LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Spring 2013

What's Inside....

Parkinson's—It's a Family Affair

April is Parkinson's Awareness Month

Saphia Khambalia is a reporter for CityNews, Toronto. In 2008 her grandfather was diagnosed with Parkinson's. She has seen first-hand the way this disease has affected the whole family unit. Then in 2012, after wanting to bring awareness for others going through the same plight, she joined forces with Parkinson Society Central & Northern Ontario. See page 3 for her personal story.

If there is an error with your contact information, please contact us so we may correct it. Email livewire.subscriptions@parkinson.ca or call 800-565-3000 ext. 3372.

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

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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. Please email editorial submissions to the editor at livewire.editorial@parkinson.ca. **Next submission deadline is June 14, 2013.**

LiveWire is offered in both hardcopy 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 or call 800-565-3000 ext. 3372.

PSCNO: 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.

- Constantly updated Website
- Information & 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 health care professionals, specifically the *Get it on time* program currently intended to educate staff at Long Term Care (LTC) facilities about the need to get medication **on time—every time.**

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. See page 9 for our upcoming 2013 events!

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.

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.

PSCNO could not fulfill its mission to ease the burden and find a cure without the generosity of its donors and volunteers! To help ease the burden and find a cure, call 1-800-565-3000 ext. 3378 or visit www.parkinsoncno.ca to make a one-time or monthly donation. ***Thank you for your continued support!***

Saphia Khambalia

When working as an international journalist, shooting a mini-documentary in the land of my roots, Uganda, East Africa, I saw a world through the lens that my forefathers succeeded in: Generations of Indians who cultivated the land and economy. I also saw the homes, businesses, and holy places that my grandparents were forced to leave in 1972 during the Asian Expulsion under then-dictator Edi Amin.

> **Saying good-bye to all that, to come to a new land...that is bravery.**

I had great role models while growing up and volunteering, interning, and holding short gigs at television stations all across the province to cut-my-teeth as a reporter; especially my grandfather who came to Canada as a refugee. He worked hard to make a name for himself and reach heights in all levels of society, working in governance and even being decorated by the Queen and Prime Ministers for years of volunteer service. Never giving up in the pursuit of life...that is strength.

That same grandfather supported a family, raised and educated three children, and never left the side of his wife, my grandmother, through her breast cancer, osteoporosis, and now Alzheimer's. After 53 years of sickness and health, they're still in love...that is dedication.

> **Now, there are those moments in life that change your existence forever. My grandfather telling us he had been diagnosed with Parkinson's was one of those moments.**

While everyone's progression is different, we didn't have a slow introduction to this disease; it came at us as quick as a freight train.

Within just a couple years of being diagnosed, he lost the ability to walk and now relies on a motorized wheel chair, requires 24-hour care, and needs help with the smallest of life's tasks. I tell you this not for pity, or to belittle; I say this for the silver lining that can be found. Remember when I said this diagnosis was a major life change? Well...I didn't say it was all bad.

In my eyes, my grandfather is even more courageous now. Parkinson's has meant another massive move. Leaving everything he's known and built at his Hamilton home of over 30 years, to continue life within the foreign world of a nursing home...that is true bravery.

Plus - I have an even tougher role model now. My grandfather continues to "work" in his golden years, a time that should be full of earned frivolity. Instead he spends it constantly trying to make sure he stays strong, agile, healthy, and properly medicated. When a disease changes your world – taking care of yourself is a full-time-job...that is true strength.

And it takes a real committed person to get up day after day, ignoring the detractors, pains and tremors, and still take that step toward moving forward. Even if progress is literally just one step each day...that is true dedication.

Who was he to know that a lifetime of surviving an exodus, arriving in a new country as a refugee with no possessions, parenting three children in a foreign land, and being a supportive husband to a wife for half a century would all really be in preparation for the biggest fight of his life. Parkinson's is his new battle. Not to be underestimated; it is a tough road ahead but one you can live with and live well.

And believe me, if your story is anything like my grandfather's, you are braver, stronger, and more dedicated just for it. Yes, it is a disease which has robbed its victims of so many things. However, it also makes them more of a role model then they knew they could be.

> **Here's to the hope that this fighting will bring an end to the battle for good, and a cure for the grandparents and granddaughters of generations yet to come.**

Meanwhile, just like I'm fighting this fight with my grandfather, YOU have the team of people at the Parkinson Society, the 100,000 other Canadians with Parkinson's plus their 400,000 caregivers alongside you. Doesn't sharing the journey with someone else already make the battle that much better? It does if you're looking through my lens...

Saphia Khambalia is an award-winning broadcast journalist, whose reports can be seen on CityNews, CityNews Channel, Citynews.ca, and heard on 680News, Toronto's only All News radio station.

Tammy Taylor—In Her Own Words

When were you diagnosed with Parkinson's Disease?
I was diagnosed with Parkinson's disease (PD) in April, 2000. I was 32 years old and had a four-year-old and a two-year-old.

What have been your coping strategies?
I really haven't thought too much about coping strategies. My children were very little when I was diagnosed and therefore I didn't have much choice but to cope and carry on, for their sakes if nothing else. Now I just try to greet each challenge as a new experience and carry on the best I can.

How does your family support you?
My family supports me in many ways. They are always there to lend a hand or even an ear when I need it, or even to tell me "suck it up" if I complain too much. They know I can do things and really try to keep me grounded, but are also willing to pitch in when I need them.

When did you become involved with the Parkinson Society?
I was diagnosed with PD when I was 32 years old. My tremor became noticeable when I was 29 and took three years to diagnose. Approximately a week after my diagnosis, I was made aware of the support group meetings in Bracebridge.

> **I went to my first meeting and continued going on a monthly basis. It was probably the first most important, and positive, influence in my coming to terms with my diagnosis. Ever since then, I have tried to do anything I can to get awareness out to the public.**

Porridge for PARKINSON'S

Sunday November 3, 2013
10 AM – 12:30 PM, THE VAUGHAN ESTATE
2075 BAYVIEW AVENUE, TORONTO
Visit www.porridgeforparkinsons.ca for updates.

Parkinson's is viewed much differently when people hear that I was 29 when my symptoms first appeared, and 32 when I was diagnosed. I have had many people tell me how grateful they are that I was able to inform them of the disease; not a lot of people realize that it really can affect anyone.

Are you involved with Parkinson events (e.g., SuperWalk, support group meetings) and how does your family participate and support you?
I am involved with SuperWalk and support group meetings. I am a twin and my sister co-ordinates the SuperWalk here in Bracebridge. I also help Karen Boyer, along with another wonderful PLWP (person living with Parkinson's) and his lovely wife, run the support group meetings when she cannot be there. My family has been a wonderful support system for me; they always have an ear and a shoulder when I need them. My sister and mom help me a lot with housework, especially the parts that I struggle with, as do my children and husband. The support of my family and friends has been overwhelming. I consider myself very fortunate to have all of the people I do in my life. It definitely has made the disease easier to deal with.

Is there other information about your experience that you'd like to share with our LiveWire readers?
I think the most important thing for everyone to realize is that it really is a "life-altering" disease, NOT a "life-threatening" disease. You really do need to exercise, and a positive attitude ALWAYS helps in dealing with all of the things life throws at us, including Parkinson's.

Young Onset Parkinson's Disease (YOPD)

FOCUS GROUP

Have you been diagnosed with Parkinson's and still have a young family at home? Still working? Making plans for your future? Help us help you!

Regional Focus Group Discussion

Saturday, May 11, 2013, 9:30 a.m. to 2 p.m.
Ajax, Ontario

Join us for a day of conversation, great food, and a discussion on living well with YOPD. Space is limited so register early!

Topic: How can Parkinson Society Central & Northern Ontario serve you better?

· support group meetings · web chats · education sessions ·
· Skype · conference calls · social networking · blog · etc. ·

To register, call Diane at 800-565-3000 ext. 3315 or email diane.newmanreed@parkinson.ca by April 26.

Plan Now to Attend World Parkinson Congress 2013!

Where: Palais des congres, Montréal
When: October 1–4, 2013
www.worldpdcongress.org

PSCNO has developed plans to assist people in getting to Congress. Please contact your support group facilitator to get the details about the plans in your area. If you do not know who to contact, and you would like to know what assistance is available, please contact Debbie Davis at debbie.davis@parkinson.ca

Special thanks to Nora Fischer for her generous donation that will help us in our World Parkinson Congress plans

Registration is open
http://www.worldpdcongress.org/?page=RegistrationDetails

Don't forget to sign up for the Parkinson's Buddies Program that matches WPC registrants (those who have signed up to attend the WPC in Montréal 2013) with Canadians with Parkinson's disease who have also signed up to attend the Congress: http://www.worldpdcongress.org/?page=WPCBuddies

CALLING ALL ARTISTS!

We are fortunate to have funding again this year to produce our third Hope on Display calendar. If you are an artist of any kind—painter, photographer, jewellery maker, quilter, woodworker, etc.—and would like to be considered for the 2014 calendar, please send an email and high resolution image of your work to Debbie Davis at debbie.davis@parkinson.ca by August 1, 2013.

Registration opens April 3, 2013!

WWW.PARKINSONSUPERWALK.CA

PARKINSON
SUPERWALK

For more information on how you can get involved, please call

1-800-565-3000 ext. 3374

Dystonia

Sandie Jones, RN

People living with Parkinson's often ask us "Is there pain associated with Parkinson's?" Pain is a common symptom and it is our bodies' way of telling us that something isn't right and other causes need to be investigated—we should not jump to the conclusion that any and all pain is due to Parkinson's disease (PD). We all can get different kinds of aches and pains for various reasons, so it is important to talk to your doctor to sort out what the cause might be.

That said, pain is common among those living with Parkinson's but does not get much publicity. Just as with everything else related to Parkinson's, everyone is different and not everyone will experience this problem. For some people, pain can be the main symptom of their condition.

For those people, it may be discomfort brought on by stiff muscles, which have a harder time moving. Hard muscles may bring on some cramps, but this can usually be "worked out" by gently stretching the muscle. For some people, there may be a much more difficult type of cramping pain, which is referred to as *dystonia*.

Dystonia can be confusing to understand, and when people try to get information about it, especially online, they end up more confused. In general, dystonia can be described as involuntary muscle contractions, which can cause twisting and jerking, and can tighten different parts of your body, for a **SUSTAINED** period of time. Muscles that should be relaxed are tensed and tight.

Dystonia typically twists, turns, or contorts some part of your body and often results in spasmodic and repetitive movements or abnormal involuntary postures. People who have dystonia often refer to it as a painful cramp which lasts a long time. Unlike typical cramps, however, which usually resolve when we stretch the muscle, dystonia muscle contractions are sustained—like a "charley horse" that doesn't go away.

If you were to just look up 'dystonia' online or in a medical book, you might read that dystonia, like Parkinson's, is a movement disorder and is the most common movement disorder after PD and essential tremor. This does not mean that you now have two different movement disorders! Some kinds of dystonia happen independently for different reasons, but with a diagnosis of Parkinson's, it is usually just another secondary symptom that your specialist will have to treat.

Dystonia is more common in Young Onset Parkinson's, but it can affect anyone with PD. The most common forms of dystonia related to Parkinson's happen in the lower legs, for a **SUSTAINED** (lasting a long time) period, and can include the following:

- curling or arching of the toes—spasms in your muscles may make toes curl into a claw-like position
- in-turning of the foot—your foot may turn in at your ankle and your big toe may extend
- cramping in the calves

The symptoms mentioned above typically reflect an untreated or undertreated state and often develop several hours after a dose of levodopa when the beneficial effect of the medication has worn off. As a result, they often occur during the night or early in the morning, many hours after the last levodopa has been taken. Dystonia can also occur during the day and may be present continuously if the person living with PD is underdosed or undertreated.

I have been talking about dystonia affecting the lower limbs, especially toes, feet, or calves. But dystonia can also involve the head and neck, with the head turning, the face contracting, the eyes blinking, or the tongue thrusting outwards. There is also a type of dystonia, called blepharospasm, which involves involuntary eye closure, where the eyes tend to close unintentionally. As with the other types of dystonia, all of the above symptoms most often occur during the levodopa off-state.

In summary:

- Dystonia is a sustained (lasts a long time), involuntary, usually painful, muscle contraction that can affect different parts of the body.
- Dystonia happens most often when levodopa treatment is "wearing off" —when the drug becomes less effective before the next dose is due.
- It is most likely going to happen when you wake up, because it has been some time since your last dose of medication, and is most likely going to affect your feet and legs.
- It is more common in Young Onset Parkinson's but can affect anyone.
- It is often mistaken for muscle cramps caused by rigid muscles, but rigid muscles are hard because they are less elastic or flexible; the hardness in dystonia comes from muscles contracting without relaxing.
- The first step is to identify the cause of your dystonia. Keep a diary that will show how your dystonia relates to your medications. Speak to your doctor about changing the type and timing of your medications.
- For dystonia that does not respond to changes in PD meds, discuss other drug treatment options with your doctor, e.g., Botox (botulinum toxin), a nerve toxin that is sometimes injected in small doses into the affected muscles.

If you have further questions, please don't hesitate to call me at 416-227-1200/800-565-3000 ext. 3375.

Perception and the "System"

Robert TerSteege, CIRS-CAN

"You've got to check out the new grocery store! It's huge; it's got everything; it's so well laid out!" With my friends' enthusiastic endorsements, I decided to do my grocery shopping one Sunday afternoon. It was huge, it had everything…and it was jammed full of people checking it out. An hour into the adventure, I realized I had lost my list, and had just about had it with people posing for pictures of everything, while I struggled to find basic foodstuffs.

One of the frequent complaints I hear from people is how difficult the "system" is to get through. When they think of the "system," most people have a vague sense of something like a grocery store, where they can find everything that they need in one place: just walk in, walk around, and you're out with everything you need. People do it all the time, so how hard can it be?

Only when you first have to learn about services, programs, and the agencies who deliver them do you realize how complicated the "system" is. The good thing is that you usually only have to deal with a few staff from a few agencies to get what you need. The bad news is, if you don't know what you are doing, it can be as tough walking into a new grocery store without a list at the busiest time of the week!

That's not to say that my friends were wrong about the new store, but because they went early on a Monday morning, and weren't doing a full grocery shop, they were able to easily manoeuvre around, and check things out.

> **We all have different perspectives on the situation, but the more complex the situation, the more different ways there may be to look at it.**

Here are a few different ways of looking at dealing with the "system," which may help reduce the frustration you may have experienced:

- Different people have different perceptions of the exact same thing. Have you ever gone to an emergency room at the hospital, and had to sit there while everyone else seems to go first, even if they seem to be in better shape than you? Keep in mind when you go to any agency, there may be someone worse off. Your situation may seem bad to you, but it may not be viewed as urgent as others.

- No one agency or program can fix all your problems; because you are being directed elsewhere does not mean you are getting the run-around. If you call the Parkinson Society for information on medication, and for whatever reason get through to the IT department, you will talk to a very nice gentleman who will want to put you through to client services—because he doesn't have the information you need, and not because he doesn't want to help you! It is frustrating to hear "Sorry, not my department," but don't take it personally.

- Learn everything you can about the program or agency you are dealing with, and try and find out if they are able to help with your situation, and what the process is. For example, if applying for a financial assistance program, what is the application process, and how long does it take?

> **If you don't know the process, you may be very frustrated later when you are waiting for an outcome. If you don't know, ask!**

- Know what an organization can and cannot do for you. Identify reliable sources of information and support. If your second cousin's sister's neighbour's pastor's ex-wife told you that the Parkinson Society provides dog-walking services, you would have very wrong information—we don't! Likewise, be careful of on-line blogs and testimonials, unless you personally know the person. A grinning picture of Mr. S from Coober Pedy, Australia, endorsing a service does not mean that it is a good service!

- Document your activities: date, time, who you spoke to, what you discussed, next steps. I say this one a lot, but it is important! Documenting helps you, not only to remind yourself, but to remind the people that you spoke to. Remember, you are not the only person that they are trying to help.

- Be prepared to educate people about Parkinson's, in case the person you are dealing with does not know anything about it. You might be very surprised at how accommodating people can be if they know what your situation entails!

While the "system" may seem overwhelming to you, keep in mind that in one sense it is like the grocery store: if you give up and leave your shopping cart, there will be no food in your cupboard; if you at least try, you will be taking something; and if you persist, you may get what you need.

APRIL IS...PARKINSON'S AWARENESS MONTH

Hope in Bloom

The Hope in Bloom Tulip Campaign…It's a Family Affair

When Marilyn Forbes, Noni McLelland, and I initiated the Cut Tulip campaign in 1984, we had no idea how successful it would eventually become. It began as an awareness project during April, which had recently been designated as "Parkinson's Awareness Month." We started by setting up tables in the concourses of several downtown office towers and a few shopping malls around the city.

The project was very "home-spun" in those early years; the tulips were delivered in bulk by our supplier to a volunteer's home where we divided them into bouquets of five blooms, wrapped them, and stuffed them with an insert providing information about Parkinson's disease.

It was a fairly labour-intensive undertaking, particularly when the temperature suddenly became summer and we were trying to keep our tulips as fresh as possible in a volunteer's garage! However, as the years went by we gradually streamlined the practical elements and we expanded the number of outlets according to how many volunteers could be enlisted. Gradually the project grew and more Parkinsonians became tulip volunteers.

The other element which was part of the project from the start was called the "pre-sales." This entailed approaching companies and inviting them to purchase tulips in support of Parkinson's as part of the day known formerly as "Secretaries' Day," now Administrative Professionals Day. This has been a very successful part of the campaign as it requires a minimum of volunteer involvement.

At a certain point some years ago, I introduced my brother, Shane Curry, to our project, and he in turn built a wonderful team who support his efforts. This group runs one of the largest and most profitable venues in the downtown core. So I am happy to say our Tulip Campaign has become a family effort!

Over the years, I believe that the volunteer efforts of Parkinsonians, their friends, and families, have done a great deal to increase public awareness of Parkinson's, and have also raised a sizeable amount of money which has been dedicated to research and patient services. The possibilities for expansion to more venues and smaller communities are constantly being realized—which is very gratifying for all of us who seek to find a cure for this debilitating condition.

Catherine Graham, tulip captain volunteer for 28 years

The **Hope in Bloom Tulip Campaign** kicks off Thursday, April 4 at the Royal Bank Plaza with Saphia Khambalia from CITY TV. Saphia will be joining the volunteer team, led by Shane Curry, and will be broadcasting from the Royal Bank Plaza.

Please help us celebrate the 29th year of the tulip campaign which has raised hundreds of thousands of dollars to help people with Parkinson's. There are a few ways that you can support the campaign:

Volunteers at the tulip venues are needed to help sell fresh cut and potted tulips during the month of April. Sales will be held throughout the region on various dates. It's easy, a fun way to meet people, and a great way to support our programs helping people with Parkinson's. Please call Naseem Jamal at 416-227-3377 or naseem.jamal@parkinson.ca if you are interested in joining our fabulous volunteer team!

Key Toronto Sales Dates:

Friday, April 5: Kick-off at the Royal Bank Plaza

Saturday, April 6: IKEA stores in Burlington & Etobicoke

Wednesday, April 10: TTC Day

Tuesday, April 16: Union Station

Wednesday, April 17: Commerce Court

Saturday, April 20: Fairveiw Mall, IKEA—North York and Vaughan

Wednesday, April 24: Sunlife, TD Tower, Scotia Plaza, College Park

Check with your local support group for a volunteer tulip sales opportunity near you!

We invite you to be a **tulip ambassador** for your company or volunteer organization by coordinating the ordering of tulips. Tulips are a great way to celebrate Easter, Professional Administration Day, and staff or volunteer accomplishments. Bouquets of tulips are $6/bunch and potted tulips are $10/pot. Email bloom@parkinson.ca to request a TULIP ORDER FORM and your name will be entered to win a **Night Out on the Town with dinner for two and a pair of Toronto Blue Jays baseball tickets.**

2013 Major Education Events

Considering joining our Partners for Parkinson's Monthly Giving program? **Join by June 1 and you will be included in a special monthly donor draw for two registrations to WPC!** Contact Lorelei Wilkinson at lorelei.wilkinson@parkinson.ca or 800-565-3000 ext. 3378 to set up your donation today!

Pitch in 2013

On August 10, Pitch In and help hit a home run in support of Canadian's living with Parkinson's. Premium tickets available for the Jays vs. White Sox at the discounted rate of $45 each or four for $150.

We're bringing back our silent auction on Sunday, July 21! In association with this event we're happy to announce that our dinner and silent auction event, hosted by Gregg Zaun (formerly of the Toronto Blue Jays), of Rogers Sportsnet, will be back for an exciting evening of dinner, drinks, and raising dollars.

Visit
www.pitchinforparkinsons.ca

Call
416-227-3377

Email
naseem.jamal@parkinson.ca

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

Pitch in
for Parkinson's

Parkinson's: It Takes a Team!

This year's theme for education is *Parkinson's: It Takes a Team!* Space is limited at some venues: watch your mailbox for local event details, or contact the staff below if you are interested in an event in another community—all are welcome!

Online registration will be available closer to the event dates below. Please visit www.parkinson.ca/conference for more information and to register.

May 7: Hamilton/Burlington (Royal Botanical Gardens, 7:00–9:00 p.m.)

Keynote Speakers: Dr. Mary Jenkins; Angela Roberts, SLP, plus other multidisciplinary allied healthcare professionals, *Building Your Healthcare TEAM*—includes practical coping strategies to deal with different aspects of Parkinson's

To register, or for more information, please contact Karen karen.dowell@parkinson.ca or 1-800-565-3000 ext. 3376

May 14: Midland (Midland Cultural Centre, 7:00–9:00 p.m.)

Keynote Speaker: Dr. Naomi Visanji, *What's New in Parkinson's Research*

To register, or for more information, please contact Karen karen.boyer@parkinson.ca or 1-800-565-3000 ext. 3371

June 1: Sault Ste. Marie (Delta Waterfront, 9:00 a.m.–3:00 p.m.)

Keynote Speakers: Dr. Amir Burhan, *Psychiatric Issues Related to Parkinson's;* Dr. Mark Guttman, *Update on Treatment & Management of Parkinson's*

Afternoon concurrent sessions: Karen Boyer, *Carepartner Workshop (Carepartners Only)*; Sandie Jones, RN, *Parkinson's 101*

To register, or for more information, please contact Karen karen.boyer@parkinson.ca or 1-800-565-3000 ext. 3371

June 12: Toronto (Toronto Botanical Gardens, 7:00–9:00 p.m.)

Keynote Speaker: Dr. Galit Kleiner-Fisman, plus a multidisciplinary team of allied healthcare professionals, *Building Your Healthcare TEAM*—includes practical coping strategies to deal with different aspects of Parkinson's

To register, or for more information, please contact Naseem naseem.jamal@parkinson.ca or 1-800-565-3000 ext. 3377

June 13: Kingston (Harbour Restaurant Portsmouth Olympic Site, 10:00 a.m.–2:00 p.m.)

Keynote Speakers: Dr. Aarlenne Khan, *Benefits of Cognitive Training in Parkinson's*; David Simmonds, Motivational Speaker

To register, or for more information, please contact Diane diane.newmanreed@parkinson.ca or 1-800-565-3000 ext. 3315

Ontario Trillium Foundation

The Ontario Trillium Foundation Makes Strategic Investment in Parkinson Societies of Ontario

Central & Northern, Southwestern, and Eastern Ontario have joined forces to collaboratively use new funding to build more awareness of Parkinson's disease.

Parkinson Societies of Ontario are pleased to formally announce that we received a $163,200 grant from the

Ontario Trillium Foundation (OTF) last November. Over the next two years, this province-wide grant will be used to develop a new communications plan promoting awareness surrounding Parkinson's disease and access to available services across Ontario.

"The Foundation is pleased to make what we consider to be a strategic investment, enabling your organizations to continue raising awareness of Parkinson's," says Andrea Cohen, Chief Executive Officer, OTF. "This is a terrific example of collaboration and serves as a more efficient resource in reaching larger audiences. We believe it will positively affect fundraising levels as well."

With this financial support, Parkinson Society Central & Northern Ontario will be expanding its communication efforts to better serve families living with Parkinson's. Funds from the grant have been used to hire a Communications Specialist and will also support costs to boost communication projects.

"Dedicated to making a difference in the lives of families living with Parkinson's, we are happy to have received support from the Ontario Trillium Foundation," says Debbie Davis, Chief Executive Officer, Parkinson Society Central & Northern Ontario. "This funding will play an integral role in helping our organization promote its research, education, support, and advocacy initiatives across the community."

The grant will help Parkinson Society Central & Northern Ontario achieve its objectives such as reinforcing knowledge about the disease through Parkinson's Awareness Month held in April. Also, it will contribute to enhancing the level of engagement in the community by spreading the word on projects such as the recently published and first official 'Canadian Guidelines on Parkinson's Disease.' As well, it will provide our organization with the resources to develop communication strategies to generate more awareness and grow participation at events like the annual Parkinson SuperWalk held in September to continue to increase fundraising levels.

More than 100,000 Canadians are living with Parkinson's and with this OTF grant, Parkinson Society Central & Northern Ontario is one step closer to providing better support and making positive change.

A leading grant-maker in Canada, the OTF strengthens the capacity of the voluntary sector through investments in community-based initiatives. An agency of the Government of Ontario, the OTF builds healthy and vibrant communities. For more information, please visit the Website at: www.otf.ca

New Pedaling for Parkinson's Website Launched

Visit www.pedalingforparkinsons.ca to see our new look.

Join our riders in Parry Sound, July 12–14, and enjoy the beautiful country, the camaraderie, and the challenge.

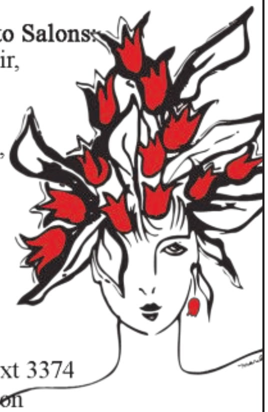
Parkinson Cut-a-thon 2013

April 7, 2013

Save the Date

Participating salons in: Barrie, Bracebridge, Collingwood and Guelph

Thank you Toronto Salons:
Donna Dolphy Hair,
Haartek,
Hair2Inc,
Oskar on Scollard,
Paul Peccorella
Hair Studio,
Robin Barker
Hair'sociates
and Sassoon.



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

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 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, summer, and fall. Expect our Spring edition in early March, our Summer edition in July, and our Fall/Winter edition in November.

Support Group Facilitators Wanted

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. These groups are held once a month in the evening on weekdays.

Training will be provided. Our next training session is scheduled soon. Once training is completed, the commitment is 3–5 hours per month.

Background in nursing, social work, physiotherapy, speech language pathology, and/or another medical aspect of Parkinson's disease is an asset. Experience in facilitation of groups or meetings is also an asset. Active Seniors are welcome!

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

HOPE ON DISPLAY

When: Sunday, April 14, 2–4 p.m.

Where: Churchill Place, Oakville
345 Church Street

Come out and see some wonderful art created by people living with Parkinson's: it's a perfect setting for our local painter, potter, and quilt maker.

The event is free and you have the opportunity to learn more about Parkinson's disease, and purchase the artists' work and some lovely tulips too!

We are still looking for a local musician to round out the day.

For further information, contact Karen at 800-565-3000 ext. 3376 or karen.dowell@parkinson.ca

Do you know someone who would like to receive our LiveWire newsletter? Simply contact livewire.subscriptions@parkinson.ca or call 800-565-3000 ext. 3372.

Did you know?

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

LiveWire
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