activities. In addition to difficulties with movement, people with Parkinson's may experience the following:

- Symptoms such as tremor, rigidity, loss of facial expression and speech impairment reduce body language – a key tool humans use to communicate with one another. Partners can mistakenly think they are being ignored or not loved.
- Parkinson's can affect one's self-image. The person with PD may feel less sexually attractive or their partner may find it psychologically difficult to move beyond PD symptoms and see their partner as a sexual being.
- The slowness of Parkinson's can manifest as loss of initiative and greater passivity. This can impose a more active role on their partner. Sexual role changes require healthy dialogue and a willingness to adapt.

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- Parkinson's disease can cause fatigue & energy fluctuations. It may be necessary to change your routine, or be flexible in terms of when intimacy may occur. Don't be afraid to schedule time together in your calendar.
- Depression can create or aggravate sexual dysfunction. Anti-depressant medications may be required. Mood-regulating drugs may also need to be adjusted as some can impair sexual desire or delay orgasm.
- Some PD medications can cause hyper-sexuality as well as other compulsive behaviours such as excessive shopping or gambling. These behaviours may be quite foreign to the person and extremely distressing and embarrassing. Drug adjustments may be required in such cases. It is very important to notify your physician about these behaviors if they should occur.
- In men, common dysfunctions are erectile dysfunction and delayed or premature ejaculation. Sometimes low sexual desire is a problem. Women with or without PD may, at times, experience a decrease in sexual desire, difficulty with arousal and orgasm and painful intercourse. Interestingly, it is the women whose male partners have PD that report very distressing sexual lives – far more so than women who have PD themselves. For this reason, it is important for women whose partners have PD to communicate any sexual challenges they are experiencing with their partner and, if a solution can't be negotiated, to speak with their physician.

Helping to care for a loved one with PD can potentially change sexual relationships. Often, there is a tendency for sexuality to be focused on the frequency and quality of intercourse as a benchmark of their relationship and sexual health; however, sexuality extends far beyond intercourse. Chronic illnesses like Parkinson's can challenge couples to expand their perception of sexuality and intimacy to include gentle kisses, loving eye contact, listening deeply to what is said or and hugging as part of caring for one another. Genital sensations can be enjoyed, with or without orgasms, and intercourse is not necessary.

### Treatments for consideration

Communication is the cornerstone of healthy relationships. It may include frank dialogue with both your primary care physician and neurologist to treat causes of sexual dysfunction. Many find sexuality difficult to speak about, yet it can have devastating effects on quality of life. There are many options to treat changes in sexual function which may involve speaking with a clinical counsellor, seeking out a sex therapist, changing anti-depressant treatments, referral to a specialist, or taking medications. It is also important to realize that sex does not have to include intercourse, and if it is persistently painful, it is best to "take it off the menu" and experience pleasure in other ways.



**PSBC resources:**

- Dr. Laurel Paterson's Carepartner Connect webinar, titled Maintaining sexual intimacy while coping with Parkinson's is available here: <https://www.youtube.com/watch?v=004RgmVyelo>
- Shannon Griffin's presentation on Sexual Intimacy in PD is available here: <https://vimeo.com/116124115>

**Options for professional consultations:**

- BC Centre for Sexual Medicine (physician referral required)  
500 – 575 West 8th Avenue, Vancouver, BC  
Phone Number: 1-604-875-8282  
Fax: 1-604-875-8249  
<http://psychiatry.vch.ca/bccsm.htm>
- GF Strong Sexual Health Rehab Centre (physician referral required)  
4255 Laurel Street, Vancouver, BC  
1-604-737-6291  
Fax: 1-604-730-7904  
[http://www.vch.ca/locations-and-services/find-health-services/?program\\_id=12800](http://www.vch.ca/locations-and-services/find-health-services/?program_id=12800)
- Victoria psychiatrist Dr. Gail Knudson (physician referral required)  
201 – 1770 Fort Street, Victoria, BC  
1-250-592-6183
- Victoria sexual medicine physician Dr. Marjon Blouw (physician referral required)  
101 – 1964 Fort Street, Victoria, BC  
1-250-721-9494
- Clinical counsellors as per BC Association of Clinical Counsellors (services may not be covered by Pharmacare)  
[www.bc-counsellors.org](http://www.bc-counsellors.org)
- BC Psychological Association  
1-800-730-0522  
[www.psychologists.bc.ca](http://www.psychologists.bc.ca)
- Confidential sexual health information  
1-800-SEX-SENSE

*The above summation was adapted from a 2010 publication by Maureen Matthew, BSW, Parkinson Program Coordinator at Victoria Epilepsy and Parkinson's Centre and edited by Dr. Rosemary Basson, Sexual Medicine Physician with the BC Centre for Sexual Medicine in Vancouver. Dr. Basson has published numerous articles on Parkinson's and Sexuality.*

**Sources:**

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Parkinson's UK. (2014, Sep.) *Intimate Relationships and Parkinson's*. Retrieved from [https://www.parkinsons.org.uk/sites/default/files/publications/download/english/b034\\_intimaterelationshipsandparkinsons.pdf](https://www.parkinsons.org.uk/sites/default/files/publications/download/english/b034_intimaterelationshipsandparkinsons.pdf).

## BY LINDA BLEACKLEY – *PERSON WITH PARKINSON'S*

The year 2016 ended on a high note when I got a better score on my assessment at UBC's Movement Disorder Clinic than the previous year! I attribute this improvement to the weekly Rock Steady Boxing (RSB) classes I began last August.

There was an exceptional surge in my fitness level after just four RSB classes with Allie Saks, an Occupational Therapist who began to offer Rock Steady Boxing classes in Vancouver in 2016. After completing the classes, I could reach things on higher shelves, increase my level on a stationary bike, feel more confident about balance and experience significantly less pain due to rotator cuff problems. Also, by the fourth week I no longer poured with sweat during the class!

There are four levels of classes, with Allie determining the appropriate level during an initial assessment. Each class incorporates a variety of exercises, starting with standing stretches and cycling on spinner bikes to warm-up, and a host of challenging, fun things to do between strenuous punching sessions on the bags. We may balance on wooden planks, skip ropes, do fancy footwork on a floor agility ladder, push-ups, or a variety of other challenging exercises. A timer is used throughout the class to keep us moving at a fast pace, whether on or off the bags, and great music adds to the mix. Cognitive skills and multi-tasking are tested with math flashcards and we yell out our punches in loud voices. Happiness is getting on the mat for a cool down at the end!

The camaraderie of working out with others with PD is a plus, and RSB lets you bring along a caregiver or friend to act as a corner person, to help with putting on the cumbersome gloves, offer sips of water, steady the punching bags or generally provide support. More friendships were formed by joining the RSB Vancouver team for Parkinson SuperWalk in September.

In December, there were more holiday-themed exercises, with medicine ball squats becoming Santa Squats; high knees were Running Reindeer; and jumping jacks were Snow Angels. We enjoyed a holiday luncheon, with platters of food, a festive cake and a chance to bring friends and loved ones to socialize. It was especially moving to see tears in her eyes when Allie read the following poem she had composed about her passionate hard work to bring RSB to Vancouver to help those with PD:

Just last year I saw Rock Steady Boxing on CBS,  
I'd been seeking a new direction and it called out "Yes"!

Rock Steady Boxing – a glimmer of hope,  
For a disease that makes it hard to cope.

But could I bring this program to Vancouver?  
It seemed like it would be quite the maneuver.

Parkinson's disease is close to my heart,  
But boxing wasn't exactly my art.

I flew to Indiana to train with the pros,  
Learning boxing techniques from my head to my toes.

I got home from Indy excited, but scared,  
Could I do this in Vancouver, if I dared?

But boxers kept calling and before I knew,  
Lo, I had met each and every one of you!

In your own little ways you have made my life much better,  
Boxing fitness for Parkinson's is the new trendsetter!



Each day I leave classes more and more inspired,  
Shocked by how hard you work and what has transpired.

Boxers, your spirit is truly amazing,  
You go and hit those bags, all guns a-blazing!

And now for the thank you's – I can't forget those;  
There's lots of people to thank, so here it goes...

Firstly to Lucy, thanks so much for all that you have done,  
From volunteering to teaching, in honour of your mum.

Volunteers, I thank you for your support and dedication;  
For Rock Steady Vancouver – you are truly our foundation.

Corner men and corner women, thanks for pushing to the max;  
Keep encouraging your loved ones through their planks and jumping jacks.

And last but not least, I can't thank you all enough,  
You teach me every day not to sweat the small stuff.

This Rock Steady community doesn't cease to amaze,  
I wish you all a Joyous New Year and Happy Holidays!

So far there are three RSB locations in BC: Vancouver, New Westminster and Parksville, but maybe Allie's poem will inspire fitness professionals to bring the program to other cities throughout the province. The PSBC website has additional information about RSB, including a listing of exercise classes across the province, at the following link:

<http://www.parkinson.bc.ca/resources-services/exercise-active-living/rock-steady-boxing/>

