

## Inside

Free Summer Speaker Series.....	3
Research Update.....	3
Inspirations.....	4
Advocacy Update.....	5
Newsworthy.....	6
Sandie Jones, RN.....	7
April Awareness Events.....	8
Around the Region.....	9
SuperWalk Locations 2011.....	10
SuperWalk Pledge Form.....	11
SuperWalk fundraising tips.....	13
Get it on Time letter.....	14
3rd Party Personal Events.....	16

## Our Mission

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

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 spring, summer, and fall. This year, expect our Spring edition in early March, our Summer edition in mid July, and our Fall/Winter edition in November.

## Marathon Man



Matthew Okell has a job many young people—and old people!—dream of. Since Matthew is a golf pro at one of Canada's premiere courses, you may picture him spending his days leisurely patrolling the course, and getting paid to put in a quick 18. However, that picture could not be further from reality. While he certainly has skill and a passion for the game, leisure does not appear to be a part of his vocabulary. Matthew is driven to push his body to extremes—and his motivation comes from a connection to Parkinson's.

Matthew had a close relationship with his grandfather John, and credits his lessons and time spent on the golf course with John as what led him to develop his game, and to take his interesting career path. However, by the time Matthew began at Glen Abbey, Parkinson's had taken its toll on his grandfather, and unfortunately he was unable to share in the joy of Matthew's new-found career.

Recently, Matthew has found a new passion: running. After joining a 10-km clinic with the Running Room, Matthew joked that one day he would run across Canada.

In November 2009, injuries sustained from a cycling accident required that Matthew have surgery on his shoulder. During the process, he talked to some of his closest friends about life and its meaning. From those discussions, he realized that "it is time to do more with my life"; in other words, make a difference. And so this quest to raise money in support of Parkinson's research was born, as part of the "Live Life Outdoors" project.

During his journey, inspired by those closest to him, Matt hopes to make a difference not only for his grandfather John and for his mom who has been diagnosed with "atypical" Parkinsonism, but for all those affected by Parkinson's.

In 2010, with just two wheels and a goal, Matthew set off on his bicycle across Canada to raise funds and awareness for the fight against Parkinson's, and to push his body to its limits. On his first day, Matthew cycled 120 km and didn't look back, completing the journey between June and October.

For 2011, while most adventurers would be content to sit on their laurels and take pride in the accomplishment, Matthew is upping the ante. In 2011, Matthew is running 12 marathons in 12 months, again with the goal of raising funds and awareness for Parkinson's. After a whopping three-marathon month of May, he is halfway to his goal.

While the task seems hard to conceptualize for some, Matthew stays driven by focusing on his motivation. "My grandfather always has been my truest friend. He is the source of my inspiration for this project and cause. My grandfather John was diagnosed with Parkinson's over 20 years ago and battled this debilitating disease valiantly until his recent passing. My hope is that someday soon no one will have to suffer the effects of living with Parkinson's. My running this year will be to honour John's memory and for all those who currently suffer from Parkinson's disease," he says.

Matthew is just one example of those doing extraordinary things in the battle against Parkinson's. Visit [www.parkinsoncno.ca](http://www.parkinsoncno.ca) for more details on personal event supporters within the Region and to support Matthew's event, or [www.livelifeoutdoors.ca](http://www.livelifeoutdoors.ca) to learn more about Matthew Okell and his 2011 goal.



# Parkinson Society Central & Northern Ontario



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

## CNO ADVISORY BOARD

John Parkhurst	Chair
Sherri Brand	Co Vice Chair
AB Rustin	Co Vice Chair
Jackie Ruderman	Treasurer
Dr. Gordon Hardacre	Member at Large
Kathy Marlin	Member at Large
Stephanie Ossanna	Member at Large
Kate Pitfield	Member at Large
Larissa Ruderman	Member at Large
Lorraine Silk	Member at Large

## STAFF

### Chief Executive Officer

Debbie Davis 416-227-3373 debbie.davis@parkinson.ca

### Community Development Coordinator Toronto and East

Naseem Jamal 416-227-3377 naseem.jamal@parkinson.ca

### Community Development Coordinator West

Karen Dowell Ext. 3376 karen.dowell@parkinson.ca

### Community Development Coordinator Central (York Simcoe)

Amanda Stanton Ext. 3371 amanda.stanton@parkinson.ca

### Community Development Coordinator North (Interim)

Karen Boyer 705-646-7677 karen.boyer@parkinson.ca

### Coordinator of Volunteers, Toronto

Louise LeBlanc Ext. 3304 louise.leblanc@parkinson.ca

### Coordinator, Client Services and Education

Sandie Jones, RN 416-227-3375 sandie.jones@parkinson.ca

### Information & Referral Associate

Robert TerSteege 416-227-3372 robert.tersteege@parkinson.ca

### Accounting and Administration Coordinator

Stella Recchiuti Ext. 3301 stella.recchiuti@parkinson.ca

### Major and Planned Giving, Senior Development Officer

Lorelei Wilkinson 416-227-3378 lorelei.wilkinson@parkinson.ca

### SuperWalk and Event Coordinator

Melissa Campisi 416-227-3374 melissa.campisi@parkinson.ca

### Education Program Development Coordinator

Jon Collins 416-227-3370 jon.collins@parkinson.ca

The LiveWire newsletter is published to provide people affected by Parkinson's in Central & Northern Ontario with helpful information. It is not meant to be medical advice and does not necessarily reflect the view of the Parkinson Society or the LiveWire Editorial Committee. Readers should contact their doctors in all matters relating to health concerns and/or medication.

The Editorial Committee is made up of volunteers and staff. The Committee welcomes feedback on current and past issues, as well as suggestions and submissions for future issues.

LiveWire is offered in both hardcopy and electronic form: **please let us know if you prefer to receive it electronically.**

Contact us at 1-800-565-3000 ext. 3371, or email to livewire@parkinson.ca

**Next submission deadline is October 15, 2011.**

*Parkinson Society Central & Northern Ontario is grateful for the support of the Brampton Support Group who have sponsored the publication of LiveWire for 2011.*

## PSCNO: What We Do

### Advocacy:

Our Ontario-wide Advocacy Committee has the following objectives:

1. Influence the behaviour of key government officials and agencies in support of people living with Parkinson's.
2. Influence the behaviour of Ontario MPPs in support of people living with Parkinson's.
3. Strengthen the scope and capacity of the Ontario Advocacy Committee.
4. Ensure consistent, coordinated advocacy communications across Ontario.
5. Build strong relationships with the Local Health Integration Networks across Ontario.

### Education:

Our goal is to bring excellent seminars and conferences to different areas in the region so that this information is readily available. We strive to provide four to six sessions each year in addition to the smaller sessions offered during support group meetings.

### Sessions during 2011:

- Thunder Bay, April
- Royal Botanical Gardens (Hamilton/Burlington), May
- Collingwood, May
- Durham Region, May
- Toronto Speaker Series, July through October

### Support Services:

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

- Constantly updated website
- Information and Referral line that fields approximately 6,000 calls and emails every year and sends out personalized information packages
- Individual support as required
- Regional newsletter sent out free of charge three times a year
- Support group network—40+ in the region—including newly diagnosed, young onset, and carepartner groups
- Fundraising and awareness events
- In-service sessions provided to healthcare professionals, specifically the new *Get it on time* program currently intended to educate staff at LTC facilities about the need to get medication **on time—every time.**

### Research:

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

*Parkinson Society Canada (PSC) strives to make an impact on the Canadian Parkinson's research community by working as investors in Canadian Parkinson's research potential. By funding meaningful and innovative projects and promising young researchers in their professional development, PSC aims to encourage continued growth and revitalization in the fields of Parkinson's research in Canada.*

*Thank you for your continued support!*

*PSCNO could not fulfill its mission to ease the burden and find a cure without the generosity of its donors and volunteers!*

## Coenzyme Q10 (CoQ10) Clinical Trial Stopped

Coenzyme Q10 is an antioxidant that was being investigated as being possibly neuroprotective in Parkinson's disease. The compound is approved in Canada as a supplement used for vascular and overall health.

The National Institute of Neurological Disorders and Stroke (NINDS) stopped the Phase III trial of CoQ10, at the recommendation of the Data Safety Monitoring Board (DSMB), stating that "During the most recent DSMB review, the results of an interim analysis showed that it was futile to complete the study because longer patient follow-up was not likely to demonstrate a statistically significant difference between active treatment and placebo."

Walter Koroshetz, M.D., Deputy Director of NINDS, stated, "Although we had hoped the results would be more promising, the study answers the important question of whether CoQ10 can delay the progression of Parkinson's disease." While the compound was found to be not harmful at certain levels, in terms of it being beneficial to treat Parkinson's, the evidence is not there.

## Parkinson's disease and Melanoma

Studies of people living with Parkinson's have shown that they may be at an increased risk of developing melanoma, a form of skin cancer, when compared to people without Parkinson's. This problem may be associated with Parkinson's or the drugs used to treat it. At several education events this year, presenting movement disorder specialists have shared that they encourage their patients to have yearly examinations by dermatologists. This may be a worthwhile subject to discuss at your next appointment with your physician and/or specialist.

## Porridge for Parkinson's

*Porridge for Parkinson's* is Toronto's must-attend charity event, so mark **Sunday, November 6, 2011, at 10:00 a.m.** in your social calendar. Once again, Ise Treurnicht welcomes us to her historic Rosedale home at 93 Highland Avenue.

A breakfast tasting of exquisite culinary treats will be prepared in view and served by five of Toronto's best known and celebrated chefs: Jamie Kennedy of *Jamie Kennedy Kitchens*; Joanne Yolles, formerly of *Scaramouche* and *Pangaea*; Martin Kouprie and Derek Bendig from *Pangaea*; and Donna Dooher of *Mildred's Temple Kitchen*; all of whom are generously donating their time.

Media personality and CBC radio news anchor Robert Fisher will be on hand to greet guests and act as our emcee. A fantastic array of breakfast-themed silent auction items have been assembled, including a New York City weekend getaway, all-inclusive vacations at Sandals Caribbean resorts, dinner at Ruby Watchco with acclaimed chef Lynn Crawford, a Hockey Night in Canada sweater signed by Ron MacLean and Don Cherry, and much more!

New this year will be a performance by guest musician Martha Johnson of the famed musical group, Martha and the Muffins. Her international hit single *Echo Beach* continues to be an iconic summer anthem around the world.

Advance tickets are on sale through [www.porridgeforparkinsons.ca](http://www.porridgeforparkinsons.ca). If you have donations for the silent auction or would like to volunteer at the event, please let us know by contacting Debra Voorheis at 416-926-9256 or by e-mail at [porridgeforparkinsons@hotmail.com](mailto:porridgeforparkinsons@hotmail.com). Visit us on Facebook at Porridge for Parkinson's.

All revenues will benefit Parkinson Society Central & Northern Ontario, a regional partner of Parkinson Society Canada.

## Free Summer Speaker Series

*Limited capacity, please register early.*

### August 10—Speaker Series #2

**Janice Abramowitz, Speech Language Pathologist, Lee Silverman Voice Therapy**

6:30 p.m.--9:00 p.m.: Parkinson Society Conference Centre, 4211 Yonge Street, Suite 308

### September 14—Speaker Series #3

**Dr. Soania Mathur—Shakin' but not Stirred—Living with Young-onset Parkinson's disease**

6:30 p.m.--9:00 p.m.: Parkinson Society Conference Centre, 4211 Yonge Street, Suite 308

### October 12—Speaker Series #4

**Dr. Mario Masellis, MSC, MD, FRCPC—Mind, Mood, and Memory**

5:30p.m.--9:00 p.m.: Toronto Botanical Gardens, 777 Lawrence Avenue East

*\*Light refreshments to be served*

**Please call 1-800-565-3000 ext. 3377 or email [naseem.jamal@parkinson.ca](mailto:naseem.jamal@parkinson.ca) to register.**





## How Exercise Helps Me—by Daniel S.

At the age of 6, I suffered a stroke on the right side of my brain, which left me with severe physical limitations on my left side. I had to learn how to walk again, and I lost significant motor control of my left arm; in fact even today, fine motor movements of my left hand are still limited.

Throughout my childhood I was restricted in terms of my participation in team sports or other physical activity that required eye and hand coordination. While finishing my grade school education, it was my physical education teacher who encouraged me to take up running.

In my mid twenties I became an active runner completing 5-km and 10-km races regularly. I completed the first of nine marathons in 1994, with a time of 3 hours and 36 minutes. I have excelled in half marathons with a personal best of 1 hour and 28 minutes.

In 2008 I was diagnosed with “early onset” Parkinson’s. Short-term disability leave and modifications to my daily job duties did not seem to reduce my work load, anxiety, or stress level. Cognitive limitations, high anxiety, and depth perception problems were severely affecting my job performance and resulted in the loss of my driver’s license. As a result, I took long-term disability by the fall of 2009. Today, tremors, rigidity, and general slowness on my right arm continually frustrate me.

Throughout my adult life, exercise has always been present, and running has always been a passion for me. I am very fortunate to be in good physical shape, to have the support of my wife, to have exercise as part of my daily routine, and to have the time to focus on exercise.

Although I am approximately 3 minutes a mile slower than in my “prime running” days, I continue to run 3 to 5 times a week, with runs ranging from 4 to 13 miles, accumulating 30 miles per week. I have run over 1,000 km in 2011. I also belong to a gym where swimming, light weights, Pilates, and yoga approximately twice per week are a part of my regular routine. While running, I feel more of a “flow” in my body movements, which is absent when completing daily routine tasks at home.

During the week I walk everywhere—from dropping off kids at school to the local shopping plaza. In May I was privileged to see my eight-year-old compete in her first track meet participating in the “4 by 100” relay. I was a proud Daddy. You do not need to be a fitness addict to benefit from exercise. I believe that walking, swimming, light stretching, and an introduction to yoga class would be beneficial to all of those living with Parkinson’s, regardless of what stage of progression you are currently experiencing.

I truly believe that exercise has helped me cope with my physical life challenges.



## Greg’s Reality

This May, at the Innisbrook Golf Course, Greg McGinnis hosted a fundraising golf tournament and great awareness day for Parkinson’s. The annual event, attended by Mayor Mike McEachern of Barrie, MP Patrick Brown (pictured), and Dr. Anthony Lang, among others, continues to be well

liked by participants, and raises the level of Parkinson’s awareness in the community. Greg’s advocacy efforts extend beyond this event, as he also testified to the Parliamentary Subcommittee on Neurological Diseases this past November. While there, Greg delivered a very honest and compelling talk about how living with Parkinson’s has affected him and his family. Greg was joined at the Subcommittee testimonies by Parkinson Society Canada CEO, Joyce Gordon, and Movement Disorder Specialists, Dr. Jon Stoessel and Dr. Michael Schlossmacher.

This year, attendees of the golf tournament were treated to a poem written and read by Greg’s sister, Kelly Litwiller. It is reproduced below.

*An awful disease  
Stealing my life  
Robbing me from  
My Son and Wife*

*I’m not that old  
I hear what they say  
This is our reality  
Each and every day*

*I try to stay strong  
I’m still the same man  
This slows me down  
But I do what I can*

*So many tears  
I have cried  
Thank God for my family  
Always by my side*

*I pour Tyler’s milk  
In the morn when he wakes  
I tremble so badly  
It’s now a milkshake.*

*We try to make lightly  
And joke it away  
But the truth remains  
At the end of the day*

*This is more  
Than one should endure  
I pray someday  
They’ll find a cure*

*I promise to you  
With all that I am  
I vow to do  
All that I can*

## Advocacy: Driving Better Policy—by Yvon Trepanier

In 2005, Parkinson Society Canada's national advocacy committee set a big goal — to launch a national study to learn about the impact of Parkinson's disease in Canada. Little did they know that this national study would grow to become Canada's first-ever study of not only Parkinson's disease, but 13 other neurological conditions as well. Nor could they have imagined that the \$15 million study would be funded entirely by the Government of Canada, with full support from the federal health portfolio (Health Canada, Public Health Agency of Canada, Canadian Institutes of Health Research).

Fast forward to 2011.

- The National Population Study of Neurological Conditions is well underway, with Parkinson's included in 17 of 18 research projects.
- Neurological conditions have been added to the federal surveillance system for chronic disease.
- The first-ever Parliamentary Subcommittee on Neurological Diseases heard 30 hours of testimony (including 4 hours of Parkinson's-specific testimony).
- A framework for a national brain strategy has been tabled with federal policy makers.
- As evidence of how much attention neurological conditions have garnered in recent years, policy related to brain health was included in every national party platform during the recent federal election.

"The progress is staggering," says Joyce Gordon, CEO of Parkinson Society Canada and Chair of Neurological Health Charities Canada (NHCC). "Credit goes to volunteers and staff within the 26-member organizations of the NHCC. Everyone has rolled up their sleeves and pitched in with commitment and a real sense of partnership."

Looking ahead, Parkinson Society Canada is committed to building on our positive and productive working relationship with the Government of Canada. During the election, the Conservative Party of Canada made two important commitments to our community:

- to invest up to \$100 million in neuroscience research; and
- to implement a new Family Caregiver Tax Benefit.

These two promises begin to address key elements of the proposed national brain strategy, and Parkinson Society Canada will work with members of Canada's 41st Parliament and federal policy makers to realize these commitments as soon as possible. This is an excellent start but much more is needed to improve the quality of life of more than 100,000 Canadians with Parkinson's, and more than 5 million Canadians with neurological conditions.

Your support for this work is critical.

To learn more about our advocacy work, please contact [debbie.davis@parkinson.ca](mailto:debbie.davis@parkinson.ca)



Yvon Trepanier,  
Chair, National Advocacy Committee

*Reprinted from e-Parkinson Post.*

### THE PARKINSON LEGACY

**Give hope for today  
and a cure  
for tomorrow**

By making a planned gift through The Parkinson Legacy, you will be providing Parkinson Society Central & Northern Ontario with the resources to fund research, education, support services and advocacy. Your Legacy Gift will give hope for those living with Parkinson's today and will lead to a cure tomorrow. This will be your Legacy.

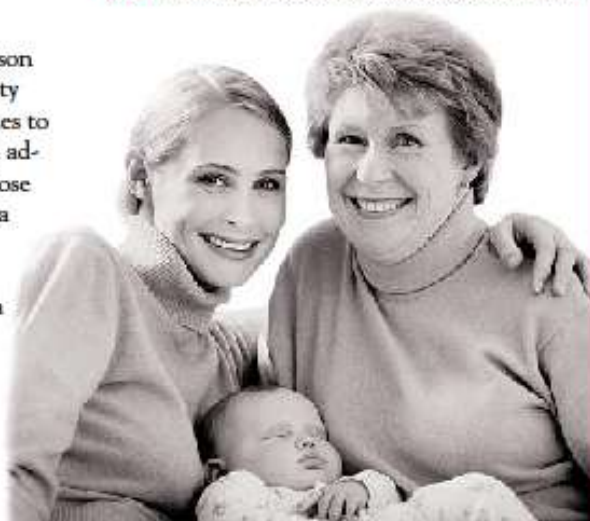
There are numerous ways that you can make a Legacy Gift. Here are a few examples:

- Include a Bequest in your Will
- Give a Gift of Life Insurance
- Give a Commemorative Gift

To discuss your Legacy Gift or to request an information kit, please call: (416) 227-3378  
Toll Free: (800) 565-3000, ext. 3378.



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







Burlington residents Dr. T.J. Dhillon and Mrs. Yvette Dhillon have generously donated \$8,000 in support of Parkinson Society Central & Northern Ontario's work in the Burlington area. A portion of this donation supported the Royal Botanical Garden education event.

"We were thrilled to receive this donation which will further our

work in education, advocacy, and support services for the Burlington area," says Karen Dowell, Community Development Coordinator-West for Parkinson Society CNO. "There are active local support groups that meet monthly in the area for those interested in attending."

Yvette is now working with Burlington support group leader Maureen Thun on a Cut-a-Thon for April 2012 and several other awareness events.

Pictured: Karen Dowell and Yvette Dhillon



## 2011 PSCNO Volunteer Awards

On May 25, 2011, we held our Spring Volunteer Tea where we came together to celebrate the contributions of our volunteers. The Ian Davidson award is presented in recognition of individuals 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 and Northern Ontario, and/or increased public understanding of their situation through such activities as leading support groups, public speaking, advocacy, volunteering, and fundraising.

Pictured: PSCNO Ian Davidson Award winner Maureen Thun with past winners Marg and Don Turner

## Project Give Back Student teaches class about Parkinson's disease

Hi my name is stefan Haikonen I am in grade 4 at armour Heights P.S. I was assigned a project to teach my class about a charity that touched my heart. I chose Parkinson society of Canada because my grand father had it. For my activity I made the class write with there wrong hand. Inside this envelope please find pitures of my lesson. Thank you for sending me posters of people that have parkinson I learned alot.

STEFAN Haikonen

A Project Give Back Student



## How to Get the Most Bang for Your Buck—Part 1—the Protein Question

No, I'm not going to give you financial advice, so if that's what you're looking for, stop reading now! I just want to share some information about the timing of your medications in relation to your meals with the hope of helping you to "get the most bang for your buck." This issue we are going to focus on is a common question about the "protein diet."

If you are taking levodopa/carbidopa (Sinemet™) or levodopa/benserazide (Prolopa™) your prescription bottle probably instructs you to "Take with food." This is good advice if you have just started to take this medication as sometimes it can cause nausea and light-headedness, and taking it with food can help to reduce these bothersome side effects. After several years of a smooth response to levodopa, many people notice that when they eat a high-protein meal and take their medication with that meal as they have always done in the past, the medication isn't as effective as it was in the past and doesn't "kick in" the way it used to. Why? Let me try to explain.

Levodopa is an amino acid. The proteins we eat from food like meat, cheese, dairy products, etc., are broken down into amino acids in our digestive system. With me so far? Good. Because here's the important part.

The digestive system doesn't discriminate between the amino acids from food protein and the amino acids from levodopa. So now there is a competition between the food amino acids and the levodopa amino acids, for passage into the bloodstream. In fact, some of the amino acids from levodopa never make it into the bloodstream. Not only that, the amino acids from food can block levodopa from getting into the brain so your levodopa is not as effective as it could be, and that's the last thing you want: loss of improvement of your Parkinson's symptoms!

As with everything else related to PD, not everyone notices that their levodopa is less effective if they take it at the same time as they eat a high protein meal. It is usually those with more advanced PD whose relief of symptoms is dependent on a narrower range of levodopa levels in the brain to begin with, and those who have off/on motor fluctuations.

(An ON state = adequate dopamine present in the brain, and the person can perform tasks normally. An OFF state = insufficient dopamine is present—the person becomes very slow, stiff; tremor may increase; and the person may have difficulty dressing or walking.)

Some folks may think if protein is going to affect the benefit from my medication then I just won't eat protein anymore—BAD IDEA! That would have serious consequences for a person's general health.

There are a couple of things you can do to get around this problem:

1. **After consulting with your specialist, you could take your meds on an empty stomach, either one hour before your meals or two hours after a meal. If you simply can't tolerate taking the meds on an empty stomach, take it with a slice of bread, or a piece of fruit. Avoid all proteins at this time.**
2. **You could shift your protein intake to later in the day, so levodopa absorption is enhanced during the earlier hours when you want to be more active.**

Remember, everyone is different. If you are taking levodopa and have not noticed any adverse effects from dietary protein, then you will not benefit from either of the above suggestions. It might be a good idea to pay attention to this now that you are aware of it, as changes may have been gradual. Also, those of you who are not taking levodopa, there is no need to follow the above suggestions.

In summary, only those people who have a clear loss of benefit when they take levodopa with a protein meal and folks who are experiencing poorly controlled motor fluctuations may benefit from this info. Again, **before making ANY changes to your medication timing, please discuss with your specialist!**

## Travelling and PD

The Canadian Air Transport Security Authority (CATSA) has confirmed that Parkinson Society Canada's medication card qualifies as documentation to be presented to screening officers before they begin the screening process.

Upon presentation, screening officers will approach screening in a more sensitive and delicate manner, while still adhering to the operating procedures required of them. A passenger, for any reason, may request a private search if additional screening is required and/or if the passenger is uncomfortable with being screened in public view. Further, to the issue of privacy, the CATSA protocols stipulate that screening officers must not outwardly disclose or discuss a person's condition or medical documentation in front of other passengers, and also handle medical devices and supplies with utmost care when conducting a physical search...with a heightened degree of sensitivity.

Also, Travelling and PD is available on our website at [www.parkinsoncno.ca](http://www.parkinsoncno.ca).  
Have a safe and happy summer!



## April Awareness Events



Parkinson Society Central & Northern Ontario along with sponsors McLean Budden and TD Commercial Banking were honoured to open The Toronto Stock Exchange on Wednesday April 13, 2011 (*pictured*). Before ringing the bell, Jim Vlahos, a VP at Franklin Templeton Investments, gave a keynote presentation of his journey training for and participating in the 2,500th Athens Classic Marathon. This difficult run was in tribute to Jim's late father-in-law, Peter Macheras, who suffered from Parkinson's for 20 years. Jim raised an astonishing \$13,290 and completed the 42-km marathon in 4 hours and 30 minutes.

The 2011 Tulip Hope in Bloom campaign was a tremendous success this year with \$116,000 raised! These funds will be used for education and services for people living with Parkinson's. Thanks to the hundreds of volunteers who made this happen—everyone from Tulip Captains and the many other volunteers running the GTA Venues, to Chapter and Support Group leaders, to CNO staff, and to Tulip Ambassadors who facilitated the tulip pre-sales at their organizations. **THANK YOU!!!!!!** We look forward to working with all the volunteers again next year. If you are interested in becoming involved in the 2012 Hope in Bloom campaign, please contact Naseem Jamal at 416-227-3377 or [naseem.jamal@parkinson.ca](mailto:naseem.jamal@parkinson.ca).

**Cut-a-Thon for Parkinson's**—On April 17, 2011, salon stylists in Yorkville, Barrie, Bracebridge, Collingwood, and Guelph participated in the annual Cut-a-Thon. By donating their time and talents, these stylists raised over \$13,000 to help ease the burden and find a cure!

Many thanks to our sponsors **Pizza Nova**, **JOICO**, and **MAC Cosmetics** for their generous contributions to the Yorkville event.

If you would like to host a Cut-a-Thon in your community next April, please contact Melissa Campisi at [melissa.campisi@parkinson.ca](mailto:melissa.campisi@parkinson.ca) or at 1-800-565-3000 ext. 3374.







**TEA for TULIPS IN NORTHUMBERLAND:** Last year, Heather Sinclair and Margaret Anderson of Port Hope created a unique idea for the annual Tulip Campaign for the Parkinson's Society. For the past two years, they have invited their friends and neighbours to their home for Afternoon Tea. In return, the participants purchased pots of tulips—hence the name, Tea for Tulips. This year over 50 people attended the tea and collectively purchased 120 pots of tulips. As you can see from the photo (left), many came dressed for the occasion!

**Sudbury Chapter News:** We would like to acknowledge the speedy recovery of our president Mike Leclair. Very inspiring! Our group has been quite busy this past while, keeping our fo-

cus on the two E's, education and exercise. We have been fortunate to have several guest speakers at our monthly meetings, from kinesiologists, to a research doctor, to a panel of members explaining, "If I knew then what I know now, what would I have done differently?" We are very pleased with the participation in, and the results we are achieving from, our twice-weekly workout sessions led by the kinesiologists of KinnectToWellness. As a wise man once said, "Never underestimate the power of people who are together overcoming similar obstacles," and we are finding it true.

**The Vaughan Parkinson's Support Group** has been very busy the last few months with a visit from the York Regional Police (Sgt. T. Kuttschutter), a talk given by Lori Canlas from the Community Home Assistance to Seniors (CHATS), an exercise class given by Ellen Allen, a demonstration of electric and battery-run bikes and scooters by E-Bike, and an auction luncheon held at Mr. Greek's before the summer break. The group is happy to say that a donation in the amount of \$200 has been made to Parkinson Society Canada.



*Auction Winners: Al (Peter & Paul's Basket) and Jack (Lowes gift card)*



**The Brampton support group** recently received a bequest to be used for the Parkinson's community in Brampton. The bequest was used to purchase important and useful materials for the support group, such as books, a DVD library, and an LCD projector.

Pictured here is the Leadership team with some of the program materials and equipment.

**The North Simcoe Support Group** meetings are held on the fourth Thursday of the month, from 3:00 to 5:00 p.m. in the second-floor meeting room of the Loblaw's Super Store, 9292 County Rd. 93, in Midland. There will be no Support Group meetings in July or August, but meetings will resume on Thursday Sept 22, 2011.

On Sat. June 25, Lee Hansen and team held a very successful "Tag Day" in Midland. \$1340.54 was raised for PSCNO. A big thanks to all who participated.

This year we won't be holding a SuperWalk in Midland, but we will be joining the Barrie SuperWalk on Sunday Sept 11. We look forward to having a great day together.

Contacts: Elaine Jones at 705-526-3879 and Penny McDowell at 705-538-1377



# Register Now!



*Team CNO!*

## Find a Parkinson SuperWalk near you!

### **Saturday September 10, 2011**

Alliston: Riverdale Park Lions Pavilion  
Bracebridge: Bracebridge Public School  
Collingwood: Harbourview Park  
Georgetown Halton Hills: Gellert Community Centre  
Guelph: (new location) First Christian Reform Church, 287 Water Street  
Huntsville: Canada Summit Centre  
Kingston: Lake Ontario House  
North Bay: North Bay Waterfront Pavilion  
Sudbury: Delki Dozzi Playground  
Thunder Bay: Intercity Mall

### **Sunday September 11, 2011**

Barrie: Heritage Park  
Belleville: Zwicks Island Park  
Burlington: Burlington Seniors Centre  
Durham Region: Rotary Park  
Hamilton: St. Peter's Hospital  
Newmarket/Aurora: Fairy Lake  
Niagara: Lock 3 St. Catharines  
Peel Region: Erindale Park  
Peterborough: Thomas A Stewart Secondary School  
Toronto: Earl Bales Park

### **Support Group Fundraisers for SuperWalk**

Kirkland Lake, September 7, 2011  
Timmins, September 8, 2011  
Mindemoya/ Manitoulin Island, September 15, 2011



## FUNDRAISING FORM & WALK DAY INSTRUCTIONS

Register and fundraise using this form or online at [www.parkinsonsuperwalk.ca](http://www.parkinsonsuperwalk.ca)

1. Complete the registration form and sign the waiver.
2. Print clearly and include full mailing addresses for your supporters.
3. Bring the completed form(s) and money to registration on walk day.
4. Cheques are payable to: Parkinson Society or Parkinson SuperWalk



**PARKINSON  
SUPERWALK**

## PARKINSON SUPERWALK 2011 REGISTRATION FORM

### WALKER INFO

Last Name \_\_\_\_\_ First Name \_\_\_\_\_ Walk Location \_\_\_\_\_  
Address \_\_\_\_\_ E-Mail \_\_\_\_\_  
City \_\_\_\_\_ Province \_\_\_\_\_ Postal Code \_\_\_\_\_ Telephone \_\_\_\_\_  
*Teams – Save time by registering online!* ☐ I am part of a team Team Name \_\_\_\_\_

### WAIVER

I agree that I am participating in Parkinson SuperWalk (PSW) voluntarily and do so at my own risk. I hereby fully release Parkinson Society Canada (PSC), the corporate sponsors of PSW, and any other parties connected in any way with PSW, as well as their respective officers, directors, agents, employees, staff and volunteers, from all claims or lawsuits for any injuries, death, property damage or theft, losses, or any other liability of any kind, arising directly or indirectly out of my participation in PSW or any of the activities associated therewith. I consent to being provided with emergency treatment in the event of my illness or injury during my participation in PSW, and agree not to hold PSC responsible for any costs associated with such treatment. I consent to the publication and/or other use of my name, voice, photograph or other likeness without further notice or compensation in any publicity or advertisement carried out by PSC in any manner whatsoever, including print, broadcast, or the Internet. By signing below, I confirm that I have carefully read this Release and Consent and fully understand and agree to its contents.

Signature of Participant \_\_\_\_\_ Signature of guardian if under 18 years of age \_\_\_\_\_

**INCENTIVE PRIZES** There is a cost for Parkinson Society to provide incentives to our walk participants (Roots gift cards). Please indicate your choice, below.

If neither box is checked, your fundraising incentive will not be sent and the money saved will be invested to help Canadians living with Parkinson's. You will be included in the National Draws for prizes which have been generously donated.

- ☐ NO, please do not send me fundraising incentives so that more money can be directed to services in my region. I will be included in the National Draws.
- ☐ YES, please send me incentives.



### DID YOU KNOW?

- Over 100,000 Canadians have Parkinson's.
- Parkinson's is a chronic, degenerative brain disease that affects every aspect of daily living for those with Parkinson's and their families.
- There is no known cause or cure for Parkinson's.
- The average age of onset of Parkinson's is 60, but it can affect people as young as 30 or 40.
- Parkinson's strikes men and women in every culture and race.

 **Parkinson Society Canada** Since 1965  
**Société Parkinson Canada**

**Need Help? Call the SuperWalk Hotline 1-800-565-3000 [www.parkinsonsuperwalk.ca](http://www.parkinsonsuperwalk.ca)**

# PARKINSON SUPERWALK 2011 PLEDGE FORM

## WALKER INFO

Last Name \_\_\_\_\_ First Name \_\_\_\_\_ Walk Location \_\_\_\_\_

**PLEDGES** *Print clearly* including full mailing address and postal code. If the information is incomplete, no tax receipt will be issued. Tax receipts will be mailed by February 28, 2012. Tax receipts will automatically be issued for all pledges \$20+.

NAME	ADDRESS REQUIRED TELEPHONE	CITY EMAIL OPTIONAL	PROV.	POSTAL CODE	PLEDGE	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
					\$	
					<input type="checkbox"/> Cash <input type="checkbox"/> Cheque	
Copy this page if you need more space or download one at <a href="http://www.parkinsonsuperwalk.ca">www.parkinsonsuperwalk.ca</a>					PAGE _____ OF _____ PAGES	TOTAL COLLECTED THIS PAGE \$
					ONLINE TOTAL	\$
Charitable Registration # 10809 1786 RR0001					GRAND TOTAL	\$

**PRIVACY STATEMENT** Parkinson Society Canada collects personal information to communicate with supporters about initiatives/ fundraising. By providing your information, you give consent to be contacted. For a copy of our privacy policy call 1-800-565-3000.

**THANK YOU FOR YOUR SUPPORT**

**Need Help? Call the SuperWalk Hotline 1-800-565-3000 [www.parkinsonsuperwalk.ca](http://www.parkinsonsuperwalk.ca)**



## SuperWalk Fundraising Tips!

Go above and beyond asking friends and family for support! Here are some fun and exciting ways you and your team members can help fundraise for SuperWalk!

- **Candy Grams**—people can sign up to have a candy gram sent to one of their co-workers with a personal message attached. This is a great way to show your appreciation to a colleague or, if you are a manager or supervisor, to give to your staff as a thank you for their hard work.
- **Bake Sale**—Perfect fundraiser for your office, church group, or social club. Have everyone bake their most delicious treat with all proceeds going to SuperWalk. Want to make it more interesting? Host a **Bake Off**—this is where people pay to taste all the different desserts and then vote on their favourite one!
- **Garage Sale**—You know all that stuff that's been hanging around your house? Gather it up, put it in your front yard and, sell, sell, sell! Ask your neighbors to participate and make it a street sale in support of SuperWalk! **No Yard? No Problem!!!** Gather all your unwanted items and post them on EBAY or Craigslist.
- **Bowling Nights**—Plan a fun night of bowling at your local lanes. Ask the owner to waive the cost of bowling for the night and you can collect that money and turn it into pledges! Not into bowling? Don't worry, try and book a mini putt, paintball, laser tag, tennis, or go-cart night instead.
- **Birthday Gift Pledge**—This is a very simple way to raise money, and it will be a lot easier for your family and friends to sponsor you instead of spending hours trying to find that perfect gift.
- **Host a craft workshop**—Use your creative talents to help others learn new skills! Teach others to scrapbook, quilt, bead, or even knit! Admission goes towards your fundraising efforts!



**For more information on how you can get involved or host a SuperWalk in your community, please contact Melissa Campisi, SuperWalk and Special Events Coordinator, at 1-800-565-3000 or email [melissa.campisi@parkinson.ca](mailto:melissa.campisi@parkinson.ca)**

## Get It On Time

*\*The following letter has been created to help you communicate your needs to health care professionals. For those with Parkinson's who are anticipating a trip to a hospital or long term care facility (or, have an unplanned visit) this letter should help lend a voice to your concerns. Please save a copy, and make use of it.  
Contact us to order additional letters.*



Parkinson Society Central & Northern Ontario

Société Parkinson du Centre et du Nord de l'Ontario

In Partnership with Parkinson Society Canada

I have Parkinson's disease. It is a brain disorder that can cause a number of motor and non motor symptoms. Parkinson's gets worse over time. It is unpredictable; no two people will experience it in quite the same way and my ability to control my symptoms is always changing.

Since I've been living with Parkinson's for a while, I have become an expert. Let me share with you what I have learned so you are able to understand my condition and my needs. Since I rely on medications to help me function, it is most important that you give me my meds on time every time. I ask you to do your best to understand me and my condition.

Giving medication on time is important because the uneven release of dopamine means that I may suddenly not be able to move, get out of bed, or walk down the hall. More serious problems can include bowel obstruction and aspiration pneumonia. I am highly reliant on my medications, and getting the most out of each dose is essential. I can be extremely sensitive to a change in my medication routine.

Since you are going to be involved in my care, I ask you to pay attention to giving me my meds on time – every time. This will have a direct impact on my health, recovery and well being. Once my medication routine is disrupted, it may take hours, days or even weeks for my condition to get back to normal. Neither of us wants this to happen.

If you can't be flexible with my medication, you are probably going to have to provide a higher level of care. To help you, I have written down my routine on a medication card. Please ask me to see a copy. If you follow this routine and I get my medications at the prescribed times, you should find that I am more able, more independent and generally require less help with activities of daily living. Completing daily tasks when I am more mobile and independent means that your job should be easier, more efficient and the quality of life for both of us will improve.

Please work with me to ensure that I can be at my best, and be part of my own care.

If you have any concerns, or want to request a *Get it on time* education session, please contact Parkinson Society Central & Northern Ontario at 1-800-565-3000 or [www.parkinsoncno.ca](http://www.parkinsoncno.ca).

Sincerely,

A person living with Parkinson's



"Get it on time" is a national program of Parkinson Society Canada.  
Based on a design and text created by Parkinson's UK.



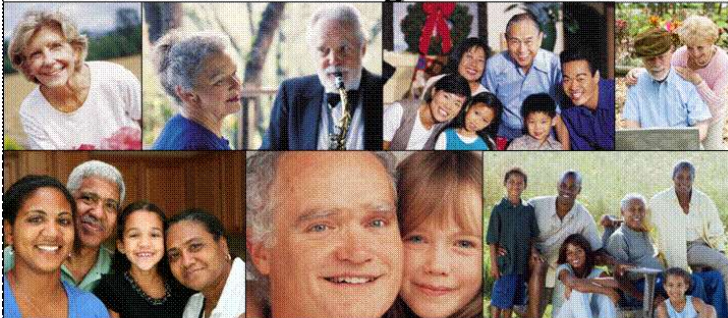


### Pitch-In for Parkinson's

Parkinson Society Central & Northern Ontario hosted its 21st annual Pitch-In event, and as always, our supporters enjoyed a great night at the ballpark watching the Jays battle the Pittsburgh Pirates. Thanks to the generous support of our season ticket donors and those who bought tickets to the event, we were able to raise \$4,000 for support services, education, and research—and fans in attendance were treated to a win by the home team!

Pictured: Dee Dee, Barb, Clare, and Ryan

## Mind, Mood & Memory— the Hidden Challenges of Parkinson's



**Wednesday, October 12, 2011**

5:30 p.m.—7 p.m. —

Information Booths

7 p.m. to 9 p.m. —

Main Presentation

**Toronto Botanical Gardens**

777 Lawrence Avenue East  
(Lawrence Ave. and Leslie St. area)

**FREE EVENT Space is Limited:**  
**Registration required**

To RSVP, please call:

1-800-565-3000 ext. 3377

naseem.jamal@parkinson.ca

### Keynote Speaker

**MARIO MASELLIS, MSC, MD,  
FRCP**

*Clinician—Scientist  
Department of Medicine  
(Neurology)*

*University of Toronto  
&*

*Staff Neurologist  
Sunnybrook Health Sciences  
Centre*



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



**If you are interested in planning an event with proceeds benefiting Parkinson Society Central & Northern Ontario, please contact us at 1-800-565-3000 ext. 3301, or 416-227-1200, or by email at [info.cno@parkinson.ca](mailto:info.cno@parkinson.ca)**

☒ Yes, I will help support people affected by Parkinson's in my community. I've enclosed my gift of ☐\$35 ☐\$50 ☐\$100 ☐\$250 ☐Other\$ \_\_\_\_\_

☐Cheque (payable to Parkinson Society Central & Northern Ontario) or ☐VISA ☐MasterCard ☐Amex

Card No.: \_\_\_\_\_ Expiry Date: \_\_\_\_\_ / \_\_\_\_\_ Signature: \_\_\_\_\_

This donation is made on behalf of: ☐an individual ☐a business

### Please complete the following information:

☐Mr. ☐Mrs. ☐Ms. ☐Miss: ☐Other: \_\_\_\_\_ First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ Province: \_\_\_\_\_

Postal Code: \_\_\_\_\_ Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

☐Please sign me up as a monthly donor. I have completed the information above and understand the amount indicated will be charged to my credit card or deducted from my bank account on the 15th of each month (please enclose a void cheque for monthly direct withdrawals). Please begin deductions effective \_\_\_\_\_ (Month/Year)

☐I would like to receive email updates about Parkinson Society Canada activities.

☐I would like to receive The Legacy, a free newsletter on financial and estate planning.

**Please return your reply form with your gift today in the enclosed prepaid envelope.**

*Tax receipts are issued for donations of \$20 or more, or upon request. I understand that I can revoke*

*or make changes to this authorization at any time in writing or by calling Donor Services at 1-800-565-3000 with 30 days notice. I have certain recourse rights if any donation does not comply with this agreement (i.e., I have the right to receive reimbursement for any debit that is not authorized or is not consistent with this pre-authorized payment agreement). To obtain a sample cancellation form, or for more information on my right to cancel a pre-authorized payment agreement or my recourse rights, I may contact my financial institution or visit [www.cdnpay.ca](http://www.cdnpay.ca).*

LWIRE

**Thank you for  
your support!**

### 3rd Party Personal Events

Parkinson Society Central & Northern Ontario has been fortunate enough to benefit from the success of many events using our online Personal Event Manager. The events span a broad spectrum, from Jim Wilkinson's birthday celebration, to Peter Istvan's 100,000 bicycle pedal strokes, to the peaks of Kilimanjaro with Erica Curtis and our Kili Conquerors, and everything in between. We are grateful for the support of our many event coordinators and look forward to seeing the Personal Event Manager grow!



*Congratulations to the Kili Conquerors who raised over \$40,000 across the country and made it to the peak!*



**250 Davisville Ave, 2nd Floor,  
Toronto, ON**  
(Mt. Pleasant & Davisville—close to Davisville subway)

The Canadian College of Massage & Hydrotherapy's regular rate for a one-hour session is \$32 + HST, but has a special rate of just \$12 + HST for people living with Parkinson's! Additionally, they are extending a reduced rate of just \$16 + HST to care providers.

Appointments at the Student Intern Clinic can be made online or by calling Reception. Each appointment will include a thorough assessment to determine the best treatment on any given day for the patron.

**Toll Free:** 1-877-748-7800

**Phone:** 416-736-4576

**Fax:** 416-736-9382

**Email:** [sueng@collegeofmassage.com](mailto:sueng@collegeofmassage.com)

Or book online at [www.collegeofmassage.com/toronto/](http://www.collegeofmassage.com/toronto/)



### Did you know?

LiveWire is now offered in both print and electronic forms. If you would prefer to receive the electronic edition, please contact [livewire@parkinson.ca](mailto:livewire@parkinson.ca) to be added to our email notification list.

### LiveWire

Parkinson Society Canada  
Central & Northern Ontario  
321 – 4211 Yonge St.  
Toronto, ON M2P 2A9

Canada Post  
Canadian Publications Mail  
Sale Product Agreement  
No. 40624078