

LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Fall & Winter 2012



What's Inside....

- SuperWalk 2012
- New Regional Spokesperson
- Nutrition Tips
- Get it on time
- Intimacy and Parkinson's
- And so much more...

Parkinson CNO SuperWalk—a Huge Success!

Through the support of our walk coordinators, volunteer teams, donors, and more than 3,000 walkers throughout the Central & Northern Ontario Region, we've done it—raising in excess of **\$900,000** in PSCNO in 2012—a new fundraising record! Thank you to everyone who had a part in this. Funds raised from SuperWalk are used to support our four pillars of Support Services, Education, Advocacy, and Research.

Our sincere apologies to anyone whose name and address information was incorrect last issue or this issue! We are in the process of transferring to a new database, and there were some unexpected glitches. If there is an error with your contact information, please email livewire@parkinson.ca or call 1-800-565-3000 ext. 3372 so that we can make the corrections.



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



PSCNO ADVISORY BOARD

John Parkhurst	Chair
Sherrí Brand	Vice Chair
Jackie Ruderman	Treasurer
AB Rustin	Member at Large
Dr. Gordon Hardacre	Member at Large
Kathy Marlin	Member at Large
Stephanie Bruder	Member at Large
Kate Pitfield	Member at Large
Larissa Ruderman	Member at Large
Rebecca Hogan	Member at Large

STAFF

Chief Executive Officer—Debbie Davis	416-227-3373	debbie.davis@parkinson.ca
Community Development Coordinator Toronto—Naseem Jamal	416-227-3377	naseem.jamal@parkinson.ca
Community Development Coordinator East—Diane Newman Reed	613-827-8421	diane.newmanreed@parkinson.ca
Community Development Coordinator West—Karen Dowell	800-565-3000 ext. 3376	karen.dowell@parkinson.ca
Community Development Coordinator North and Central—Karen Boyer	705-645-9513	karen.boyer@parkinson.ca
Coordinator of Volunteers, Toronto—Louise LeBlanc	416-227-1200/800-565-3000 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
Office Manager—Stella Recchiuti	416-227-1200/800-565-3000 ext. 3301	stella.recchiuti@parkinson.ca
Manager, Major and Planned Giving—Lorelei Wilkinson	416-227-3378	lorelei.wilkinson@parkinson.ca
SuperWalk and Event Coordinator—Kim Murdoch	416-227-3374	kim.murdoch@parkinson.ca
Manager, Programs and Events—Jon Collins	416-227-3370	jon.collins@parkinson.ca

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, and does not necessarily reflect the view of the Parkinson Society or the LiveWire editorial staff. 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.

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

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

Next submission deadline is February 4, 2013.

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 8 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!**

PSCNO SuperWalks Raise Over \$900,000!

PSCNO is proud to be celebrating another successful SuperWalk! With more than 3,000 participants in 23 walk locations, our walkers raised over \$900,000—a new fundraising record!—to help us realize our vision of a better life and a brighter future for Canadian's living with Parkinson's today, and a world without Parkinson's tomorrow.

Around our region there are many stories of success from SuperWalk. Here are a few:

- We are proud to announce this year's TOP TEAM in PSCNO! Congratulations to the 19 members of Hughie's Hustlers who collectively raised an astonishing **\$54,455.20** at the Toronto walk! What a great accomplishment!
- PSCNO is also home to a number of members of 'Team Parkinson' recognized for their fundraising success. This includes our TOP WALKER Margot Greenberg, Harry McMurtry, Kenny Bearg and Clive and Nan Curtis! Margot has been an avid supporter of SuperWalk since 1994 and this year she raised **\$48,688.07!** Way to go! Congratulations to our other runners up! Harry McMurtry **\$41,120.00**, Nan Curtis **\$27,500.00**, Kenny Bearg **\$17,292.51** and Allison Nielson -Jessome **\$12,345.00!**
- In 2012 SuperWalk welcomed a new walk location in Markham/Unionville engaging 42 new walkers and raising **\$7,851.61**. A great success for the first year and we are looking forward to 2013!
- 2012 marked the second annual SuperWalk Long Term Care Challenge. Twenty-six retirement residences and long term care facilities hosted fundraising events to help support SuperWalk in their community (from mini walks, bbqs, raffles, and more!). Congratulations to Granite Ridge Retirement Residence in Gravenhurst for raising **\$2,115.00** to become our top home winner!
- In addition to the success of the funds raised, PSCNO is home to 8 of the top 20 online walkers in all of Canada. Congratulations to Margot Greenberg, Harry McMurtry, Nan Curtis, Kenny Bearg, Allison Nielsen-Jessome, William Gardner, and Maureen Thun who collectively raised a total of **\$162,775.58!**
- We had a number of 'Support Group Walks' this year, including events in Kirkland Lake, Sault Ste. Marie, Timmins, and Manitoulin Island. They all achieved great fundraising success and helped us achieve our goals, proving that any walk, large or small, can be a big success!
- PSCNO is also home to 12 of the top 20 online teams in all of Canada. Many thanks to all 155 participating members of Hughies Hustlers, Sullivan Mahoney Slam Dunk Parkinson, Mississauga Warriors, Team Bearg, The Parkinson Society Canada Employees, Team Bacchus, Bertha's Tulip, Team Nielsen, Mo's Angels, Team Billy, The Shakey Petes, and Irish who collectively raised a total of **\$220,293.24!!**



SuperWalk could not have happened without the help of our fantastic walk committees, walkers, participants, teams, media supporters, volunteers, and sponsors. Many of these individuals gave their time freely to ensure that SuperWalk was a tremendous success, and we sincerely thank them for all of their hard work and commitment to this fabulous event.

SuperWalk

We are so proud of all of our dedicated walkers and grateful for all of the hard work that each and every one of them puts into fundraising for SuperWalk.

Regional Totals

Alliston.....	\$3,862.00
Barrie.....	\$18,380.00
Belleville.....	\$4,729.95
Bracebridge.....	\$10,624.85
Brampton.....	\$12,377.50
Burlington.....	\$80,646.55
Collingwood.....	\$6,384.30
Durham Region.....	\$91,696.29
Guelph.....	\$25,955.65
Hamilton.....	\$24,036.00
Huntsville.....	\$6,536.00
Kingston.....	\$23,354.49
Kirkland Lake.....	\$2,372.00
Manitoulin Island.....	\$1,215.00
Markham.....	\$7,851.61
Mississauga.....	\$60,020.78
Newmarket/Aurora.....	\$29,310.00
Niagara.....	\$36,947.50
Peterborough.....	\$44,269.48
Sault Ste. Marie.....	\$1,285.00
Sudbury.....	\$15,254.43
Thunder Bay.....	\$10,334.50
Timmins.....	\$1,330.00
Toronto.....	\$385,383.96



Top Walkers

Alliston	Robert Nicholls
Barrie	Hazel Newport
Belleville	Jamie Fobert
Bracebridge	Tammy Taylor
Brampton	Alan Farmer
Burlington	Allison Neilson-Jessome
Collingwood	Eshrat Arjomandi
Durham Region	William Gardner
Guelph	Erven Mackintosh
Hamilton	Anna Sbrissa
Huntsville	Pauline Diamond
Kingston	Joe Davis
Kirkland Lake	Dianne Arney
Manitoulin Islands	Marilyn Proulx
Markham	Adil Suleman
Mississauga	Betty Tansley
Newmarket/Aurora	David Gallagher
Niagara	Ray Coatsworth
Peterborough	Vivian Heinmiller
Sault Ste. Marie	Evelyn Horner
Sudbury	Bruce McCulloch
Timmins	Mariette Rains
Thunder Bay	Dan Balacko
Toronto	Margot Greenberg



Top Teams

Alliston	Hammill Family
Barrie	One of a Kind
Bracebridge	Classy Cuts
Brampton	Movers and Shaker
Burlington	Team Nielsen
Collingwood	WillCure
Durham Region	Team Bacchus
Guelph	Saskmacks
Hamilton	The Duarte Group
Huntsville	Huntsvillians
Kingston	The Walking Runnings
Markham	Dianne's Rebels
Mississauga	Mississauga Warriors
Newmarket/Aurora	Irish
Niagara	Sullivan Mahoney Slam Dunk Parkinson
Peterborough	The Shakey Petes
Sault Ste. Marie	SSM Support Group
Sudbury	FJ Morassutti
Thunder Bay	The Ham Clan
Toronto	Hughies Hustlers



Parkinson Society Central & Northern Ontario would like to sincerely thank Subway Restaurants for providing nine of our walk sites with six-inch subs for our participants!

Also, thank you to Wahta Springs for providing water to this year's participants.



Parkinson SuperWalk Long Term Care Challenge

We are proud to announce that the winner of this year's challenge is GRANITE RIDGE RETIREMENT RESIDENCE in Gravenhurst. Over \$2,115.00 was collected from the residents, friends, and families, and a contribution was made to the Bracebridge Region SuperWalk.

We would like to thank all of the following homes who supported SuperWalk and participated in the challenge:

CHAMPLAIN MANOR RETIREMENT RESIDENCE, Orillia

OAKWOOD PARK LODGE, Niagara Falls

APPLEFEST LODGE, Brighton

SIMCOE MANOR, Beeton

RICHMOND RETIREMENT RESIDENCE, Belleville

CAVENDISH MANOR RETIREMENT RESIDENCE, Niagara Falls

Community Care Access Program Total Wellbeing Committee HNHB CCAC, Hamilton

EXTENDICARE PORT HOPE, Port Hope

COPERNICUS LODGE, Toronto

EXTENDICARE GUILDWOOD, Toronto

PINE GROVE LODGE, Woodbridge

GRAVENHURST MANOR, Gravenhurst

CAMA WOODLANDS, Burlington

HELEN HENDERSON CARE CENTRE LODGE, Amherstview

ATRIUM VILLA, Hamilton

SOUTHBROOK RETIREMENT COMMUNITY, Brampton

THE VILLAGE OF SANDALWOOD PARK, Brampton

KING GARDENS RETIREMENT RESIDENCE, Mississauga

PALISADES ON THE GLEN, Mississauga

TOWER OF PORT HOPE, Port Hope

GRANITE RIDGE RETIREMENT RESIDENCE, Gravenhurst

ABBEYLAWN MANOR, Pickering

BRACEBRIDGE VILLA RETIREMENT LODGE, Bracebridge

BELVEDERE HEIGHTS LONG TERM CARE, Parry Sound

RIDEAUCREST HOME, Kingston



Participants from Granite Ridge Retirement Residence, Gravenhurst, (above) and Belvedere Heights, Parry Sound.

We are always looking to expand our horizons and include additional walk sites in our fundraising campaign. If you would like to take on the exciting challenge of bringing SuperWalk into your community, please contact Kim Murdoch at (416) 227- 3374 or kim.murdoch@parkinson.ca

**Remember to visit
www.parkinsonsuperwalk.ca
in early April 2013 to register for a SuperWalk
in your community.**

Unique Fundraiser with Unique Idea Helps Make SuperWalk a Success



2011 was Harry McMurtry's first year fundraising for SuperWalk and he received a great deal of support from friends, family, and others. However, like many fundraisers, Harry struggled with the notion of collecting donations with pledge form in hand through direct solicitation. This is a very successful fundraising method for some and makes up the bulk of SuperWalk monies raised throughout the country, but this year Harry wanted to try something different. He decided that while fundraising for the event was very important to him, he wanted to give something back to his supporters as well.

Harry has had Young-Onset Parkinson's disease for ten years. In 2011,

he underwent Deep Brain Stimulation (DBS) surgery; together with medication therapy, DBS helps to alleviate his symptoms.

Harry knows first-hand the benefits of research and passionately works to support the work of the Parkinson Society.

Drawing on the support of connections in different industries, McMurtry hatched the idea for Parkinson SuperWalk Concerto at Centro. Harry hosted a cocktail reception and concert at Centro Restaurant and Lounge in Toronto on September 14. In addition to an open bar, guests enjoyed a sampling of hors d'oeuvres from Centro's unsurpassed kitchen. The evening featured a special concert presentation by the sensational Canadian singing duo of Giovanni Amenta and Diana Kazakova. Diana and Giovanni have performed on many major stages across North America and Europe.

The event was a great success in-



cluding wonderful performances by the evening's entertainment, a heartfelt look at life with Parkinson's from the host, and a humorous perspective held by his brother Michael. Also, it raised a net total of \$32,600.00 for Parkinson SuperWalk—making Harry one of the country's top three walkers.

Regardless of the scale, Harry and others like him (team Bertha's Tulip in Durham, for example, and other 'non-traditional' fundraisers throughout the region) have shown that creativity with fundraising can pay big rewards.

Parkinson Society Central & Northern Ontario would like to thank the Toronto SuperWalk Sponsors who helped bring us closer to a cure!

Gold

- CB Richard Ellis
- Menkes Developments
- Rio Can
- SMC Project Realization

Silver

- STATE Building Group
- Sears Canada

Bronze

- CanFirst
- CaTech
- CentreCourt Developments
- Mobile Business Communications
- M-O Freightworks
- Taoist Tai Chi Society



Parkinson Society Central & Northern Ontario pleased to announce a new Regional Spokesperson



Saphia Khambalia is an award-winning broadcast journalist, whose reports can be seen on CityNews, CityNews Channel, and Citynews.ca, and heard on 680News, Toronto's only All News radio station. In 2008, Saphia's grandfather was diagnosed with Parkinson's, and in the time between his diagnosis and her involvement with Parkinson Society Central & Northern Ontario, she became acutely aware of the challenges faced by her grandfather individually and the strain that a diagnosis of Parkinson's places on the entire family. Particularly noteworthy were some of the non-motor symptoms that can come with Parkinson's that aren't always discussed as part of the reality of living with a *movement* disorder.

Saphia Khambalia started her career with Citytv on the news writing desk in 2007, before moving to East Africa to follow her roots and shoot an independent documentary in Uganda and Tanzania. Upon return she spent time reporting in Sudbury and Windsor

Ontario and working as a national television host for the 2009 World Cup coverage. Saphia returned to Citytv in 2011 where she now works as a reporter for CityNews and Anchor for CityNews Channel.

In her role as Regional Spokesperson for Parkinson Society Central & Northern Ontario, Saphia hopes to bring heightened awareness to the organization, its events, and Parkinson's in general.

She will work closely with the Society on a number of major events (including Cut-a-thon, SuperWalk, the Spring Tulip Campaign, and other third party events) as well as help to bring coverage to these events and to relevant issues and news about Parkinson's. Parkinson Society Central & Northern Ontario is thrilled to have her support.

"I joined the Society because there are many issues that I think I can help bring greater understanding to, given my role with CityNews. I've seen firsthand the impact that Parkinson's has on the person and the family. I think by opening the conversation in a broader context, I will help to address an issue that is very important to me—the impact of stigma and negative perceptions on the person with Parkinson's and those who care for them. I want others to know this disease isn't a

death sentence. You CAN live an active life with Parkinson's and while we're at it, we can strive for a future with a cure. Parkinson's is a disease that the general public is not fully aware of, and this can lead to confusion and misunderstanding of the person with Parkinson's. This is compounded in ethnic communities."

Born in Ottawa and raised in the Hamilton-Niagara area, Saphia graduated from Ryerson University with a Bachelor of Journalism. She was honoured with one of the prestigious Donaldson Scholar Awards in 2009. She's been awarded and funded by the Canadian Millennium Goals to travel to East Africa and work as an international journalist.

Saphia counts herself privileged to be part of the great groups of hardworking, passionate, and talented people at Citytv and Parkinson Society Central & Northern Ontario. She's thankful to the viewers who let CityNews into their homes every day, allowing her to bring them the news and community initiatives that are truly reflective of their community.

Saphia currently lives in the Oakville-Mississauga area and loves spending time with her family and friends, as well as reading, cooking, and travelling.

Major Education Events in 2013—Mark Your Calendar!

Join us at any of our five major education events in 2013—see future issues for more details:

- April 27, Midland Cultural Centre, Midland—TBA
- May 7, Royal Botanical Gardens, Burlington—Dr. Mandar Jog, Movement Disorder Specialist, London, ON
- June 1, Waterfront Delta, Sault Ste. Marie—Keynote speaker: Dr. Amer Burhan
- June 12, Toronto Botanical Gardens—Plenary panel, Dr. Galit Kleiner-Fisman's Interdisciplinary Team from the Jeff and Diane Ross Movement Disorders Clinic
- June 13, Olympic Harbour, Kingston—Keynote speaker: Dr. Aarlenne Khan, Researcher, and David Simmonds, Motivational Speaker

Plus don't forget WORLD PARKINSON'S CONGRESS in Montréal, October 1–4, 2013; registration opens January 2013!

Nicole Shuckett, a registered dietitian, works with people living with Parkinson's. She works at the Jeff and Diane Movement Disorder Clinic in Toronto for the Assistive Technology Clinic.

I am often asked each time I see a person with Parkinson's if they should be following a special diet. I tell them "No." You should follow a healthy diet, drink enough fluids, and try to keep your bones and bowels healthy.

Eating a well-balanced diet by following "Eating Well with Canada's Food Guide" is very important. It helps you feel well and maintain your energy level. Eating a well-balanced diet will also help Parkinson's-related symptoms. A person should try and eat a diet rich in vegetables and fruit; high fibre grain products; dairy products such as milk, yogurt, cheese, and fortified soy beverages; meat and alternatives such as meat, poultry, fish, eggs, legumes and nuts; and try to maintain a healthy weight. Eating regularly during the day and avoiding skipping meals is also very important. People also may benefit from having a morning, afternoon and/or evening snack.

It is very important to drink enough fluids. Aim to drink 6 to 8 cups of fluids each day. Keep a water bottle handy and take sips during the day. Aim to keep your bones healthy. Try and have 1200 mg of calcium and 1000 IU of vitamin D each day from dairy products and other calcium-rich foods. If you do not get these nutrients in food, consider taking a supplement.

Some people taking Levodopa feel it works better if taken separate from protein-rich foods. Try taking your Levodopa half an hour before or two hours after you eat protein-rich foods such as meat, chicken, nuts, and dairy products.

Many people with Parkinson's experience different nutrition-related symptoms. This table lists some common symptoms and tips to try.

Symptom	Tips to Try
Constipation	<ul style="list-style-type: none"> • Eat foods high in fibre such as fruits, vegetables, whole grain bread, bran cereals or muffins, beans, and legumes. • Make sure you drink plenty of fluids (6–8 cups per day). • Exercise within your ability. • Some people need a medication to help with constipation.
Nausea, poor appetite	<ul style="list-style-type: none"> • Eat and drink slowly. • Eat small meals more often. • Avoid drinking during a meal. • Take medication with a small meal or snack (juice, soda cracker, cookie, or fruit). • Sit upright after eating and then rest. • Try fresh lemon juice, mint, or ginger ale.

Eating Slowly	<ul style="list-style-type: none"> • Do not skip meals even if it takes effort to eat. • Allow enough time to eat. • Have pre-cut foods or finger foods. • Eat in a quiet setting.
Light-headed when standing up	<ul style="list-style-type: none"> • Eat small meals more often. • Have less sugar. • Increase salt intake. • Increase fluid intake. • Decrease or limit alcohol.
Heartburn, reflux and bloating	<ul style="list-style-type: none"> • Limit or avoid alcohol, caffeine, and carbonated drinks (soda). • Sit upright at meal time and for 45–60 minutes after eating. • Limit or avoid foods that trigger symptoms such as spices, peppermint, chocolate, citrus juices, onions, garlic, and tomatoes. • Avoid straws and sucking on candies which may cause gas and bloating.
Problems chewing food (coughing when eating)	<ul style="list-style-type: none"> • Eat soft foods like cooked cereals, soft scrambled eggs, gravies, sauces, thick soups, ground meat, or soft casseroles. • Try mincing foods.
Problems swallowing food or thin fluids	<ul style="list-style-type: none"> • Ask for a swallow assessment from your family doctor. • Alter the texture of the foods and/or liquids in your diet. • You may need soft, minced, or pureed foods, or thick liquids. • You can meet all your nutrition needs with an altered texture diet.
Weight loss	<ul style="list-style-type: none"> • Keep a record of your weight. Weigh yourself once per week. • Eat when you have the most energy. • Eat small frequent meals. • Increase the calories in your diet. Eat high-calorie and high-fat foods such as nuts, cookies, ice cream, and pudding. • Add oil, butter, and gravy to foods. • Avoid low-fat foods. • Try nutrition supplements like Boost or Ensure to increase calories.



The following is a recent interview with Dr. Galit-Kleiner Fisman, Medical Director of the Jeff and Diane Ross Movement Disorders Clinic at the Assistive Technology Clinic (ATC) at Baycrest Hospital in Toronto, regarding her support of our 'Get it on time' message for staff

working in hospitals and care facilities.

At the Parkinson Society, we share a message regarding the importance of medication timing with staff working in care facilities, hospitals, and similar settings. Can you speak, from a medical perspective, about the importance of specific, individualized medication timing for people living with Parkinson's?

Together with my patients, their unique symptoms and their priorities, we work on an individualized, finely tuned, medication schedule. Parkinson's is a dynamic condition, and the way that the symptoms respond to treatment varies significantly from person to person, and changes over time. Typically, people with more advanced Parkinson's need to change their medications frequently in response to symptoms. As a result, by the time they arrive in your care, they have a very specific schedule that has been adjusted to meet their specific needs. Failure to acknowledge this unique schedule upon admission and throughout their stay can have a significant impact on the quality of life of a person living with Parkinson's and on the level of care that they will require from staff.

As the symptoms become more advanced, which if someone is moving into a long term care facility is likely to be the case, a delay of even 15 or 30 minutes can substantially affect a person's ability to function. The importance of staying on schedule increases as the symptoms progress.

For many people living with Parkinson's, their medication is able to effectively control their symptoms, control their overall physical (and cognitive) abilities, and improve their quality of life. When their schedule is altered, when doses are missed, or when problems occur with the administration of medication, not only do they become increasingly physically disabled, they become more susceptible to life threatening complications such as aspiration pneumonia, severe constipation which can result in bowel obstruction, and falls. Peo-

ple don't die of Parkinson's, although it is not uncommon for them to succumb to some of the secondary problems as listed previously.

We see many issues with adherence to, and alteration of schedule, when people are first admitted to new facilities, or at points of transfer. Can you share your thoughts on the impact that this may have?

There is a significant difference between 1 tablet of l-dopa 100/25 at 7 a.m., 11 a.m., 3 p.m. and 7 p.m., and taking 1 tablet of l-dopa four times a day (breakfast, lunch, dinner, and bedtime). Again, these schedules created are structured to suit the individual and the way that their body responds to medications. We are working to achieve an optimal amount of dopamine in the system at all times. As each person is different in how they process medications and how long the medications last in their bodies, each treatment plan is individualized, and writing similar prescriptions for each resident with Parkinson's at your facility will result in poor symptom control for the person living with Parkinson's disease.

Please, have a conversation with your new resident about the times they are accustomed to taking their medication at home and the way that their body responds, and write your orders to reflect that.

Also, gaps often occur when someone is admitted to a long term care facility. A new prescription is written upon admission and a 24 hour care plan is set up; if the medication regimen is changed from the one that has been working for them at home, they will likely deteriorate—which has long term consequences on a person living with Parkinson's. As such, it is imperative that their personalized medication schedule is maintained when they are admitted.

What does this mean for staff working with the patient/resident?

Given the minimal amount of time staff (PSWs) are allotted to spend with each patient, it is important to ensure that people with Parkinson's receive their medication as close as possible to the times that they were being taken when they were living at home. Doing so will maximize the person's ability to be as independent as possible and reduce the burden on their care-givers. Deviations from their regular routine will result in unnecessary periods of extreme immobility; thus increasing the amount of time it takes to assist them with provision of care and activities of daily living.

In April of 2012, Dr. Kleiner-Fisman was asked to share her vision of care in PD with the Parliamentary Committee

on Health while they considered a health care “roadmap” for Canadians over the next decade. The following is an excerpt from that speech, to help you understand her perspective on Parkinson’s and person-centred care. It makes clear the reason why we asked her to support our “Get it on time” educational campaign.

“It can start with a slight tremor in the hand. Or stiffness. Or maybe it becomes difficult to walk. You know there is something wrong but are told it is “old age” or “arthritis” or “it’s in your head,” which only makes it worse. But sooner or later, the diagnosis is confirmed. You have Parkinson’s disease. PD for short.

You, a once vibrant person, are transformed into a full time patient, requiring increasing levels of care from a spouse or family and ultimately long term care placement as the care needs become too overwhelming for partners and families.

One hundred thousand Canadians battle Parkinson’s disease. It robs each of them, ultimately, of their dignity and hope. And when they need it most, our health care system fails them, providing “solutions” that do not match the disease and cannot hope to help them back to a better life. But there is another way to dramatically improve the quality of lives of people living with PD while actually saving the health care system money.

Untrained in recognizing or managing the complex and debilitating symptoms of PD, family doctors are caught between the increasing needs of desperate patients and an overstressed health care system. All too often and needlessly, patients end up in emergency rooms where they do not get the care they need.

At our Center, the Baycrest-ATC Parkinson’s Clinic, that’s exactly what we do. In our model, the patients do not revolve around their health care professionals. We revolve around them.

It starts with the philosophy of patient-centered care. In addition to the subspecialist, our patients have access to allied health professionals including physical therapists, occupational therapists, specialized nurses, dietitians, social service workers, health psychologists, and pharmacists—all under one roof. It is called “interprofessional care.”

Our basic philosophy for our model of care is based on the following:

1. Patient perspectives define services.
2. Care is organized around SOLUTIONS.
3. Multidisciplinary teams provide care.
4. Results need to be measured to accelerate learning.

Building on these four fundamental principles, we believe the time has come to set up inter-professional “Centres of Excellence for Neurological Care” across Canada.

Parkinson Proud

*I'm not proud I have Parkinson's, nor am I ashamed.
For this disease I have got, I am not to blame.
It eventually takes over your body slow but sure.
Thousands are searching, they haven't found a cure.*

*I wake up each morning hoping it's gone away,
Then realizing I must endure for another day.
My body is very rigid, not willing to move.
I know I must fight, I have something to prove.*

*I get up and feel the tremors still there,
Wondering how many people are going to stare.
I start my day, but not moving too fast.
You see most of my speed has long since past.*

*I shuffle my feet as best I can,
Trying to hide that shake in my hand.
All of my muscles want to curl into a ball,
Making it difficult to stand straight and tall.*

*That's how our lives are lived each day,
But there's one more thing I've got to say.
We with Parkinson's will not give in,
For this disease we will not let win.*

*We have support from within each other,
Those who have it are all sisters and brothers.
We get our strength from those who love us,
And put up a fight that is very courageous.*

*So every morning we get up and stand,
Then continue to live life, we know it's grand.
We are still battling and will shout it loud.
Now that is what I call Parkinson proud!*

Dave Rackham

WORLD PARKINSON CONGRESS IMPORTANT DATES

January 2, 2013

Registration Opens for Hotels and Congress

October 1–4, 2013

WORLD PARKINSON CONGRESS
Palais des congrès in Montreal, Canada

Intimacy & Parkinson's: A Look from the Inside Out

Are you looking for deeper intimacy in your life? Do you have questions or concerns related to sexuality? Not sure where to start? I can help you figure that out. I'm Cheri Michael, an Intimacy and Sexuality Coach; Erotic Pleasure Advocate and Educator. I also have a unique understanding of Parkinson's.

In 2010 I was diagnosed with Young Onset Parkinson's disease. The immobility, frustrations, and pain that consumed my life devastated my relationship with my sexual self, and significantly threatened my sexual experiences. Once the shock of my diagnosis began to ease, I was able to start taking some control of my sexuality again. I began to combine my 10 years of professional training, my own personal experiences, and the knowledge I gained about Parkinson's, to explore new approaches and adaptations to sexuality and intimacy. As a person with Parkinson's ("PWP"), I have faced many challenges related to my sexuality, but I can happily say I once again enjoy a fulfilling sex life. And this journey has given me the tools needed to continue to create a wonderful sex life, even when a new challenge may arise.

I share my stories in hopes that it will offer you a place to start on this path of discovery and reclamation. Here is one of my favourites: Early into my Parkinson's symptoms, I was in the middle of sharing intimate touch with my partner when I suddenly stopped. When asked, I expressed my frustration that I was unable to caress my partner's arm because of my tremor and rigidity. My partner simply took my hand and ran their arm over the top of my fingertips. This was one of the most touching experiences I've had in my life. This simple and deeply profound act opened the box I didn't know I had created around sex and intimacy and how they should be.

Intimacy, sexuality, and sexual engagements—aren't they the same thing? Isn't intimacy just another word for sex?

The words "intimacy" or "intimate" are sometimes used as euphemisms for a sexual act. This limited definition can confuse matters, particularly when writing about intimacy, sex, and sexuality. I use the words "intimacy," "sexuality," and "sex" in a specific, non-limiting way. Intimacy is a close and familiar connection with another person or group. There is usually some form of affectionate, caring, and/or loving personal relationship which can include spouses, lovers, friends, children, parents, etc. Intimacy involves being authentic and open with someone as well as communicating any needs, wants, and desires that are important to share. I have also come across the phrase, "into me see" as another way to explore the world of intimacy; it includes the relationship we have with ourselves and others. Touch and inti-

macy are vital parts of life. Enjoying non-sexual touch and intimacy sustains us and strengthens our bonds with others, offering us much comfort and healing. For some it can take the pressure off to "have sex," while for others, it can make sex more of a possibility. Make time daily for intimate touch—put your hand on a shoulder, share a hug, or hold hands. I'm sure you can add one more to this list, maybe more: Why not jot down a few of those ideas right now?

Sex and sexual engagements are any sexual act we mutually choose to share with another, or do on our own. I do not limit the word "sex" to mean intercourse, nor is intercourse required to "have sex." Sex may (or may not) involve intercourse, manual stimulation, oral stimulation, fantasy, sex toys, or any number of experiences. We might choose to "have sex" to experience pleasure, to share intimacy, to express an emotion, or for other reasons. Sexuality is a key part of who we



are, just like our physical body, our emotions, our mind, and our spirit. To work with all of who we are and to be fully in balance, our sexuality needs to be considered. I do not mean we need to "have sex" but that we ask ourselves if our sexuality is where we want it to be. Awareness is key. Awareness of our personal views, challenges, likes, and dislikes can help us to have a fulfilling life overall—perhaps even more fulfilling than we ever imagined.

Dealing with the impact of health changes

How much we desire intimacy and sexual engagements may vary day to day. Everyone has "off" days—perhaps you're dealing with a cold, a bruised knee, or a headache. We can be impacted in many ways including how we see ourselves; how we feel in and about our bodies; our desire for sex; how we are able to have sex; and even our desire to connect with those we love. The impact of these daily ups and downs often ends when the specific circumstance is resolved. For some, there is little or no impact at all. However, if we are dealing with a long-term condition or permanent change in our bodies and abilities, we may need to get to know our bodies again. Whether it is related to surgery, injury, age, or illness, we may need to rediscover what we like/don't like, relearn what we are able/not able to do, and recognize when something that used to feel good is no longer right for us. Of course sometimes medical factors need to be considered and talking with a qualified health

Intimacy & Parkinson's: A Look from the Inside Out

care professional is very important when there is a potential risk to your health in some way.

Whether you need to find medical answers or not, there are other important issues to consider. Some answers can only be found within ourselves such as our preferences for intimate and/or sexual touch, when we feel the best in our body, and when we prefer to be intimate and/or have sex (e.g., before or after taking medications). At times, we just don't know how to find out those answers or we may need information on how and what is possible. We can often get stumped by some very practical questions such as, "Where do I put my arm when I'm pleasuring a partner?" or "What position will keep my leg from going numb?"

Achieving your goals

You deserve to have deeply connected intimacy in your life as well as the great sex life you desire. My approach is uniquely suited to working with PWP and the issues surrounding intimacy, sexuality, and sexual experience. It is important to consider, and at times adapt for, various factors related to illness, injury, and disability. PWP may need to consider factors such as: mobility, fatigue, timing of meds, the on/off effect, and the impact of medication. Other considerations include the direct and indirect impact of Parkinson's on intimacy and sexuality, mood, desire, libido, arousal, erection, orgasm, and other aspects of the body.

Through my explorations, one of the most significantly useful techniques I found was somatic sex education. The practice of listening to the body, the approach of staying present and connected, and the awareness of allowing oneself to truly experience touch and pleasure, offer effective strategies for addressing the physical, mental, emotional, and spiritual aspects of life, sex, and sexuality. My philosophy is to build on what is already working well for you. This focus on the positive allows you to move towards your goals with a "let's make it work" attitude while addressing any areas of concern in a safe manner.

I believe a collaborative process, with the right support (e.g., a trained coach, somatic educator, or therapist), is the best way to address your goals related to intimacy, sex, and sexuality. What should you consider when seeking and working with a practitioner related to sexuality and intimacy? I discovered that shorter consultations and sessions, customized workshops, and sliding scale options make the work accessible to more people. Individual and relationship coaching with sessions in person, by phone, by email, or online makes support even more accessible. When looking for a coach, therapist, or other support, prepare your wish list as best you know it and discuss all the options. Even if

what you need is not mentioned on a Website or pamphlet it might still be an option. Topics that can be addressed related to intimacy, sex and sexuality may include, but are not limited to, injury, illness, (dis)ability, increasing pleasure, sexual self-acceptance, sacred sexuality exploration, and enhancing orgasm.

We all need to adjust to something sometime and although it may take some time to find what you are looking for, keep looking, keep asking, and keep exploring.

I wish you a life filled with more intimacy, pleasure, and authenticity than you thought possible.

You can contact Cheri via her website www.cherimichael.com or info@cherimichael.com

Resources:

The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness by Miriam Kaufman, Cory Silverberg & Fran Odette Available online and at some specialty stores

A wider selection of resources can be found at www.cherimichael.com



The poster features a central image of a human head in profile with a glowing brain, set against a background of autumn leaves. Text on the poster includes: "3rd WORLD PARKINSON CONGRESS Montreal 2013", "VIDEO COMPETITION", "Join us at the WPC 2013 by submitting your story!", "Film Submission Categories" (with sub-categories: "General Parkinson's Category" and "Creativity and Parkinson's Category"), "Submission Dates: November 5, 2012 to May 8, 2013", and "Learn more at: www.worldpdcongress.org/videocompetition".



Pedaling for Parkinson's

The roads around Parry Sound were buzzing with cyclists who participated in Pedaling for Parkinson's 2012, on July 13–15, 2012. The purpose of this event was to raise awareness and funds for research to help make a difference in the lives of people and families affected by Parkinson's.

Long time friends and cycling partners Dr. Peter Istvan and David Newall founded Pedaling for Parkinson's in 2011. In just one year, the event has grown tremendously. In 2011, Istvan, Newall, and about 20 other cyclists raised just under \$18,000. This year, more than 70 cyclists signed up at www.pedalingforparkinsons.ca and raised just under \$54,000. Triple the riders and triple the funds raised. Amazing!

"Pedaling for Parkinson's is a way to honour our friends and family members living with Parkinson's. Cycling 400 kilometres may seem like a lot of work, but it's a small challenge compared to the challenges people with Parkinson's can face," Dr. Istvan and Newall say. The event took place over three days with riders being able to choose from shorter or longer routes; between this and the close-knit-family feel of the event, there truly was something for everyone.

"Parkinson's disease affects individuals, families, friends, employers, and employees. We are honoured that Peter Istvan and David Newall have been involved with us, helping to raise awareness and funds so that we can continue to support many families, while crucial research into causes and a cure continues," says Debbie Davis, CEO of Parkinson Society Central & Northern Ontario.

As an acknowledgement of the exceptional fundraising achievement and the research focus of the event organizers, Parkinson Society Central & Northern Ontario has founded the Pedaling for Parkinson's Pilot Project Grant. This year's recipient will be Dr. Joanne Nash, a University of Toronto Researcher who is working to study the effects of 'Sirtuin 3' as a potential neuroprotective agent in the treatment of Parkinson's.

Riders, organizers, and Society representatives alike had a great time as part of Pedaling for Parkinson's 2012 and are already looking forward to growing together on July 12 to 14, 2013.

Pitch in for Parkinson's is an event with a rich history of more than 20 years; however, the dinner and silent auction element was a new experience, thanks to our partnership with our very gracious host Gregg Zaun. This year, in addition to enjoying a night out at the ballpark, PSCNO offered supporters a chance to enjoy an evening of great food and exciting silent auction prizes. This year, Pitch in for Parkinson's has raised in excess of \$15,000! The reviews of the evening were fantastic, thanks to our host Arron Barberian of Barberian's Steak House, our donors/supporters, the major league baseball players who donated priceless memorabilia, and our friend Gregg Zaun. We're very grateful to Gregg for his time and commitment to the cause. Learn more about his other charitable efforts at www.zauntourage.com.

~Continued on page 16

Pedaling for Parkinson's is just one of the named grants that have been awarded as part of the current National Research Cycle.

We would also like to acknowledge:

*The Lawrason Foundation
Graduate Student Award*

*The Peterborough Chapter Basic
Research Fellowship*

*Porridge for Parkinson's Pilot
Project Grant*

*Parkinson Society Canada is the only organization that specifically funds Parkinson's research in Canada. The National Research Program invests in Canadian research from the ground up—starting with the discovery stage—funding only those projects that meet a standard of excellence and that are relevant to Parkinson's. Our approach to funding means that rather than awarding a limited number of large projects, we fund a larger number of smaller grants to researchers working on a wide variety of projects. The result is more researchers exploring novel ideas, providing a crucial foundation for advancing knowledge, improving treatments, developing potential therapies, and ultimately finding a cure. Funds raised through the **Pedaling for Parkinson's** event will fund, in its entirety, one of these research projects in Central & Northern Ontario that has met the standard of excellence applied by the Scientific Advisory Board.*

*Debbie Davis,
CEO*

Thank you to our sponsors for generously supporting our Education Sessions this year.

- Major Educational Event Sponsors
Nora Fischer and an anonymous donor in honour of the Peterborough Chapter
- Bayshore Home Health
www.bayshore.ca/locations/toronto-home-care.aspx
- Comfort Keepers
www.comfortkeepers.ca/office-3001/
- Eldercare Home Health
www.eldercarehomehealth.com
- Medtronic
www.medtronic.ca
- NHI Nursing & Homemakers
www.nhihealthcare.com
- Home Instead Senior Care
www.homeinstead-northtoronto.ca
- Homewatch CareGivers
www.homewatchcaregivers.com
- Marcia Culbert, Dental Hygienist
- MEDchair Halton
www.halton.medichair.com
- Nordixx Pole Walking Canada Inc.
www.nordixx.com
- Nurse Next Door Home Care Services
nursenextdoor.com
- Philips Lifeline
www.lifeline.ca
- A-Supreme Nursing & Homecare
www.asncare.com
- Speech Therapy Solutions
www.speechtherapysolutions.ca
- TEVA Canada Innovation
www.tevacanada.com

A Monthly Donor Shares Her Reasons for Giving

Did Parkinson's disease sneak up on you? It did on us—Ed and Mary Krucker. Several years ago my husband Ed had a stroke that left him with some weakness on the left side and seemed to affect his swallowing a bit. He recovered very well from his stroke and we thought life would go on just fine. However, following his recovery, many things seemed to get harder—balance, talking, walking, etc. Nothing dramatic! We were sent to a neurologist—that was when Ed was diagnosed with Parkinson's. The news was difficult to accept.

When we moved to Dundas, I contacted the local Parkinson Society Central & Northern Ontario support group in Hamilton. Ed and I went to a few meetings, which I found very helpful but Ed didn't like being there. He was still in denial about having Parkinson's, but I needed to learn more about this disease.

I wanted to do more. I came to realize that money was needed for research so that one day we may find a cure for this life-changing disease.

We began to give a monthly donation to Parkinson Society, believing it is the right thing to do! If we want to find a

cure tomorrow and help support others living with Parkinson's today, it takes money.



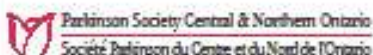
Our life has changed! Bit by bit, Ed has found life to be more of a challenge. How to find enjoyment in little things and how to access events outside the home has become our family's challenge. Being involved with Parkinson Society Central & Northern Ontario's Hamilton support group has really helped me find out how to lighten the load.

What have I actually learned? There are umpteen symptoms of Parkinson's and many of them can be helped or managed. Each person's Parkinson's journey is unique. I have learned that individuals with Parkinson's disease and their carepartners are really special people and very brave. In spite of life becoming harder to deal with, the support group members and Parkinson Society Central & Northern Ontario staff are friendly, kind, and helpful. None of us need to feel alone and hopeless.

To receive your resource package please contact

Lorelei Wilkinson
416-227-3378 or
1-800-565-3000 Ext. 3378
lorelei.wilkinson@parkinson.ca

Or visit our website at
www.parkinsoncno.ca



How to leave a legacy

Leaving a legacy to Parkinson Society Central & Northern Ontario is easy. Simply:

1. Share this with your lawyer or the person looking after your will.
2. Advise your lawyer you want to make a bequest legacy gift to "Parkinson Society Central & Northern Ontario."
3. Your lawyer will then revise your will to include a written statement like the one below.

Sample statement to add to your will: "I give (all/or ___%) of the remainder of my property (OR \$_____ a specific amount) to Parkinson Society Central & Northern Ontario, Toronto, Ontario to be used as its board of directors deems appropriate."

Please consider telling us about your bequest so we can thank you personally.

Support Services

Education

Advocacy

Research

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.


Pitch in for Parkinson's

~Continued from page 14

Zaun, who appeared in the Summer 2006 issue of Parkinson Post with his mother, Cherie who is living with Parkinson's, is a big supporter of the Society and its link with baseball.

"In 2003, my mother Cherie was diagnosed with Parkinson's and it changed her life. It changed mine, too, and I've been involved with raising funds and awareness for Parkinson's research ever since," says Gregg, about his relationship with Parkinson Society.

Thank you for supporting Pitch in! 2012. Don't forget to check back to see what we're planning in 2013!

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



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 generally held once a month on weekdays, evenings or afternoons.

Training will be provided; our training sessions are scheduled regularly. Once training is completed, the commitment is three to five 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



Did you know?

LiveWire is offered in both print and electronic forms. If you would prefer to receive the electronic edition, please contact 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