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If you wish to personally receive GroupLink please connect with Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 and you will be added to the GroupLink e-mail distribution list.

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

Spring is here and it's time to re-energize your exercise program! Walking is an easy way to start or add in some movement to your day. Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps taken by an individual. PSBC has a tracking resource to help you get started with a walking program, and gradually improve. Please contact Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 for more details.

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 local Parkinson's community.

Topics covered at this conference will include:

- Parkinson's Disease - the big picture globally and locally: Dr. Daryl Wile, Kelowna based Movement Disorder Specialist
- Fire & Life Safety: Rick Euper, Fire & Life Safety Educator/Fire Inspector
- Stabilizing Dizziness and Finding Stability - Falls Management: Pauline Martin, Masters of Science, Physiotherapist, NeuroMotion Physiotherapy

Date: Saturday, June 16, 2018
 Time: 1:00pm – 4:30pm (registration opens at 12:30pm)
 Location: Kelowna Ramada Hotel & Conference Centre
 2170 Harvey Avenue, Kelowna ([map](#))
 Cost: PSBC Member \$15.00 | PSBC Members (couple/pair) \$25.00
 Non-member \$25.00 | Non-members (couple/pair) \$45.00
 Registration: www.parkinson.bc.ca/kelowna-conference
 Special note: This conference does not include a meal, however light refreshments will be provided.

This regional conference has been made possible through the generous support of AbbVie.



ASK THE EXPERT WEBINAR: NATUROPATHIC MEDICINE RESEARCH UPDATES

Dr. Laurie Mischley, Naturopathic Doctor from Seattle, Washington, is back to present on her newest research findings involving naturopathic medicines for people with Parkinson's disease. Don't miss out on her important updates! Dr. Mischley presented for Parkinson's Society British Columbia back in 2016. You can watch her presentation, *Food for Thought: Diet & Nutrition in PD* [here](#).

Date: Tuesday, June 19, 2018
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.
Cost: Free
Registration: www.parkinson.bc.ca/naturopathic-webinar

ACTIVE LIVING WEBINAR SERIES: KEEPING YOU ACTIVE AT ALL STAGES OF PARKINSON'S

Exercise is an important part of healthy living. This is especially true for people with Parkinson's disease, since exercise helps maintain balance, strength and mobility. If you want to learn how different healthcare professionals promote active living for those with Parkinson's, join Parkinson Society British Columbia (PSBC) as we host, for the first time, an Active Living Webinar Series every Tuesday in August.

- Tuesday, August 7, 2018
Occupational Therapists support people in maintaining meaningful everyday activities in order to lead productive and joyful lives. Gina Fernandez joins us for this webinar looking into the benefits of Occupational Therapy for people with Parkinson's and their carepartners.
- Tuesday, August 14, 2018
Recreation therapists Katrina Guenther and Nicole Sales use leisure and interest activities to promote the well-being of people with Parkinson's. Join them as they discuss the benefits of Recreation Therapy and available programs.
- Tuesday, August 21, 2018
Chiropractic Neurologists specialize in treating problems with the nervous system including balance and coordination, breathing, eye movement and cognitive and sensory impairments. Dr. Ashkan Jalili joins us to discuss how Chiropractic Neurology helps people with Parkinson's.
- Tuesday, August 28, 2018
Nicole Neilson, RN, an imaging coordinator at UBC, closes the series with a look into new research findings on exercise and Parkinson's.

Date: Every Tuesday in August 2018
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.
Cost: Free
Registration: www.parkinson.bc.ca/active-living-series



Champions FOR PARKINSON'S

- Elk Valley Parkinson's Support Group Golf Tournament: June 2 ([read more](#))
- Car Free Day Henna: June 16 ([read more](#))
- Shifting Gears for Parkinson's: Continuing until October 31 ([read more](#))
- Donate a Car Canada: Ongoing ([read more](#))
- Naturally Urban Pet Food Delivery Sales: Ongoing ([read more](#))
- Tea Parky: 35% from every sale on TeaParky.com will go to PSBC, ongoing. 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.

PARKINSON SUPERWALK

Join Parkinson Society BC for the largest fundraising event of the year, Parkinson SuperWalk! Beginning the weekend of September 8th, incredible British Columbians in over 24 communities will walk together to help give hope to approximately 13,000 people with Parkinson's in BC. Funds raised through SuperWalk will help provide valuable support services and education offered by PSBC as well as assist in funding research efforts across Canada. To learn more, visit www.parkinson.bc.ca/superwalk or call Mirela Prime at 1-800-668-3330.



SAVE THE DATE: WORLD PARKINSON CONGRESS 2019, KYOTO

The 5th [World Parkinson Congress](https://worldparkinsoncongress.site-ym.com) (WPC) will be held in Kyoto, Japan from June 4th – 7th, 2019. Registration will open in September 2018. Please note that there is a cost to attend this conference. Return flights from Vancouver to Tokyo in the early summer range in cost from about \$1,350 – \$1,500 CAD per person, including taxes. WPC will provide further details about conference hotel accommodations closer to the event, but are recommending that travellers budget approximately \$150 USD per night per room. Further details are available at <https://worldparkinsoncongress.site-ym.com>.

Would you like to make the most out of your trip to Japan? Most travel agencies can begin booking a year prior to the travel date. If you have a connection with a local travel agency that you have used for past trips, you may want to inquire with them soon. The following is an example of what a travel agent could provide in addition to your travel and accommodations for WPC 2019. This particular travel package example was produced by Expedia CruiseShipCenters.

Sample Itinerary:

- Depart Vancouver May 29, 2019 > Depart Tokyo June 8, 2019
- Airfare = \$1,339/person including taxes*
- Hotel, select meals and entertainment = \$2,530 – \$3,400 per person

This would include:

- First class hotel accommodation as per itinerary based on double occupancy
- All transfers and transportation is by private, air conditioned coach with driver/guide
- Arrival & departure guide assistance
- Sightseeing and admissions as per the itinerary
- Bullet/express trains
- Select meals

Please note that the sample itinerary and costs do not include costs incurred during WPC 2019. For more information about travel and excursions before or after WPC 2019, please contact Pat Thompson at pthompson@cruiseshipcenters.com or 250-763-2900.

The following travel agencies may be able to provide additional options:

- [Intrepid Travel](#)
- [Marlin Travel](#)

*Airfare is based on May 2018 rates and subject to change

For questions about WPC and making travel arrangements, contact Jaclyn at jwillems@parkinson.bc.ca or 1-800-668-3330.



A COMPREHENSIVE GUIDE FOR PARKINSON'S CAREGIVERS IS NOW AVAILABLE

Parkinson Society British Columbia (PSBC) is pleased to announce the official release of a new resource: A *Comprehensive Guide for Parkinson's Caregivers*. The primary contributor of this guide is Kaitlyn Roland, PhD, whose grandfather was diagnosed with Parkinson's. She holds a Masters in Health and Rehabilitation Sciences that focused on new ways to measure caregiver burden.

Access the digital version of the guide [here](#).

This booklet has been made possible thanks to the support of our Title Sponsor, The Tenaquip Foundation, and grants from UCB and The Hamber Foundation.

Print versions of the guide are available upon request. To order your copy, please contact Jaclyn at jwillems@parkinson.bc.ca or 1-800-668-3330.

WATCH NOW!

Wills and Estate Webinar Recording

Did you miss our recent webinar with Mary-Jane Wilson? You can watch the recording online now:

<https://youtu.be/yPLvh7BfvZo>

Annual General Meeting Recording

The Parkinson's disease and Pacific Parkinson's Research Centre Update by Dr. Martin McKeown is also available to view online: <https://vimeo.com/269260319>



Note: Any listing 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.

TIP JAR

Do you find your Parkinson's symptoms keep you from wearing your favourite jewellery? Do you have trouble with small, intricate and time consuming clasps? Some of our members replace their original jewelry clasps with magnetic clasps.

One woman from our community brought her favourite pendant necklaces to a jewellery and repairs store. For a small fee, the staff were able to change all of the clasps on her jewellery to easy-to-use magnetic clasps. She is now able to wear all of her favourite pendants again without any stress or difficulty!

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

DISCUSSION QUESTIONS:

1. What are some challenges that people with YOPD might face that other people with Parkinson's may not come across?
2. What advice would you give someone with YOPD or early stage Parkinson's? Or, if you had known that PD would impact you, what advice would you have given "younger you"? Would you have done anything differently?

WHAT IS YOPD?

Young Onset Parkinson's Disease (YOPD) is defined as a diagnosis of Parkinson's disease between the ages of 21 and 40, although, in some clinical contexts, subjects up to the age of 50 are classified as having YOPD. YOPD accounts for 35% of all cases of Parkinson's. A small percentage of people with YOPD might have an inherited form of Parkinson's.

EARLY STAGE PARKINSON'S DISEASE VS. YOPD

Early stage Parkinson's disease (PD) is known to be the initial stages of the disease. People with early stage PD might have mild symptoms that generally do not interfere with daily activities. Tremor and other movement symptoms might occur on one side of the body, then spread to the other side as time goes by. Changes in posture, walking and facial expressions can occur. The main difference between early stage PD and YOPD is the age at which the person is experiencing symptoms; it is possible that many people who are 50+ experience early stage Parkinson's disease. Someone who is in their thirties, and experiencing early stage Parkinson's disease, would be classified as having YOPD.

Studies have found that people with YOPD have a more frequent family history of Parkinson's (such as genetic mutations, like SNCA, PARK2, PINK1 and LRRK2) and typically live well into their elder years. People with YOPD tend to experience more side effects from dopaminergic medications as well as dystonia (cramping and abnormal muscle postures) compared to the general PD population. Because of this, as well as the length of time people with YOPD experience Parkinson's symptoms, Deep Brain Stimulation (DBS) can be a viable option for people with YOPD.

CHALLENGES THAT FACE YOUNG (AND YOUNG AT HEART) PEOPLE WITH PARKINSON'S

Communicating with the family

Parkinson's disease is a family affair, meaning that everyone in your family is affected by the disease. As a parent or grandparent, it is valuable to consider the unique impact that PD can have on your children and what can be done to continue to live a full family life.

Children are perceptive. They feel when something is not right and they often imagine things that are much worse than the truth. Whatever the age of your child, consider:

- Sharing your PD diagnosis
- Providing information on the disease
- Communicating your best understanding of what is to come in the future

Maintaining intimacy

Many people with PD and YOPD find that the conditions can affect emotional intimacy and sex life, especially since Parkinson's might affect your mood, self-image and how you communicate with others. PD can also impact physical coordination and movement. Our community members sometimes find that other kinds of physical affection, like cuddling, caressing and massage, can help maintain intimacy with a partner. Remember, some fluctuations in mood, as well as the desire to be intimate, may be due to natural fluctuations in hormones and energy that are not PD related (Parkinson's UK, 2018). View a webinar recording about intimacy and sexual health [here](#).

Parkinson's and the Workplace

Work is not only a way of making a living, it can also be important for confidence, self-esteem and personal satisfaction. It can be fulfilling and give you a sense of purpose. Having YOPD or PD with well managed symptoms shouldn't interfere with your ability to hold a job. Employers have a duty to accommodate, a legal requirement arising out of human rights legislation and case law in Canada. Its goal is to enable full and equitable participation of all members of society (BC Human Rights Clinic, 2016).

What constitutes a reasonable accommodation will depend on the facts of a particular case. Generally, an employer must be willing to modify aspects of the job or the workplace that are necessary to alleviate or eliminate the impact of the requirement on the particular employee that is related to the prohibited ground of discrimination. The employer must do everything that is legally considered reasonable in the circumstances, even if it means incurring some hardships, such as some additional expenses, negotiating with unions, adjusting job requirements, etc. View a webinar recording about the duty to accommodate and disability insurance [here](#).

ADVICE FOR PEOPLE WITH YOPD

Dr. Soania Mathur once said:

"You have young onset Parkinson's disease – words you were likely not expecting to hear and once spoken, are life changing. My diagnosis came at the age of 27 at the start of my career as a family physician and as I was expecting my first child. That was over fifteen years ago but I can still vividly recall that day and the shock, fear and confusion that followed; fear of the future, confusion about the present. These are normal reactions to an overwhelming and unexpected life hurdle [...] Experience has also shown me that you cannot be a passive bystander and expect to live well with Parkinson's. You must play an active role in your own [symptom] management" (Ravenek, 2014).

Dr. Mathur provides 10 lessons she's learned living with Parkinson's disease (PD) in this video, courtesy of Parkinson Society Saskatchewan [[view video](#)]:

1. *Acceptance. You need to understand and feel that you do have control over how you approach the disease.*
2. *Optimism is a choice.*
3. *It's all about quality of life.*
4. *Build your support team.*
5. *You must be an active participant in your symptom management.*
6. *Education is key.*
7. *The power of exercise.*
8. *Focus on your abilities.*
9. *Parkinson's disease does not define you.*
10. *You have to let go of your fear of the future in order to begin living your present* (Mathur, 2014).

ADDITIONAL RESOURCES

- Advice for the Newly Diagnosed from Individuals Currently Living with YOPD [[booklet](#)]
- Young Onset Parkinson's Disease [[helpsheet](#)]
- Young Onset Parkinson's Disease (YOPD) Webinar Series [[view videos](#)]
- Planning for the Future [[view slides](#)]
- Langley YOPD, Online YOPD & Working Professionals support groups [[more information](#)]
- A Family Affair: Talking to Children about PD [[helpsheet](#)]
- What is Parkinson's Disease: Information for Teens about PD [[helpsheet](#)]
- PSBC's Lending Library – children's books [[view list](#)]
- Carepartner Connect – Maintaining Sexual Intimacy [[view video](#)]

Sources

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- Mathur, S. [Parkinson Society Saskatchewan]. (2014, April 26). *10 Lessons I've Learned, Living with Parkinson's* [Video File]. Retrieved from <https://vimeo.com/97459335>
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