Summer 2014

LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

PARKINSON SUPERWALK

EVERYDAY HEROES. EXTRAORDINARY HOPE.

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It's a bird…it's a plane… IT'S A SUPERWALKER!

Calling all superheroes! This is your opportunity to make a difference for people living with Parkinson's across Canada and in your community.

Parkinson SuperWalk will be taking place the weekend of September 6 and 7, with additional support group walks happening throughout September.

In 2013, more than 3,000 participants at 30 walk locations in Central & Northern Ontario came together to raise over $960,000! **This year, please join us at one of our 31 walk locations throughout the region as we set our sights on the regional goal of $1 million,** funding support services, education, advocacy, and research, through individual pledges and corporate sponsorship.

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

Parkinson Society Central & Northern Ontario

I hope you are enjoying a lovely summer and have taken some time to enjoy yourself!

As you read through the summer newsletter, I think you will find some valuable information—we are fortunate to have some specialists on our staff who have shared their expertise in their articles. If there is ever anything you would like to hear about through this publication, please let me know.

On page 9 you will also find the event details and registration information for our 2014 Regional Conference held on October 24 and 25. We have some wonderful presentations planned to warm your minds and a little dancing to warm your heart. I hope you can join us for a great experience.

As a final note, I would like to personally invite all of you to join us for a Parkinson SuperWalk close to you this year, and bring your family and friends for a day of warmth and fun! Parkinson SuperWalk is the 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.

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 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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Everyday Heroes

Cheyenne Twiner: SuperWalker

At 29 years of age, Cheyenne Twiner is a proud Torontonian, a passionate jewelry designer, and yes, an avid SuperWalker. In fact, this year will mark her fourth consecutive year participating in Parkinson SuperWalk.

For Cheyenne, September is a very special month. It is not only when Parkinson SuperWalk is annually held, but also the month her grandma, Mavis Gracey, passed away after fighting a long and hard battle with Parkinson's disease. That was in 2010.

Since then, naturally, September can bring forth many sentiments every year for Cheyenne. But, instead of dwelling on the profound loss of a loved one physically gone from this world, Cheyenne chooses to celebrate Mavis' life by being an active part of a positive mission—that is, partaking in Parkinson SuperWalk to help raise awareness and funds for this chronic neurodegenerative disease.

"After my nana passed away, we started participating in Parkinson SuperWalk every year. It's a nostalgic time of the year, so it's a nice way to pay a tribute to her memory," she says.

Cheyenne was very close to her grandma, and Mavis' death has had a strong impact on her life.

"Nana lived with me as I was growing up and she was diagnosed when I was very young. So, I pretty much saw the progression of the disease through her and I've been exposed to it my whole life," says Cheyenne.

It may be fair to say that Cheyenne's passion for, and commitment to help, the Parkinson's community through Parkinson SuperWalk, year after year, is nothing short of heroic, extraordinary, and driven by her love for Mavis, or as she likes to call her, 'nana.'

Keen to raise as many dollars as possible for the upcoming walk this year, Cheyenne reaches out to her family and friends every year for donations.

"We are a pretty big family, so that helps," she says.

For this year's Parkinson SuperWalk, Cheyenne has already kicked off her fundraising plans by selling jewelry she designed herself and plans to continue fundraising throughout the summer. She'll be walking alongside her family and friends in Toronto, taking the steps to make a difference.

If you'd like to join Cheyenne, and thousands of other inspiring participants at Parkinson SuperWalk, please visit www.parkinsonsuperwalk.ca for details. Together we can help ease the burden for the Parkinson's community and one day find a cure.

Birthday Wishes to a PSCNO Hero!

Melitta Bumeister is a very special person who has lived with Parkinson's for approximately 40 years. She has been a generous supporter of the Parkinson Society Central & Northern Ontario (PSCNO) for over 16 years and is a valued member of the PSCNO family. Melitta has supported PSCNO's Parkinson SuperWalk and other fundraising campaigns throughout the years and feels it is important to support the programs, services, and education that PSCNO provides to our community.

Originally from Munich, Germany, Melitta moved to Canada in her early 20s and was diagnosed with Early Onset Parkinson's in her 40s. In July, Melitta is celebrating her 80th birthday. Here is a message to Melitta in honour of her birthday: We wish you a lovely day, not just today because it's your birthday, but all year round. May you always wake up in the morning with a smile on your face.

With love from your family, friends, Princess, and your family at PSCNO.

Parkinson SuperWalk 2014

Find a Parkinson SuperWalk near you!

Saturday, September 6th, 2014

Alliston: Riverdale Park

Barrie: Heritage Park

Belleville: Zwick's Centennial Park

Bracebridge: Bracebridge Public School

Collingwood: Harbourview Park

Guelph: First Christian Reformed Church

Kingston: Lake Ontario Park

Mississauga: Living Arts Centre

Oakville: RioCan Oakville Place

Peterborough: Thomas A. Stewart School

Sudbury (Sept. 13, 2014): Delki Dozzi Park

Thunder Bay: Intercity Shopping Centre

Sunday, September 7th, 2014

Brampton: South Fletcher's Sportsplex

Burlington: Burlington Senior's Centre

Durham Region: Ajax Rotary Park

Hamilton (Sept. 14, 2014): St. Peter's Hospital

Markham: Fred Varley Art Gallery

Newmarket/Aurora: Fairy Lake

Niagara Region: Lakeside Park – Pavilion

Northumberland: Cobourg District Collegiate Institute E.

Orillia: Couchiching Park – Pavilion 1

Timmins: Timmins Regional Athletic & Soccer Complex

Toronto: Earl Bales Park

Vaughan: Vaughan City Hall

Parkinson SuperWalk: Support Group Walks

Haliburton: Haliburton Public Library – **Sunday, September 21**

Huntsville: Faith Baptist Church – **Monday, August 25**

Kirkland Lake: Kinross Pond Walking Trail – **Wednesday, September 10**

Manitoulin Island: VON Office – **Thursday, September 18**

North Bay: Rotary Waterfront Pavilion – **Thursday, September 11**

North Simcoe: Real Canadian Superstore, Midland – **Thursday, September 25**

Parry Sound: Belvedere Heights – **Wednesday, September 17**

Sault Ste. Marie: Senior Citizens' Drop-in Centre – **Thursday, September 11**

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

Parkinson SuperWalk 2014

Parkinson SuperWalk: What's New?

This year, please join us at one of our 31 walk locations as we set our sights on the regional goal of $1 million!

A highlight this year is our new and improved website: www.parkinsonsuperwalk.ca

Visit the website to register, and check out some of the following great features:

- Create a custom link for your personal or team profile pages.
- Sponsor yourself in the registration process and receive a Personal Achievement Badge on your profile.
- Add a co-captain to help the Team Captain manage their team.
- Easily import email contacts (i.e., Yahoo and Gmail).
- Set up Parkinson SuperWalk stationery for your custom emails asking for donations.

In addition to our National Parkinson SuperWalk incentive prizes and draws, we are happy to be able to offer two new regional incentive prize draws this year. To celebrate our new online fundraising platform, both prizes will focus on making use of the online tools available to our walkers. Check out the website for more details.

If you're looking for even more excitement, consider joining us in Toronto for our Superhero 5K Run. Participants are encouraged to run the course dressed as their favourite Superhero as part of our Everyday Heroes theme for 2014. Prizes will be awarded for best costume, best costume racer time, best team costume, and more!

Form a team with your friends, family, and colleagues, grab your superhero capes and masks, and be sure to join us in September at a sensational Parkinson SuperWalk in your community!

Top 10 Social Media Fundraising Tips

When it comes to fundraising, social media can be a great tool. Here are some tips to get you started...

1. **Connect** with PSCNO and Parkinson SuperWalk on Facebook and Twitter

https://www.facebook.com/pages/Parkinson-Society-Central-Northern-Ontario/101248525517

https://twitter.com/ParkinsonCNO

https://www.facebook.com/ParkinsonSuperWalk.ca

https://twitter.com/SuperWalk

2. **Share** using the sharing buttons on our website. Many pages on our Parkinson SuperWalk website have the sharing buttons which allow you to post to Facebook, Twitter, and Google Plus. Clicking these links is a fast and convenient way to update your contacts!

3. **Ask permission** to have your workplace or other social organizations post, retweet, or otherwise share your message on Parkinson SuperWalk.

4. **Empower** your team via social media. **Recognize** the fundraising efforts of your peers and acknowledge team members via congratulatory messages.

5. Direct asks yield **results**. Make sure you're asking your friends to do something. Use words such as, "Donate now!" or "Share this!" Unless you're direct, you won't get results. **Be clear**: make sure you include a brief explanation of how and where they can donate to you.

6. **Challenge** yourself and your team. Set a lofty goal for yourself, and let everyone know what it is. Tell them they're the only ones who can help you reach that **goal**. Give them something to care about.

7. **Personalize** your approach. Why are you participating in Parkinson SuperWalk? Tell your friends why this is important to you, and why you need their support. Make it **personal**.

8. **Be thankful**. If someone donates to you or your team, thank them publicly through social media; doing so via social media is yet another reminder to your other contacts about the cause.

9. **Hashtag** your tweets and link back to the event on Facebook. Use the hashtag **#SuperWalk** in your message to ensure people outside of your network see what you have written!

10. Enjoy your fundraising experience. Raising money and participating in Parkinson SuperWalk is **fun**.

At the end of the day, **feel good** about what you're doing for the cause, and let others know this.

Contact us for more tools and tips on how to engage your social networks.

The Nurse's Desk

Platypi and Parkinsonisms

Sandie Jones, RN

Many of you have heard the old saying "If it looks like a duck, swims like a duck, and quacks like a duck, then it probably is a duck." But just because it has a bill and swims doesn't always mean it's a duck: it could be a platypus!

So what does this have to do with Parkinson's disease (PD)? Actually, nothing … and that is the point of my article today!

As you probably know if you've called us before, we often ask you "who made the diagnosis of PD, and who is treating you?" You know that whenever possible, we encourage people to see a movement disorder specialist—a neurologist further specialized in PD and related conditions—or at the least, a general neurologist.

Those 'related conditions' are often referred to as 'Parkinson's Plus' but more correctly as atypical parkinsonism. You might think that parkinsonism and Parkinson's disease are one and the same, but in actual fact, the term parkinsonism encompasses a group of conditions and disorders that mimic PD in some ways, but are distinct from PD in other ways. This is just like ducks and platypi—both lay eggs and swim, but are otherwise very different!

The adjective used to describe the common symptoms is *parkinsonian*. The four main parkinsonian symptoms common to the parkinsonism disorders are the following:

T – tremor
R – rigidity
A – akinesia (lack of movement) or bradykinesia (slowness of movement)
P – postural instability (loss of balance, falls, loss of coordination)

Indeed, the most common, slowly-progressive, condition that causes parkinsonism is Parkinson's disease, but the point of today's article is to begin the conversation about other conditions that can be mistaken for PD—those that are similar to, and often confused with, Parkinson's.

Before we go further, I am in no way suggesting that people should engage in self-diagnosis. **A careful medical history and neurologic examination, combined with the passage of enough time to indicate how symptoms are progressing**, **generally provides an accurate diagnosis**. Again, this is why we look to movement disorder specialists (MDS) and neurologists to make the distinction.

Because none of the parkinsonisms that I am talking about today have initial tests, the MDS has to gather certain clues that may lead to an initial diagnosis of Parkinson's disease, and follow it with a list of clues that lead to the fact that you don't have typical Parkinson's disease. While some of these clues may be symptoms that also occur, it is *when* they turn up that makes them the biggest clue: the problematic symptoms typically turn up within a few years of diagnosis in atypical parkinsonism, but not until years or decades into Parkinson's disease!

Parkinson's Disease Clues	**Atypical Parkinsonism Clues**
Onset of one-sided tremor; typically with a limb at rest, which has slowly gotten worse over 1–2 years	Early onset of blood pressure problems: fainting, dizziness when standing
A leg dragging or moving slowly while walking	Lack of response to antiparkinson's medications
Difficulty doing up buttons, brushing teeth, using utensils	Early onset of balance problems and falls
An arm failing to swing while walking	Early onset of forgetfulness
Soft or muffled voice	Early onset of swallowing problems
Lack of facial expression	Early onset of bladder dysfunction
Stooped posture when you stand or walk	Difficulty with eye movements

So just what are these atypical parkinsonisms? On page 11, I am going to briefly describe three of the most common, which are still very rare!

Continued on page 11

Starting the Talk Now About The End

Robert TerSteege, CIRS-CAN

There are two shared life experiences that everybody has: we are all born, and we all die. Birth usually is associated with joy, and death often with grief. The truth is, regardless of whether you have Parkinson's or not, one day we all die.

Every single second in between birth and death is life. When you think about it, someone is never *dying*, they are still *living*. While anyone is living, we want him or her to have the best life possible right up to the last breath.

The number one question that we hear from newly diagnosed people is "when am I going to die?" According to the World Health Organization, in their report *World Health Statistics 2014*, the life expectancy in Canada is on average 82. That's an average, not a guarantee, which is part of the problem when we start talking about the progression of PD: the best doctors can't give you exact numbers or guarantees on what is going to happen and when.

When you are confronted with a chronic health care condition like PD, you are being given an opportunity to put some plans in place. You know your symptoms will increase at some point down the line.

The idea is to plan for the worst and hope for the best. Life, in general, usually falls somewhere between those two ends of the spectrum.

Because we don't have a cure for Parkinson's, the best treatments are to offset the symptoms that you may be having. As things progress, you may experience new or worsening symptoms. Where you may have had some stiffness in one arm that was just annoying, you may get increased stiffness on both sides of your body, making it harder to move. Medications may need to be changed and carefully taken—on time, every time—in order for you to keep symptoms more under control, for as long as possible.

While specific symptoms are often difficult to predict, so are their impact on your life. There may be increased mobility problems, which can increase the possibility of falls. There may be changes in cognition, making it more difficult to plan and carry out certain day-to-day tasks. There may be psychiatric symptoms, such as depression or anxiety. All of these can have different impacts on your life, depending on what resources you may have available to you: medical, social, financial, and inner resources.

Before we go further, take PD out of the equation for a moment. Did you ever stop to consider what the end of your life would be like? Many of us have heard of family members or friend's situations where there had to be some big health decisions made in a crisis situation, and our thought often is simply "I hope that never happens to me."

Nobody will care about your own life more than you do, so what steps have *you* taken to make sure that *your* best vision for the end of *your* life takes place? Do you know right now what the government does and does not pay for in terms of in-home support, equipment needs, home modifications, or caregiver support? Do you have your legal work in place in terms of Powers of Attorney (both for financial and health issues) and a will? Do your loved ones know what your wishes are, to avoid family fights in the hospital over who really knew what Dad wanted? In case of an emergency, does someone know what your medication schedule is?

Because the changes with PD are so slow, it could be years—even decades—into the progression before people realize that things have gotten to a point that is more difficult to deal with and then do not have the opportunity to voice their opinion. That's a frightening thought for some people. That's why we try to discuss these types of things early on, and then periodically.

It is not uncommon for someone who is newly diagnosed, upon meeting someone more progressed, to say "I don't want to end up like that," yet a person who is further along the path may think "This isn't as bad as I thought it would be." Though things may not be going in a way you originally planned, you may still be enjoying your life.

The aim of palliative care is to ensure that you continue to have the best quality of life possible. It is not about trying to cure you, or treat the disease, but to ease any symptoms that could be troubling you, like pain. There may be options offered at some point, such as using a feeding tube if choking has become an issue. For some people, the same situation will lead to different choices. There is no right or wrong, provided you are making an *informed* choice.

Sometimes there are no easy answers but that doesn't mean that we shouldn't ask the questions. While we cannot plan for every contingency in life, sometimes having a plan can be a comfort at the end of life.

Around the Region

2014 PSCNO Volunteer Awards

Debbie Davis, Heather Sinclair, and Monica Davidson

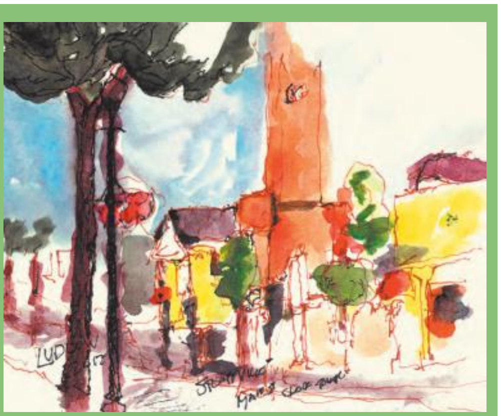
On June 11, 2014, we held the annual Spring Volunteer Tea, where we came together to celebrate all of the contributions of our volunteers, focusing on our April Hope in Bloom Tulip Campaign and our annual Volunteer Awards.

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 & Northern Ontario, and/or increased public understanding of their situation through such activities as leading support groups, public speaking, advocacy, volunteering, and fundraising. This year, the 2014 award was presented to Heather Sinclair. It was a special treat to have Monica Davidson, Ian's daughter, attend the event and help present the award with Debbie Davis.

The Derek Curwen Volunteer Award is presented in Derek's memory to volunteers who exemplify his fundraising expertise, his ability to inspire and lead others, and his wholehearted support of Parkinson Society Central & Northern Ontario. The 2014 award will be presented to Peter Istvan and David Newall at the Pedaling for Parkinson's event in July by Debbie Davis.

The Marilyn Forbes Volunteer Award is presented in Marilyn's name to volunteers nominated by their peers, who exemplify Marilyn's dedication to their chapter, support of people living with Parkinson's, and the work of the Parkinson Society Central & Northern Ontario. The 2014 award will be presented to Nora Lea and Wayne Arcand at the Sudbury Support group meeting in September by Debbie Davis and Karen Boyer.

CALLING ALL ARTISTS!



We are fortunate to have funding again this year to produce a 2015 Hope on Display calendar. If you are a person with Parkinson's, an artist of any kind (painter, photographer, jewelry maker, quilter, woodworker, etc.), and would like to be considered for the calendar, please send an email telling us a little bit about yourself, attaching a high-resolution image of your work, to Debbie Davis at debbie.davis@parkinson.ca by August 29, 2014.

What's Making News

Bill 21, the Employment Standards Amendments Act (Leaves to Help Families), 2014, received Royal Assent with all party support in the Ontario legislature. The legislation allows caregivers to focus their attention on what matters most—providing care to their loved ones—without the fear of losing their job. Bill 21 provides three separate job-protection leaves; the one of utmost concern for the Parkinson's community is the Family Caregiver Leave, which provides up to eight weeks of unpaid, job-protected leave for employees to provide care or support to a family member with a serious medical condition.

There are many reasons why the Parkinson Society championed the passing of this legislation. Family caregivers are critically important to the health and well-being of people living with Parkinson's, and it has been shown that their care helps people live in their homes longer and with a better quality of life. Many caregivers are spouses, sons, or daughters of the person with the condition and many are of working age. With the abolishment of a mandatory retirement age, there are many people continuing to work into their senior years, whom this legislation will help in addition to those who are younger and working. It is also important to note that the number of people being diagnosed with young onset Parkinson's disease is growing.

Supporting caregivers is part of the government's economic plan to create jobs for today and tomorrow.

Thank you for Participating in Parkinson Cut-a-Thon and Celebrating our 25th Year!

On April 13, 2014, we were proud to show hundreds of stylish new looks throughout Central & Northern Ontario. This year in our region, Cut-a-Thon was hosted in Barrie, Bracebridge, Burlington, Collingwood, Guelph, Port Hope, and Toronto. We thank the 23 participating salons and 76 stylists who cut and styled 450 clients in one day—raising more than $20,000 throughout our region. We couldn't have done it without you and the support of generous and dedicated volunteers.

Around the Region

Thanks to our major sponsors, who helped to significantly reduce the registration fee for our conference attendees with their generous donations.

abbvie

TEVA Canada Innovation

nordiX

MOSAIC

Register Early

Space is Limited

On-line registration available:

http://bit.ly/1kMpgW4

or please contact Naseem Jamal

800-565-3000 ext. 3377

naseem.jamal@parkinson.ca

Cancellation Policy:
Any cancellations must be emailed to naseem.jamal@parkinson.ca by October 17, 2014 for a full refund.

Regional Education Dinner, Dance, and Conference

Friday, October 24 and Saturday, 25, 2014

Westin Bristol Place, 950 Dixon Road, Toronto

Friday, October 24 Dinner and Dance

5:15 p.m. – 9:00 p.m.

$30 per person
speaker, dinner, and dance

- **Dr. Joseph DeSouza,** Associate Professor in the Centre for Vision Research, Recipient of a Parkinson Society Research Grant, Keynote Address: **Why Dance Helps** (includes a dance demo)

Saturday, October 25 Regional Education Conference

8:00 a.m. – 3:30 p.m.

$40 per person
education sessions, continental breakfast, lunch, refreshments, and conference materials

Saturday Morning Session

- **Dr. Ron Postuma,** Assistant Professor Neurology, McGill University, **The Everything Else of Parkinson's Disease**
- **Dr. Galit Kleiner-Fisman,** Medical Director of the Jeff and Diane Ross Movement Disorders Clinic & The Interdisciplinary Allied Healthcare Team, **Pharmacological and Dietary Aspects of Living Well with Parkinson's Disease: Introduction to 'livewellwithparkinsons.com' website**

Saturday Afternoon Session

- **Greta Mah,** Pharmacist and Facilitator of the Living Well with Parkinson's Program at NYGH, **Medication & Parkinson's**
- Exercise therapy demonstrations

**A block of reduced rate hotels rooms are available. Call the hotel directly at 416-675-9444 and indicate you are booking under the Parkinson Society Central & Northern Ontario special rate.*

Around the Region

Riding Researchers—Pedaling for Parkinson’s connects supporters and scientists

This year, for the fourth consecutive summer, riders took to the streets of Parry Sound as part of Pedaling for Parkinson’s—a community fundraising event in support of Parkinson Society Central & Northern Ontario. The event has grown in recent years, from a small group of friends to more than 160 riders, all taking part in the three-day event in 2014.

Local supporters, and those from around our Region, came together on the weekend of July 11 to 13 and made a big impact—raising more than $140,000. Funds raised from this event have been supporting the Pedaling for Parkinson’s Research Grant since 2012. This year’s recipient, Dr. Ali Salaphour, is investigating new medications that could potentially enhance dopamine transmission. Earlier this spring, he spoke to residents of Parry Sound about his research and he returned to the area during the event to ride alongside participants.

Dr. Salaphour wasn’t the only researcher involved in the pedaling weekend. The ‘Toronto Western Hotwheels,’ spearheaded by Dr. Naomi Visanji and featuring Dr. Susan Fox and other colleagues from the Toronto Western Hospital Movement Disorders Centre, took a break from their own research activities to take to the road this July. The impact of researchers, supporters, and the Parkinson community working together—seeking to eradicate Parkinson’s one pedal stroke at a time—cannot be overstated!

Dr. Naomi Visanji and Dr Susan Fox

Dr. Visanji has been involved with research in Parkinson's disease for the last 13 years. However, more recently, her interest in Parkinson's has evolved from a keen Scientific interest into a more personal one, as her mother was diagnosed with the disease four years ago. Seeing the ever-increasing challenges her mother faces each day as a result of living with Parkinson’s truly inspires Naomi in her work. Naomi strongly believes that through research there is hope that one day better treatments will be discovered that significantly improve the lives of those living with Parkinson’s.

“We truly enjoyed the ride this weekend,” Naomi says of herself and her teammates. “The event itself was great. Having the opportunity to participate with so many people who are truly committed to Parkinson’s was very inspiring to us as researchers. It was very meaningful for us to demonstrate that the research community wants to make a difference as supporters and allies, as well as doctors.”

Organized by Peter Istvan and David Newall, winners of this year’s Derek Curwen award bestowed by PSCNO in recognition of fundraising excellence and community impact, this year’s event was a great success ensuring that the Pedaling for Parkinson’s Research Grant carries on another year—supporting work by some of Canada’s finest researchers in support of PSCNO’s vision of a better life and a brighter future for Canadians living with Parkinson’s today; a world without Parkinson’s tomorrow.

Thank You Hope in Bloom Tulip Volunteers!

Thank you for donating your time as a Hope in Bloom Tulip volunteer. This year with the help of hundreds of energetic and wonderful individuals on the campaign trail, we raised $142,000! Monies will go to support our four pillars: Support Services, Education, Advocacy, and Research. We couldn’t have done it without you!

Are you under the age of 60 and living in the Kingston area? Have you been diagnosed with Parkinson’s disease? Still working? Making plans for your future? Would you like to connect with others who share your concerns?

Join us for a morning of discussion and light continental breakfast:

Saturday, September 27, 2014

9:30 a.m. — 11:30 a.m.

Rideaucrest Home,

175 Rideau St., Kingston, ON

This is a free event but registration is required. For more information and to register, please email ***diane.newmanreed@parkinson.ca*** or call ***800-565-3000 ext. 3315***

Around the Region

Platypi and Parkinsonisms

Continued from page 6

Multiple System Atrophy (MSA): The main features of this disorder involve a combination of symptoms that affect the autonomic nervous system, balance, coordination, and movement. The autonomic functions are body functions that occur automatically, such as bladder control, blood pressure regulation, sexual function, and bowel control, to name a few. Medications effective in PD are less effective or ineffective.

While people with advanced, late-stage Parkinson's may also have many of the above symptoms, in people with MSA these symptoms are evident within the first two to three years after the original diagnosis of PD, so the timing of the onset of these symptoms is very important when it comes to differentiating it from PD. Just like PD, MSA does not appear to be inherited, there is no known cause, and it is not contagious or infectious.

Progressive Supranuclear Palsy (PSP): The primary distinctive symptom of PSP is difficulty with eye movement, particularly moving the eyes up or down, resulting in the inability to see food on a plate, or obstacles in the road.

People living with PSP also usually have the parkinsonian symptoms of rigidity, slowness of movement, severe gait, and balance problems. Again, it is important to note that these symptoms are more prominent, severe, and appear earlier in PSP than in PD. Antiparkinson's medications are less effective than in the treatment of PD.

Corticobasal degeneration (CBD): Symptoms affect one side of the body much more than the other. Individuals have profound clumsiness and difficulties in knowing how to perform complex movements. Movements may be jerky and are sometimes mistaken for tremor. Behaviour, language, and cognitive changes are all common early in the course of the disease.

Some people who contact us have been told that they have a parkinsonism, but the specialist isn't sure what is going on. Some people diagnosed with PD may find that the specialist changes the diagnosis, due to new symptoms appearing that don't match with PD. These are the reasons we want people to get connected with the right professionals, in order to maximize the treatment options that may be available, as well as put some future planning into place.

Some health care professionals have never heard of these conditions, and you may need help getting the help you need! If you or a loved one receives the diagnosis of an atypical parkinsonism, you may find yourself in need of information. Please contact us, and let us help you make the connections.

Welcome Linda Reid to Parkinson Society Central & Northern Ontario

We are pleased to introduce Linda Reid, CFRE, as our new Manager, Major and Planned Giving. Linda brings with her more than 13 years' experience in the financial services sector working for Canada Trust, and 12 years' experience in Fund Development Management as Area Manager for the Heart and Stroke Foundation of Ontario, the Canadian Diabetes Association GTA, and most recently, as Director of Development at Environmental Defence Canada and MCC Toronto, where Linda was responsible for all Philanthropic programs and activities of the Development staff.

In 2010, Linda achieved her Certificate Fundraising Executive designation. Originally from Toronto, Linda now resides in Orillia, Ontario, where she enjoys spending time with her three grandchildren. Linda is very excited about the arrival of her latest grandchild in PEI later this year.

Please feel free to contact Linda to introduce yourself or to inquire about making a legacy gift at 416-227-3378, toll free at 800-565-3000, or linda.reid@parkinson.ca.

Get it on time Campaign Getting Noticed

We continue to work throughout the region to educate staff working in long term care, hospital, and other settings with this important message. Beyond that, PSCNO has benefited from some strong partnerships in 2014 that help us carry this message to broader audiences. We hope that our partnerships with the Registered Nurses Association of Ontario (RNAO) and the Senior Friendly Hospital Initiative help to raise understanding of all staff about the importance of individual medication timing for people living with Parkinson's—particularly in those areas where this issue is most prevalent.

In six joint sessions hosted with the RNAO over the past year, we have reached over 100 sites throughout the province and reinforcement of our *get it on time* message with this professional association is loud and clear.

More recently, we spoke via webinar with 42 representatives from Ontario Hospitals as part of the Senior Friendly Hospital Initiative. While a speaking opportunity does not guarantee change, we now know that they have heard us—the first step to impacting change. Beyond that, we hope that when people living with Parkinson's arrive in hospital, their own self-advocacy efforts will be more readily heard by those familiar with the *get it on time* message.

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.

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

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

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

Next submission deadline is October 10, 2014.

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

WOULD YOU LIKE TO HELP EASE THE BURDEN?

Milton/Scarborough/Bolton/Lindsay/Brampton/Newmarket

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

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

Did you know?

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

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