# VIEW OUTS

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

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The following are the many ways you can support your society:

Membership—\$25 annual fee

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#### **Special Events**

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# research

## New Hope to Halt Compulsive Gambling

For people with Parkinson's disease, it's usually a tremendous relief to find a drug to treat the tremors, stiffness or the freezing that causes some of them to halt in place.

But for a significant minority of people – up to 20 percent – the class of drugs that is often most effective in controlling these motor symptoms comes with a devastating side effect. These synthetic dopamine drugs, called dopamine agonists, can introduce risky behaviour, including compulsive gambling that may cause people to drain their life-savings or ruin their relationships.

At the University of British Columbia, behavioural neuroscientist, Catharine Winstanley, uses animal models to investigate the link between a protein called GSK3beta and the impulse control problems some people develop when taking these drugs. The risky behaviours often make both doctors and people with Parkinson's reluctant to turn to dopamine agonists for treatment. Although GSK3beta is associated with several psychiatric disorders, so far researchers don't know its precise role in causing them. What they do know is that certain other drugs, including lithium and new lithium derivatives, seem to block GSK3beta, preventing the development of impulse control problems.

Winstanley and her colleagues are testing these drugs, which have already been demonstrated to be safe. They're hoping that giving one of these drugs to people already taking dopamine agonists will prevent them from developing these impulsive behaviours. If Winstanley is successful, "it would make the experience of being treated with these compounds (dopamine agonists) a lot safer and less

#### **RESEARCH GRANT**



New hope to halt compulsive gambling

**RESEARCH PROFILE** Dr. Catharine Winstanley

INSTITUTE University of British Columbia PILOT PROJECT GRANT Parkinson Society British Columbia Pilot Project Grant of \$45,000 over one year\*

worrying for the patients," she says. People with Parkinson's could take both the synthetic dopamine agonists and the additional medication, relieving their motor symptoms without jeopardizing their supportive relationships and livelihood.

Currently, the impulse control issues are "the worst outcome for someone who is trying to develop a new medical treatment," says Winstanley, an associate professor at UBC. "The drug they've developed turns out to cause something worse than the disease they were trying to treat." The heart-rending effects of compulsive gambling and other impulsive behaviours compelled Winstanley to tackle this research project, she says. She empathizes with people with Parkinson's, whose hopes are raised by the prospect of taking the dopamine agonist medication, only to have those hopes dashed when the risky behaviours emerge.

"You don't have to look very far before you find a friend or a relative who is dealing with the fallout from Parkinson's disease," says Winstanley. "I just want to do the little bit I can to make that better. This is the area where I think my own research can make a difference."

# ask an expert

## Genetics, Environment and Parkinson's disease

#### with DR. BEATE RITZ



**Dr. Beate Ritz** received her MD and a PhD in Medical Sociology from the University of Hamburg Germany in 1983 and 1987; she was a research fellow and resident at the Psychiatric University-Hospital in Hamburg from 1987-1989,

and received doctoral training and a PhD degree in Epidemiology in 1995 from the University of California at Los Angeles (UCLA). Upon graduation, she joined the faculty of the School of Public Health at UCLA and is currently Professor and Vice-Chair of the Epidemiology Department.

Dr. Ritz is also a member of the Center for Occupational and Environmental Health (COEH), the Southern California Environmental Health Science Center (SCEHSC) and co-directs the National Institute of Environmental Health Sciencesfunded UCLA Center for Gene-Environment Studies of Parkinson's disease. She was one of the plenary speakers at Parkinson Society British Columbia's most recent provincial conference, *Moving Forward, Together*, on June 3, 2017.



#### What are gene-environment interactions, and how have they been underexplored in Parkinson's disease (PD) related research so far?

Gene-environment interactions (GxE) are the processes by which an individual person's genetic make-up interacts with agents in the environment. These agents can include food and medications, mould, pesticides and air pollution, just to name a few. Even the smallest differences in genetic factors can change how an individual reacts to the environment around them. Almost all diseases are the result of GxE interactions.

Gene-environment interactions can be challenging to study since researchers need to both measure environment exposures reliably as well as determine the appropriate genes to examine. For example, one of the studies I was involved with determined that an increase in PD risk is associated with variations in the paraoxonase 1 – an enzyme also known as PON1 that breaks down pesticides that enter the human body – and dopamine transporter genes.

# Can you tell us a bit about your research interests and how they pertain to PD?

My research focuses on the effects of both occupational and environmental toxins. Toxins such as pesticides and air pollution can impact neurodegenerative diseases and cancers. One of our major studies that garnered interest in Canada and the United States was a large-scale project in rural areas of Southern California. We used detailed information collected by a large group of patients with Parkinson's in California's Central Valley. I worked with a team of researchers to evaluate both genetic and environmental risk factors and how they interact in PD. This study established that the combination of

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the fungicide maneb and the herbicide paraquat can increase the risk of developing Parkinson's disease by 75%. The earlier the exposure, the greater the risk of developing the disease. Furthermore, people who were exposed to paraquat, maneb and ziram (a fungicide) at work were three times as likely to develop Parkinson's than those who were not exposed to these chemicals at all. I believe that it is very likely these pesticides work to lower peoples' natural defenses to disease. The results of these investigations have provided a foundation for a number of other projects that evaluate pesticide exposure and genetic vulnerability.

# ? Are all pesticides neurotoxic?

The short answer is some, but not all. Different pesticides may work in combination with each other. Insecticides are specifically designed to kill insects by targeting their nervous system. However, insecticides don't distinguish between insects, people and animals, therefore insecticides, as well as some herbicides and fungicides, have been proven to have neurotoxic effects.

# 2 Can you briefly explain some of your research that focuses on occupations and lifestyle in Parkinson's?

In 2016, I co-authored a study that concluded that individuals who engage in moderate to vigorous physical activity in youth are at the lowest risk of developing Parkinson's disease. Particularly interesting was the finding that participation in competitive sports in youth seems to lower the risk of developing PD more than life-long physical activity. That being said, it could be possible that participating in sports and physical activity could be markers for pre-existing factors that lower risk already. It becomes a question of nature versus nurture. Right now, evidence is inconclusive whether exercise or genetics is a stronger protective factor.

# What else would you like our readers to know about the direction of your work?

Parkinson's disease is incredibly complex. I'm a strong believer that approaching its study from a cross-disciplinary approach is the most appropriate way to better understand the condition to improve treatment and potentially find a cure. However, community studies that focus on PD patients need to be an integral part of such research efforts. Currently, there are too few of them.

Only long-term studies of humans with PD can improve our understanding of how the disease progresses. By analyzing clinical symptoms of Parkinson's, my team has concluded that our current method of classifying the symptoms of Parkinson's disease – both motor and nonmotor – are grossly inadequate and do not provide sufficient reflections of health-related quality of life. Now, we are continuing to follow a large group of community-based patients to document different aspects of PD. This will provide a better understanding of the disease and eventually identify factors that affect its progression.

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#### What drew you to study the health effects of occupational and environmental toxins on chronic diseases?

The ubiquitous exposure to neurotoxins delivered via a variety of means, such as air, soil, water contamination as well as pesticides, is unprecedented in human history. Similarly, the large aging population is much more vulnerable to these toxicants and will likely have to live with a diminished quality of life for many years. This is a looming public health crisis we need to address, now.

#### As a researcher who has worked with subjects who have been exposed to environmental risks, are you optimistic about policy changes that may protect communities from environmental toxins, or are current policies still worrisome for you?

I wish I could be more optimistic, but agricultural and chemical industries are very resistant to making changes. The current political climate in the US is certainly not in favour of expanding Environmental Protection Agency type regulatory efforts to reduce human pesticide exposures. I hope this trend will change as more scientific evidence of the harm done to human life accumulates.

# Is there anything you would like to add about genetics, environment and Parkinson's?

One myth that we should debunk is that 'natural' means harmless or non-toxic. The natural pesticide called rotenone – derived from an African tree root – has been used in organic farming because it is considered natural. It is, however, a strong toxicant that causes PD like symptoms in animals and has been shown to also be involved in the development of Parkinson's in humans.

Do you have Parkinson's related legal issues?



# Through a partnership with PSBC, the law firm of **Blake**, **Cassels & Graydon LLP** offers free of charge legal services to people with Parkinson's in British Columbia.

The Litigation Support Program from Blakes addresses legal issues such as discrimination against individuals with Parkinson's in the workplace; discrimination in accommodations, services or facilities that are generally available to the public; and, wrongful denial of disability insurance or denial of government services.

If you have a legal problem relating to Parkinson's disease, please contact **Jean Blake, CEO at jblake@parkinson.bc.ca** for more information.

# ask an expert

# Stem Cell Research and Parkinson's

#### with DR. ROGER BARKER



**Roger Barker** is the Professor of Clinical Neuroscience at the University of Cambridge and Consultant Neurologist at the Addenbrooke's Hospital Cambridge. He is a guest professor at the University of Lund, Sweden and a Principal

Investigator in the MRC-Wellcome Trust Stem Cell Institute in Cambridge.

For the last 25 years he has run research that seeks to better define the clinical heterogeneity of two common neurodegenerative disorders of the central nervous system (CNS) - namely Parkinson's disease (PD) and Huntington's disease (HD). This has helped him define the best way by which to take new therapies into the clinic. In this respect he has been heavily involved in gene and cell based trials for patients with these conditions and currently co-ordinates an EU funded transplant program using human fetal tissue for patients with PD, following an earlier Medical Research Council (MRC) funded trial using similar tissue in HD. He is part of a new EU project (NeuroStemCellRepair) and a global initiative (GFORCE-PD) that is seeking to take stem cells to trial in these disorders.

# First of all, what are stem cells?

Stem cells are cells that have both the capacity to divide and also give rise to differentiated cell types. One example is embryonic stem cells (ESCs) which are found in the newly fertilized egg and which give rise to all the different cells we have in our body.

#### What is the principle aim of the Parkinson's research you are currently a part of?

The main aim of my research group is to better define the different types of Parkinson's disease (PD) that we think exist. From there we try to understand why this may happen and how we can best treat each subtype – including with new therapies such as dopamine cell transplants.

#### In your research into neurodegeneration, why is it necessary to use embryonic stem cells?

We use stem cells in two main ways in our research: (i) as a source of cells which we can then turn into dopamine cells lost in PD which we can graft back into the brain to repair this aspect of the disease process. This is mainly done using ESCs. Alternatively, (ii) we have been making patient-derived stem cells (so-called induced pluripotent stem cells – iPSCs) and then turning them into dopamine nerve cells to try to understand what goes wrong in these cells in the disease in that particular type of patient. This also opens up the possibility of testing different drugs on these cells to see if we can slow down or alter aspects of the disease process.

# ?

#### Why do dopaminergic drugs (such as levodopa) fail, or become less effective over time?

Drugs that operate through the dopamine system work well in the early stages of disease. They come in two forms: one that replaces dopamine (L-dopa in the form of sinemet or madopar), or one that stimulates dopamine receptors (dopamine agonists such as ropinirole/pramipexole). Over time, these drugs become less effective as the patient's own dopamine system continues to degenerate.

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## British Columbia can do better. Together, we can improve patient outcomes.

Learning you or a loved one has Parkinson's disease can be devastating news. Although it is a complex disorder with its exact cause unknown, it is one of the most treatable neurological conditions. Most people are able to control their symptoms for many years by working with physicians and their healthcare team to find the right therapies.

People with advanced Parkinson's disease may become frail, and combinations of medications need to be delivered in the right dosage at the right time to maintain independence and quality of life. The contrast between optimal versus ineffective therapy may be the difference between independent living and a hospital or nursing home.

Key to effective treatment is early diagnosis. There is no single test for Parkinson's and many other conditions may mimic the disease, so a comprehensive exam by a neurologist with additional experience in Parkinson's is required. Unfortunately, patients in British Columbia can face long waits of up to 24 months, which often means delayed treatment and unnecessary disease progression. Once diagnosed, patients often find that health professionals such as nurses and physiotherapists lack knowledge of Parkinson's and best practices. This means patients can receive improper treatment in emergency rooms, hospitals and care homes.

For these reasons and more, Parkinson Society British Columbia (PSBC) has developed a Four Point Plan to better coordinate and increase access to critical supports and better care.

Parkinson's already costs the B.C. health system about \$112 million annually, and we believe we can help reduce further impact by making strategic investments we estimate will cost \$2 million a year. We invite you, the Parkinson's community, to join us in our advocacy campaign for:

# Developing a B.C. Parkinson's disease strategy

Engaging health system planners, clinical experts and the experience of people living with PD to develop an evidenced-based strategy to improve and better coordinate the services provided to PD patients around B.C.

# Adding specialized staff to existing PD programs

Adding physicians and allied health professionals to allow additional assessment capacity at PDspecific treatment programs in the province. Patients can face an 18-24 month wait to see a specialist, during which their disease will continue to progress.

# **③** Funding PD-specific training for allied health professionals

For example, people living with PD regularly use physiotherapy services to maintain mobility, but very few of the province's 3,500 physiotherapists have training related to PD and movement disorders. PSBC has partnered with UBC's Continuing Medical Education to develop a proposed program that would train physiotherapists in Parkinson's disease.

#### Expanding the Deep Brain Stimulation program

Like DUODOPA<sup>®</sup>, this is an option for a small number of patients with advanced Parkinson's disease. The surgery has enabled people to live independently in their own homes for many more years than they would be able to without receiving this treatment, but patients can wait many years to access it given current funding limits.

By taking action in these four areas, the province can help those with PD lead independent lives for as long as possible and reduce their overall impact on the healthcare system. If you are interested in joining our provincial advocacy network, please contact:

Jean Blake, Chief Executive Officer Parkinson Society British Columbia jblake@parkinson.bc.ca 604-662-3240 or 1-800-668-3330

#### A victory for the Parkinson's community! Your voice helped make the difference.

n 2016, Parkinson Society British Columbia (PSBC) began ramping up its campaign for the funding of DUODOPA<sup>®</sup> through BC Pharmacare. DUODOPA<sup>®</sup> is used to treat patients with advanced Parkinson's disease who have severe and disabling motor symptoms that cannot be well controlled with available combinations of medications. It is a levodopa and carbidopa drug combination delivered in the form of a gel through an intestinal pump.

The therapy enables people to continue to live independently in their own homes. For a young person, it means greater employment options or the opportunity to go back to work. For an older person, life at home continues instead of disabling symptoms forcing an individual into long term care or hospitalization. Furthermore, it can provide relief to caregivers by reducing their responsibilities in the role, improving their own health and offering more flexible employment options.

While the drug was approved by Health Canada and funded in a number of other provinces, BC PharmaCare excluded its coverage – until February 14, 2017. At this time, the Ministry of Health announced that it would work with the Pacific Parkinson's Research Centre (PPRC) to identify and prioritize patients for coverage of the therapy. This victory was largely due to the advocacy efforts of British Columbians with Parkinson's, in coordination with PSBC.

"This is an enormous victory for the Parkinson's community of British Columbia," says Jean Blake, CEO of Parkinson Society BC. "We would like to thank those who brought the issue to the attention of their MLAs, signed our petition and wrote letters to government officials. Above all, we would like to thank the tireless efforts and courage of those who participated in our advocacy videos and agreed to act as spokespersons with the media."

▶ If you would like to read more about DUODOPA<sup>®</sup> and the advocacy efforts for the implementation of our Four Point Plan, please visit our website at: www.parkinson.bc.ca/ advocacy

#### STEM CELL RESEARCH AND PARKINSON'S

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In addition, the drugs stimulate the remaining dopamine system in an abnormal non-physiological way (as they are simply taken orally one or more times a day) which leads to the development of side effects, most notably drug induced movements called dyskinesias. These drugs can also produce behavioural and psychiatric problems which in part relate to the fact that they stimulate areas of the brain where dopamine normally works. Thus cell based transplants have the advantage that they could be used for the local delivery of dopamine, released in a normal physiological way at the site it is needed, which may avoid some of these long term complications with the current oral agents we use to treat this condition in the clinic.

#### How long do you estimate it will take for stem cell treatment for PD to enter the mainstream course of treatment?

It is estimated that stem cell derived dopamine transplants from centres of expertise in this area will come to the clinic in about 2019. If they work in these early trials then it will probably be another 5–10 years before they could enter mainstream use depending on how well they work and ultimately what they cost!

#### What are some additional barriers that exist for stem cell research and treatment?

The main barriers are:

- (i) the necessary regulation and testing that is required to make sure the cells are safe – and this takes some time to complete;
- (ii) the use of stem cells in unlicensed ways in clinics around the world which may derail the work of the whole field (so-called stem cell tourism);
- (iii) the ethical concerns and debates about which stem cells are the best to use – and this varies from country to country.

# ?

#### There are a number of studies currently under way at The Barker Lab. Are there any that are particularly promising at this point in time?

Our most promising work at the moment in PD is on translating cell based therapies to the clinic. We are three quarters of the way through a fetal dopamine cell transplant trial and would hope to go to a first in human ESC derived dopamine cell trial in 2019. In addition, we have identified that inflammation may be a driver of disease progression in PD, which may allow us to study anti-inflammatory drugs as a way to slow down the disease process.

#### Is there anything else you would like to add for our readers and members in Canada?

I think the ability to do research across international borders is now very exciting and is speeding up progress in our understanding and thus treatment of PD. We, for example, work with the team of Francesca Cicchetti at Laval University in Quebec City on blood markers in PD as well as possible new therapeutic agents. Thus, supporting research in one country has an international impact, and it is important for people and patients to understand the difference they make when they help support research in any capacity.



VIEWPOINTS

# living well

# Champions Break a Sweat for Parkinson's



Exercise has been proven as one of the most effective tools for managing the symptoms of Parkinson's disease. In a long term study conducted by National Parkinson Foundation (NPF), it was discovered that 2.5 hours of exercise each week can improve quality of life and help reduce the rate at which the disease progresses. A combination of stretching, aerobic activity and strength training is ideal. The additional components of incorporating problem solving or learning a new sport can improve brain plasticity - this is part of the reason why participating in Parkinson's specific exercise programs such as PWR! and Rock Steady Boxing can be beneficial. Explained simply, brain plasticity is the brain's maintenance of existing neural pathways as well the establishment of new connections. Exercise can also improve memory, posture and balance while reducing anxiety, depression and freezing (National Parkinson Foundation, 2017).

If you're looking for ways to stay active, there are a number of programs and techniques developed specifically for people with Parkinson's disease (PD), that you may wish to consider trying. Parkinson Society BC arranged to have experts visit British Columbia to lead Dance for PD<sup>®</sup> and PWR! training programs for local exercise professionals. In the case of Rock Steady Boxing, Parkinson Society British Columbia (PSBC) has a scholarship program to assist a select number of exercise professionals in communities lacking Parkinson's services with the costs of attending training in the United States. All of this is in an effort to better provide "exercise as medicine" to a larger proportion of approximately 13,000 British Columbians living with PD. Regardless of what type of exercise people with Parkinson's may choose to take part in, PSBC emphasizes the importance of consulting with a physician before starting a new program as well as inquiring into the training and qualifications of exercise instructors.

#### **Dance for PD®**

Dance for PD® is an acclaimed program of dance classes for people with Parkinson's disease and carepartners. It was launched as a collaboration between the Mark Morris Dance Group and the Brooklyn Parkinson Group. It has been proven to benefit Parkinson's patients by mitigating the decline of some motor symptoms over time. Participants indicate that the program allows for an opportunity to socialize with others, stick to a routine and enjoy themselves (Westheimer et. al., 2015). Through an international network of partners, including PSBC, Dance for PD® classes are offered in 120 communities across 16 countries (Dance for PD®, 2017). In BC, Dance for PD<sup>®</sup> is currently offered in Vancouver and West Vancouver. You can learn more at https://www.parkinson.bc.ca/exercise.

#### **PWR!**

If you subscribe to PSBC emails or follow us on social media, you may have heard about PWR! (Parkinson Wellness Recovery) exercise classes for Parkinson's disease. PWR! Was developed by Dr. Becky Farley and incorporates research-based exercise programming. The program is based on 4 PWR!*Moves* which are performed with large amplitude, high effort and attention to action in multiple postures. These moves specifically target four skills that have been shown to

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#### CHAMPIONS BREAK A SWEAT FOR PARKINSON'S

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interfere with mobility in people with PD. They can be incorporated and progressed into any exercise program by a PWR! trained professional.

In 2015, PSBC partnered with PWR! to provide training to qualified physiotherapists and fitness instructors in British Columbia. More information about PWR! is available at http://www.pwr4life.org. To browse a listing of PWR! exercise programs for people with Parkinson's in BC, visit https://www.parkinson.bc.ca/exercise.



#### Step by Step

Walking is one of the simplest, most underrated forms of physical fitness. According to Statistics Canada, only 35% of adults hit the recommended target of 10,000 daily steps. The likelihood of an individual reaching this targets decreases with age (Colley et. al., 2009). For anyone

looking to improve their overall health, walking can be a good starting point. This is why, beginning in April 2015, PSBC began an annual program working with volunteers in various communities across BC to deliver Step by Step, a 12 week walking program that aims to help individuals with Parkinson's to increase their number of daily steps. This program only officially runs once per year, but the hope is that it will help people either begin a walking program or increase their level as well as connecting socially with a group once a week. Information, including a useful program booklet, is available year-round at www.parkinson.bc.ca/stepbystep.

#### Rock Steady Boxing

Recently, there has been a surge of interest in community boxing programs specifically intended for people with Parkinson's disease. Rock Steady Boxing (RSB), is a non-profit boxing program that began in Indianapolis. It is a contact free, boxing-inspired fitness routine that helps people with Parkinson's manage their symptoms (Rock Steady Boxing, 2017). At this time, there are five RSB-affiliated instructors and fitness facilities in British Columbia: Vancouver, Surrey, Parksville, New Westminster and Richmond. To learn more, visit www.parkinson. bc.ca/rocksteadyboxing.

#### Champions for Parkinson's

A number of individuals and groups have tapped into the benefits and enjoyment of exercise for their independent fundraising initiatives through Champions for Parkinson's. These events can take on any form and scale the organizers wish while raising much-needed funds for Parkinson Society BC (PSBC) services, programs, advocacy initiatives and contributions to research. In the past, British Columbians have done everything from donating birthday gifts to coordinating concerts for 300-plus people. This year, a number of events combine the benefits of exercise with the power of fundraising.

#### Shifting Gears for PD

Following a cycling trip across Canada in 2013, Paul Gully and Lois Leslie continued their circumnavigation

PSBC is grateful to members, volunteers, event organizers and exercise professionals who come together for the sake of improving the quality of lives for people with Parkinson's. If you would like to learn more about exercise programs or Champions for Parkinson's events, we encourage you to consult with the appropriate PSBC staff contacts. Champions for Parkinson's Mirela Dzaferovic

mdzaferovic@parkinson.bc.ca

Exercise Programs Caroline Wiggins cwiggins@parkinson.bc.ca

Telephone inquiries can be directed to staff by calling 1-800-668-3330 or 604-662-3240



of the globe earlier this spring as they departed for a journey that began in Lisbon, Portugal and was scheduled to end in Auckland, New



Zealand. Not only do they want to draw attention to the benefits of exercise for those living with Parkinson's disease, but they also want to raise a total of \$50,000 for the Society in honor of their friend, Marg de Grace. Lois and Marg met in high school and have remained life-long friends. Twenty-five years ago, Marg was diagnosed with Parkinson's disease. While she experiences tremor, dyskinesia, fatigue and issues with balance, she makes use of a number of PSBC programs to counteract these effects. She consistently works on fall prevention, voice projection and muscle maintenance.

After cycling through Portugal, Spain and France, Paul and Lois' trip came to an unfortunate and unexpected halt. In early May, while cycling up a hill on a sunny afternoon on the Italian Mediterranean coast, Paul was hit by a car from behind. Thanks in part to the great care he received at a local trauma centre, Paul is expected to make a full recovery. While their journey has been cut short for the time being, Paul and Lois look forward to soon continuing their trip and "circling the world, exploring those countries we've never had a chance to see, raising awareness of Parkinson's, chasing the perfect espresso and enjoying the life that we have once again been reminded is so vitally precious". When the couple are able to resume their trip, they plan on continuing their travel by foot or public transportation until they can both cycle again. If you would like to send words of encouragement or a donation to PSBC, their blog is online at http://cycling.loisandpaul.com/.

#### Shakin' the Rock for Parkinson's

Victoria resident Alf Todd has been an avid cyclist his whole life, including cycling with his son in 1987 from Victoria, BC to San Francisco, California. In 2007, Alf was diagnosed with Parkinson's disease. Since then, he has completed a number of outdoor adventures that benefit Parkinson's-related programs (The Parky's Pedalers, 2011). From June 11–16, with a team of 20, his cycling team known as The Parky's Pedalers, plan on riding from the most northern city of Vancouver Island to Victoria while meeting with a number of Parkinson's support groups along the way. All participants in this event have been personally affected by PD, and are committed to helping to build awareness and raising funds for much-needed services and program.

To learn more about their ride and donate, visit: www.shakintherock.org.

#### **Pull for Parkinson's**

Anyone can participate or plan active fundraisers for Parkinson's! Every year, high school students in Surrey organize Pull for Parkinson's, an ultimate frisbee tournament. Each year, this event brings in thousands of dollars for PSBC programs and services, in addition to providing a day of wholesome fun for local teens.

#### Sources

Champions for Parkinsons. (2017). Shakin' the Rock for Parkinson's with The Parky's Pedalers. Retrieved from http:// www.kintera.org/faf/home/default.asp?ievent=1173121.

Colley, R. et. al. (2015). Physical activity of Canadian adults: Accelerometer results from the 2007 to 2009 Canadian Health Measures Survey. *Statistics Canada*. Retrieved from http://www.statcan.gc.ca/pub/82-003-x/2011001/ article/11396-eng.htm.

Dance for PD<sup>®</sup>. (2017). *About Dance for PD<sup>®</sup>*. Retrieved from http://danceforparkinsons.org/.

Leslie, L. (2017, May 13). San Remo to Via Aurelia km 631 – 41kms. Site of collision. Retrieved from http://cycling. loisandpaul.com/2017/05/13/may-10-2017-day-38/.

National Parkinson Foundation. (2017). *Everything you need to know about exercise and Parkinson's*. Retrieved from http://www.parkinson.org/find-help/blogs/tips-for-daily-living/ Everything-You-Need-to-Know-About-Exercise-and-Parkinsons.

Rock Steady Boxing. (ND). *About*. Retrieved from https:// www.rocksteadyboxing.org/about/.

The Parky's Pedalers. (2011). About. *Facebook.* https://www. facebook.com/pg/The-Parkys-Pedalers-218447824845255/ about/?ref=page\_internal.

Westheimer et. al. (2015, April 3). Dance for PD: a preliminary investigation of effects on motor function and quality of life among persons with Parkinson's disease (PD). *Neurology and Preclinical Neurological Studies*. 122:1263-1270. Retrieved from https://dl.dropboxusercontent.com/u/62847270/Website/Dance%20for%20PD%20 JNT%20FINAL.pdf.

# newsworthy

## Champions for Parkinson's - Fundraising Events



#### **BEER AND CHOCOLATE**

The 4th annual Chocolate and Beer Tasting brought together delicious flavours and taste aficionados for a good cause on Sunday, March 5 at the Clough Club in Vancouver. Guests enjoyed some of the best craft beer BC has to offer alongside artisan, handmade chocolates. Over \$2,675 was raised in support of Parkinson Society BC!

#### **PULL FOR PARKINSON'S**

Thank you to everyone who came together for the Pull For Parkinson's – Charity Ultimate Tournament! This Ultimate Frisbee tournament for high school students took place in Surrey on April 28 and raised \$3,100 for PSBC.

#### **KELOWNA HEALTH FAIR**

The Kelowna Health Fair brought together 100 people and 11 exhibitors to raise a total of \$925 for PSBC's programs and services.

#### WHOLEY FIT SPIN CLASS

On World Parkinson's Day, April 11, 2017, Wholey Fit ran a 75-minute long Cycle, Core & More class in support of Parkinson Society BC. The class pushed participants to meet their fitness and fundraising goals, and raised an impressive \$725!

#### **SPRING ONLINE AUCTION**

From April 11 – May 2, individuals bid on scrumptious restaurant gift cards, cultural experiences, vacation getaways, and items specifically geared to helping people with Parkinson's in a spring online auction coordinated by PSBC. PSBC would like to thank all the generous donors and bidders for their support. Thanks to you, we raised more than \$2,539!



#### EDUCATION AND SUPPORT SERVICES EVENTS

#### SEPTEMBER

#### **COMMUNICATION AND SWALLOW WORKSHOP – COURTENAY/COMOX**

**Date:** Saturday, September 23, 2017 **Time:** 10:00am – 2:30pm

- 23 Time: Place:
  - Place: Crown Isle Resort & Golf Community | 399 Clubhouse Drive, Courtenay, BC
    Cost: \$40.00 Member / \$70.00 Member (Pair)
    \$50.00 Non-Member / \$90.00 Non-Member (Pair)

Further information and registration for our Education Events can be found on our website at www.parkinson.bc.ca/education-events

## Join us for Parkinson SuperWalk!

Everyday Heroes. Extraordinary Hope.

#### www.superwalkbc.kintera.org

Heroes come in all forms – register today to bring extraordinary hope to British Columbians affected by Parkinson's disease. You can register online or on walk day using the enclosed pledge form.



#### SUPERWALK LOCATIONS IN BC

#### Saturday, September 9

- 100 MILE HOUSE Centennial Park (Cedar Avenue Entrance)
- BURNABY Confederation Park / Track (4585 Albert Street)
- CHILLIWACK Landing Sports Centre (4530 Spadina Avenue)
- ELK VALLEY/SPARWOOD Senior Drop In Centre (101 4th Avenue, Sparwood)
- KAMLOOPS Riverside Park / Rotary Bandshell (100 Lorne Street)
- KELOWNA Waterfront Park / Concession Plaza (1200 Water Street)
- PARKSVILLE
   Parksville Community Park
   (193 Beachside Drive)
- PITT MEADOWS / MAPLE RIDGE

Spirit Square, Pitt Meadows (12027 Harris Road, behind community centre)

- PRINCE GEORGE Lheidli T'enneh Memorial Park (Use 17th Avenue Entrance)
- RICHMOND Minoru Park / Running Track (7191 Granville Avenue)
- VICTORIA Esquimalt Gorge Park (1070 Tillicum Road)

#### Sunday, September 10

- CHASE
   Chase Memorial Park
- OLIVER
   Oliver Community Centre
   (6359 Park Drive)
- **POWELL RIVER** Timberlane Park Track (4500 Timberlane Avenue)
- SURREY Bear Creek Park / Bear Creek Pavilion (13570 88th Ave)
- VANCOUVER Stanley Park at Ceperley Playground
- VERNON Polson Park (2600 Highway 6)

• WHITE ROCK Location TBD

#### Saturday, September 16

- FORT ST. JAMES Nak'azdli Health Centre (284 Kwah Road West)
- SALMON ARM
   McGuire Lake Park
   (599 10th Street North East)
- TERRACE Grand Trunk Pathway (Millenium Trail)

#### Saturday, September 23

• CRANBROOK College of the Rockies / Track (2700 College Way)

#### TBD

GINGOLX
 Location TBD

#### SPONSORED BY



VIEWPOINTS

#### ABOVE AND BEYOND AWARDS

On Saturday, June 3, Parkinson Society British Columbia recognized the outstanding contributions of thirty-three people with Parkinson's and carepartners within British Columbia. These individuals have been nominated by their peers for their courage in the face of adversity and commitment to celebrating each day with joy, compassion and understanding. Despite the challenges faced, they continue to live rich, full lives by creating new opportunities for themselves and others.

In light of the nominations, we wish to extend special recognition to:

#### **Edith Elliott**

long-time facilitator of the Maple Ridge Pitt Meadows support group and Parkinson SuperWalk walk coordinator

#### **Anne Langdon**

exercise enthusiast, awareness builder and co-facilitator of the Comox/Courtney support group

#### **Pat Mauch**

carepartner, community educator and active co-facilitator of the Vancouver West Side support group Our deepest gratitude to all other nominees:

Alana Appel Ralph Ayers Elaine Barnes Georgina Beddome Wayne & Elaine Benning Frank & Linda Bruder Ronald Corbett Diane Daignault Linda Dawson Elizabeth Holroyd Alan Jacques Jan Koeman Carolyn & Harold Krahn Barry & Joan Mansfield George Mauch Richard Mayede Chris & Harold Olsen Rendy Olthuis Gary Schroeder Alf Todd Renice Townsend Hilary Vanderliek Todd Wallace Patricia & Brian Wood

- If you have questions about volunteering with PSBC, we encourage you to visit www.parkinson.bc.ca/how-to-help/volunteer
- If you would like to connect with a PSBC staff member about volunteering, please reach out to Mirela Dzaferovic, Resource Development & Volunteer Coordinator mdzaferovic@parkinson.bc.ca | 604-662-3240 or 1-800-668-3330.



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