

Viewpoints

Parkinson
Society
British
Columbia



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

SPRING
2014

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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 the many ways you can support your society:

Membership—\$25 annual fee

Monthly or Quarterly 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.

Self-Help Support Groups

Abbotsford, Burnaby, Campbell River, Chilliwack, Chinese Speaking (Vancouver), Courtenay/Comox Valley PWP, Courtenay/Comox Valley Caregivers, Cowichan, Cranbrook, Creston, Denman Island, Fort St. John, Kamloops, Kelowna PWP, Kelowna Caregivers, Ladner, Langley PWP, Maple Ridge/Pitt Meadows PWP, Maple Ridge/Pitt Meadows Caregivers, Mission, Nanaimo PWP, Nanaimo Caregivers, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, North Shore, Osoyoos, Parksville/Qualicum PWP, Parksville Caregivers, Penticton, Powell River, Prince George, Quadra Island, Richmond, Shuswap/Salmon Arm PWP, Shuswap/Salmon Arm Caregivers, South Sunshine Coast (Sechelt), Sparwood, Squamish, Surrey, Terrace, Trail/Castlegar, Tri-Cities PWP, Tri-Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver West Side, Vernon, West Vancouver Caregivers, White Rock

First clinical study of new gene therapy shows promise for reducing motor symptoms of Parkinson's disease

A new triple gene therapy called ProSavin might safely improve motor function in Parkinson's patients by reprogramming brain cells to produce dopamine - a chemical essential for the proper control of movement - according to a phase 1/2 trial published in *The Lancet*.

"Lack of dopamine results in the tremors, limb stiffness, and loss of balance that characterize Parkinson's", explains study leader Professor Stéphane Palfi from AP-HP, Groupe Henri-Mondor Albert-Chenevier in Créteil, France.

"ProSavin uses an inert virus to deliver three dopamine-making genes directly into the striatum region of the brain that controls movement, with the aim of converting non dopamine-producing striatal neurons [nerve cells] into dopamine-producing factories to replace the constant source of dopamine that is lost in Parkinson's disease."

The most widely used treatment is the drug levodopa, a precursor of dopamine that can cross the blood-brain barrier. However, over time cell death is so great that effectiveness lessens and patients can develop involuntary muscle spasms (dyskinesias) and other side effects.

The current study tested the safety, tolerability, and efficacy of three different doses of ProSavin in 15 individuals aged 48 to 65 years with advanced Parkinson's disease who were no longer responding well to other treatments.

Patients were rated on a Parkinson's disease scale of motor functions that includes speech, tremors,



rigidity, finger taps, posture, gait, and bradykinesia (slow movement). The lower the rating, the better the function.

All patients injected with ProSavin had only mild to moderate side-effects related to the treatment; the most common being on-medication dyskinesias (20 events, 11 patients) and on-off phenomena (12 events, nine patients).

Significant improvements in motor scores were seen in all patients in the off-medication state (when patients had been off their medications for 12 hours) at both 6 months (38 vs 26) and 12 months (38 vs 27) after surgery.

However, the authors warn, "Although the efficacy findings show promise, the magnitude of effects are within the placebo range reported in other clinical trials for Parkinson's disease using surgical techniques, and must be interpreted with caution."

They conclude, "Our findings suggest that this therapeutic approach that provides continuous and stable dopamine replacement might provide an effective long-term treatment without the onset of behavioural complications." Dr. Jon Stoessl from the University of British Columbia, says, "The approach taken by Palfi and colleagues is novel in that it is the first time that

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SPOTLIGHT ON VOLUNTEERS:

The Hougan Sisters

In December 2007, families were preparing for the holidays, children were writing letters to Santa and shoppers were filling the streets. For the Hougan sisters that time will forever be remembered as the moment they were told their father, John, was diagnosed with young onset Parkinson's disease.

The initial shock of their father's diagnosis has since led to an emotional adaptation for Sean and Kendra. They have come to terms with the fact that someone they love deeply has a disease that will only get worse or, if they're really lucky, may stay the same. But what is most powerful about these two young women is that they feel fortunate; fortunate that the disease is progressing slowly and fortunate that their father has remained the man he's always been—positive and strong.

A passionate desire to take action motivated Sean and Kendra to start volunteering with PSBC in 2011. As Sean says, "I am not a neuroscientist researching a cure for PD, so it made me feel good to support the cause in some other way."

Their first event was the Concert for a Cure and we quickly recruited their talent for SuperWalk. Waking up at 5:00 am to place signage around Vancouver's



seawall, we rely on their commitment every year to fulfill the role of Course Marshall. For Kendra, "The most rewarding part

of being a volunteer is giving back to an organization that has provided my dad and family with support."

Both sisters are full-time students at Simon Fraser University (SFU) with academics, sports, friends and family taking up much of their time. However, they continue to show remarkable dedication to building awareness for Parkinson's. Recently Sean, with the help of a team of classmates, organized a high-energy cardiovascular kick-boxing event at the SFU campus, titled *Kickin' it for Parkinson's*. With the goal of ensuring a strong Parkinson's voice for generations to come, she used the event as an opportunity to educate and engage a younger audience.

The Hougan sisters have demonstrated an amazing capacity to carry on as they watch their father progress with PD. Though their hearts may sometimes feel heavy, sharing their experience offers inspiration to others.

With futures open to the brightest of possibilities, Sean and Kendra share a similar goal for what they hope to achieve: satisfaction in knowing that they have tried to bring the world to a better place and most importantly, happiness.

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"It's hard for any family to adjust when a loved one is diagnosed, and considering that each family is unique, I'm sure each one learns to deal with unfortunate situations in their own way. I think open and loving dialogue between family members is really important and an understanding that people will deal with it in different ways."

—SEAN

"I would tell someone who recently had a family member diagnosed with Parkinson's to take advantage of the time you have with that person because you cannot be certain the extent or how quickly symptoms will progress."

—KENDRA

The power of volunteerism can be seen in the tireless dedication of our committed volunteers. We are extremely appreciative of their time, knowledge, positivity, and enthusiasm. Thank you to Kendra and Sean and all of our PSBC volunteers!

FIRST CLINICAL STUDY OF NEW GENE THERAPY SHOWS PROMISE FOR REDUCING MOTOR SYMPTOMS OF PARKINSON'S DISEASE

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lentiviral vectors have been successfully applied to the treatment of neurological disease in humans and does not depend on survival of dopaminergic neurons, but rather assumes that transfected striatal neurons preserved in Parkinson's disease will develop the capacity to synthesise dopamine."

However, he adds, "Despite numerous imperfections, we have reasonably good treatments for the motor manifestations of Parkinson's disease in the form of levodopa, infusion therapies, and deep brain stimulation. The challenge of Parkinson's disease is the management of non-motor problems, many of which have a non-dopamine basis. The therapy described here will not address these issues, but the safety of the approach could be seen as a proof of principle for future studies focused on rigorous assessment of efficacy as well as targeting these devastating problems."

Source: Article adapted from Medical News Today.

DO YOU HAVE PARKINSON'S RELATED LEGAL ISSUES?

Blakes
LAWYERS

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.

Exercising tips for brain health

Rarely do you find neuroscientists, psychologists and physicians agreeing unequivocally on one thing. But here's an exception: They all say that exercise is hands down the single best thing you can do for your brain.

The latest research shows that people can continue to learn throughout life. Yes, brain volume shrinks slightly, and some cells die. But the brain continues to make new neurons and fine-tune their connections, even very late in life.

Aerobic exercise, “builds and maintains connections in the brain and research supports that exercise can be neuro-protective and reverse some Parkinson’s symptoms or slow down the progression of the disease,” states the Pacific Parkinson’s Research Centre.




Several studies over the last few years show that all of us—young, old, healthy or not—can pump up our brainpower by exercising regularly. Exercise also reduces stress, lowers the risk of stroke, helps control blood sugar and lessens the chances of falling by improving balance and coordination. So if you're worried that your memory is fading as fast as your tennis game, get moving!

Start now

It's never too late to start exercising for brain health, says Laura DeFina, M.D., medical director of research at the Cooper Institute, a non-profit research and education organization dedicated to preventive medicine.

“People often say, I’m 55 and I’ve never exercised. Does starting now really make a difference? The answer is simple—yes, it absolutely matters.”




TIPS:

-  If your doctor gives you the go ahead, find an activity that feels good to you. The best exercise to do is the one you'll keep doing.
-  Recruit a friend or family member to take a fitness class with you. Being with others can motivate you to keep going.
-  Plug in your iPod. Studies show that those who work out while listening to music exercise harder, and longer—without even realizing it.

Aim for 150 minutes of moderate exercise a week

Seem like too much? That's just over 20 minutes a day and every little bit counts. In a recent Canadian study, researchers followed a large group of elderly adults for 2–5 years. None were fitness fanatics; their daily activities included walking, cooking, gardening and cleaning house. The results were stunning: Year after year, 90 percent of those who were consistently active showed no decline in their ability to think and remember.

TIPS:

-  Go green. People are more likely to stick with an exercise regimen when they are exercising outdoors. And researchers in Britain found that people who strolled through a park or other outdoor environment, as opposed to exercising indoors, had a measurable boost in focus, energy and well-being.
-  If joints are stiff and muscles weak, try a low-impact workout like walking in the pool or taking a spin on a stationary bike. Pilates, yoga and tai-chi also place minimal stress on the body but still strengthen core muscles and improve balance. Never done any of that? All the better! Learning something new is another important pillar of brain health.
-  Try light strength training and work all the major muscle groups—arms, shoulders and

continued on next page...

chest; abdomen and back; hips and legs. Go to the gym or buy your own hand weights and resistance bands. Then stow them next to the couch so you can squeeze in reps while you watch the news or catch up on Mad Men!

Dance like nobody's watching

Dancing is terrific exercise; it's fun and something most people can easily do. Besides giving you a great cardio boost, dance strengthens bones, improves balance, coordination and flexibility, works all the major muscle groups and builds stamina. What's more, if you learn new steps, and dance with a partner, you banish loneliness and ramp up brainpower since you combine two other key elements of brain health: learning new things and socializing.

A 2005 study by researchers at McGill University in Montreal compared two groups of older adults—one group danced the tango twice a week, the other simply walked. After 10 weeks, both groups did better on several cognitive tests. But the dancers outperformed the walkers on multitasking tests and saw additional gains in their coordination and balance.

TIPS:



The next time you have friends over, shove the coffee table aside, put on some music and just move it.



Feeling rusty? Check out dance classes at your local community centre; you'll be surprised at the variety. Learning new moves, or refreshing old ones, challenges your brain and builds new connections.



Too shy? YouTube offers thousands of videos that can get you up to speed before you put on your dancing shoes.

COMMUNITY SPOTLIGHT!

Evert Thor, Everyday Hero

Imagine a man that has difficulty going for a short walk, but has cycled around the world. Sound impossible? Meet Evert Thor.



Diagnosed with Parkinson's more than 25 years ago, Evert's journey has included hardship, triumph and many, many kilometers on a stationary bike. In 2008, Evert walked into his local community centre and signed up for a program where participants would virtually cycle 10,000 km to Beijing. Evert completed that ride and kept on going. To date, he has logged 64,000 km!



Evert maps out specific routes around the world and as he virtually passes through different cities, he changes his diet to match the local fare and posts regional tourist attractions on his Facebook page.

“Exercise is especially important for the newly diagnosed,” says Evert. “You have no idea what to expect with Parkinson's and exercise helps to have a positive mindset for the journey.”

Evert is currently cycling to South America. Let's hop on our bikes and join him—virtually that is!

Doctor's orders

There's no one-size-fits-all exercise strategy, but we can all make simple lifestyle changes that go a long way toward boosting brain fitness. Just be sure to consult your doctor before starting any new exercise program.

Source: Excerpts adapted from *Exercise and Parkinson's Disease* at www.parkinsons.ubc.ca and *Brain Health & Wellness* at aarp.org.

How to gradually introduce in-home care

For the past year or so, you've noticed your loved one slipping, but to avoid making waves, you've tried to keep your concerns to yourself. Now, you're seeing obvious signs that the problem is worsening.



The kitchen that used to be spotless is piled high with dirty dishes. There's very little food in the refrigerator, and the lawn that has always been kept perfectly manicured is popping with weeds. Perhaps most disconcerting is that they appear to be losing weight and their hygiene is suffering.

You try to gently suggest that perhaps they need some help and are met with intense resistance. The answer, plain and simple, is "No!"

Be realistic

If this sounds familiar, one way to ease your stress is by lowering expectations. Someone who has spent a lifetime being independent is not likely to agree the minute you suggest hiring a helper. They may have feelings of denial and fear and will likely see this as the beginning of the end of their independence. Loss of privacy may cause anxiety, or they may just be uncomfortable with the idea of a stranger in their home. Simply acknowledging these feelings can do wonders for easing their worries.

One step at a time

Here are some tips for introducing assistance very gradually to calm fears and reduce push back.

♥ Tug at the heartstrings a bit—tell your loved one you would rather spend your time together doing enjoyable things than catching up

on household chores. Remind them that you have other responsibilities and commitments, so bringing in some assistance would actually help you too.

♥ When hiring a household helper/companion, make sure the person is also trained in personal care services and can assume those duties as time progresses. Be sure to explain this planned progression to potential candidates during the interview process, so there are no surprises.

♥ Initially, introduce the new caregiver as a housekeeper. Your loved one will probably be more apt to accept help with household chores than personal care. Let them assist with defining the helper's responsibilities. As a relationship and sense of trust develop, they may begin to ask for assistance with other things.

♥ Present the help as a gift rather than as something that is needed. On the next special occasion, tuck a "gift certificate" for cleaning services inside a card and let them know you thought it was something they would enjoy.

♥ After a few weeks, ask the helper to call your loved one before arriving to ask if they need anything at the store. When offered as a courteous, helpful gesture, it will likely be appreciated. As the relationship continues to develop, have her suggest bringing ingredients for a simple meal they can prepare and enjoy together.

♥ If necessary, solicit help from a home health case manager or physician. Trained to objectively assess these situations, these professionals can often present recommendations in a non-threatening manner that your loved one will be comfortable with.

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Slow and steady wins the race

However you decide to proceed, begin the conversations early and don't rush things. A gradual introduction is best, so start with short visits and let the relationship develop naturally.

The decision to introduce in-home care may be a difficult step for you and your loved one. If you are struggling or need help assessing your situation, please contact PSBC or your local health authority to find a home-health office near you.

Source: Article adapted from a post by Ann Napoletan on caregiving.com. Having lost her mother to Alzheimer's disease, Ann is a passionate advocate for helping other caregivers navigate their own unique journey.

Participate in Research

Understanding caregiver well-being across neurodegenerative diseases

Caregivers are invited to **complete a questionnaire** (*in-person, over the telephone or via mail*) that looks at the unique demands of care in different disease groups, including **Alzheimer's disease, Dementia with Lewy Bodies, or Parkinson's disease**. We

understand that your time is valuable—however your participation could have a positive impact on the development of caregiver resources targeted to reduce stressors and support care needs across different neurodegenerative diseases and dementia presentations.



Who can participate?

Adults over 45 years of age that are in a committed relationship with someone diagnosed with: Alzheimer's disease, Dementia with Lewy Bodies or Parkinson's disease.

For more information, please contact Kaitlyn Roland at 250-853-3679 or kroland@uvic.ca.

your feedback

Five years later, how are we doing?

At PSBC, we continually strive to meet the needs of the Parkinson's community by ensuring that our programs and services are of the highest quality. We understand that, as an organization dedicated to those we serve, we need to adapt and improve as new information becomes available on how to best support those impacted by the disease.

Background

In 2009, we conducted two comprehensive online surveys; one for people living with Parkinson's and the other for care partners. Our objectives were threefold:



To discover more information on the reality of life with Parkinson's and as a care partner

(symptoms, medication costs, care options, coping strategies, etc.)



To gain feedback on PSBC's services, programs, fundraising activities and marketing strategies

**The survey was unpaid and conducted anonymously.*



To gather demographic information* that would help us better understand who uses our services

Results Clear trends emerged from both surveys. The results are summarized below:

People Living with Parkinson's Survey

A TOTAL OF 315 PEOPLE RESPONDED.

- Most individuals, diagnosed less than 10 years earlier, were experiencing mild to moderate symptoms.
- A range of motor symptoms were common and non-motor symptoms were almost equally as common and distressing.
- 96% of respondents were on medication, including 89% on Sinemet.
- Close to half of the respondents were seeking healthcare from sources other than doctors (physiotherapists, massage therapists, psychologists, nurses, etc.).
- Respondents found PSBC's information package, newsletter (*Viewpoints*) support groups and education events very valuable.
- The areas where people felt PSBC could improve included: access to legal advisors, community exercise programs, an increase in affordable and province-wide fundraising activities, more available resources (including resources for healthcare practitioners) and positive messaging in marketing and advertising campaigns.

Care Partners Survey

A TOTAL OF 180 PEOPLE RESPONDED.

- 90% of respondents were the spouse or partner of the individual living with Parkinson's.
- Most individuals indicated a high level of satisfaction with caregiving, however many found it challenging to carry out daily activities, find time to themselves and some felt exhausted and frustrated at the loss of freedom.
- Respondents found PSBC's information package, newsletters (*GroupLink* and *Viewpoints*), education events and direct access to referral services very valuable.
- Care partners were interested in more information relating to: progression of Parkinson's, living well with Parkinson's, care partner self-care, coping strategies and support groups.

Action

You are our greatest supporter and our most valuable critic. We took care in evaluating the survey results and developed a five-year strategy to fulfill your most urgent needs.

Here is what we've accomplished:

RESOURCES

We continue to develop new resources and regularly revise older information to ensure all of our pamphlets, brochures and help sheets are appropriate and up-to-date. We have also demonstrated a concerted effort to further educate the healthcare community.

Highlights

- Comprehensive new resource, *Parkinson's Disease. Understanding and Moving Forward.*
- Legal series of help sheets (Representation Agreements, Enduring Power of Attorney, Pension Plan Issues with Progressive Disability, Making Changes in the Workplace to Adapt to Parkinson's: The Process of Accommodation, Disclosing Your Disability to Employers, Estate Planning and Trusts).
- More than 25 new or revised help sheets.
- Launch of a Healthcare Professional campaign that included pamphlets and an online educational video.
- Clinical Guidelines for Parkinson's disease for healthcare providers.

EDUCATION

We have increased the number of education events we host each year and take time to choose topics

based on your feedback. In 2011, we started a series of workshops (*Time Out for Caregivers*) specifically designed for care partners.

EXERCISE

We started the Exercise Revolution in 2012 by hosting Dr. Becky Farley who delivered a two-day clinician training to 50 physiotherapists, as well as four community lectures to 400 people across BC. We are continuing the revolution with The Parkinson's Movement, see page 13 for more details.

AWARENESS

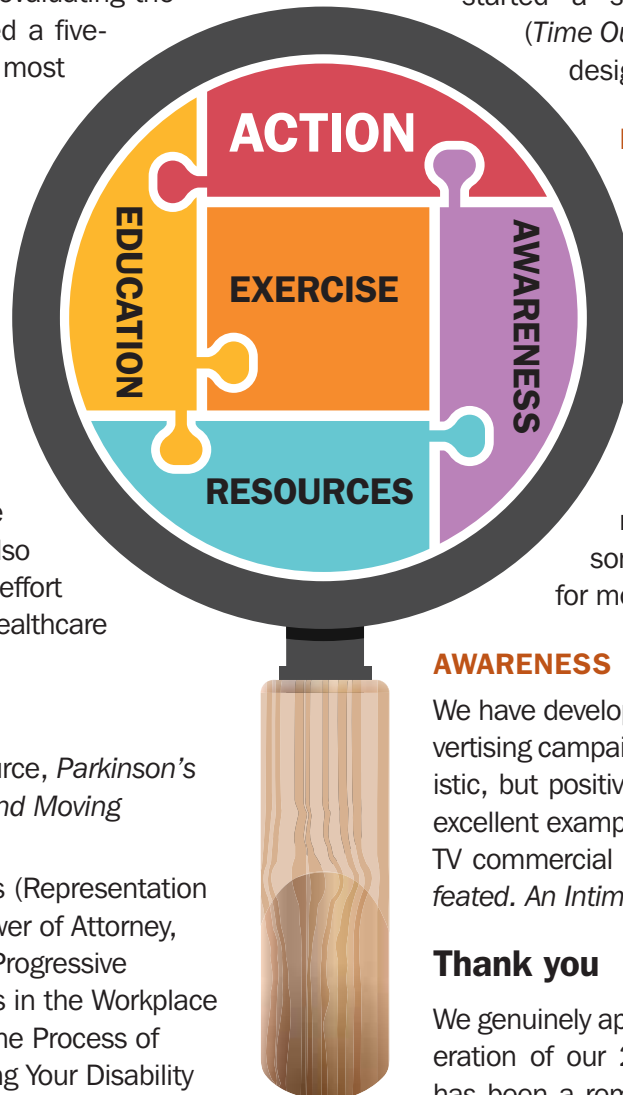
We have developed strong marketing and advertising campaigns that communicate a realistic, but positive and hopeful message. Two excellent examples are the *You Are Not Alone* TV commercial and the documentary, *Undeated. An Intimate Portrait of Parkinson's.*

Thank you

We genuinely appreciate the time and consideration of our 2009 survey respondents. It has been a remarkable five years of continued improvement. Thank you!

If you have feedback you would like to share regarding PSBC and its services, please email us at: info@parkinson.bc.ca. We are always happy to hear from you!

Please visit www.parkinson.bc.ca to access our latest resources, register for education events or to participate in fundraisers for the Society.



brain teasers

Enhance cognitive health



Time to flex your thinking muscles! Doing crosswords and puzzles, learning a new language and spending time with friends and colleagues are all important parts of preserving your brain health and memory. Get started today with these brain teasers:

- 1 Johnny's mother had three children. The first child was named April. The second child was named May. What was the third child's name?
- 2 A clerk at a butcher shop stands five feet ten inches tall and wears size 13 sneakers. What does he weigh?
- 3 Before Mt. Everest was discovered, what was the highest mountain in the world?
- 4 How much dirt is there in a hole that measures two feet by three feet by four feet?
- 5 What word in the English language is always spelled incorrectly?
- 6 Billie was born on December 28th, yet her birthday always falls in the summer. How is this possible?
- 7 In British Columbia you cannot take a picture of a man with a wooden leg. Why not?
- 8 If you were running a race and you passed the person in 2nd place, what place would you be in now?
- 9 Which is correct to say, "The yolk of the egg is white" or "The yolk of the egg are white?"
- 10 A farmer has five haystacks in one field and four haystacks in another. How many haystacks would he have if he combined them all in one field?
- 11 My first is often at the front door. My second is found in the cereal family. My third is what most people want. My whole is a united state.
- 12 Smell me, buy me, and deliver me. I won't change.
- 13 A man and his son are in a car accident and the man is killed. The boy is rushed to the hospital. The doctor takes one look at him and says, "I can't operate on this child, he's my son!" How is that possible?
- 14 We hurt without moving. We poison without touching. We bear the truth and the lies. We are not to be judged by our size. What are we?

Answers: 1. Johnny. 2. Meat. 3. Mt. Everest. It just wasn't discovered yet. 4. There is no dirt in a hole. 5. Incorrectly (except when it is spelled incorrectly). 6. Billie lives in the southern hemisphere. 7. You can't take a picture with a wooden leg. You need a camera (or iPad or cell phone) to take a picture. 8. You would be in 2nd place. 9. Neither. Egg yolks are yellow. 10. One. If he combines all his haystacks, they all become one big stack. 11. Matrimony: mat-rye-money. 12. Scent, cent, sent. 13. The doctor is the boy's mother. 14. Words.

April is Parkinson's Awareness Month

Move to improve.
Join The Parkinson's Movement

The goal of our April Awareness campaign is to spread the word around the benefits of exercise **and** to raise funds for specifically-designed exercise programs for people living with Parkinson's.



Here's how to join The Movement:

1 **Commit** to doing your favourite form of exercise from now until at least the end of Parkinson's Awareness Month. April 30th. Plan to carry on!

2 **Register** online (www.parkinson.bc.ca) and create your own personal profile detailing your exercise commitment.

Example: I'm committing to start a walking program and to walk a total of 50km (or bike 200km) from March 10th to April 30th. Please support me as I walk and raise funds for much-needed exercise programs for people living with Parkinson's.

3 **Ask** for pledges from family, friends, co-workers, neighbours, that woman you wave Hi! to when you walk your dog, the bank teller, the grocery store clerk, everyone on Facebook, and of course, the server at your local coffee shop!

4 **Feel good.** If regular exercise is new to you, feel good that you've made a lifestyle change. If you're already breaking a sweat regularly, feel good that you've raised money to help the Parkinson's community.

More and more research supports the theory that exercise is one of the best non-medical options to manage Parkinson's symptoms. Help us improve the lives of those living with Parkinson's.

Go to www.parkinson.bc.ca to register or donate to **The Parkinson's Movement** today!

Other ways you can participate in Parkinson's Awareness Month:

- Organize an information day at a shopping mall, community centre or church and distribute PSBC brochures and information materials.
- Become a **Champion for Parkinson's** and host a fundraiser—it could be a garage sale, pub night or an *Undeclared* movie screening in your home. Contact Betty Hum bhum@parkinson.bc.ca for your step-by-step planning guide, materials and event kit.
- Deliver information to general practitioners, neurologists, hospitals, and residential care facilities in your community.
- Spread the word through Facebook and Twitter. Remember to “like” our Facebook page to share our posts!

Make an Impact

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! From bake sales, birthday parties and beer tastings, to tennis tournaments and car shows, no event is too big or too small. Take the lead, get creative, build awareness, raise funds and don't forget to have fun!

We are here to help you plan a successful event.

We provide:

- FRIENDLY SUPPORT
- STEP-BY-STEP PLANNING
- WEBSITE & SOCIAL MEDIA SUPPORT
- EVENT KITS

Your actions have an impact. Start planning your event today!

For more information, contact Betty Hum
bhum@parkinson.bc.ca
604 662 3240 | 1 800 668 3330
www.parkinson.bc.ca/champions

Champions
FOR PARKINSON'S
Parkinson Society British Columbia



Small Change, Big Hearts

We want to highlight the tremendous support of Danya and Dwayne Carter. Since 2009, they have personally donated and collected over \$14,000 in spare change from their McDonald's customers for Parkinson Society British Columbia.

The Carters initiated their fundraising drive in honour of Danya's mother, Maria. Maria fought a long and courageous battle with Parkinson's and recently passed away in November. She was described as a kind, caring, beautiful mom, wife, sister, and truly loved grandma of four beautiful grandchildren. Danya shared with us her reason to give, "We are proud to support the Society. We know how this disease affects people and their families, and we hope this money adds to all the other generous supporters to find a cure."

We are grateful to the Carters for their amazing commitment to the Society and the Parkinson's community. Thank you.

West Coast College of Massage Therapy

613 Columbia Street
New Westminster, BC

(Near 6th Street, one block from Columbia Skytrain Station)



West Coast College of **MASSAGE** Therapy

For the third year in a row, the College is holding a special massage clinic for people with Parkinson's, caregivers and support workers.

The clinic is on **Thursdays from 4:15 p.m. to 8:00 p.m.** The cost is \$12 for people with Parkinson's and \$20 for carepartners and support workers.

We have received excellent feedback from those who have attended the clinic. If you are interested, please call the clinic receptionist at **604 520 1830**.

Access is through the back entrance on Clarkson Street and is wheelchair accessible.



Support Group News

March 29th, 2014

PSBC Annual General Meeting

Location: Broadway Church, Vancouver
Time: 10:00 am to 12:00 noon
Keynote Speaker: Dr. Ron Postuma, Neurologist
Registration: Priority will be given to members. Non-members will be waitlisted.
Renew or purchase a new membership at www.parkinson.bc.ca.

May 10th, 2014

Nanaimo Regional Conference

Non-motor symptoms of Parkinson's
Location: Nanaimo, Vancouver Island
Conference Centre
Major Speaker: Dr. Silke Cresswell, Pacific
Parkinson's Research Centre
Registration Opens: April 1st

May 31st, 2014

Kamloops Regional Conference

*Non-motor symptoms of Parkinson's &
World Parkinson Congress review*
Location: Kamloops Ramada Inn
Major Speaker: Dr. Jennifer Takahashi,
Neurologist
Registration Opens: April 1st



June 10th, 2014

Me-n-Ed's 7th Annual Charity Golf Tournament

Proceeds to support Parkinson's disease
Location: Riverway Golf Course, 9001 Bill Fox
Way, Burnaby
Registration: 11:30 am
Shotgun Start: 1:00 pm
Cost: \$200 per person, includes golf cart,
lunch, dinner, tee gift, auction and more!
Registration: Please call Cris at 604 931 2468

September 2014

Young Onset Conference

Coming September 2014—check our website
for details!

Mid-month check-in email directly to group members

To enhance our connection with members of support groups, we have started mid-month email updates sent directly to group members. This is in addition to *GroupLink* which continues to be sent to group facilitators.

The mid-month connection is optional and any group member may contact us with their email address in order to receive more personal communication during the month. Topics covered will include notices and announcements that are time-sensitive, plus conversation and check-ins of a less formal nature. If you wish to be on this email list, please send your email to Stacey Dawes (sdawes@parkinson.bc.ca).

RESOURCES

Navigating Life with Parkinson's Disease

Sotirios Parashos, Rosemary Wichman, Todd Melby, 2013
A guide containing the most up-to-date information emphasizing lifestyle adjustments that will provide a better quality of life and moderate the burden for those with the disease and their loved ones.

Parkinson's Disease: A Complete Guide for Patients and Families

M. Shulman, Anthony E. Lang, 2013
Updated versions containing new understandings gained by five years of additional research on Parkinson's disease.

Making the Connection Between Brain and Behaviour: Coping with Parkinson's Disease

Joseph Friedman, 2013
Updated and revised including three new chapters and two new appendices. The resource includes more information on a variety of treatment options, including Electroconvulsive Therapy.

notice of annual general meeting

Saturday, March 29, 2014

10:00 am—12:00 pm | Registration 9:30 am

BROADWAY CHURCH

2700 East Broadway, Vancouver | Entrance on Slocan Street

GUEST SPEAKER

Dr. Ron Postuma
Neurologist, McGill University

*Understanding and Coping
with Non-Motor Symptoms
of Parkinson's Disease*

Dr. Postuma studies non-motor manifestations of Parkinson's disease, particularly sleep disorders. He is testing how to predict Parkinson's disease, particularly by studying patients with REM sleep behaviour disorder, which is a major risk factor for the disease.

He is also looking for ways to improve detection and treatment of non-motor problems, including clinical trials for treatments of sleepiness and insomnia. He has ongoing studies for dance therapy in Parkinson's disease cases, and is initiating a large-scale study of caffeine for treatment of the disease.

Free parking, wheelchair and elevator accessible
Light refreshments will be served

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