LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Summer 2015

Parkinson Society Central & Northern Ontario
Société Parkinson du Centre et du Nord de l'Ontario
In Partnership with Parkinson Society Canada

I cannot get enough of summer, especially with the last two long winters we have experienced— I hope you are enjoying it as much as I am!

As you make your way through the summer issue of LiveWire, I think you will find some great information from our education staff and of course our new "Ask the Doctor" section. As you look through the information about our upcoming education sessions around the region (page 4), take note of the directions to connect to our new popular "lunch time chats with Sandie" (page 15).

I would like to personally invite all of you to join us for a Parkinson SuperWalk close to you this year. Every walk I have ever attended has a feeling of warmth, intrinsic to the day, so bring your family and friends and join in! Parkinson SuperWalk is our largest fundraising and awareness event in Canada and it will take all of us, joining together, to fight Parkinson's. Just visit www.parkinsonsuperwalk.ca and register.

On behalf of the dedicated staff and board at PSCNO, I want to thank you for your continued support—we could not accomplish all that we do without each and every one of you. We welcome suggestions so please feel free to contact me at debbie.davis@parkinson.ca.

Happy reading!

Debbie

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. We also provide support to facilitators and participants of more than 50 support groups and chapters throughout the region.

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 (PSCNO) 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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Ask the Doctor

Is there a special diet for Parkinson's?

There is no "special" diet for Parkinson's disease—except a healthy, balanced diet that everyone else eats. That being said, we know that protein interferes in the absorption of l-dopa, and if protein and l-dopa are in the stomach at the same time, l-dopa may not be as well absorbed, leading to a reduction in the control of symptoms. This effect is not noticed by everyone, or may be noticed variably, depending on how many years one has lived with Parkinson's disease (PD). Often early on, people are not aware of any difference. Sometimes when people begin to experience motor fluctuations, they begin to notice that protein does affect their symptom control. Sometimes after people have had PD for many years, the effect of protein may no longer be noticeable. In general, I advise my patients to try to take pills one half hour before, or two hours after a meal, to try to reduce the interaction between protein and l-dopa. However, I also caution people not to take this to extremes and to live their lives, not being a slave to their meal and medication schedule. Nothing bad will happen if once in a while a pill is taken with food. Those who take l-dopa at close intervals may adopt a protein redistribution diet which means eating low protein during the day when most active, and a high protein meal at night when more sedentary. It is important to realize that this is a redistribution diet and NOT a low protein diet. Protein is essential to health and the same amount of protein needs to be eaten to meet daily requirements—it is just eaten primarily at night.

Is weight loss associated with Parkinson's disease? If so, what can be done about it?

Weight loss may be associated with PD due to several different mechanisms. To lose weight, there needs to be less intake of calories than calories expended. Weight loss may either be due to not enough food intake or too much burning of calories.

Not enough intake may be due to swallowing problems, slowness in chewing that results in taking too long to eat so less is eaten in the end, depression resulting in reduced appetite, in addition to being sedentary and losing muscle mass. Additionally, if dyskinesia is present, there is increased movement and therefore burning of calories. If dyskinesia is severe, such that a person is moving continuously, this could result in significant weight loss.

The treatment depends on the cause. If someone is having swallowing difficulties, this needs to be assessed and modifications made accordingly, such as changing the texture of food or using other maneuvers to reduce the risk of choking. If eating slowly results in less food intake, as it is too laborious to chew for long periods of time, it may be that medications need to be modified to improve slowness, or meals need to be eaten in the "ON" state. Talk to your doctor regarding whether a medication schedule could address this. In some people, meal supplements are effective in maintaining nutritional requirements.

For those with depression and reduced appetite, it is important to have the depression assessed and treated accordingly. For those with dyskinesia, it is possible that, with a change in medication regimen, these could be reduced; talk to your doctor regarding alternatives. It is important to maintain a high-calorie diet, so people should feel encouraged to eat ice cream, butter, cream, and many other high-fat foods. While many of these are high in protein, the priority is to maintain weight, which is essential to overall health and well-being.

Is constipation a symptom of PD?

Constipation is another "pre-motor" symptom that may precede PD by several years. There are effective strategies to manage constipation, and this is crucial to ensuring health and well-being. In addition to that fact, if someone is very constipated, PD meds won't be absorbed as efficiently and symptoms may be less well controlled. In addition to eating high fiber foods (including fruits, vegetables, and bran cereals), exercising, and drinking fluids, talk to your doctor or pharmacist about using polyethylene glycol products like Lax-a-day, which is a safe and effective strategy to managing constipation with a goal of a bowel movement every day.

Galit Kleiner-Fisman is a Movement Disorders Specialist who is the Medical Director of the Jeff and Diane Ross Movement Disorders Clinic at Baycrest Hospital and an Assistant Professor of Medicine in the Division of Neurology at the University of Toronto. She has developed a multi-media patient website (www.livewellwithparkinsons.com) and is involved in numerous research projects related to movement disorders in geriatrics.

Education Sessions

New Parkinson's Treatment Options: Duodopa® & Deep Brain Stimulation

Date: Wednesday September 9, light refreshments 6:30 p.m.–7:00 p.m.; presentation will begin at 7 p.m.

Location: Toronto Botanical Gardens, 777 Lawrence Ave East, Toronto

Keynote speakers: Dr. Alfonso Fasano and nurse specialists from the Movement Disorders Centre of Toronto Western Hospital

This is a free event but registration is required. To register, visit **www.parkinson.ca/cnoeducation** or call 800-565-3000 ext 3377.

Caring for Ourselves and Others

Dates: Friday September 25, 7:00 a.m.–9:00 a.m. and Saturday September 26, 10:00 a.m.–3:00 p.m.

Location: Radisson Hotel, Sudbury, 85 Ste. Anne Road, Sudbury (for room reservations call 705-675-1123)

Keynote speakers: Friday September 25: Sandi Emdin

Saturday September 26: Dr. Naomi Visanji, recipient of funding from the National Research Program, Parkinson Society Canada; and Dr. Elizabeth Slow, Movement Disorder Specialist. Afternoon Panel Presentation: "We're in this together" with moderator and allied health care professionals and community resource experts speaking on topics such as caregiver support, symptom management, communication, and mental health.

Cost is $40 for the full conference; $35 for those wishing to attend on Saturday only. To register, visit **www.parkinson.ca/cnoeducation**

Conférence francophone sur le Parkinson

Quand : Vendredi le 9 octobre, 201

Où : Club de golf Pine View, Ottawa, Ontario

Conférencier : Ceux-ci reste à confirmer. Les sujets seront : Se prendre en charge; Aider l'aidant naturel; Maintenir l'amitié et l'intimité avec une condition neurologique.

Information : gtrottier@toh.on.ca ou 1-800-565-3000 ext 3329

Simcoe County Education Session

Date: Tuesday October 13

Location: Taoist Tai Chi Building, Collingwood ON

Keynote speaker: TBA

This is a free event but registration is required. To register, please email Amanda at amanda.stanton@parkinson.ca or call 800-565-3000 ext. 3371.

Making Informed Decisions on Your Journey with Parkinson's

Date: Saturday October 17, 10:00 a.m.–4:00 p.m.

Location: Niagara Holiday Inn, 327 Ontario Street, St. Catharines

Keynote speaker: Dr. B. Connolly

This will be a health fair format with Dr. Connolly giving a keynote address at 1:00 p.m., a caregiver session in the morning, and a Young Onset meet-and-greet at 2:30 p.m. Various local agencies will be invited to share information about their services. Lunch will be provided.

Cost is $20. To register, visit: **www.parkinson.ca/cnoeducation**

Helping You Make Informed Decisions about the Future

Date: Tuesday October 27, light refreshments 5:15 p.m.–6:30 p.m.; presentation will begin at 6:45 p.m.

Location: Toronto Botanical Gardens, 777 Lawrence Ave East, Toronto

Panel presentation: Audrey Miller, Managing Director, Elder Caring Inc.; Bev Moir, Associate Director, Senior Wealth Advisor, ScotiaMcLeod; Sandra Stephenson, Lawyer, Evans Sweeny Bordin LLP

This is a free event but registration is required. To register, visit **www.parkinson.ca/cnoeducation** or call 800-565-3000 ext 3377.

The Nurse’s Desk

The Flip Side: Understanding the Patient’s Role in Hospital Care

Sandie Jones, RN

Imagine that you are embarking on a journey to a foreign land. You know that the language and customs are different but you really haven’t prepared for the trip, instead trusting in the generosity of strangers that you will encounter. All you know is that a room awaits you.

If you are thinking “That’s ridiculous—I would never do that,” then you need to know how much planning you need to do before going to that foreign land: ‘The Hospital’. You know that health care crises make the headlines regularly. You must take responsibility for your own care!

The experience of staying in the hospital, regardless of whether the admission is a planned surgery or result of an emergency room visit, is stressful for anyone. For people living with Parkinson’s disease (PD), hospital stays can be very challenging.

PD can be managed effectively for several years through regular visits with your movement disorder specialist or neurologist. For these reasons, people are unlikely to be admitted to the hospital because of Parkinson’s itself, but rather for (usually advanced) disease-related events, such as a fall with fractures, urinary tract infection, pneumonia, confusion, or hallucinations.

Hospitals may be first-rate institutions, in which life-saving surgeries are performed and critical emergencies fixed, but generally speaking, they are not well-suited to care for the day-to-day management of Parkinson’s. Keep in mind PD affects only 1 to 2% of the population, and there are countless diseases and health issues that hospital staff deal with. Understand that while PD is at the top of your mind, hospital staff cannot be expected to know everything about it.

We know that everyone with PD is different when it comes to symptoms, progression, and medications, so even if the health care team has a basic knowledge of PD, they don’t know your specific needs. This is why challenges may arise amongst hospital staff, as they are focussed on treating the condition that has brought you to hospital, not your overall health.

I believe your health care team wants to give you the best care, but need your help. Take charge of your own care by educating hospital staff about PD, especially YOUR Parkinson’s. Communication is key, as a lack of communication may seriously affect your quality of life, both in the hospital and after you are discharged.

Before Crisis

Like any other potential emergency plan, prepare now! We have a *Get it on time!* emergency hospital bag available to help you convey important information about your PD to the health care team. You will need to add to it your Parkinson’s drugs in the original bottles; several copies of your current list of your meds, with dosages, in an easy-to-follow schedule of what you take and when you take them, as these details may differ from what is written on the bottles.

Admission

Bring someone you trust who can take charge of communication with the hospital staff during your stay. This should be someone who is not embarrassed to ask the staff for help on your behalf and who can make sure they understand your situation.

Discuss your normal medication schedule at the time of admission. Many of you need to take your meds frequently with varying doses at specific times. In addition, some people find that their meds work better if taken 30 to 60 minutes before a meal or 1 to 2 hours after. Hospital staff are accustomed to giving meds at their set times and some nurses may not realize that being half an hour too early or late can mean a marked difference to someone living with PD.

Given pressures on hospital staff, a complicated schedule of oral medications may be difficult to follow with great accuracy. Rather than becoming upset with staff for not bringing your meds on schedule, take a proactive position.

Continued on the next page.....

Get it on time!

To learn more about the *Get it on time!* campaign, please visit www.parkinsoncno.ca, click on Support & Education on the top menu, then *Get it on time!* campaign from the left menu.

To order a hospital kit, please call 1-800-565-3000 ext. 3474.

The Flip Side Continued

Ask about options for self-administering, or having a loved one administer just your anti-parkinson meds, in order to control your PD symptoms while staff focus on your acute care needs. Be sure to share your med list with everyone involved in your care. Many PD meds come in different-sized tablets and formulations—an inadvertent substitution can cause problems. Hospital staff may not be familiar with the problems of motor fluctuations—"on-off" times—and dyskinesia. Some may think the patient is trying to be difficult when they are "off" and need help dressing or eating when they had been sauntering down the hall only a few minutes earlier, or that dyskinesias are attention-getting tricks. Letting staff know about the motor fluctuations in advance will help avoid misunderstandings.

Contraindications

Certain medications are contraindicated with PD and PD medications, meaning they should be avoided. Ensure that hospital staff are aware of the following:

Condition	Medication to Avoid	Better Choice Medication
Nausea and vomiting	Maxeran ™, Reglan™ (metoclopramide), Stematil™, Compazine™ (prochlorperazine)	Gravol™ (dimenhydrinate), Zofran™ (ondansetron)
Post-operative confusion	Conventional antipsychotic drugs i.e., Haldol™ (haloperidol), Risperdal™ (respiridone), Zyprexa™ (olanzapine)	Seroquel ™ (quetiapine), Clozaril™ (clozapine)
Pain	Demerol™ (meperidine)	Morphine

Surgery

When surgery requires general anesthetic, generally you can't take anything by mouth starting the night before surgery, including your PD meds. Ask if you can take an early morning dose of your levodopa with a sip of water just prior to surgery to avoid long unmedicated periods. If your bowel is working properly and your swallowing reflex is OK, you should be started back on your meds immediately after surgery. If nothing can be taken orally for some time following surgery, request that a nasogastric tube (NG tube) be inserted prior to your surgery. This means levodopa and most tablets can be crushed and dissolved to be administered.

Recovery

Some of you may be at risk for developing pneumonia because it is difficult to produce the deep coughing necessary to prevent accumulation of fluid in the lungs. Ensure that you receive and understand instructions for postoperative management of the lungs. Others may be prone to aspiration pneumonia, which results from swallowing issues. If prior to going into hospital you know swallowing is a problem for you, make doctors and nurses aware of this so that special precautions can be taken to prevent aspiration pneumonia.

Recovery time is generally longer for people with PD as the body simply takes longer to readjust and recover from any surgical procedure. This is nothing to be overly concerned about—it simply has to be planned for. You may need to work harder to recover your previous level of functioning than the average patient who is in hospital for a similar reason.

Discharge

After you are discharged, you may need to spend some time at a rehabilitation facility or care centre. With any new health care team, the education process starts all over again. It takes another round of persistence to educate staff about your symptoms, medications, and needs. Health teams want patients to be well-cared for. Always assume staff want what is best for you, their patient. Explain things in a supportive manner, e.g., "Let me explain my husband's situation and give you some literature." Do not accuse the staff of being uncaring. If you don't feel you are getting your point across, suggest they call your own neurologist who may be able to advocate.

Parkinson Society is actively working to educate health care teams: the Parkinson Clinical Guidelines now have Continuing Medical Education credits so that doctors will want to learn more about PD; *Get it on time!* continues to be presented to professionals; and advocacy efforts include getting an interdisciplinary system of care. These are long-term advocacy goals. It is still up to you to be prepared to self-advocate and communicate your needs with your health care team.

Parkinson SuperWalk

Find a Parkinson SuperWalk near you!

Saturday September 12, 2015

Alliston: Riverdale Park
Barrie: Heritage Park
Belleville: West Zwick's Park—Tom Gavey Pavilion
Bracebridge: Bracebridge Public School
Collingwood: Harbourview Park
Guelph: First Christian Reformed Church
Kingston: Lake Ontario Park
Mississauga: Living Arts Centre
North Bay: Rotary Waterfront Pavilion
Oakville: RioCan Oakville Place
Peterborough: Thomas A. Stewart School
Sudbury: Delki Dozzi Park
Thunder Bay: Intercity Shopping Centre

Sunday September 13, 2015

Brampton: South Fletcher's Sportsplex
Burlington: Burlington Seniors Centre
Durham: Ajax Rotary Park
Hamilton: (Sept. 20, 2015) St. Peter's Hospital
Markham: Crosby Memorial Community Centre
Newmarket/Aurora: Fairy Lake Park
Niagara Region: Lakeside Park
Northumberland: C.R. Gummow Public School
Orillia: Couchiching Park—Pavilion 2
Timmins: Timmins Regional Athletic & Soccer Complex
Toronto: Earl Bales Park
Vaughan: Vaughan City Hall

Support Group Parkinson SuperWalk

Haliburton:	Head Lake Park—Band Shell	**Sunday September 20**
Huntsville:	Faith Baptists Church	**Monday August 24**
Kenora:	Kenora Recreation Walking Track/Urban Trail	**Saturday September 12**
Kirkland Lake:	Kinross Pond Walking Trail	**Wednesday September 9**
Manitoulin Island:	VON Office Mindemoya	**Thursday September 17**
North Simcoe:	Real Canadian Superstore	**Thursday September 24**
Parry Sound:	Belvedere Heights LTC	**Wednesday September 23**

For more information on how you can get involved or host a Parkinson SuperWalk in your community, please contact Amanda Stanton at 1-800-565-3000 ext. 3371 or amanda.stanton@parkinson.ca

Here’s an easy way to raise $100 for Parkinson SuperWalk! Simply tear out this page and bring it to work, a family BBQ, or a social gathering. You’ll be surprised at how readily people will ‘pick their square’!

Celebrate 25 years of Parkinson SuperWalk by filling these 25 squares in support of Parkinson Society’s mission.

$1 for the cause	$2 for: ______	Sure here’s a buck	$4 for: ______	$5 because I was asked	$1: 4 quarters to celebrate 25 years
		Here’s $5	$3 to PSC		
Sure here’s a buck	$4 for 4/2015 Parkinson Awareness Month	$3 because I care	$5 to support a friend	$4 for an everyday hero	Here’s $5
$3 to contribute to community support					$5: 50 dimes for Parkinson Society’s 50th year
100 cents to support 100,000 Canadians with Parkinson’s	$4 for: ______	$5 to support a friend	$2 for: ______	Sure here’s a buck	$5 to search for a cure

$10 for a better life with a brighter future for Canadians living with Parkinson’s today	$10 to make a difference	$10 for a world without Parkinson’s tomorrow

Pick the square that has meaning to you, and make a gift. Thank you for supporting my Parkinson SuperWalk campaign.

Walker name: ______________________

Team Name (If applicable) : ______________________

Parkinson Society Canada | Since 1965
Société Parkinson Canada | Depuis 1965

Pedaling for Parkinson's

For the fifth consecutive year, cyclists took to the streets of Parry Sound on July 10 to 12 in support of Pedaling for Parkinson's, a community fundraising event which supports Parkinson Society Central & Northern Ontario (PSCNO) and the National Research Program.

This year, 200 riders raised $160,000, riding a variety of distances over the course of the three-day event. Originally launched in 2011 as a three-day event with 100,000 pedal strokes (one for each Canadian living with Parkinson's), the event has evolved into an enjoyable experience for riders of all skill levels and ages, offering different routes and participation on one, two, or three days.

Organizers Peter Istvan and David Newall, their families, and volunteers—with tremendous support from the Parry Sound community—drive this event with enthusiasm and a keen interest for riders and their support of the organization and the people it supports.

In its five-year history, Pedaling for Parkinson's has now raised more than half a million dollars in support of people living with Parkinson's in our region. Specifically, funds raised through this event make a difference via the National Research Program's Pedaling for Parkinson's Research named grant. New researchers will soon be announced as recipients of the award, and they'll join the list of past recipients working hard to make a difference through better treatments, research into causes, and ultimately a cure.

Past recipients have done some great work in the world of Parkinson's, including the following:

2014 Recipients

Pedaling for Parkinson's New Investigator Award: Dr. Scott Ryan. Dr. Ryan's research will target mitochondrial defects in a human stem cell model of Parkinson's.

Pedaling for Parkinson's Clinical Movement Disorders Fellowship (2014–16): Dr. Camila Henriques de Aquino. Dr. Henriques de Aquino's research will aim to improve Phase IIa clinical studies of new treatments for Parkinson's (using intravenous levodopa).

2013 Recipient

Dr. Ali Salahpour, from the University of Toronto, investigates mechanisms of dopamine transmission that may affect movement in Parkinson's patients. Research being conducted is paving the way for a new class of drugs that can be used for treatment of Parkinson's. Dr. Salahpour's team is now assessing the potential pharmacological targets of two novel compounds in order to understand how they may be enhancing dopamine transmission. The results to date from this study have helped Dr. Salahpour gain additional funding from another body, allowing him to significantly expand the scope of his research.

2012 Recipient

Dr. Joanne Nash, who notes, "We have shown that our novel target was neuroprotective and neuroregenerative in two rodent models of Parkinson's disease. We are now applying for funding to move this project forward into more clinically relevant models, namely primates and human stem cells." Dr. Nash's team has also been able to leverage the support of the Pedaling for Parkinson's Research Grant into additional grant opportunities from other organizations, demonstrating a reach that goes beyond single-year support.

This 'leverage funding' is an important hallmark of our National Research Program. By funding novel research and new investigators in the Parkinson realm, we support innovative projects that may have challenges in obtaining funding elsewhere. As Dr. Nash notes, our support (and specifically in her case, the support of Pedaling for Parkinson's and its organizers, riders, and volunteers) allows them to translate their efforts into meaningful results, and they can use the data they collect with our support to apply for more funding from other granting agencies.

For the first time, Pedaling for Parkinson's received support from a Presenting Sponsor: The Harbour Group, of RBC Dominion Securities, and acknowledges two Gold Sponsors: Clairvest and HollisWealth. Their support, along with countless other cash and in-kind sponsors, ensures that pledges are directed where they should be—to supporting research.

Dance for Parkinson's

Celebrating with Dance for People with Parkinson's

As part of Canada's National Ballet School's (NBS) commitment to the community, its artistic staff provide a dance program for people with Parkinson's disease (PD) on the school's Toronto campus. The program is called Dancing with Parkinson's (DwP@NBS) and is offered on Tuesday mornings from September to June. The class began almost two years ago with fifteen dancers and several volunteers. Since that first session in September 2013, the class has grown considerably. Now every class has more than 20 participants, as others living with Parkinson's are drawn towards experiencing the live music, movement, and social engagement the classes provide.

To develop the DwP program, NBS collaborated with leaders in the field from the Mark Morris Dance Group for PD® program in New York; established local instructor Sarah Robichaud, the founder and executive director of Dancing with Parkinson's; and researchers from York and Ryerson Universities.

NBS has developed a program that caters to, and benefits, Toronto's PD community, while also informing scientific research seeking to better understand the effects of dance in people with PD. The main objective of the project is to study how dance is able to seemingly bypass the neurodegeneration occurring in the PD brain and facilitate improvement in movement in those with PD. While several studies have already demonstrated the physical benefits dance may have for a person with PD, this unique study is trying to understand how these benefits are experienced in the brain. Participants in the class are invited to join the research study, but it's strictly voluntary and not a requirement of taking the dance class.

For the past two years, dancers from DwP@NBS have participated in a dance celebration in Yonge-Dundas Square. Presented each May by Canada's National Ballet School, Sharing Dance Day sees community participants performing a dance routine several times over the course of an afternoon. Other dance-related classes and performances are also programmed, encouraging participation by anyone interested in joining in. DwP@NBS participants performed a dance they had learned in their Tuesday classes to much acclaim, and also participated in performing the 2015 routine. Fundraising for several charity partners is another aspect of the Sharing Dance celebration—with the Parkinson Society of Canada being one of the four key charities on the roster.

For several years, Hamilton City Ballet has offered six to eight classes of Dance for Parkinson's, recurring several times a year. Live flute and violin music is provided. The company is involved in a study with McMaster University's Digital Music Lab to produce technology-based dance activities for people with Parkinson's. For details of the study and the classes, visit www.hamiltoncityballet.com.

Save the Date!

Porridge for PARKINSON'S

Sunday November 8, 2015

Visit www.porridgeforparkinsons.ca for updates.

It was a Hope in FULL Bloom Tulip Campaign for 2015

We did it, again! We exceeded our campaign goal and raised more than $142,000—selling beautiful tulips this past April across the Central & Northern Ontario region. A HUGE thank-you to our dedicated volunteers who devoted their time for the cause. Because of you, we are another step closer to help ease the burden and find a brighter future for those living with Parkinson's. The Hope in Bloom Campaign could not have happened without your amazing support! To you, our volunteers: you are simply the best!

Our 2014 Community Impact Report is now available through Chapters and Support Groups, by request at 800-565-3000 or online at www.parkinson.ca/cnoimpact. We're working hard to meet your needs and are proud to show our efforts toward our vision of a better life with a brighter future for Canadians with Parkinson's today; a world without Parkinson's tomorrow. This report details our 2014 efforts across our four pillars of support services, education, advocacy, and research.

Tiny Dancer

One of the regular dance participants in the Tuesday NBS class is Robert Kendrick, who lives in Port Credit, Ontario, and is the author of a blog on living with Parkinson's (https://imshakydad.wordpress.com). Here's one of his posts, describing what his Tuesday looks like as he prepares for his dance class.

I'm not a dancer. I don't know a demi pointe from a derrière, a piqué from a passé. I am slightly overweight, lose my breath when climbing stairs, and have an aversion to wearing tight clothing of any description. You will not find me in spandex riding with the guys on Sundays. I won't be at your local health club spinning or working on a treadmill. I am not athletic, I do not have graceful or flowing movements, and I have no desire for the perfect sculpted body.

Except on Tuesdays.

On Tuesdays I have a date. Every week, I wake up to my normal routine: take my medication, make coffee, get everyone set for school/work, walk the dog. But on Tuesdays, it's different. I have different affairs to attend to. It starts early as I think back to last Tuesday and remember fondly the music of that day. I try to remember the movements and new positions I learned. I linger a little longer at my closet trying to pick my wardrobe. I pack up everything I might need in a discrete bag and spirit off to the city for my "rendezvous." As I draw closer to downtown, I feel an almost giddy excitement come on.

And then I am there. A beautifully modern six-storey glass and stainless steel structure accented by warm woods. It is snuggled up against a few century homes and older apartment buildings. Once inside, the building is teeming with young, healthy, toned bodies. The first time I entered here I felt very much out of place. Uncomfortable with what I was about to do. Though today I have no shame. I'm happy to be here.

Here, you see, is Canada's National Ballet School. I am here for my weekly class "Dancing with Parkinson's." Each week 20 to 25 people with PD, of varying age and ability, gather with the support of 8 to 10 fabulous volunteers and 2 to 3 talented instructors to spend the morning dancing. We go through regular stretching, practice steps and maneuvers, and dance in different configurations to different (mostly live) music. We're always trying something new too, and, more often than not, I'm not the only one to awkwardly stumble through a routine. Yet—and here is one of the keys to the success of this program—never do you get the feeling of being embarrassed or looked down upon. It's a supportive and reassuring group of people.

Yet there is more to it than this. I recall in my second class, we had a visiting instructor from NYC come to lead the class and we were divided into two groups on opposite sides of the stage. In our dance, we were to represent the two rival gangs of West Side Story, slowly moving towards each other—alternating between vicious, aggressive affrontations and the occasional fearful retreat. The aggression ends with a powerful assault aimed at the other gang and, as the music becomes more serene, each gang member slowly approaches a rival gang member, reaches out, and gently we press each others hands together. Face to face and eye to eye, hands move slowly in unison in and around each others' bodies—almost caressing, gentle and caring. Very peaceful. Very loving. Very moving.

For me, that dance points to one of the most beneficial aspects of dance. I can't think of another group activity or leisure pursuit where you actually look at other people. Not just glance in the direction of another person, but look at someone with your eyes. Not only is this extremely positive for people with PD, many of whom live fairly isolated lives, but for we as humans. In an ever increasing technological world, we are becoming further removed from our fellow human beings. Dance helps bring that back to us.

Robert Kendrick

Further, and somewhat related, I believe that what makes this program successful is that dance is something you rarely do alone. You have to do it with a partner. Or with a small group. Or with the entire group. In our "Dancing with Parkinson's" class, we are dancing together with a shared challenge—a shared purpose. When each class ends, we gather holding hands in a large circle to bid one another adieu, and, though this signifies the end of the morning's activity, it only serves to cement the shared experience we've just been through. Yes, we've been dancing together and as we pack up our things, I'm sure many are already looking forward to reassembling next week.

We'll gather together briefly for coffee and socializing before heading home. As I walk towards the exit, I pass a studio where young boys and girls are practicing their routines. I pass the library teaming with dance magazines, books, and posters. Another group assembles in the cafeteria for lunch. The bulletin board is crowded with upcoming dance events across the city. In another studio, a group of young men dart and fly through air. I linger for a moment before moving on. I am struck by their talent, their energy, their heart. "They are dancers," I think to myself. But I'm a dancer too!

Parkinson SuperWalk

PSCNO Team Challenge

We're stepping up the challenge this year with separate team categories in an effort to inspire friendly competition among groups. Which category best fits you? Be sure to let us know when you register, or contact events.cno@parkinson.ca to register for the appropriate challenge. In addition to the challenge prizes below, PSCNO teams will be eligible for the nationwide top team prizes.

Five Ways to Participate:

Family and Friends Team

What is it? You and a collection of 2 to 25 of your closest friends, family members, and other contacts working together to make an impact.

How are they recognized?

- The top team at each walk site is acknowledged on event day, and after the walk in our LiveWire newsletter.
- The top fundraising team overall, and the top team on a per-member basis, are invited for a private audience (in person or by teleconference) with a Parkinson Society Canada funded researcher this November.

Seniors' and Lifestyle Healthcare

What is it? Long Term Care Organizations, Hospitals, Retirement Homes, Personal Support Agencies, and other allied healthcare professionals forming teams (of staff, clients and/or residents) and working together for a cause they have in common. In the past, our Seniors' Lifestyle teams have hosted BBQs, talent days, and other such fundraisers in support of Parkinson SuperWalk.

How are they recognized?

- Each participating team is recognized on our ParkinsonSuperWalk.ca website and in our LiveWire newsletter.
- There is an opportunity to join your local walk as a Seniors' Lifestyle Team.
- The top fundraising team from throughout the region wins a themed movie and entertainment evening for clients, residents, or staff as appropriate.

Youth and School Team

What is it? Any team captained by, and composed of, a school teacher or youth under 16.

How are they recognized?

- SuperHero SWAG on walk weekend.
- Class-wide Pizza Parties for the top four teams in our region.

Parkinson SuperWalk

Corporate Team

What is it? A team registered under the name of their business, promoting Parkinson SuperWalk within their place of business, and engaged as corporate participants.

How are they recognized?

- Corporate social responsibility and team building opportunities.
- An invitation to join our community on walk day.
- Recognition of all participating businesses on ParkinsonSuperWalk.ca, including publication of a corporate leaderboard and acknowledgement of the top 10 fundraising teams in LiveWire newsletter.
- Social media interaction and acknowledgement.
- Recognition at the Toronto Walk in descending order for funds raised.

Support Group Team

What is it? Any full scale Support Group Walk or a team registered at ParkinsonSuperWalk.ca as 'Location Support Group'.

How are they recognized?

- Acknowledgement on a plaque at PSCNO offices for the top team each year.
- Lunch provided at a fall meeting for the top team in each district.

Jim Wilkinson

SuperWalk teams are essential to our success, and PSCNO was proud to have the 2014 top team in Canada—the Mississauga Warriors. Sadly, team captain Jim Wilkinson passed away earlier this year. Here is an excerpt of a tribute written by teammate Lorie Miller.

Our late friend and leader Jim Wilkinson was a tenacious and determined warrior in the fight against Parkinson's disease since being diagnosed some 15 years ago. He refused to let the disease win as it slowly affected more and more of his life.

Maureen, his devoted wife of 50 years, worked with Jim to better understand the disease and how to live with it. Jim and Maureen learned as much as possible about the disease, research in the Parkinson's disease field, and the support available. They shared this information through their involvement with the Mississauga Parkinson Support Group. Over the years, they became inspiring role models for people with Parkinson's and their families, showing them how to live with the disease and not under it.

Jim and Maureen worked diligently and set high expectations for all to help find a cure for Parkinson's disease. In their honour, the Mississauga Parkinson Support Group changed the name of its Parkinson SuperWalk team to the **Mississauga Wilkinson Warriors.**

To read the full tribute, please visit this link: http://on.fb.me/1cW75fh

Partners for Parkinson's
Our Monthly Giving Program

OUR MONTHLY DONORS – WHAT SAY YE?

BETTY FOULKES

"If you had a family member with PD, you would realize that it takes lots of resources. We want to help find a cure."

KATHY TOPPING

"I am impressed that Parkinson Society Central & Northern ON works for the individual, at the same time as it is campaigning for more funds for research and improvements in treatment. The focus is on the individual dealing with the illness…"

MARGARET AND DON TURNER

"We support the monthly giving program and consider it just like taking a dose of medication, "It evens out the bumps (income) so one can plan better. Monthly giving allows those donating to have more 'bang for the buck' in terms of its impact."

RYAN TRIPP

"I am reaching out to the entire Parkinson community with a 'message of hope' and asking you to please 'pay it forward'…"

CALLY MCCONNACHIE

"I attended the walk in Guelph for many years and when that was no longer an option I decided to donate on a monthly basis. It is a very convenient way of contributing, the money automatically comes out of your bank account, you can increase or decrease your donation when you choose to do so and with little or no effort ."

Please consider joining our ***Partners for Parkinson's Monthly Giving Program*** and tell us what inspires you to give.
Please fill out the form below and send to: Parkinson Society Central & Northern Ontario
4211 Yonge Street, Suite 321, Toronto, ON M2P-2A9
For more information, please contact Naseem Jamal at 1-800-565-3000 ext 3378 or naseem.jamal@parkinson.ca

☐ **YES**, **I want to join *Partners for Parkinson's* and become a monthly donor to Parkinson Society Central & Northern Ontario.**

Each month I would like to give:
☐ $15 ☐ $25 ☐ $40 ☐ $50

I prefer a monthly gift of $________

Payment Options: two ways to join

1 Please withdraw this amount from my bank account each month. I have enclosed a 'VOID' signed cheque.

2 **Please charge my credit card each month.**
☐ VISA ☐ MasterCard ☐ American Express

Card #: ____________________
Expiry Date: ____/____ Signature: ____________
Name on card: ____________________
☐ Mr. ☐ Mrs. ☐ Ms. ☐ Miss ☐ Dr.
First Name: ____________________
Last Name: ____________________
Address: ____________________
City: ______________ Province: ______
Postal Code: ____________________
Phone: ____________________
E-mail: ____________________

Thank you for your monthly gift to Parkinson Society Central & Northern Ontario. Please provide your e-mail address if you would like to receive updates via e-mail in the future.

You can change or cancel your monthly donation at any time by calling 1-800-565-3000. Your preauthorized monthly gifts will be processed monthly on the 15th and you'll receive one tax receipt at the end of the calendar year.

From time to time, we trade our mailing list with like-minded charities in order to find new donors to support our work. However, if you prefer not to have your name traded, please check here ☐.

Charitable Registration #: 10809 1786 RR0001

Queen's Park, Health Care, and April Awareness

From left to right: **Ryan Tripp, France Gélinas, MPP (Nickel Belt), Debbie Davis, CEO of Parkinson Society Central & Northern Ontario, A.B. Rustin**

On April 15, 2015, Parkinson Society Ontario visited Queen's Park to meet with MPPs to discuss issues that concern those affected by Parkinson's. Our top priority was to explain how the health care costs of Parkinson's can be mitigated by reducing the time it takes to see a neurologist who specializes in movement disorders. In addition to raising this concern, we offered the following solutions:

- Adoption of the McGill Movement Disorders Program: the program specializes in training nurses to care for people with Parkinson's.
- Greater support in the access of video conferencing services such as Ontario Telemedicine Network. Such services help more remote families get access to neurologists.
- Stronger effort on training, retaining, and increasing the number of neurologists specializing in movements disorders.

"It is very important to maintain and develop strong relationships with our MPPs," said Debbie Davis, CEO of Parkinson Society Central & Northern Ontario. "These relationships not only add credence to our mission, but give us the opportunity to offer input and solutions on issues that concern those affected by Parkinson's."

October 15 Webinar

Balance and the Brain

Dr. Mark Carpenter

Balance problems and falls are a major problem for people with Parkinson's disease. At the University of British Columbia, neuroscientist Mark Carpenter is using imaging technology to scan the brains of people with Parkinson's disease as they perform a balancing task, to discover what structures of the brain control balance and might be receptive to new treatments to restore balance and reduce falls.

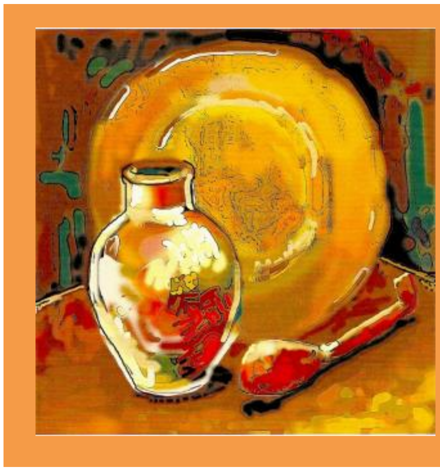
☎ Lunchtime Chats with Sandie

Join Sandie on the second Tuesday of each month at noon for our monthly education presentation. Sandie will talk briefly about the theme of the month and then answer questions sent in by you. Please send in your questions ahead of time to debbie.davis@parkinson.ca.

You can connect to the call in one of the following two ways (*you only need to access the call one way; if you do both you will have double audio playing*):

· On your computer, log into the call via the following link: http://parkinson.adobeconnect.com/sandie/. Once you have opened the link, choose to enter as a guest and then turn on your speaker.

· To connect by phone, call our toll-free number 866-850-3418 (Toronto callers may dial 416-915-8692), and the participant code is 9415905.



LOOKING FOR ARTISTS!

We are excited to be working on our fifth Hope on Display calendar, featuring the creativity of people living with Parkinson's in our region. If you are a person with Parkinson's, enjoy being creative (painter, photographer, jewelry maker, quilter, woodworker, etc.), and would like to be considered for the calendar, please send a high-resolution image of your work to Debbie Davis at debbie.davis@parkinson.ca by August 28, 2015. And don't forget to tell us a little bit about yourself too!

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
4211 Yonge St. Ste 321
Toronto, ON M2P 2A9
www.parkinsoncno.ca
800-565-3000 or 416-227-1200
Charitable No: 10809 1786 RR0001

LiveWire is published three times annually: in the spring, the summer, and the fall. Expect our spring edition in March, our summer edition in August, and our fall and 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 October 9, 2015.

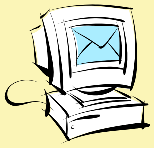
LiveWire is offered in both hard copy and electronic form. If you are reading this copy and would like to be added to our mailing list, or if you would prefer to receive the electronic edition, please contact livewire.subscriptions@parkinson.ca to be added to our email notification list or call 800-565-3000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

WOULD YOU LIKE TO HELP EASE THE BURDEN?

Scarborough/North York/Bolton/Newmarket/Sault Ste. Marie

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 three to five 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.*

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