



ANNIVERSARY

Parkinson Society British Columbia

CELEBRATING 50 YEARS OF SERVICE IN 2019!

Since 1969, Parkinson Society British Columbia has been proud to empower people with Parkinson's across the province, through education, support services, advocacy, and fundraising. This year, join us as we celebrate the strength of our community, and the many milestones we have reached together. We hope to extend our reach wider than ever before – within the Parkinson's community and beyond.

Throughout the year, we will be sharing inspirational stories from the people with Parkinson's, carepartners, and advocates in our community. If you have a story to share about your life with Parkinson's, we would love to hear it! For more information, email us at info@parkinson.bc.ca, or call 1-800-668-3330.

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 email info@parkinson.bc.ca or call 1-800-668-3330 for more details.

COMMUNITY TALK: ANXIETY AND EXERCISE

On January 28, join us in Vancouver for a talk with occupational therapists from Enable OT. They will address the effects of anxiety and apathy on the willingness to exercise, and offer suggestions for overcoming these challenges. The session will also include a dance component and opportunity for discussion.

Date: Monday, January 28
 Time: 12:30pm – 2:00pm (registration opens at 12:00pm)
 Location: Sunset Community Centre - Hall
 6810 Main St, South Vancouver ([map](#))
 Cost: Member \$5.00 | Non-member \$10.00
 Registration: www.parkinson.bc.ca/vancouver-community-talk

ASK THE EXPERT WEBINAR: CANADA REVENUE AGENCY'S TAX CREDIT TIPS

Need clarification on the tax credits you qualify for as a person with Parkinson's or carepartner? On January 29, Lukas Siliverdis from the Canada Revenue Agency will be presenting the tax credits available to you and your loved ones, as well as how to access them.

Date: Tuesday, January 29
 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.*
 Capacity: 200
 Cost: Free
 Registration: www.parkinson.bc.ca/cra-tax-credit-webinar

ONLINE EXERCISE CLASSES

Exercise is key to improving and maintaining function in those living with PD. Regular exercise not only helps improve balance, strength, mobility, gait and overall physical function but can also help to combat the depression, fatigue and apathy associated with PD.

This February, we are helping you get your 2019 exercise routine started on the right track. For 6 weeks, we are answering your questions and bringing live Parkinson's specific exercise right into your home!

Naomi Casiro is a PWR! certified physiotherapist and the founder of [NeuroFit BC](#), a Parkinson's specific physiotherapy company in Vancouver. She will lead us through 6 live PD exercise sessions that you can do in your home with minimal to no equipment.

The first 4 sessions will be geared towards those who are able to stand, walk, and get up and down off the ground independently. The last 2 sessions will be done in seated or supported standing positions, and are best suited to those who have mobility concerns, including trouble balancing, or difficulty standing for 30 minutes or more.

Join us in this fun and informative 6-week series. Register today to reserve a spot for yourself, your household or group! If you will be watching the webinar on the same computer or screen as another person or group, only one registration is required.

Please note: *Class participation will be done at your own risk within your home. Please ensure you have space to follow the exercises and that there are no obstacles or barriers in your way. PSBC and NeuroFit BC will not be held liable for accidents or incidents that may occur in your home. By participating in this series, you recognize that risk of illness and/or injury may be inherent in any movement or exercise class and are participating with the express agreement of, and understanding that NeuroFit BC, PSBC and its directors, officers, employees, partners and agents are hereby released from any and all claims, costs, liabilities, expenses, or judgments associated with this Parkinson's exercise program.*

Date: Thursdays from February 7 – March 21. No class February 28.
 Time: 10:45am – 11:45am
 Location: Via webinar. *Instructions on how to access the presentation will be sent out 24 hours before the event's start time.*
 Capacity: 175
 Cost: Free
 Registration: www.parkinson.bc.ca/online-exercise-class

COMMUNICATION AND SWALLOW WORKSHOP, VANCOUVER

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.

Date: Saturday, February 9
 Time: 10:00am – 2:30pm (registration opens at 9:30am)
 Location: Italian Cultural Centre Vancouver
 3075 Slocan Street ([map](#))
 Cost: Member \$25.00 | Members (Pair) \$40.00
 Non-member \$35.00 | Non-members (Pair) \$60.00
 Registration: www.parkinson.bc.ca/vancouver-communication-workshop

ASK THE EXPERT WEBINAR: SELF-MANAGEMENT AS SELF-CARE

Self-management refers to the tasks that an individual must undertake to live well with one or more chronic health conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management. John A. Murphy, Coordinator of the Vancouver Coastal Region of Self-Management BC, will give us an introduction to self-management, and how learning these skills can improve your quality of life with Parkinson's – today, and in the future.

Date: Tuesday, February 19
 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.*
 Capacity: 200
 Cost: Free
 Registration: www.parkinson.bc.ca/self-management-webinar

UPCOMING EVENTS

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REGIONAL CONFERENCE, VICTORIA

Parkinson's disease is a unique and complex condition. To assist in expanding your knowledge of the disease, on March 2nd, Parkinson Society British Columbia 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. The conference does not include a meal, however light refreshments will be provided.

Topics covered at this conference will include:

- **Frequently Asked Questions:** Dr. Tara Rastin, *Movement Disorder Specialist from the Pacific Parkinson's Research Centre*
- **Speech and Technology:** Susan Edwards, *Registered Speech-Language Pathologist*
- **Research Updates at the Pacific Parkinson's Research Centre:** Emma Kiss, *Research Assistant*, and Michelle Doo, *Research Coordinator*

Date: Saturday, March 2
Time: 1:00pm – 4:15pm (registration opens at 12:30pm)
Location: Sandman Hotel
2852 Douglas Street ([map](#))
Cost: PSBC Member \$15.00 | PSBC Members (Pair) \$25.00
Non-member \$25.00 | Non-members (Pair) \$45.00
Registration: www.parkinson.bc.ca/victoria-conference

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

UPCOMING FUNDRAISING EVENTS

Champions FOR PARKINSON'S

- Donate a Car Canada: Ongoing [[read more](#)]
- Naturally Urban Pet Food Delivery Sales: Ongoing [[read more](#)]
- Tea Parky: In this ongoing fundraiser, 35% of proceeds from every sale on TeaParky.com will go to Parkinson Society BC. *Special: Use promo code PSBC at checkout for 10% off your purchase.*

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 Mirela Prime at mprime@parkinson.bc.ca or 1-800-668-3330.

NEWS & ANNOUNCEMENTS

NEW! SURREY SUPPORT GROUP

This group is intended for anyone affected by Parkinson's disease. Carepartners, friends and family members are welcome.

Date: 2nd Monday of each month
Time: 6:00pm – 7:00pm
Location: Amenida Seniors' Community - Downstairs Activity Room
13855 68th Ave, Surrey ([map](#))

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SAVE THE DATE: WORLD PARKINSON CONGRESS 2019, KYOTO

The 5th World Parkinson Congress (WPC) will be held in Kyoto, Japan from June 4th – 7th, 2019. Are you interested in attending? Registration is open now. Early registrants benefit from a discount until February 27, 2019. Full information on registration categories is available at www.wpc2019.org/page/RegFees.

Are you interested in travelling to WPC2019 and require financial support? This fall, PSBC circulated a survey with the intent of gathering the names of those interested in a scholarship program to attend the World Parkinson Congress in 2019. As a result of the overwhelming response and budgetary constraints, unfortunately, we will be unable to fund all interested respondents. Further selection criteria for the scholarships have been established to assist in determining the most qualified and suitable candidates. For more information, and to apply, please visit the links below:

Scholarships for People with Parkinson's & Carepartners: bit.ly/WPCScholarships-PwP

Scholarships for BC Healthcare Professionals and Student Researchers: bit.ly/WPCScholarships-HCP

DEEP BRAIN STIMULATION PETITION: HELP US REACH 15,000 SIGNATURES!

The wait time for Deep Brain Stimulation surgery in British Columbia is 3 years for an initial consult, followed by a further 2 year wait for the actual surgery. Only one neurosurgeon in our province is qualified to do this procedure. **We want to change this.**

Sign and share the petition today at www.parkinson.bc.ca/dbspetition

GIVE BACK: SUPPORT GROUP FACILITATOR NEEDED IN RICHMOND

Due to the increasing demand for peer support groups, PSBC is actively recruiting a volunteer Support Group Facilitator to assist in strengthening the Parkinson's community in **Richmond**.

The responsibilities of Support Group Facilitators include:

- Working to create an environment that is safe and respectful, and where participants feel comfortable sharing their experiences, insight and knowledge with others.
- Assisting with the delivery of information, education and resources for people with Parkinson's and their carepartners/families.
- Leading support group meetings once a month, for a couple of hours, from September to June.

Facilitators are supported by Parkinson Society British Columbia through access to information and resources, teleconference calls, bi-annual one-on-one follow-ups, advocacy/awareness campaigns and educational opportunities. Please contact Stacey Dawes at sdawes@parkinson.bc.ca or 1-800-668-3330 for more details.

Note: Any listings above 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.

DISCUSSION QUESTIONS:

1. What does the Parkinson's community mean to you?
2. Where do you go to learn more about Parkinson's disease and self-management?

This year marks 50 years of service for Parkinson Society British Columbia (PSBC). Since 1969, PSBC has been a crucial resource for people with Parkinson's across the province, and their carepartners, families and friends. Throughout the years, our mission has always stayed the same: to support, educate, empower, and advocate for the Parkinson's community.

As we celebrate this milestone, we are reminded that there is strength in numbers, and the effort to ease the burden of Parkinson's disease (PD) is a global one. Communities like ours are part of a worldwide network of care, support, research, and fundraising, all geared towards finding the cause and cure of Parkinson's. Until these discoveries are made, people with PD and their carepartners rely on local organizations like PSBC for accessible education and support services. We are, and have always been, dedicated to providing the best service we can, starting with timely educational resources provided both online, and through our print resources, like this one.

As new facts about Parkinson's are discovered through research every day, and new knowledge gets shared about PD care, self-management, and quality of life, certain truths remain timeless. In this month's GroupLink, we look back on some of the tips we have shared throughout the years, as well as some timeless words of wisdom from the PD community.

PARKINSON'S AND EXERCISE

"The best medicine I had been given was a prescription for exercise," wrote B. Williams, in our Fall 1987 newsletter.

Williams' doctor was an ex-Olympian fitness expert, a physician for Canada's international and Olympic track and field teams, and a personal friend. Both Williams and his doctor had fathers with Parkinson's, so they understood the unpredictability of the disease. Of his conversation with the doctor on the day of his diagnosis, Williams wrote: "We mutually agreed that I should remain somewhat ignorant of how the disease would probably progress to avoid my anticipating future problems. If it got worse, which he knew it would, then we would discuss everything."

PARKINSON'S vs FITNESS --- B. Williams

PARKINSON'S DISEASE! My gawd. It sounded so awful, but I didn't have a clue as to what it meant. My doctor had just given me the news but I didn't know how upset to be. My knees felt a little wobbly as I walked back to my car, from confusion not fear. My dad had been a victim of Parkinson's but as he was dying from some form of leukemia his Parkinson's was hardly anything to be concerned about; in fact it was passed off as nothing but old age. But I wasn't even 40; still, nothing to be concerned about as I had a prescription in my hand for a couple of drugs I had never heard of. No Problem.

Despite the wealth of information we have learned about Parkinson's since 1987, the disease remains largely unpredictable, as progression varies between individuals. However, exercise has always been a primary method of slowing PD, and making its symptoms more manageable. For Williams, it was weight lifting that gave him a "new outlook on fitness." He writes about the intimidation of visiting a gym for the first time, "as a crowd of body builders seemed to dominate the place." It was his diagnosis that kept Williams coming back, and justified the time, money, and effort spent on strength training – his wellbeing was his priority.

Williams faced a dilemma: should he lift light weights with many repetitions, for muscle tone? Or should he lift as much weight as he could, to build strength, and bulk up. "I think the proper way would have been the lighter weights," he writes, "but I went more the other way – vanity, I would think." Nonetheless, this exercise worked for him, and continues to work for many others with Parkinson's disease, so long as a safe and steady routine is followed. Many healthcare professionals today recommend to do any form of exercise you enjoy, and to which you can, and want to commit.

Sometimes, Williams would experience a sudden, rapid tremor when lifting very heavy weights. To push past the discouragement of slow progress, he writes, "I blamed everything on age, and nothing on Parkinson's. So I used Parkinson's as an incentive to work hard and stick to a regular schedule." This mindset, of using PD to motivate yourself, applies to all forms of exercise. And for weight lifting in particular, Williams shares one more timeless tip: always have a spotter!

THE POWER OF COMMUNITY

Today, Parkinson Society BC has a network of over 50 support groups. Local community groups are a crucial support for people with PD. The disease can be isolating for many, so it is important to connect with those who share similar experiences. In our Spring 1989 newsletter, we shared an excerpt from the newsletter of the Parkinson's Syndrome Society of South Australia, known today as [Parkinson's South Australia](#), about the purpose of support groups.

For many people with Parkinson's, their support group is the first place they go to ask for advice, and to be connected with further support services, or reputable healthcare professionals. Beyond this, a support group is also a place to turn to for comfort, as a reminder that you are not alone in your struggle.

Support groups are also a critical resource in and of themselves. As noted in this excerpt, support groups can serve as a collective voice for the local Parkinson's community. As a group, you can educate healthcare professionals on the unique needs of people with PD in your area, lobby policymakers for better PD care and resources, and campaign for greater public awareness in your city. Without help from our support groups, PSBC would not have accomplished all that it has in these 50 years of service!

Alongside this 1989 excerpt stands a quote in our newsletter: "If you believe that you are in control of your disease, together with the health team, you will actually do better in the long term." We know this holds true today, 30 years later. A strong support network is the best defense against the uncertainty and anxiety around a Parkinson's diagnosis. To be truly in control of your disease, it is important to have access to the information, advocacy, connections, and, most importantly, the compassion that can be found in support groups.

THERE IS MORE TO LIFE

A Parkinson's diagnosis affects all aspects of life, especially family. Many people with PD are diagnosed at a time in their lives when they have established themselves in a career, gotten married, had children, and found financial stability. Parkinson's can come as a shock, and disrupt one's entire way of life. In our September 1998 newsletter, we are reminded that the disease does not define a person, and there is more to life than the role of 'person with Parkinson's.'

My mother has had Parkinson's disease for 8 years now. She was diagnosed when I was only 6 years of age. Since then things have changed. She can no longer play sports as well or for a long period of time, she is not able to be with a large group of people too long anymore and her energy level has severely dropped. But some things have not changed at all. For example, my mum is just as smart as she used to be before diagnosis and if I ever need to ask her a question about some project, she is almost always able to answer the question. She is also good at giving hugs. Parkinson's does not affect the whole brain - this I am thankful for. My mother having Parkinson's has affected me in more ways than one, but some things are still the same. She's still my mother and I love her."

This was the story shared with us in 1998 by Toby, aged 13, about his mother with Parkinson's. His wise words serve as an important reminder that, regardless of all of the challenges it brings, Parkinson's disease is not an identity. People with PD are people first, as are their carepartners. Just like 20 years ago, PSBC continues to proudly support the families and carepartners of people with PD. The message remains for all affected by Parkinson's in BC: *You are not alone.*

ADDITIONAL RESOURCES

Exercise & Active Living | www.parkinson.bc.ca/active-living

Support Groups | www.parkinson.bc.ca/support-groups

Talking to Your Children About Parkinson's | Helpsheet | bit.ly/pdguidekids

Caring in the Family | Helpsheet | bit.ly/pdffamilycare

PURPOSE OF SELF HELP GROUPS

SHARE MUTUAL EXPERIENCES

LEARN TOGETHER

PROMOTE A RESOURCE GROUP

BE A SOURCE OF INFORMATION

EDUCATE MEDICAL & PARAMEDICAL PROFESSIONS
& COMMUNITY ABOUT GROUP'S NEEDS

HOLD SEMINARS

BE A VOICE

WORK TOWARDS SOCIAL CHANGES

BE A LOBBYING GROUP

PROMOTE ACCEPTANCE

PROMOTE INTEGRATION

CHANGE ATTITUDES

. . . Pauline Brooks