



VIEWPOINTS

A quarterly newsletter for the
Parkinson's Community of British Columbia

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WINTER
2018

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OUR MISSION Parkinson Society British Columbia exists to address the personal and social consequences of Parkinson's disease through education, outreach, scientific research, advocacy and public awareness.

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Your support is essential!

PSBC would not exist without the generosity of its members, donors and volunteers since it receives no government support.

The following are some of the ways you can support your society:

Membership—\$25 annual fee

Monthly, Quarterly or Annual Donation

United Way—Remember PSBC when giving through United Way

Special Events—Your participation in our special events makes a difference

Planned Giving and Bequests—Consider PSBC as a beneficiary in your Will

Editorial Statement

The views and opinions expressed within the pages of *Viewpoints* are not necessarily those of Parkinson Society British Columbia. The intention is to provide the reader with a wide range of material. Parkinson Society British Columbia welcomes submissions for the newsletter. The editor reserves the right to edit material and to withhold material from publication.

Articles contained in *Viewpoints* are for information only. PSBC does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

Support Groups

100 Mile House, Abbotsford, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Duncan/Cowichan Valley, Kamloops, Kelowna, Kelowna Caregivers, Kelowna West, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Caregivers, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, Osoyoos/Oliver, Parksville/Qualicum, Parksville/Qualicum Caregivers, Penticton, Port Alberni, Powell River, Prince George, Quadra Island, Quesnel, Richmond Caregivers, Shuswap/Salmon Arm, Sunshine Coast (Sechelt), Terrace, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, West Vancouver, West Vancouver Caregivers, White Rock, White Rock Caregivers, YOPD Online

holiday message



As 2018 draws to a close, I would like to take this opportunity to thank all of you, our members, donors and volunteers, for your continued support. We are proud of what we have accomplished, with your help, this year. Without you, our work would not be possible.

When I joined Parkinson Society BC five years ago, it was our plan to expand programs and services to more holistically and extensively serve the Parkinson's community in British Columbia. By adding more regional conferences, workshops for carepartners and communication and swallow seminars, we've been able to reach more people than ever. Posting videorecordings of some of these events on our website has increased our reach even more.

Additionally, we have focused greater efforts on offering webinars, which can be accessed across the province, regardless of location. These webinars also present us with the opportunity to cover new, relevant topics in a more timely fashion.

Earlier this year we published *A Comprehensive Guide for Parkinson's Caregivers*, one of our responses to the need for further support to caregivers/carepartners. It has been well received, and it is our hope that it continues to serve as a valuable resource.

With 2019 marking the Society's 50th anniversary, we look forward to sharing with you inspirational stories from the Parkinson's community, while continuing to serve as a caring and trusted resource for all those affected by Parkinson's disease.

Wishing you and your loved ones a wonderful holiday season.

Sincerely,

Jean Blake As
of

Jean Blake
Chief Executive Officer
Parkinson Society British Columbia



DR. FARRER

Answers Your Questions on The Genetics of Parkinson's Disease



Dr. Matthew Farrer, UBC Professor of Medical Genetics, Canada Excellence Research Laureate in Applied Neurogenetics, and the Don Rix BC Leadership Chair in Genetic Medicine, is leading a global effort to discover

new genes for Parkinson's and to accelerate the translation of these discoveries into new disease-modifying therapies. Dr. Farrer's lab has played a leading role in the discovery of every causal gene for typical late-onset Parkinson's disease (PD), and he has also identified some of the genes for atypical and early onset forms of parkinsonism.

Here are some of the highlights:

Alpha-synuclein (SNCA):

Alpha-synuclein's role is to maintain neurotransmission (communication between nerves). However, the protein is also the major constituent of Lewy bodies (protein clumps) that build up in nerve cells in most patients with Parkinson's.

Leucine rich repeat kinase 2 (LRRK2):

LRRK2 is an enzyme that is overactive in PD. Many rare mutations have been found in the gene which directly lead to familial Parkinson's. In addition, there are many genetic variants that present a risk for sporadic PD.

LRRK2 G2019S and G2385R:

These genetic mutations are the most common mutations for Parkinson's disease, affecting hundreds of thousands of individuals worldwide.

Dynactin p150Glued (DCTN1):

This gene is responsible for coding the protein complex called dynactin, involved in intracellular trafficking. Mutations cause Perry Syndrome, a rare familial and rapidly progressing form of Parkinsonism marked by hypoventilation (respiratory problems).

Vacuolar Protein Sorting 35 (VPS35 D620N):

Mutations in this gene have been found to cause late-onset familial Parkinson's in at least 70 families. The protein is needed to sort, traffic and recycle many intracellular cargos including nerve cell receptors. The most important cargo that VPS35 recycles may be the dopamine transporter.

Glucocerebrosidase (GBA):

One mutation in this gene is associated with risk of developing PD, but inheriting two mutant copies may lead to Gaucher's disease.

Receptor-mediated endocytosis 8 (DNAJC13):

Identified in Canadian Mennonite families with late-onset Parkinson's, the protein encoded works cooperatively with VPS35.

Heat shock protein 40 (DNAJC12):

Last year, Dr. Farrer's team discovered loss of this gene may cause early-onset, levodopa-responsive parkinsonism. Loss of the same gene may also lead to dystonia.



As a geneticist, how did you come to research Parkinson's disease

I've been interested in brain health and disorders since I worked in hospitals and care homes when I was a teenager. I appreciated that physicians were at a loss to remedy these conditions, so I chose genetics as a way to understand them. Genes are the blueprint of life. I completed a degree in Biochemistry and a PhD in statistical and molecular genetics focusing on complex traits, i.e. disorders that are considered to be 'sporadic'. My early interests were in cognition and Alzheimer's disease genetics, but I quickly learned that Parkinson's

had been inadequately studied so I thought there was an opportunity and need for my skills.

When I started in the field back in 1996, there weren't any genes implicated in Parkinson's disease. Our team has discovered a great many, and that has given us a rather unique perspective on what's going wrong at a molecular level and, as importantly, how we may be able to fix it.



What kinds of research are you currently working on? What are your methods?

There are two fields in genetics: association and linkage. Association is where you find there's a difference in one group compared to another. However, an association does not imply causation. To give an analogy: birds have beaks, but it's not the reason they fly. Nevertheless, birds and beaks are indisputably associated. With linkage on the other hand, that's where a genetic mutation is inherited with disease, and there is a causal influence. Namely, if you have the mutation, then you're likely to get the disease. Thus I've made linkage my foundation.

When I was a kid, my dad suggested I join the navy to see the world. I have navigated my career differently, still seeing the world but seen through genetics. For example, right now, I'm working with families in the Faroe Islands, a group of 19 islands inhabited by 50,000 people in the North Sea. There are 2–3 times as many people with Parkinson's in the Faroes as there should be, compared to neighbouring islands. It's such an isolated place, it has a well-defined boundary in terms of genetic variability and exposures, so I think it may tell us how genes and environment work together to cause Parkinson's disease.

I've also worked in Scandinavia for many years. It's where we originally discovered LRRK2 G2019S, in families with Parkinson's living in fishing villages along

the Norwegian coast, and where we identified SNCA multiplications in Sweden, in the Lister peninsular. I have wonderful collaborations in Tunisia and Taiwan. In Tunis we found that 1/3 patients with Parkinson's disease (>30%) have LRRK2 G2019S, and in Taiwan we found 1/15 patients (>6%) have LRRK2 G2385R.

Once we've implicated a gene, the molecular neuroscience begins as we must study the effects of normal gene function and mutant dysfunction in the brain. Here we turn to mice, and precise genetic engineering, to make a model of each mutant gene. From these animals we learn what effects each mutation has on brain function and physiology, and more specifically on dopamine-related biology, from motor behaviour to neurotransmitter release. The genetic insights we've made are only because of the generous assistance of families around the world; they have become our foundation for subsequent research and our motivation.



What do these genetic findings contribute to our general understanding of Parkinson's disease?

Before 1997, we had no understanding of what was going wrong in PD on the molecular, or even cellular, level. We had no idea what was wrong within the cells of the brain and why dopaminergic cells were dying. Through genetics, we found an unbiased way of identifying those molecular pieces of the puzzle, if you like, that are essential and that in some families are faulty.

However, when we find a mutant gene, we don't understand how it leads to disease, we just know that it must. This leads us to ask questions like, how can individuals have a certain gene mutation all of their lives yet only go on to manifest Parkinson's at 70 years of age? How do they manage to mask all of these symptoms and signs? Why are their neurons

continued on page 8...

Adaptive Clothing

Part of adjusting to life with Parkinson's may include adapting the way you do everyday tasks. Getting dressed and finding comfortable and accommodating clothing can be difficult for those who experience motor symptoms. Small changes to your dressing routine and attention to the kinds of clothing you buy can make getting ready for the day a less frustrating process.

When getting dressed, it helps to allow yourself enough time to get into your clothes comfortably, taking care to dress your stiffer limbs first. If possible, try to dress during times when your medication is most effective. You may also find it helpful to rely on a chair and/or footstool, along with other assistive devices such as the following:

- **Long-handled shoe horns and sock aids**
Both of these devices eliminate the need to bend forward to put on socks and shoes, and may be helpful for those with an unsteady hand or who have trouble gripping.
- **Elastic shoe laces**
Specialized laces can help to adapt your footwear so that you can slide your feet in without having to untie them.
- **Button hooks**
These small hooks can make it easier to button and unbutton clothing, even with only one hand.
- **Zipper pulls**
A small ring or similar easy-to-grip handle can be attached to make zippers easy to grasp and pull.

For those with more advanced motor symptoms, adaptive clothing options may be necessary. Adaptive clothing refers to any modified articles of clothing intended to make it easier to put on and take off, either by the wearer or their carepartner. Although people with Parkinson's may experience cognitive issues, most are acutely aware of how, with

the progression of the disease, some tasks are far more difficult or even impossible without the help of a carepartner. Alongside this, being restricted to athletic, oversized, generic or clinical-looking clothing can have a profound impact on one's dignity and sense of identity.

Researchers have used the term "encloded cognition" to describe this association of clothing and style with mood and mental wellbeing (Matchar, Emily, 2018). One 2012 study by Adam Galinsky of the Kellogg School of Management at Northwestern University even showed that people who were given white doctor's coats to wear during cognitive tests scored significantly higher than those not wearing the coats. This had to do with the symbolic association of attentiveness and carefulness with the coats – traits which were then heightened or assumed by physically wearing them (Galinsky et al.). Clothing and its social connotations can impact how we see ourselves and how we think others see us.

When most people think of clothing that's easier to get on and off, they may think of sweatpants and a sweatshirt – however comfortable this may be, this does not provide a solution for those who wish to have variety in their clothing. Mindy Scheier, founder of the Runway of Dreams Foundation, described her inspiration to advocate for more inclusive and individualized adaptive clothing options in a recent TED talk (Scheier, 2017). Her son, Oliver, has a form of muscular dystrophy and uses a wheelchair and leg braces. This forced him to wear baggy athletic clothing every day, to which he told Mindy, "Mom, wearing sweatpants every day makes me feel like I'm dressing disabled." This sentiment represents a perspective that has influenced a slow shift in the fashion industry to provide a more mainstream market for people with disabilities, movement disorders and difficulties dressing themselves or fitting into conventional clothing.

Many adaptive clothing brands now provide more inclusive options and greater style varieties. New



clothing technologies also offer more durable, stretchy, soft, and moisture-wicking fabrics, which can be particularly useful for those with difficulty dressing, or who may not be able to do laundry often or on their own.

Here are a few clothing brands helpful for people with Parkinson's available in Canada:

- **Silvert's** offers a wide range of adaptable clothing options for easy dressing featuring Velcro and magnetic closures and wheelchair-friendly options. www.silverts.com
- **MagnaReady** specializes in men's business casual options with magnetic closures including button down shirts, polos, dress pants, khakis and ready-to-wear ties. www.magnaready.com
- **Super Fly** guarantees easy-on, easy-off casual clothing that can be put on or taken off in under 30 seconds. www.super-fly.com
- **Buck & Buck** makes colourful and comfortable options that offer ease of dressing without a generic or clinical design. www.buckandbuck.com
- **Ably Apparel** uses Filium technology in their natural fabrics to produce water, stain and odor resistant clothing that requires less frequent washing. www.ablyapparel.ca
- **Under Armour** focuses on athletic clothing featuring seamless fabrics, heat and cold barriers, moisture-wicking and stretch, making them easier for dressing and reducing some of the need for layering or changing clothes. www.underarmour.com
- **Lifeware Steady** stabilizing eating utensils for those who experience hand tremors. www.store.lifeware.com
- **PenAgain Y-shaped ergonomic pens that use the natural** weight of your hand to apply the necessary pressure to ease ink into paper. www.penagain.net
- **Electric can and jar** openers, available at most homeware retailers, that operate with the touch of a button, and reduce the risk of injury from sharp can edges or dropping glass jars
- **Motion activated nightlights**, available at most homeware retailers, or other houseware retailers, to reduce the risk of falling when getting up during the night, particularly useful for those who experience Nocturia
- **Computer gear** such as keyboards and mice with large buttons and steady controls. www.infogrip.com
- **Automated pill dispensers** to ensure medication is taken on time with alarms and visual alerts and motorized dispense mechanisms, like this one available on Amazon: [amzn.to/2yoQq15](https://www.amazon.ca/dp/B07YQ15)

Sources:

Galinsky, Adam et al. *Encloded Cognition*. Journal of Experimental Social Psychology, 48.2. 2012. pp. 918-925. <https://www.sciencedirect.com/science/article/pii/S0022103112000200>

Matchar, Emily. *Designing "Adaptive Clothing" For Those With Special Needs*. Smithsonian Magazine. May 2018. https://www.huffingtonpost.ca/entry/adaptive-clothing-brands-for-kids-women-men-seniors_us_5b27cb27e4b056b2263c77e7

Scheier, Mindy. *How Adaptive Clothing Empowers People with Disabilities*. TED. Nov. 2017. Lecture. https://www.ted.com/talks/mindy_scheier_how_adaptive_clothing_empowers_people_with_disabilities?language=en

Giftng for Everyday Ease

Alongside adaptive clothing, there are many products which can help alleviate the burden and frustration of difficult everyday tasks. This holiday season, consider giving the gift of quality of life to a loved one with Parkinson's with some of these assistive devices:

ASK AN EXPERT

continued from page 5...

susceptible? What are the molecular processes that are happening?

It's my belief that if you're going to try to fix something, you had better first find out what's wrong. However, a real, true, understanding of what's going on, and how you might fix it, remains quite elusive in most neurologic diseases. Unfortunately, our medical system and our pharmaceutical industry see this as a long-term aim. Thus, in Parkinson's disease, there are no drugs that slow or stop disease progression as there are no drugs that target the underlying cause(s). Similarly, most neuroscience research is based on models, i.e. you have an idea, you set up experiments and control them as well as you can, and you test out your particular theory. However, the results are always going to be limited by the experimenter's question and the model they used.

My lab does it differently. First, with the help of patients and families, we look at human genome without any preconceived notion of what may cause the disease, of which gene it is, or what the mechanism involved might be. The mutant genes we have found have always been a major surprise. Our experimental questions and neuroscience are then "genetically-defined," and those mouse models are starting to reveal the precise molecular machinery perturbed, suggesting how we can fix it.

How can genetics help us develop ways to treat or prevent PD?

Medical genetics is about diagnosis, treatment and prevention. Our aim is to relieve symptoms by modifying disease progression. You can't turn back the clock, unfortunately, but I think we can develop ways to slow and perhaps halt disease progression – especially in

patients where we've identified a particular genetic risk – and that's a lot of patients right now.

Why should people with PD and their families support genetic research?

The federal and provincial funding landscape for Parkinson's research is complex. While these agencies are supportive, there are many competing healthcare issues; and their risk tolerance is relatively low. The same is true for industry. Philanthropic gifts enable high-risk, high-reward projects, and have enabled researchers like me to explore novel strategies, to get the data to be competitive for larger scale funding.

However, I'd also like to highlight that none of my innovation in the genetics of Parkinson's would have happened without patients and families contributing their DNA for research studies. I've been humbled by their support, and it has made me all the more determined to succeed in the science needed. Our efforts have been successful as genetic discoveries, and the molecular neuroscience based on it, have encouraged that large-scale investment in novel therapies. Many clinical trials are now focused on genetic targets, and aim to slow or halt disease progression. It has been incredibly gratifying to play a part in it.

The research programs within the Centre for Applied Neurogenetics at the Djavad Mowafaghian Centre for Brain Health provide an integrated, multidisciplinary environment for clinical, genetic, and translational neuroscience research and education. To learn more about Dr. Farrer's research or to participate in a clinical research study, please visit www.can.ubc.ca.



Thank you to our fundraisers and donors

Nanaimo Yoga Challenge

This April, the Nanaimo Parkinson's Support Group took part in a 30-day yoga challenge to promote exercise and wellbeing. As part of the challenge, they also raised \$422!

Me-n-Ed's Golf Tournament and Champions for Parkinson's Raffle

This spring, Me-n-Ed's Pizza brought in \$9,000 through the Champions for Parkinson's raffle and their yearly golf tournament! Parkinson Society BC would like to extend a big thanks to organizers Cris and Rich Florian and the entire Me-n-Ed's team!

Full Throttle

On May 27, 2018, Jim Smerdon and his family organized the second annual Full Throttle ride. Riders set off on a scenic car and motorcycle ride from downtown Vancouver to Whistler, ending with a lunch at the Longhorn Saloon. Together, they raised \$13,315!

Ride to Parksville

To show support for his father, Clifford, Mika Anderson cycled all the way from Calgary to Parksville from June 18th to July 2nd. He raised \$6,250!

SMASH Tennis Tournament

This year's exclusive SMASH tournament raised a total of \$12,600! Thanks to organizer Mike Vrlak and all who attended – the event was a grand slam!

Pickleball for Parkinson's

The Society would like to thank organizer Lana Nunweiler for another successful Pickleball for Parkinson's tournament! Hosted July 6th to 8th, the tournament raised a total of \$500!

Parke Pacific Charity Golf Tournament

The first annual Parke Pacific Charity Golf Tournament in support of PSBC took place on August 9th. Parkinson Society BC would like to give a warm thanks and congratulations to organizer Stewart Parke for an amazing \$15,000 contribution!

Additional thanks to RBC Royal Bank for awarding the Society their annual Team RBC Grant, totaling \$1,000!

UPCOMING EDUCATION EVENTS

Ask the Expert Webinar: Understanding Palliative Care

Date: Tuesday, December 11
Time: 10:00 am – 11:00 am
Location: Via webinar
Cost: Free



NEW! Online Newly Diagnosed Support Group

Date: 4th Thursday of the month
Time: 9:00 am – 10:30 am
Location: Via webinar
Cost: Free
Register: Email Caroline Wiggins at cwiggins@parkinson.bc.ca or call 1-800-668-3330

For more information, or to register for these events, please visit

 www.parkinson.bc.ca/education-events or call PSBC at 1-800-668-3330.

2019

Programs and Services at a Glance

Parkinson Society British Columbia (PSBC) is pleased to announce our tentative education and support services plan for the upcoming year. More details will be provided on our website as they become available. Schedule is subject to change.

UPCOMING EVENTS 2019



Moving Forward, Together

Our provincial conference, *Moving Forward, Together*, is set to take place in 2019. As in 2017, the event will feature a wide variety of expert speakers. New this year, we will be introducing a stream for healthcare professionals! Stay tuned to our website for upcoming details.

Regional Conferences

- Victoria – Spring
- Kelowna – Spring
- Abbotsford – Fall

Communication and Swallow Workshops

- Prince George – Spring
- Kelowna – Fall
- Vancouver – Winter

Annual General Meeting

- Lower Mainland – Spring

YOPD Event

- Vancouver/Richmond – Summer

Webinars

- Every second month

Time Out for Carepartners

- Pitt Meadows – Spring
- Kamloops – Summer

Community Talks

- Cranbrook – Spring
- Nanaimo – Fall
- Courtenay/Comox – Winter

Debriefing the Caregiver Role Workshop

- Bi-annually (in-person/online)

Step by Step

- 12 week walking program in communities across the province in April

ONGOING

- **Information and referrals**

- **Support groups**

- **Counselling:** *due to increasing demand, we have expanded this program from three days per week to four days per week, with the support of a counselling intern*

- **In-service presentations** for community members and healthcare professionals

- **PD Link:** peer-to-peer

NEW RESOURCES

- **A Comprehensive Guide for Parkinson's Caregivers** is now available! This book has been made possible thanks to support from The Tenaquip Foundation and a grant provided by UCB Canada. <http://bit.ly/PDCaregiverGuide>
- **Comprehensive Care Plan Checklist:** This checklist may help track symptoms over time, start conversations with your doctor and guide you to appropriate services <http://bit.ly/CareplanChecklist>
- **PD Connect:** A program where healthcare professionals refer patients with Parkinson's and their carepartners to PSBC for support services such as counselling/ consultations, educational events, printed resources and more. <http://bit.ly/PDConnect>

For more information on our programs and services, please visit our website at

 www.parkinson.bc.ca/resources-services.

2019

50th Anniversary

Join us in celebrating our 50 years of service in 2019! To commemorate this anniversary, we hope to extend our reach further than ever before – within the Parkinson's community and beyond.

Parkinson Society British Columbia will continue to grow our online resources like webinars, online support groups and educational materials to reach those affected by Parkinson's across the province.

We could not have reached this milestone without the support of our community so, in 2019, we are also celebrating you! Throughout the year, we will be sharing the stories of those touched by Parkinson's to increase public awareness and honour the strength of our community.



World Parkinson Congress

The 5th World Parkinson Congress (WPC2019) will be held in Kyoto, Japan from June 4th – 7th, 2019. Are you interested in attending? To learn more, visit <https://wpc2019.org>.

Registration is open now. Early registrants benefit from a discount until February 27, 2019. Full information on registration categories is available at <http://www.wpc2019.org/page/RegFees>.

Are you interested in travelling to WPC2019 and require financial support?

This fall, Parkinson Society British Columbia 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: <http://bit.ly/WPC19Scholarships>.



Pitt Meadows Maple Ridge



Vancouver



100 Mile House

With your help, we've raised \$432,142 and counting!

Thank you to everyone for your enthusiastic participation in, and generous donations to, the 28th annual Parkinson SuperWalk. This year, your incredible support has helped to raise over \$432,142 and counting. These funds will allow the Society to extend its reach, providing advocacy, programming, support services and contributions to research for the 13,000 British Columbians living with Parkinson's disease living with Parkinson's disease, and their loved ones.



Comox Valley

Total Raised by Community¹

▪ 100 Mile House	\$2,600	▪ Port Alberni	\$4,197
▪ Burnaby	\$4,195	▪ Powell River	\$10,375
▪ Chilliwack	\$7,523	▪ Prince George	\$11,646
▪ Courtenay/Comox	\$19,272	▪ Richmond	\$12,065
▪ Cranbrook	\$1,302	▪ Salmo	\$1,051
▪ Elk Valley	\$11,548	▪ Salmon Arm	\$6,161
▪ Fort St. James	\$653	▪ Surrey	\$10,248
▪ Kamloops	\$30,912	▪ Vancouver	\$116,784
▪ Kelowna ²	\$83,657	▪ Vernon ³	\$19,145
▪ Nanaimo	\$13,903	▪ Victoria	\$9,955
▪ Oliver	\$2,504	▪ White Rock	\$28,800
▪ Pitt Meadows/Maple Ridge	\$22,206	▪ Virtual Walkers	\$1,440

PHOTO CREDITS: 100 MILE HOUSE – DAVE REIMER; COMOX VALLEY – MICKEY DONLEY; WHITE ROCK – HILARY VANDERLIEK; VANCOUVER – BRANDON PERRETT, MAMI ITO DELANEY, SANNA WOO

¹We endeavour to provide accurate listings using the information available at the time of publishing. If there is information you are aware of that has been overlooked, please contact us at the office.

²Includes \$2,500 sponsorship from Home & Garden RONA, Kelowna and \$1,000 sponsorship from Connect Hearing, Kelowna.

³Includes \$500 sponsorship from Connect Hearing, Vernon.



Comox Valley



White Rock



Vancouver



Vancouver



Vancouver



Comox Valley



Kamloops



Prince George

**Superb SuperStar Walkers
(Raised \$5,000–\$14,000)**

Kamloops: Jane Osterloh

Kelowna: Deborah Hartley, Wendy Olinger, Shelley Schreyer,
Top Individual Fundraiser:
Garry Toop \$15,650.15

Nanaimo: Tanya Lesstrange

Powell River: Henry Cummings

Vancouver: Holly Parrish, Janet Stuehmer, Valerie Swannell, Deborah Yeates

**SuperStar Supreme Walkers
(Raised \$2,500–\$4,999)**

Comox Valley: Wayne & Elaine Benning, Margaret Elson

Kamloops: Wesley Stevens, Bryan White

Kelowna: John Hallam, Verena Morel, Carole Taylor, Bob Thompson, Cory Walsh

Pitt Meadows/Maple Ridge: Edith Elliott

Prince George: John Corbett

Vancouver: Elspeth Banerd, Tracey-Lee Eddy, Larry Gifford, Deana Grinnell-Smerdon, Margaux Hennebery, John Hougan, Natalie Moser, Grant Sheinin, May Wong

Vernon: Colleen Vollan

White Rock: Elizabeth Holroyd, John Manuel

**SuperStar Walkers
(Raised \$1,000–\$2,499)**

Burnaby: Linda Dawson

Chilliwack: Carolyn Krahn, Ann Oenema

Comox Valley: Barry Bowen, Louise Dillabough, Anne Langdon, James Stevenson

Elk Valley: Shelly Hume, Terry Hume, Merl Shelley

Kamloops: Daryl Arden, Rodney Hobbs, Ruth Konrad, John McCurrach, Rendy Olthuis, Brianna Senner, Case Van Diemen

Kelowna: Ralph Ayers, Peter Baigent, Deanna Begrand, Jean Flintoft, Beulah Walsh

Nanaimo: Allan Banasch, Andrew Rickaby

Pitt Meadows/Maple Ridge: Audrey Cerny, Rheanna Corpuz, David Hardie, Wim Hunfeld, Richard Maki

Port Alberni: Raymond Nicklin

Powell River: Dennis Dyer, David Fisher

Prince George: Caroline Lamb

Richmond: Donna Dobbie, Don Henderson, Helge Nielsen, Jean Nykyforuk, Alan Reynolds

Salmon Arm: Roberta Jordan

Surrey: Jagpaul Sandhu, Jessica Whyte

Vancouver: Stephen Bates, Felicia Bogosoff, Jan Carley, Teagan Cartwright, Jennifer Crawford, Andrea Feldman, Jennifer Flaming, Jill Goertzen, Diane Janzen, Brian McConville, Daniel McPhee, Adrian Millington, Margaret Mutch, Chris Parrish, James Smerdon, Gilberte Thompson, Courtney Vasquez, Michael Winter, Elizabeth Yip, Holly Yip

Vernon: Wray McDonnell, William More, Judith Nelson, Karen Whittle

Victoria: Terence Gorsuch

White Rock: Lynda Bennett, Shelley Jackson, Pat Jones, Micheline Stevens

**BC Teams
(Raised \$1,000+)**

100 Mile House: Caribookonrads

Chilliwack: Parkrahn, Walk 4 Pake

Comox Valley: Dillabough Family, Stir It Up

Elk Valley: Movers and Shakers, Team Merl

Kamloops: Sandy's SuperWalkers, Shake, Rattle & Roll, Team Daryle, Team Glennis

Kelowna: Top Fundraising Team: Good Vibrations \$17,910, Group Therapy, Percs for Parks, Shelley Schreyer, Team Thor

Nanaimo: ProPacific DKI

Pitt Meadows/Maple Ridge: Are we there yet?, Elliott Walkers, Lumbering Lloyds, Maple Ridge Seniors Village, Pop's Posse, Team Whonnock, Victor's Striders

Port Alberni: Port Alberni Support Group

Powell River: Ginny & Dave

Richmond: Donna's Doddlers, Team Henderson

Surrey: Bachan Singh Sandhu, Women of Wisdom

Vancouver: A&W Cruisers, Air Hole, Cha-Cha Blazers, Chris's Crew, Gifford, Hopefull, J Walkers, Red Hot Chili Steppers, Remembering Bryan, Saskatchewan Roots, Shake Shake Señora, Show Me The Smerdons, Super Sai's, Team Bates, Team Elaine, Team Hennebery, Team Janet, Team Mauch, Team No PK, Team PWP, Team Val, The Hustlers, The Nag and The Tough One

Vernon: 30 Min Hit, Colin's Crusaders, In Memory of Christine More, Pacificfisher, Whiting Walkers

Victoria: Wood Pile and Dear Friends

White Rock: Albert Scremin, Buena Vista Massage, Manuel Walkers, PJ, Rock 'n' Mama and the Followers, Semiahmoo Athletic Club, Team Barry, Team Elizabeth, The Stragglers

Congratulations to our Parkinson SuperWalk BC Prize Winners:

Top SuperStar Prize: iPhone 8 generously donated by Telus – Garry Toop, Kelowna

SuperStar Draw Prize: Fitbit Alta HR generously donated by Sport Chek – Jagpaul Sandhu, Surrey

Top Fundraising Team Prize: \$300 IGA gift card generously donated by IGA – Good Vibrations, Kelowna

Provincial Team Draw Prize: \$200 IGA gift card generously donated by IGA – Movers and Shakers, Elk Valley

For individual and team totals, BC prize winners, and more, visit <http://www.parkinson.bc.ca/superwalk-totals>.



Parkinson SuperWalk in British Columbia is operated by Parkinson Society British Columbia under license from Parkinson Canada.



Vancouver

VIEWPOINTS

Deep Brain Stimulation

Parkinson Society British Columbia is calling on the provincial government to expand the Deep Brain Stimulation program in order to allow greater accessibility to this life-changing treatment. To learn more about how you can help, visit <http://www.parkinson.bc.ca/DBS>.

People with Parkinson's disease in BC who are eligible for Deep Brain Stimulation (DBS) continue to face undue hardships and suffering as a result of excessively long waitlists. The wait time for DBS in British Columbia is 3 years for an initial consult, and then a further 2 years for the actual surgery. In comparison, in other provinces, individuals are waiting six months or less.

As Parkinson's disease is a progressive neurological disorder with a window of opportunity allowing some to improve the condition surgically, a lost year of benefit may be devastating for a patient, condemning them to a life of disability with flailing limbs, debilitating tremors, and/or the inability to move, work or lead a normal life.

Expanding the DBS surgery program in BC will enable these people to live independently in their own homes for many more years. The payoff for the healthcare system will be fewer hospitalizations, fewer emergency visits and avoidance of early admissions to long-term care.

What is Deep Brain Stimulation?

Deep Brain Stimulation (DBS) is a surgical procedure used to treat a variety of disabling neurological symptoms – most commonly the debilitating symptoms

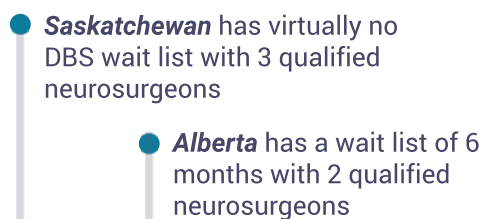
of Parkinson's disease (PD) such as tremor, rigidity, stiffness, slowed movement and walking problems. At present, the procedure is used only for patients whose symptoms cannot be adequately controlled with medications.

How does DBS work?

DBS is a way of “turning off” a small area of the brain. It involves placing a small platinum electrode or wire into the abnormal area of the brain. Instead of destroying the area (which was done in the past), high frequency electrical stimulation is used to “turn it off”. Patients with Parkinson's disease have areas of their brain that are overactive and a DBS electrode can be placed in those areas to correct the brain activity.

This electrode is connected to a pacemaker which sits under the skin, usually in the chest. When electrical pulses are produced by the pacemaker and sent to the tip of the electrode, the brain cells in the region of the electrode are “turned off”. The pacemaker can then be adjusted to maximize the benefits and minimize the side effects. That is the greatest strength of DBS – it can be adjusted to maximally benefit an individual patient and if there are unwanted side effects, it can be turned down.

VIEWPOINTS



Who makes a good candidate for DBS?

At present, the procedure is used only for patients whose symptoms cannot be adequately controlled with medications. If you are doing well on your medications, you cannot have the surgery.

Neurosurgeons and specialists will be looking for three motor symptoms that do not respond to optimal medications in order to determine if an individual is a good candidate for DBS:

- Motor fluctuations
- Dyskinesia
- Tremor

What are the benefits of DBS?

The benefits of DBS are directly related to the surgical target. Targeting different parts of the brain can reduce tremor, dyskinesia and motor fluctuations respectively. The details, of course, vary from patient to patient.

DBS does not improve the non-motor symptoms of Parkinson's disease. Non-motor symptoms include, but are not limited to, dementia, depression, loss of smell, constipation, bladder dysfunction, imbalance, impulse control disorders and REM sleep disorders.

The DBS Problem in British Columbia

Across Canada, there is at least one functional neurosurgeon for every two million people – except in BC, where it is one for every five million. Currently, there is only one neurosurgeon qualified to perform the DBS procedure in the province, Dr. Christopher Honey. The waitlist to see Dr. Honey is 3 years for an initial consult, followed by another 2 years to get the surgery.

Dr. Honey's clinic operates on the Vancouver General Hospital campus, so all of his patients must travel to Vancouver for the procedure. The Vancouver Coastal Health Authority (VCHA) holds the budget for the DBS program, resulting in considerable costs for patients as they must travel multiple times for pre- and post-surgery appointments. DBS should be a provincial program, funded through the Ministry of Health, not VCHA.

Increasing access to DBS for people with advanced PD will reduce the suffering endured by those with this neurodegenerative disease and provide them with the ability to live independently for 10 or more years. Helping people stay independent also has strong economic rationale. Many people with advanced, disruptive symptoms of PD will end up in hospital beds or long-term care in the near future. The cost of this care is roughly \$80,000 to \$100,000 per person per year, or \$1 million per person over 10 years. It makes moral and economic sense to provide DBS to those who need it, as soon as possible.

Want to help? Here is what you can do:

- 1 Write a letter to your MLA, the BC Minister of Health and the Assistant Deputy Minister.
- 2 Help spread awareness by sharing the issue via your social media networks.
- 3 Sign our petition calling for expansion of the DBS program, online at www.parkinson.bc.ca/DBSPetition

● BC patients wait 3 years for an initial consult for DBS

● The total wait time for DBS in BC is 5 years

3 YEARS

4 YEARS

5 YEARS



Champions FOR PARKINSON'S

This year, our incredible Champions for Parkinson's raised over \$100,000 to help Parkinson Society British Columbia support people affected by Parkinson's across the province. We can't thank you enough for your efforts!

Champions for Parkinson's are individuals or groups who have organized a fundraising event in their community. They play a key role in generating awareness and critical funds to support Parkinson Society British Columbia's (PSBC) programs, services, advocacy efforts and research contributions.

No idea is too large or too small, and PSBC is well equipped to help make your event a success. We are currently recruiting Champions for 2019 and invite you to join us!

▶ For more information, contact Mirela Prime at mprime@parkinson.bc.ca | 1-800-668-3330



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