



Spring 2014

LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO



What started as a simple fundraiser—two friends who wanted to raise money for the Society—has grown from a two-man ride to a 100-rider movement in just two years. The ride offers different routes to suit all fitness and skill levels.

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Pedaling for Parkinson's Rides Again

In what has become one of the Parkinson Society Central & Northern Ontario's most anticipated annual events, avid cyclists and impressive fundraisers Peter Istvan and David Newall, along with their families and more than 100 other supporters, will be hitting the roads of Parry Sound this summer to ride in support of people living with Parkinson's.

During the event, a few dedicated riders will cycle the equivalent of 100,000 pedal strokes, which represents one for each person in Canada living with Parkinson's. The grass roots nature of the event is a real appeal to participants, as is the chance for out-of-towners to take in the beauty of Parry Sound; enjoying a ride through picturesque roads and trails, and being welcomed by a group of people all with the same goal in mind—contributing to the Pedaling for Parkinson's research grant. Pedaling for Parkinson's great success (they raised over \$96,000 in 2013 as part of a lifetime total that is expected to exceed the quarter million dollar mark this year) has allowed for the development of a specific research grant named in honour of the event.

All funds raised through this campaign go to support the National Research Program. This year's recipient is Dr. Ali Salahpour, whose hope is to see his research pave the way for a new class of drugs that can be used for treatment of Parkinson's, by changing the levels of dopamine production or the effectiveness of current drug therapies. Watch for a fresh new website for 2014—check details online at www.pedalingforparkinsons.ca, or call Jon Collins at 800-565-3000 ext. 3370 for more information. Online registration opens March 10, 2014.



Parkinson Society Central & Northern Ontario
Société Parkinson du Centre et du Nord de l'Ontario

In Partnership with Parkinson Society Canada

Parkinson Society Central & Northern Ontario

As I write this message I am surrounded by cold and snow! I know that by the time you read this, spring will be in our view, if not already here, and I know you will all be as thrilled as I am that the winter has gone—it has been a long one!



As we take this time of the year to bring awareness to Parkinson's disease, I hope you will join with us in these efforts—in this issue of LiveWire, you will read about tulip sales, the Cut-a-thon, our education events throughout the region, and SuperWalk. We value your support as attendees and volunteers so thank you for helping us to be successful!

For the first time in many years, we are holding a region-wide conference on October 24 and 25. We already have the location secured, some great speakers lined up, and a great overall experience planned. Read some of the details on page 7 and don't forget to save the date.

Please let us know if there are topics you would like us to cover in our regular development of LiveWire content—things you would like to learn about, or anything we are missing in preparing LiveWire. Copies are distributed to approximately 6400 households in Central & Northern Ontario so we want to ensure it is beneficial for all of you.

Enjoy!

What We Do

Support Services

We provide consistent and excellent support to people living with Parkinson's and their families to make their lives better.

Education

Our goal is to provide excellent seminars and conferences to different areas in the region and online so that this information is readily available. We also offer smaller sessions during support group meetings all over the region.

Advocacy

Our Ontario-wide Advocacy Committee works to influence the behaviour of key government officials and agencies in support of people living with Parkinson's, and build strong relationships with the Local Health Integration Networks across Ontario.

Research

Parkinson Society Central & Northern Ontario fully supports the National Research program and sends all research donations to support this program.

PSCNO could not fulfill its mission without the generosity of its donors and volunteers! To help ease the burden and find a cure, call 800-565-3000 ext. 3378 or visit www.parkinsoncno.ca to make a one-time or monthly donation. Thank you for your continued support!

Who We Are

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Parkinson Society Central & Northern Ontario

Société Parkinson du Centre et du Nord de l'Ontario

In Partnership with Parkinson Society Canada

Clinical Study

Parkinson Cut-a-thon 2014

April 13, 2014

Book your appointment today

Participating salons in: Barrie,
Bracebridge, Burlington,
Collingwood, Guelph and Port Hope

Thank you Toronto Salons:

Anthony Passero Salon
Donna Dolphy Hair
Earth
Ferraro Salon
Haartek
Oskar on Scollard
and Sassoon.

JOICO
THE ART OF HEALTHY HAIR

www.cutathon.ca
or 800-565-3000 ext 3374
for more information



Support Group for Care-partners of Individuals with Parkinson's Disease

Are you the primary carepartner of someone with Parkinson's disease? We are looking into starting a support group in Oakville.

This group aims to provide an opportunity to interact with other carepartners and discuss experiences, challenges, or concerns.



Learn about coping strategies, research information, and community resources. Meetings would be held once a month, at a location to be announced in the Oakville region. Would you be interested in becoming a group member? Are there any barriers that may restrict your commitment to this group? If you're interested, have questions or feedback, or wish to schedule a meeting, please don't hesitate to call Karen Dowell at 800-565-3000 ext. 3376.

Studying Visual Hallucinations in Parkinson's Disease

Visual hallucinations (VH), or seeing things that are not really there, can occur in Parkinson's disease (PD). Some people see people, animals, or insects that may appear very real to the person experiencing them. Often these occur at night, but they may also occur in the day.

For some people these symptoms occur in the setting of an infection, and thus if you experience these symptoms for the first time, you should always get your family doctor to check you for any other inter-current medical problem. Other people may experience VH when they start or change their PD drugs. If this occurs, then you need to tell your neurologist, as the drug or dose may need adjusting.

For some people though VH can be just part of life with PD, and therefore chronic. **You should always tell your doctor about VH**, regardless of how long you have experienced them. Sometimes if the VH become frightening, you may need specific drugs to stop them happening. At present it is not clear why some people get VH and what really causes them.

The team at the Toronto Western Hospital are carrying out a series of studies to better understand VH in PD. They have performed a pilot study (funded by Parkinson Society Canada) that showed that there are changes in a chemical called serotonin, or 5HT2A, in a region of the brain called the infero-temporal cortex in PD patients with VH compared to PD subjects without VH. This is interesting as medications that are used to treat VH may target such 5HT2A receptors.

They are now recruiting more people with PD who have VH as well as

people with PD who do not have VH, to further compare changes in 5HT2A (funded by the Michael J. Fox Foundation for Parkinson Research). The results are being measured using a special scan called Positron Emission Tomography (PET). In addition, we are assessing all subjects for memory and other cognitive (thinking) processes to compare changes in the PET scans.

Summary

The aim of the study is to better understand the causes of visual VH in Parkinson's disease. The team at Toronto Western Hospital want to do further studies where they measure 5HT2A receptors using PET in people with PD who have VH and compare this result to those who do not have VH. They also want to measure patterns of cognition, how you remember (memory), think, and speak that may be associated with changes in 5HT2A.

Recruitment Criteria

You may be eligible if you have the following:

- Parkinson's disease
- Visual hallucinations
- No significant memory problems

If you are interested in knowing more about this study or would like to see if you are eligible to participate, please call the study coordinator, **Taneera Ghate**, telephone: **416-603-5800 ext. 3415** or email: taneera.ghate@uhn.ca

Dr Susan Fox, Dr Antonio Strafella, Dr Sarah Duff-Canning, Dr Mateusz Zurowski; Movement Disorder Clinic, Toronto Western Hospital, 399 Bathurst St., Toronto



Dr. Susan H. Fox, B.Sc, MB ChB, MRCP(UK), PhD, is an Associate Professor of Neurology at the University of Toronto, Movement Disorders Clinic at Toronto Western Hospital. She is the Director of the University of Toronto's Neurology Fellowship program. She is an IEC member of the Movement Disorder Society, on the editorial board of the Movement Disorder journal, and a member of the Parkinson Study Group. Her current research includes pre-clinical studies investigating disease mechanisms of Parkinson's disease and other movement disorders, as well as phase II and phase III clinical trials of new treatments for Parkinson's disease and dystonia.

The Nurse's Desk

Thou Shalt Exercise and Thou Shalt Feel Better—Use It or Lose It

Sandie Jones, RN

These are the words of Dr. George Turnbull, a man who was truly ahead of his time in more ways than one. Dr. Turnbull, a professor of physiology at the University of Dalhousie, Halifax, dedicated his life to people living with Parkinson's, and healthcare professionals including physiotherapists and rehabilitation therapists. He lectured all around the world about his belief in the importance of early intervention in every aspect of management of Parkinson's, including medication, speech therapy, and physical therapy as he believed that the traditional approaches being used at the time (around 1990) were much too conservative.

Because early management of the condition with medication is very effective, and symptoms are well controlled at the beginning, patients are lulled into a false sense of security and don't start to exercise until late in the game when they are already fairly disabled, and may have complicating factors such as a fractured hip. Ringing any bells yet?

Another mitigating factor was the fact that at that time, neurologists didn't understand the importance of early intervention and exercise either, so those things were never included in the discussions during patients' appointments. If the doctor didn't mention it, it couldn't be very important. Right? Wrong!

Thanks to research within the last 10 years that proves the benefit of exercise as well as more opportunities for physical activity for people with Parkinson's, the tide has turned. Now many neurologists recommend exercise for all their patients, regardless of where you are on the continuum.

So what does the research show? Exercise can

- improve posture, strength, balance, walking ability;
- limit physical decline;
- reduce some symptoms;

Live Well with Parkinson's Survey

Dr. Galit Kleiner-Fisman, the Director of the Movement Disorder Clinic at Baycrest Hospital, will be speaking at PSCNO's October regional conference addressing practical strategies to maximize symptom control and improve quality of life. **To this end, she and her team have developed a Live Well with Parkinson's website and she is now endeavoring to improve this website to make it a resource that is truly reflective of the needs of the PD community.** There is a component of the website that deals with medication and diet and so, in collaboration with George Brown College, Dr. Kleiner-Fisman has created a questionnaire to determine the current knowledge of people living with Parkinson's regarding protein and L-dopa so they can determine next steps and needs that have not been addressed. We would appreciate it if you could take five minutes to answer the online survey: bit.ly/1eKfYYE

- slow disease progression;
- be disease modifying; and
- protect your brain from cell loss.

In case you are wondering if it is ever too early or too late to start exercising, the answer is NEVER! Benefits can be seen at any stage of the disease.

There are basically four stages of intervention:

- **Pre-habilitation**
 - Start before there is a problem.
 - Begin a program even if you don't have a problem with stiffness and balance.
- **Rehabilitation**
 - Fix the problem.
 - Learn how to get out of a chair, get out of bed, improve posture, and deal with freezing.
- **Preservation**
 - Do not lose what you have.
 - Find something you like and stick with it. Be able to do tomorrow what you can do today.
- **Prevention**
 - Do not add new problems.
 - Perhaps find the right assistive device or do home modifications.

Now, for the Million Dollar Question: "What Exercise Should I Be Doing?" Your exercise should be geared to whatever mobility issue is causing *you* the most difficulty. A general Parkinson's disease program should include the following:

- Mind exercises: challenges your attention, reasoning, and timing
- Aerobic exercises: helps with endurance
- Balance exercises: helps with posture and walking
- Strengthening exercises: helps with endurance and posture
- Flexibility exercises: **S T R E T C H**

Research is showing exciting results in the use of different types of exercise including walking, swimming, yoga, Tai Chi, dancing, Pilates, and many others. The bottom line is **you name it, you like it, and you do it!**

One thing is certain when it comes to exercise: there is no question that your specialist can clearly see the differences between those people living with Parkinson's who remain physically active, and those who are sedentary and do not—you will see the difference in yourself too!

USE IT OR LOSE IT—IT'S YOUR CHOICE!

If you have not received your free exercise booklet from Parkinson Society, please call us!

Information and Referral

Considering 'Alternatives': Complementary/Alternative Medication and/or Treatments (CAMT)

Robert TerSteege, CIRS-CAN

I would be lying to say that I have never tried a complementary/alternative medication and/or treatment (CAMT). I've tried simple things like home remedies for the common cold and homeopathic treatments for cold sores. I regularly use non-intrusive complementary treatment for pain management, alongside my prescribed regiment of pills. My GP is very aware: he is open to CAMT, willing to share what he does and doesn't know about a product or treatment.

At the same time, I am a 'doubting Thomas,' and will not just randomly try any CAMT because it was recommended by a friend of a friend. Sadly, for every disease known to humankind, someone is willing to sell a 'miracle cure.' Because of charlatans over the years, the process of careful scientific research has been created so that ultimately, the same results should be demonstrated each time.

When we speak of any treatment for Parkinson's—whether it is conventional Western medicine, or any CAMT—we are careful to base our answers on research that has been published in independently peer-reviewed journals. We neither recommend nor endorse any product or treatment, but provide the information we have so people can make an informed decision on their own health. We know that the best answers we can hope to give will come from research using the gold-standard of a double-blind study: meaning neither the patient nor the researcher knows whether they are getting the new treatment or a placebo.

Often, I hear people complain about "Big Pharma" making money off of sick people, and that natural is better. There are people in drug development that may be in it for the money, but there are also people providing CAMT who are in it for the money as well. 'Natural' does not automatically equal 'safe': grapefruit juice is all-natural, but, if taken with certain medications, it will increase the absorption rate, and potentially kill you.

We need to keep in mind that unlike a pill that is consistently 100 mg, CAMT

is not regulated by drug legislation, so pills may not be consistent. Similarly, when taking food, e.g., beans or oils, it is extremely difficult to say that there is exactly the same amount of treating component in each dosage.

We need to keep in mind that many medications and treatments that we do use have their basis in herbal remedies, but have been refined to produce the pills we have today. Willow bark tea, which contains salicylic acid, was later refined to acetylsalicylic acid—better known as Aspirin. Mouldy bread poultices led to penicillin. This is why we do not speak against CAMT either: today's home remedies may have the potential to be tomorrow's treatment!

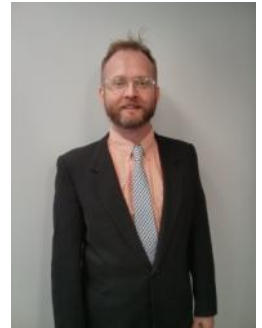
It is important to understand the proof being offered as a reason to try any treatment. Anecdotal testimonials can never replace hard facts, but hard facts may be difficult to understand. Charts of numbers and pretty graphs can look very impressive, but this is why we don't rely on self-published materials, but material published in journals: experts are able to pick out the flaws in research, but self-published material is often kept out of scientific circles, as the data will be disproved.

So where does CAMT fall in a discussion with Parkinson's? Some CAMT has undergone double-blinded studies, and some is currently being researched. Some have been proven not to work, and on some the jury is still out.

Let's take a step backward, and see what we do know. Parkinson's disease was first formally written about in 1817, though there are ancient writings that describe the condition as well. It is a condition that exists worldwide. Levodopa first became available in the late 1960s/early 1970s. It essentially replaces the missing naturally produced dopamine. That's about a 150-year window of opportunity to come up with something else.

Short of a cure, and short of halting the loss of dopamine producing cells, replacing the missing chemical with a chemical substitute is still the best treatment currently available worldwide!

Even in countries whose traditional medicines include plants that contain certain levels of natural dopamine, levodopa is still the recommended medication: it is standardized dose to dose.



Some CAMT is based on half-truths and misunderstanding. Certain antioxidants have been touted as 'cures,' and people have demonstrated certain levels of improvement, but not in double-blinded studies. Where the improvement seemed to be coming from was people not only taking supplements, but making a lifestyle change of eating healthier, and exercising—things that we have been maintaining as important as part of overall health! Looking at this from a different angle, we know that there is a lower rate of PD among smokers compared to non-smokers... but we don't promote smoking, because that comes with its own health issues!

In the absence of proof one way or the other, we consider

- if the product/treatment makes you feel better;
- if the product/treatment does not interfere with your prescribed medications;
- and if the product/treatment does not cost you an arm and a leg...then why not?

You still need to let your doctor(s) and specialists know what you are taking. If it is working, this is the way to get it to the attention of researchers, thus helping other patients. Also, there are certain compounds that may interfere with your normal medications, e.g., iron in a multivitamin may have the same effect as protein in blocking absorption.

Regardless of what therapy options you choose to explore, make an informed decision, and keep your doctor in the loop.

Around the Region

PARKINSON SUPERWALK LAUNCHES SUPER WEBSITE

The new and improved Parkinson SuperWalk website launches on May 8 to serve you better.

The parkinsonsuperwalk.ca website retains many of the features returning walkers will appreciate, along with many new enhancements.



Some of the features you can look forward to are the following:

- A simple and intuitive registration process, including the option to sign-in using your social media accounts.
- Personal fundraising pages that are easy to update and customize—it's here you can include a photo and honour someone special, or share why you are participating
- Easily upload and enter email addresses of friends and coworkers, making it simple to send donation requests and thank you emails. The process is very straightforward this year!
 - Track who has donated to you and whether or not you have thanked them with our improved message center.
- Track your fundraising progress with a fundraising thermometer on your personal fundraising page. You can still fundraise using traditional methods—simply enter the amount of cash and cheques you collect to show a complete picture of how much money you've raised!
- Find out what's happening in CNO as well as other walks across Canada.
- Most important of all, this site is well functioning—developed in partnership with an industry leader in online giving, rest assured that your walker and donor experience will be improved in 2014.

For those of you who want to get started on your personal campaign early, printed pledge forms will be available in April during Parkinson's Awareness Month. Contact Amanda Stanton (amanda.stanton@parkinson.ca / 800-565-3000 ext. 3371) for details.

We are very excited about Parkinson SuperWalk 2014 and we hope you will be too!

My Diagnosis and DBS (A Personal Journey)



Nancy Joyce Vickers

My Parkinson's diagnosis came in 2005, after some time of being told I had an essential tremor, and of me making excuses for my shaking, like too much coffee.

My husband, Doug, and I had just moved into a lovely apartment. He was busy buying furniture while I was thinking: PROGRESSIVE, DEGENERATIVE, NEUROLOGICAL DISORDER. I was thinking of my future, OUR future. Me? What? What if a wheelchair didn't fit through the door? I was worried I would find out soon enough.

I started Sinemet and the shaking stopped—until it started again. Thus began my education: dyskinesia, dysarthria, dysphagia, and dystonia. It seemed like I had all of them at one time or another, along with DYS-belief and DYS-stress.

My dyskinesia was so bad, Doug and I could not go out in the evening. After this went on for a few years, it was time to have a consultation for surgery. We were afraid to tell anyone, but it soon became obvious.

In 2010, my husband started losing weight and would not believe it, or go to a doctor, until I brought home a bathroom scale and showed him the proof, along with coordinated co-nagging from his sisters. Only when he could no longer keep food down would he stop working; and he had lost 50 lbs before he would go to a walk-in clinic. After tests and many visits, he was diagnosed with esophageal cancer. I had to step up real fast and become the caregiver.

Then it finally came, my first consultation for the DBS surgery. Doug and I were sitting in a treatment room when the question came, "Are you depressed?" I started crying, "No, just very sad. My husband has cancer." That would be the only appointment Doug could make it to. The next two years, 2010 to 2012, we spent on a fabulous trip, then taking Doug to his various appointments: first chemo, then weekly blood transfusions, and radiation. I finally found out that a wheel chair would not pass through our door. In August of 2012 Doug passed quietly in hospice, just the two of us, alone, while I was holding his hand.

Now I had to concentrate on myself. I was soon given a surgery date, one year since Doug's passing. There was my angel in the surgical theatre, giving me the courage to do alone what we had started together.

What has changed? Although I still have Parkinson's, I feel better. It's difficult to pinpoint, except that I don't worry about 'it.' I can go to restaurants I've been waiting to try. The night time 'heebie-jeebies' are gone. I finally gave in and adopted two kitties from the Humane Society (or did they adopt me?) so I have a family again. I am even going to my niece's wedding in Alberta this summer.

To all the treatment recipients past, present, and future: together we can find a cure.

Around the Region

Regional Education Event: October 24 and 25, 2014

To be held at the Westin Bristol Place, Toronto.

Friday evening dinner, key note speaker, and *So You Think You Can't Dance!*

- Key note speaker is Joseph DeSouza who is researching Dance Therapy for Parkinson's Disease. Dr. DeSouza is studying how dance is able to bypass the neurodegeneration that occurs in the PD brain and facilitate improved movement through analyzing a series of brain imaging scans of the participants to demonstrate change in brain activity.
- Dance demonstrations
- Dance for all attendees to end the evening

Saturday Education Sessions

- Dr. Ron Postuma, researcher and author of the popular booklet "A Guide to the Non-Motor Symptoms of Parkinson's Disease" will be presenting on PD, much more than a movement disorder.
- Dr. Galit Kleiner-Fisman, Medical Director of the Jeff and Diane Ross Movement Disorders Clinic at Baycrest, will speak about the Live Well with Parkinson's website, including information about low protein meals that could be the key ingredient in managing PD.
- Introduction to various options for exercise

A block of rooms has been reserved at the Westin Bristol Place for those wishing to stay overnight.

Online registration will open June 1.

Save the Date—More Details to Follow!

Other 2014 Regional Events

Mark your calendars for the 9th Annual Parkinson's Education Evening, May 7, 5:30 p.m. – 9 p.m., at the Royal Botanical Gardens in Burlington. The topic is **Living Well After a Diagnosis of Parkinson's Disease** by Dr. Soania Mathur. Free but registration required (karen.dowell@parkinson.ca or 800-565-3000 ext. 3376).

Join us in Barrie on May 20, venue to be confirmed, for our guest speaker Sarah Robichaud, **Dancing with Parkinson's**.

Enjoy an **afternoon tea** at the Golden Plough Lodge, Cobourg, on Wednesday, May 28 at 12:30 p.m. Guest speaker is Dr. Naomi Visanji. This is a free event but registration is required (diane.newmanreed@parkinson.ca or 800-565-3000 ext. 3315).

Get ready to **Putt for Parkinson's** this summer on June 23 at the Royal Ontario Golf Club. Join us as we partner with the Royal Military College Alumni Association in an event to benefit both charities. The event features a 1:30 p.m. shotgun start with dinner to follow, and some great prizes at one of the top courses in the GTA. All this for \$200 per person, or \$800 per foursome. Don't play? Help us spread the word and fill up with Parkinson Putters!

Pitch In! for Parkinson's is back this year. Stay tuned for further details about a special event coming this summer, but game day at the ball park will be Saturday July 19 against the Texas Rangers. This Saturday afternoon (1:07 p.m.) start time is sure to be a lot of fun for all Jays fans. Donated season tickets help ensure that all proceeds from the initial sale go directly to the Society, but supplies are limited.



Dance to Make a Difference!

- Register your fundraising team.
- Learn the dance online.
- Attend free rehearsals with fellow fundraisers.
- Join us for **Sharing Dance Day**, May 4, 2014, at Yonge-Dundas Square.

In support of  Parkinson Society of Canada & Parkinson Society of Ontario

In partnership with



Follow us on twitter: @sharing_dance
Find us on facebook: facebook.com/sharingdance.ca
Watch us on youtube: youtube.com/sharingdance

Check online for instructional dance videos and educational resources.
www.sharingdance.ca

Hope in Bloom

Hope in Bloom Tulip Campaign Celebrates 30 years this Parkinson's Awareness Month

Toronto's Fera Jeraj will be participating at this year's Hope in Bloom tulip campaign. Motivated to make a difference, she will be managing a tulip site with her husband, Salim Jivraj, and children, Aleena and Arman Jivraj.



Both Fera and Salim have volunteered since they were children and felt they received many positive benefits from it. Now, they want to continue with the tradition so that their children can have the same rewarding experience.

"In today's society, it's really easy to get caught up in the day-to-day routine and lose sight of what's important. I think volunteering as a family is a great way for us to bond as a unit, but even more importantly, I think it's a humbling experience for the kids," says Fera. "I believe volunteering teaches them the benefits of giving back to the community. Hopefully they will get a lot of satisfaction and pride out of this experience."

The Jivraj family will be participating on Saturday April 19 at Fairview Mall, and Fera was happy to tell us that her children are looking forward to the volunteering opportunity.

"The kids are starting to come up with strategies on best ways to attract buyers. They have a little competition going on between themselves to see who can raise the most money," she says.

In 1984, a group of dedicated volunteers began the Hope in Bloom campaign selling fresh-cut tulips across the GTA during the month of April to bring awareness to Parkinson's disease. Thirty years later, the Hope in Bloom campaign now raises \$120,000 per year while it continues to increase awareness about Parkinson's disease during April, Parkinson's Awareness Month. Although staff are more involved now, the true execution and spirit of the campaign still lies in the hands of hundreds of enthusiastic volunteers (many with Parkinson's disease) as they set out across the GTA and beyond to sell tulip bouquets and pots.

We invite you to come celebrate the 30th anniversary of the Hope in Bloom Tulip campaign with us by participating as a family or a group at one of our tulip-selling sites. For more information, please contact Naseem Jamal at naseem.jamal@parkinson.ca or via phone at 800-565-3000 ext. 3377.

2014 Membership Survey

We want to hear from you! Your opinion is valued, and we want to be sure that we're providing the highest level of service to people living with Parkinson's in our Region. Starting April 1, the advent of Parkinson's Awareness Month, we'll be collecting your responses to the end of May. For details on completion incentives, background on why we're conducting the survey, and how to participate, please visit <https://www.surveymonkey.com/s/cno2014>, ask your Chapter President or Support Group coordinator for a copy of the printed survey, or contact Parkinson Society CNO to be mailed a copy.

New Buddy Program at PSCNO

REMINDER

In January 2014, PSCNO started its own Buddy Program. We have two volunteers: Bill Sloan is the volunteer who matches PLWP and Barry Shorrocks, the primary carepartner for his wife, Ann, matches carepartners.

Not everyone is comfortable speaking at support groups, and not everyone has easy access to a support group. The Buddy Program will offer an opportunity for people to be matched with others who understand the day-to-day issues they face and can offer friendship and support.

If you are interested in becoming a buddy, you can contact Bill at bill.sloan@parkinson.ca or Barry at barry.shorrocks@parkinson.ca.

Hope in Bloom

Parkinson Society Hope in Bloom Tulip Campaign 2014

The Parkinson Society's Hope in Bloom tulip fundraising campaign is celebrating 30 years! For 30 years, our dedicated volunteers at different companies and on-site venues have been selling fresh-cut tulips in an effort to raise awareness of Parkinson's disease, and have worked together to raise funds to help ease the burden and find a cure through research, education, advocacy, and support services.



Parkinson Society needs your help by being our Tulip Ambassador at your organization; this could be any organization that you are involved with, such as

- the company you, your friends, or family work at;
- the hobby club that you belong to, such as a Book Club, Exercise Group, Sailing Club, Hiking Club, etc.

Being a Tulip Ambassador simply means encouraging individuals at your organization to purchase fresh-cut tulips in the month of April, which is Parkinson's Awareness Month. It's a pretty easy process.

Please check the box below and fax (416-227-1520) or email Naseem Jamal (Naseem.jamal@parkinson.ca), and a Hope in Bloom Package will be mailed to you.

Your participation in this fundraising campaign makes an enormous difference!

Many thanks in advance.

PARTICIPATION FORM

☐

Yes! We will participate in the April 2014 Hope in Bloom Campaign.

ORGANIZATION NAME: _____

CONTACT NAME: _____

EMAIL ADDRESS: _____

MAILING ADDRESS: _____

CITY: _____ POSTAL CODE: _____

TELEPHONE NUMBER: _____

Porridge for Parkinson's

Porridge for Parkinson's (Toronto) \$150,000 Recipe



Top Photo: Graduate Student Research Award recipient Jean-Francois Daneault with Gay Evans **Bottom Photo:** Spencer Lanthier, Jamie Kennedy and Bonnie Jackson

The Porridge for Parkinson's (P4P) committee is proud to announce that A Breakfast Tasting, held on Sunday November 3, 2013, raised over \$150,000 for Parkinson's research.

The committee could not have raised this amount if it were not for the wonderful donors and supporters who recognized the importance of Parkinson's research and gave with hope and generosity. Thanks to these donations, two Parkinson Society Canada (PSC) Graduate Student Research Awards have been funded, as well as the number one ranked PSC Pilot Project for both 2013 and 2014.

Our recipe for success?

- Book a great venue—Vaughan Estate on the grounds of Sunnybrook Hospital.
- Invite some of Canada's great chefs to prepare and serve delectable breakfast treats (including porridge).
- Secure tempting silent auction items.
- Have Canada's own Jeanne Beker as our host along with a great guest speaker, Dr. Edward Fon, to inform and stimulate the guests in attendance.

We want to thank all who gave so generously and continue to support P4P.

Sadly, our success in 2013 is bittersweet. Marg Meikle, the founder of Porridge for Parkinson's, succumbed to the disease at the age of 57. In 14 years, Marg's annual 'bowl movement' in Vancouver raised more than \$1.6 million with proceeds going to the Pacific Parkinson's Research Centre at the University of British Columbia. She will be fondly remembered for her humour, tenacity, and courage. After her death, the Pacific Parkinson's Research Institute announced that its recent endowment at UBC would now be called the Marg Meikle Parkinson's Professorship. Her legacy will always bring awareness to the human side of Parkinson's disease, and to inspire research that will help find a cure.

2014 Volunteer Award Nominations

Each year, at our Spring Volunteer Tea, we present three important volunteer awards.

The **Derek Curwen award** is presented to volunteers who exemplify his fundraising expertise, ability to inspire and lead others, and whole hearted support of Parkinson Society Central & Northern Ontario.

The **Marilyn Forbes award** is presented to volunteers nominated by their peers who exemplify her dedication to their chapter, support of people living with Parkinson's, and the work of the Parkinson Society Central & Northern Ontario.

The **Ian Davidson award** is presented in recognition of volunteers who have Parkinson's disease and have been role models in providing guidance and support that improved

the lives of others living with Parkinson's in Central & Northern Ontario and/or increased public understanding of their situation through such activities as leading support groups, public speaking, advocacy, volunteering, and fundraising.

The recipient of the Ian Davidson award is selected by previous winners of the award. The recipients of the Derek Curwen award and the Marilyn Forbes award are selected from nominations by people in the Central & Northern Ontario area.

If you would like to nominate someone, please contact your Community Development Coordinator or Louise LeBlanc, Coordinator of Volunteers, at 416 227-1200 ext. 3304 or louise.leblanc@parkinson.ca. Nominations for the 2014 awards are due by April 30, 2014.

The First Parkinson **Giant** Pumpkin Contest

Seeds are provided through Giant Vegetable Growers of Ontario.



You'll need a fairly large area as these pumpkins can grow from 200 lbs to more than 1,500 lbs. They will be ready early in time for SuperWalk promotion. If interested, contact Jim Wilkinson (905-279-0627 or jrwilkinson@sympatico.ca).

Save the Date!

2nd Annual Silver Lakes Golf Tournament for Parkinson's Research, August 14, 2014

Our Mission

Parkinson Society Central & Northern Ontario works in partnership with Parkinson Society Canada and eight other regional partners across Canada to ease the burden and find a cure through support services, education, advocacy, and research.

Parkinson Society CNO
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Toronto, ON M2P 2A9
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800-565-3000 or 416-227-1200
Charitable No: 10809 1786 RR0001

LiveWire is published three times annually: in the spring, summer, and fall. Expect our Spring edition in March, our Summer edition in August, and our Fall & Winter edition in November.

The **LiveWire** newsletter is published to provide helpful information to people affected by Parkinson's in Central & Northern Ontario. It is not meant to provide medical advice; readers should contact their doctors in all matters relating to health concerns and/or medication.

We welcome your feedback on current and past issues, as well as suggestions and submissions for future issues. If you have a story, a poem, or an article that you would like to submit for editorial consideration, please email the editor at livewire.editorial@parkinson.ca.

Next submission deadline is June 20, 2014.

LiveWire is offered in both hard copy and electronic form. If you are reading this copy and would like to be added to our mailing list, or if you would prefer to receive the electronic edition, please contact livewire.subscriptions@parkinson.ca to be added to our email notification list or call 800-565-3000 ext. 3474.

WOULD YOU LIKE TO HELP EASE THE BURDEN?

Milton/Scarborough/Bolton/Hamilton/Lindsay/Brampton/Newmarket/ Mississauga

We are looking for volunteers to facilitate monthly support groups to provide education and support to persons with Parkinson's, members of their families, and/or their caregivers in dealing with the challenges of living with the condition. We encourage group members to share experiences, ideas, and feelings; address challenges; develop supportive friendships; and receive current information about Parkinson's disease. These groups are held once a month, often during the day on weekdays. Training will be provided. Once training is completed, the commitment is for 3–5 hours per month. Experience in facilitation of groups or meetings is an asset. Active seniors are welcome!

Contact Louise LeBlanc at 416-227-1200 ext. 3304 or louise.leblanc@parkinson.ca



Did you know?

LiveWire is offered in both print and electronic forms. If you would prefer to receive the electronic edition, please contact livewire.subscriptions@parkinson.ca to be added to our email notification list.

LiveWire

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