LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Spring 2011

Inside

Our Mission

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

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Charitable No: 10809 1786 RR0001

Livewire is published 3 times annually, in spring, summer and fall. This year, expect our Spring edition in early March, our Summer edition in mid July and the Fall/Winter edition in November.

Don't Let Parkinson's Daunt Your Fortitude...

...The worst it will ever do is slow down the timing of your accomplishments

On November 7, 2010, over 45,000 people lined the streets of New York City to participate in one of the most acknowledged races in the world: The NYC Marathon.

The 42 km course winds through five New York boroughs, and can be a challenge for even the most prepared athlete.

Torontonian Richard Atkinson trained for months to prepare for the race, and he never let the fact that he has Parkinson's hold him back.

"I set a goal for myself to run the NYC Marathon in my 65th year, and I ended up running it about a week before my 66th birthday," said Atkinson. "They rejected my request to run a few times before, so I was thrilled to be accepted this time around."

Atkinson, originally from New Brunswick, came to Ontario in his early 20's to start a career in urban planning and building. He worked in a number of different industries throughout the years to fulfill his desire to always try new things. When getting ready for work one morning, Atkinson noticed some strange symptoms.

"I was trying to use a rotary shaver, and I couldn't make the motions around my face. It was around that time that I noticed my handwriting was changing as well. My sentences would trail off to nothing."

After Atkinson found out that he had Parkinson's, he made a conscious decision to stay very active.

"I've had Parkinson's for 11 years, and my symptoms are much less advanced than what is considered average. My doctor attributes the slow progression to the fact that I run and exercise regularly."

In addition to running, Atkinson skates and bikes regularly, often accompanied by his supportive wife Gina. Another source of support for Atkinson is the Achilles Running Group, which is an organization that helps runners with special needs.

A few days before the marathon, Achilles organized an event that brought together runners that have overcome serious handicaps and obstacles.

"It was very inspiring," said Atkinson.

Atkinson has had his fair share of obstacles. Aside from his Parkinson's symptoms, Atkinson also has a nagging knee injury that flared up while training for the marathon.

"One of the rescued Chilean miners was running the NYC marathon as well, and he had the exact same knee injury as me. It's the type of injury that can really affect your time."

Atkinson was hoping to run the marathon in about five hours, but ended up finishing in six. Now that he has achieved his goal of conquering the NYC marathon, he's considering training for some smaller runs or a duathlon, which involves running and biking.

"No matter what, I'll certainly be challenging myself in some way."

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

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

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

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

Contact us at 416-227-3370 or 1-800-565-3000 ext. 3370, or email to livewire@parkinson.ca

Next submission deadline is July 1, 2011.

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

PSCNO: What We Do

Advocacy:

Our Ontario-wide Advocacy Committee has the following objectives:

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

Education:

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

Sessions during 2011:

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

Support Services:

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

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

Research:

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

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

Thank you for your continued support!

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

Ask the Expert—Deep Brain Stimulation

With Dr. Andres Lozano, Professor and Chair, Division of Neurology University of Toronto, Canada Research Chair in Neuroscience

In the decades since deep brain stimulation surgery (DBS) was first used to treat Parkinson's symptoms, over 80,000 people worldwide have received DBS. Each year, about 10,000 DBS operations are conducted on people with Parkinson's disease. Canada is a leader in this area, with neurologists and neurosurgeons coming here from all over the world to train in how to do the procedure. We have asked distinguished neurosurgeon Dr. Andres Lozano to give us an overview of DBS.

What is deep brain stimulation (DBS)? DBS is the introduction of stimulating electrodes into a specific area of the brain to treat the symptoms of Parkinson's disease.

Which areas of the brain are targeted? If you imagine a loop in the brain with several stops along the loop, there are at least three targets we can choose along this circuit, depending on the Parkinson's symptom. For example, for tremor, the thalamus is the best target. For rigidity and other motor symptoms, the subthalamic nucleus and globus pallidus appear to be equivalent.

Who is the best candidate? The symptoms that respond very well to DBS surgery are motor fluctuations, tremor, rigidity and slow movement. So, if people are not getting the most benefit from their levodopa therapy, for example, the medications are not lasting as long and people are experiencing on/off fluctuations through the day, or if tremor, rigidity and slow movement are getting worse, then it may be time to consider DBS. Roughly 15% of patients with Parkinson's could benefit from DBS surgery. It is a major plus if the person has strong family support.

Are there people unsuited to DBS? Some people with Parkinson's will be excluded if they have another medical condition that makes them less likely to benefit; for example, significant cognitive problems, psychiatric problems or a condition requiring them to have many MRI images throughout their lives. The safety of MRI has not been fully established yet for patients with implants.

Is age a factor? With age, patients become less responsive to both drugs and surgery and the benefit-to-risk ratio becomes less favourable, so we are less enthusiastic about offering DBS surgery to people over 70. Since older people also have much more medical co-morbidity, such as heart disease, we think very carefully before offering DBS to people at an advanced age.

Is consideration being given to offering DBS earlier in Parkinson's?

Indeed. There can be opportunity costs associated with waiting. For example, people may have to give up their employment or may decide to decline a promotion because of Parkinson's and its rate of progression. Surgery may be able to help here. There is a general trend to offer surgery earlier and earlier. Some studies are specifically looking at using DBS within five years of onset instead of the average 12 years after diagnosis. This, of course, has to be balanced with the small, but not absent, risk of the surgical procedure and treatment.

What does the procedure involve?
We can put patients to sleep if they are anxious, but the procedure is best done with the patient awake so we can select a better spot for the electrodes. Before the procedure, patients have an MRI scan of the brain. Then a frame is placed on the patient's head. During the surgery, we make two openings in the skull and pass the electrodes through. Once the electrodes are in place, we put in a battery in the chest, underneath the collarbone. Next, we tunnel a cable from the electrodes in the head to the battery in the chest – it goes underneath the skin behind the ear, down the neck, over the collarbone and into the chest. Patients usually go to sleep for that part. We then connect the battery to the electrodes. Using a device similar to a TV remote control, we point a remote controller through the skin to the implanted battery to change the settings and control how much current is delivered to the brain.

What are the risks of DBS surgery?
Every time you operate on the brain, something bad could happen. We tell patients that there is a 1-2% risk of serious complication relating to the surgery. The worst that could happen is there could be bleeding in the brain when the electrodes are introduced. It happens in less than one in 100 cases but is potentially very serious. Next, there could be problems when the device is turned on and off; there could be a side-effect from the stimulation but this can be controlled by turning the machine down or off. Thirdly, the hardware could break down, the batteries could wear out and the person could get an infection. Those are the three kinds of at-risk effects we see: risks relating to surgery, stimulation and hardware.

Does the device stay on 24-7?
Yes. When the brain is missing dopamine, certain areas of the brain malfunction or misfire. That misfiring is transmitted in the circuits of the brain and causes a person to have tremor, not be able to initiate movement and so on. With DBS, we are able to block or stop that misfiring so the brain can work in a more normal way.

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Reprinted from e-Parkinson Post. Visit parkinsonpost.com for more information and to subscribe.

Coping with Everyday Frustrations—by Lawrence Massey

Parkinson's can steal your mind and body—but it will never touch your heart and soul

I could write volumes on this topic but I am going to limit it to this page. Most of these frustrations pre-date my DBS surgery, but at least two problems developed following the surgery: speech problems and clumsiness while walking outside or inside the house. The latter one has led to several falls, but, thankfully no damage was done.

Early in my diagnosis I asked my doctor what Parkinson's had to do with turning over in bed. He explained that PD was all about movement. To turn over in bed you use muscles in your legs, feet, back, arms and hands. It is all about coordination. The muscles have to work together. With PD these muscles work against each other. You may use satin sheets, silk pajamas, even raise the head of the bed a few inches. Be careful! If things get too slippery, you could slide right off the bed. Two or three years ago I tried using a handrail (the kind that you slip between the mattress and the box springs). It extends about 8 inches above the mattress. It helps me to get in and out of bed as well as turning over in bed.

Unless further adjustment of my DBS stimulator can be made which would improve it, I am stuck with poor handwriting that becomes smaller and smaller and tails off as I approach the right side of the page. Because of stiffness in my fingers, I am very slow at typing on the computer keyboard.

My fine motor skills (pre and post DBS) are still sadly lacking and give me much frustration. I still am very independent. When we went to church one Sunday, I thought that we had enough time to get ready. I was simply unable to get that top button on my dress shirt done up. I had to ask my wife to button it for me. While she was at it, the right sleeve button needed help too. As for my tie, forget about it. The two that I sometimes wear I leave tied up. As far as shirts are concerned, my wife has sewn velcro fasteners in behind the buttons. They have the appearance of still having buttons. I seem to be able to handle shirts with dome fasteners but not all stores have them.

Shoes with velcro fasteners, or elastic laces, have made my life easier. I simply cannot do up the ordinary shoelaces.

The difficulty of getting in or out of cars or getting up out of chair seemed at first like a natural consequence of aging, or at least due partly to an existing arthritic condition. However, I soon learned that these were classic symptoms of PD. Prior to my DBS activation on January 25 (and even back in October/November), I was frustrated by simple things like getting my pants on. I was tired of hearing, "One leg at a time." The more suitable answer is "anyway you can." Once I finally got my pants on, I had to sit in a hard wooden chair. Even then, I could barely bend over far enough to get my socks on. Some mornings I swear it took me almost *an hour* just to get dressed. On those mornings when we had to get to an early appointment in Toronto, Joanne had to get me dressed, then help me get my coat on. My symptoms were much worse if I became stressed out.

Other morning chores which seem to take me an eternity to accomplish are showering, shaving, and brushing of teeth. Back when I had dyskinesia or an active tremor, I even messed up getting the toothpaste out of the tube and onto the bristles of the brush. Toothpaste would be scattered over the sink and vanity. As for my brushing, more paste would be transferred to my gums and lips than on my actual teeth.

During those "bad" times I lived (or tried to) by the maxim, "don't ask for help unless you absolutely have to," or "never give up." Don't let Parkinson's get you down.

For the months (or years so it seemed) before DBS started doing some good, my "freezing" was a source of great frustration. I was very unpredictable. Sometimes it would happen when I came out of the washroom doorway when I made the turn towards the living room, or it would occur when I arose from my living room chair, take a few steps, and turn towards the washroom. It made life easier when Joanne placed sheets or paper every two to three feet from my chair to the bathroom. It broke up the floor and gave my brain something to aim for and "step" over.

I have two wonderful and adorable granddaughters. By the time I get my book published, they will likely be 7 and 5 years old. I have never felt comfortable in lifting them up, playing with them, or walking and running with them. This is something that the Parkinson's "thief" has stolen from me. Perhaps the DBS procedure will enable me to be a better grandfather.

I am banking on it.

This article is an excerpt from Lawrence Massey's most recent publication *Shaken: Not Stirred.*

Proceeds from sales are being directed to support Parkinson Society Central & Northern Ontario.

Contact livewire@parkinson.ca or 1-800-565-3000 ext. 3377 to order a copy today.

Ask the Expert: Deep Brain Stimulation
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How long do the benefits of the surgery last?
Parkinson's is a multi-faceted illness. For symptoms such as motor fluctuations, tremor and rigidity, the benefits will last forever. However, because Parkinson's is a progressive illness, other symptoms will appear; for example, cognitive decline, speech problems, balance problems, problems with bladder and sexual function. These will continue with or without medication, with or without surgery. Some symptoms are very well treated forever and others are not influenced by the surgery.

In what new directions is DBS heading?
My research team and others are looking at ways to address the difficult non-dopamine-responsive symptoms such as cognitive problems, depression and walking difficulties. We're looking to see if we may be able to go into different areas of the brain to treat those. DBS is also being studied for its potential to treat other neurological conditions and psychiatric

2011 Volunteer Award Nominations

Each year, at our Spring Volunteer Tea, we present three important volunteer awards.

The Derek Curwen award is presented to volunteers who exemplify his fundraising expertise, ability to inspire and lead others and whole hearted support of Parkinson Society Central & Northern Ontario.

The Marilyn Forbes award is presented to volunteers nominated by their peers who exemplify her dedication to their Chapter, support of people living with Parkinson's and the work of the Parkinson Society Central & Northern Ontario.

The Ian Davidson award is presented in recognition of volunteers who have Parkinson's 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.

The recipient of the Ian Davidson award is selected by previous winners of the award. The recipients of the Derek Curwen award and the Marilyn Forbes award are selected from nominations by people in the Central & Northern Ontario area.

Our Community Development Coordinators have been distributing the nomination forms in their respective areas. If you have not received a nomination form and would like to nominate someone, please contact Louise LeBlanc, Coordinator of Volunteers, at 416 227-1200 ext 3304 or louise.leblanc@parkinson.ca

Nominations for the 2011 awards are due by March 31.

The Information & Referral Centre

responds to increasing demands; longstanding support from foundations has made this possible

Robert TerSteege is a Certified Information & Referral Specialist – Canadian, through AIRS. Call 800-565-3000 ext. 3372 to access the Information & Referral Centre.

The Information & Referral Centre provides a high quality, free, confidential, relevant and accurate information and referral service for people with Parkinson's, their families, carepartners and healthcare professionals. As Parkinson's disease progresses, questions and needs change, but the need for timely information and support remains constant.

We, at Parkinson Society Central & Northern Ontario, wish to express our deep appreciation to The Catherine and Maxwell Meighen Foundation and The Mayvon Foundation for their longstanding support of core programs such as The Information & Referral Centre. These foundations have led the way with decades of generous donations to help us ease the burden for people living with Parkinson's. In addition, many foundations, corporations and individuals faithfully join in helping us respond to the increasing demand for information and referrals.

The Centre was contacted by 2,518 people in 2008 (phone, email, post, walk-ins) and 6,259 in 2010 due to increased demand as more people are diagnosed with Parkinson's and as awareness of our toll free line increases. Indicative of the strong, professional relationships between Parkinson Society and the healthcare community, people often hear about the Centre from their family doctor or movement disorder clinic.

The Centre provides free brochures and materials to help people understand the condition and their role in managing it; referral list of community resources, support groups and professionals; list of online resources and referrals to specific Parkinson Society programs, chapters and support groups.

New Medication Cards Have Arrived!

Our new Get it on time medication tracking/ information cards have arrived. These foldable credit card size documents allow you to keep a listing of your medications, and timings, with you at all times. These cards are also useful when interacting with CATSA personnel, police, and other groups.

Call 1-800-565-3000 ext 3372 to order yours today!

The Ontario Brain Institute

On November 15, 2010, Ontario Premier Dalton McGuinty announced $15m in start-up funds for a new research initiative called the Ontario Brain Institute. This new research initiative is focused on basic research that will lead to more effective therapies and tools for people living with a range of neurodegenerative conditions, including Parkinson's, and contribute to the hunt for the cure.

Throughout his speech, Premier McGuinty spoke eloquently about the experience of the millions of Ontarians living with a neurological condition and the need for research and innovation to improve their quality of life. "Today's announcement reinforces the Government of Ontario's commitment to brain research, and to excellence in community care and support for every Ontarian living with a brain condition. We know there's work to do in all these areas, but today's commitment is an essential step if we are to uncover new treatments and ultimately a cure for brain diseases and disorders like Parkinson's, Dementia, Alzheimer's, Autism and Schizophrenia," stated Joyce Gordon, CEO of Parkinson Society Canada and Chair of the NHCC (pictured with Premier McGuinty).

Neurological Health Charities Canada (of which the Parkinson Societies of Ontario are members) worked closely with the Premier's office to ensure that this announcement aligned with the needs expressed by Ontarians living with neurological conditions through the recent Ontario Brain Strategy consultation.

The announcement can be found at http://www.ontario.ca/premier

Volunteer Participants Needed for Research Study

Volunteer participants are needed for a telephone interview research study about the decisions that people with Parkinson's disease must make concerning whether or not to inform workplace contacts of their diagnosis. We are looking for people who have been diagnosed with Parkinson's disease within the last 5 years and who were employed at the time of diagnosis. If you are interested in participating please contact PSCNO CEO Debbie Davis at 800-565-3000 ext. 3373 or debbie.davis@parkinson.ca for details.

2011 Education Sessions Announced

"I wish to thank you with all my heart for allowing me to participate in the Saturday Conference on Parkinson's. Thank you also a million times for having organized this kind of event. My sister was like the proverbial flower in the desert finally being rescued with precious water to satisfy her need for information and moral support. Obviously, from the size of the attendance and their reaction, there was a great need for such an event in the region…"
- Micheline, North Bay

April 15 and 16 – Thunder Bay
Keynote: Dr. Mandar Jog & Dr. Doug Hobson
Breakout 1 – Linda Hall, RN – Non-motor aspects of PD
Breakout 2 – Physiotherapist –Rehabilitative aspects of PD
Breakout 3 – Sandie Jones & Karen Boyer –Carepartner Support
On Friday evening there will be a presentation for Health Care Professionals followed by a conference on Saturday for people living with Parkinson's and their caregivers.

May 11 – Royal Botanical Gardens Hamilton/Burlington

Back by popular demand, we are honored to once again have Dr. Mandar Jog and Dr. Mark Guttman, who are both Movement Disorder Specialists, debate on current issues related to the treatment, management & research of PD.

May 14 – Collingwood

New for 2011, a full day conference held at Blue Mountain Resort; in partnership with PS SouthWestern Ontario. Attendees will have the opportunity to hear Movement Disorder Specialists, receive caregiver support and feel pampered in the great surroundings.

May 28 – Durham Region

Creating a family of caring and understanding
This family conference is presented in partnership with the Durham Region Chapter, which is celebrating its 30th anniversary. Everyone impacted by Parkinson's will benefit. Dr. John Adams from the Markham Centre for Movement Disorders and Dr. Sonia Mathur from Durham Region will speak. This full-day conference with continental breakfast, hot lunch and breakout sessions will take place at the Ajax Convention Centre. More information on cost and registration to come. Check our Website for more details.

In Toronto this year we have endeavored to have our sessions spread out and offered free of charge instead of one full day session with a cost. If anyone in the Toronto area is still interested in a full day session, please feel free to register for the conferences offered in Ajax and Collingwood. All events will be held from 7-8pm unless otherwise noted.

July 13 - Speaker Series #1 - PSC Conference Centre
Jan Goldstein, PT – Practical tips for daily living

August 10 - Speaker Series #2 - PSC Conference Centre
Janice Abramowitz, SLP – LSVT technique

September 14 - Speaker Series #3 - PSC Conference Centre
TBD

October 12 – Speaker Series #4 Toronto Botanical Gardens
Dr. Mario Masellis – Mind, mood and memory
Dr. Soania Mathur
**6:30-9pm*

Helping people with Parkinson’s find the right words, one of five novel research awards granted

TORONTO, ON, December 1, 2010—Parkinson Society Canada gave five Canadian researchers a boost in funding today to improve quality of life for people with Parkinson’s through Positron Emission Tomography (PET), ultra sound imagery, connecting cognition to communication and exploring new purposes for existing drugs.

At an event hosted by Parkinson Society Central & Northern Ontario in Toronto, donors and Parkinson SuperWalk participants celebrated their contributions to improving the lives of those living with Parkinson’s while seeking better understanding it’s causes.

Awards were presented to:

- Dr. Nicola Ray, a post doctoral fellow at the Centre for Addiction and Mental Health received The Lois Harper Basic Research Fellowship, a $100,000 award to study impulsive behaviours, including pathological gambling, a side-effect of medications used to treat stiffness or tremor.
- Dr. Isabelle Boileau, a clinical research scientist at the Centre for Addiction and Mental Health, received a $90,000 New Investigator Award to study involuntary movement known as dyskinesias, one of the most common and disturbing side-effects of medication to treat Parkinson’s.
- Dr. Richard Walsh, a neurologist at Toronto Western Hospital, received a $50,000 Clinical Movement Disorder Fellowship to work with Parkinson’s patients using ultrasound images to determine types of Parkinson’s disease.
- Ms. Angela South, a PhD candidate in speech language pathology at the University of Western Ontario, received The Michael Kingdon Estate Graduate Student Award, a $30,000 award to look at the challenges people with Parkinson’s experience due to cognitive changes and to determine how language problems affect their lives and relationships.

Also receiving a grant, but not present, were Dr. Michael Schlossmacher, a world renowned physician-scientist and Dr. Julianna Tomlinson of the Ottawa Hospital Research Institute, who together received a $45,000 Pilot Project Grant to screen over 1300 drugs used in treating other diseases to see if they can be repositioned to treat Parkinson’s. If they can, it might shorten the time needed for clinical trials and will bring drugs to market faster. Funds for this grant were raised at Porridge for Parkinson’s, a biennial event dedicated to raising money to find a cure for Parkinson's disease, in Toronto in 2009.

Funding for researchers is made possible through Parkinson Society Canada’s largest fundraising event, Parkinson SuperWalk, held each September. “It is gratifying to see new hope and new discoveries in Parkinson’s coming from monies raised by Torontonians,” says Debbie Davis, CEO of Parkinson Society Central & Northern Ontario, “1000 participants raised $323,500. That’s 323,500 steps toward a better life for people with Parkinson’s.”

Also recognized at the celebratory event was Toronto resident Jim Vlahos, who completed the Athens Classic Marathon in October, raising $13,290 in memory of his late father-in-law. “I had many reasons for running this marathon but the most important one was to raise money for Parkinson’s,” says Jim.

This year, Parkinson Society Canada will contribute $1.3 million to over 30 research and pilot grants, new investigator awards, basic research and clinical fellowships, graduate student and psychosocial awards to encourage innovative ideas and foster emerging Canadian scientists who choose careers that help further understand Parkinson’s.

Parkinson Society Central & Northern Ontario is proud that the work of researchers in our Region is being recognized through these grants. Together with researchers across the country they will help us realize our vision of *a better life and a brighter future for Canadian’s living with Parkinson’s today; a world without Parkinson’s tomorrow.*

April is Parkinson's Awareness Month

At Central & Northern Ontario we are preparing for a busy month of April as part of Parkinson Society Canada's National Awareness Month campaign. Help us by being vocal about Parkinson's and spreading awareness. There are many ways that you can get involved. Please contact your local support group, or the Society at 800-565-3000 for more information.

The Tulip....A symbol of Hope!

Join us in April to raise awareness and provide hope for over 100,000 Canadian's who live with Parkinson's. You can participate by purchasing tulips through Parkinson Society Central & Northern Ontario's Hope in Bloom campaign for yourself, colleagues, friends or family.

Tulip sales are happening in your community. Dedicated volunteers work tirelessly through the month of April spreading awareness and selling tulips to raise funds to support our vision of a better life with Parkinson's today; a world without Parkinson's tomorrow. To find a sale in your community visit our website at www.parkinsoncno.ca

Notable Sale Dates in Toronto:

Union Go Train Station - April 14, 2011
Parkinson Awareness Day in the TTC - April 20, 2011
and many other venues around town.

Get your company involved!

Tulips can be ordered in bouquets or as potted plants. There are a number of ways your company can participate:

- Easter Holiday delivery - April 20, 2011
- Administrative Professionals Day - April 27, 2011
- Staff and/or customer appreciation
- Staff/Individual orders

For information on Hope in Bloom contact Naseem Jamal, Community Development Coordinator at 416.227.3377 or naseem.jamal@parkinson.ca

Artists Wanted for Hope on Display

If you are a musician, painter, jewelry maker, photographer, card designer etc living with Parkinson's we'd love to display your work and have you share your Parkinson's story.

Please call – Karen Dowell at 1-800-565-3000 ext. 3376

April 12 at the YMCA in Oakville from 4 pm till 7pm

April 20 at Origin Evergreen Retirement community in Mississauga from 3 till 7.

For more details, or if you are an artist and live outside either of these areas please contact us so that we can look at ways to grow the event.

KMTConsulting Associates presents:
Dr. Gabor Mate Weekend Seminar & Fundraiser Gala
Friday April 15, 9 A.M to 5 P.M. *Brain Development and Learning—Social and Environment Factors:* Topics to be addressed Mental Health, Bullying, ADD/ADHD, Addiction, and Stress.
Saturday April 16, 8:30 A. M to 4:30 P.M. Brain Development and Healing: When The Body Says No: *changing the brain, how the brain reacts to stress and healing the pain within.*
To Register: kmtconsultingassociates.com/conferences.html.

New Carepartner Group

A new support group for carepartners of people with PSP, MSA and CBD meets on the third Wednesday of each month in the Parkinson Society Canada Conference Centre at 4211 Yonge St. from 6:30-8:30 pm.

Please call 800-565-3000 ext. 3372 for more information.

Promoting April Awareness Month

We are pleased to offer our chapters and support groups an April media tool kit. This kit includes templates and materials that will help you promote April Awareness in your community.

Please contact your local CDC to obtain materials.

Get Involved this April….

April is Parkinson Awareness Month! Get involved in your community by becoming a volunteer at our annual *Hope in Bloom* campaign. Parkinson Society Central & Northern Ontario holds Tulip sales at over 20 sites across the GTA and other locations throughout the Region. We are currently looking for volunteers to assist our site captains. The only requirement to volunteer is your willingness to get involved and help sell tulips for a great cause!

This year's venues include: TD Bank Tower, Union Go Train Station, Sherway Gardens, St. Lawrence Market, Manulife, Humbertown, CBC Building, TTC (Bloor/Young, Eglinton, Sheppard, Islington), Sheppard Centre, St. Clair Center, Fairview and more….

To volunteer with *Hope in Bloom* contact Louise LeBlanc at 416.227.1200 ext. 3304 or louise.leblanc@parkinson.ca

Around the Region

In the Winter 2010 edition of Livewire we published the top walkers at all of our walks. Please note that Vivian Heinmiller should have been recorded as Peterborough's top walker. Congratulations to Vivian and all of our SuperWalkers!

The Mississauga Group completed our successful 2010 with a lovely lunch at the *Origin Evergreen Retirement Residence*; we are very grateful for those opportunities as well as the use of an excellent meeting room through the year.

Hamilton Support Group: Our Christmas luncheon held on December11 at St. Peter's Hospital was an outstanding success. Not only did we have Secret Santa and good food again, but this time we had music fit for a king. Joe Loncarich, his 3 daughters, and 1 granddaughter played and sang Christmas music (pictured right). It was wonderful! Joe and his wife Annie, who joined in November, were already contributing to our meetings. Sandie Jones, Coordinator, Client Services, arrived from Toronto in a snow storm on January 15 and as usual was a delightful fountain of information. Also impressive, Sandie was enjoyed by 25 members who too braved the storm. Obviously, the executive did not oversell her talk. Thank you Sandie.

Coming in 2011: Canada's Largest Exhibition for Disabilities: **People in Motion** is coming to the Queen Elizabeth Building, Exhibition Place, Toronto, Friday June 3 and Saturday June 4, 10am-5pm. 1-877-745-6555/people-in-motion.com

Vaughan Support Group: On December 16 the Vaughan Parkinson's Support Group celebrated the holiday season with a luncheon at The New Galley in Richmond Hill. Everyone walked away with full stomachs, loot bags and prizes. At our January meeting Sasha Milo, Optician and Dr. Alarcon, Optometrist, from IRIS gave the group an excellent overview of the human eye and answered questions. In February John Macaulay, Barrister and Solicitor joined the group to talk about Wills and Powers of Attorney.
We would like to welcome our new members. For more information on the group, e-mail marilyne101@hotmail.com with your name, address and phone number.

The Etobicoke chapter has many members and has quite a few interesting speakers throughout the year. Twice a year we have socials which the members really enjoy.

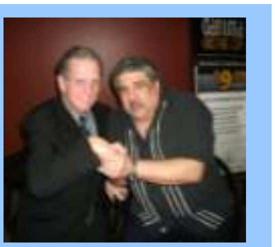
The 8th Donald Calne Lectureship: awarded to Dr. Stanley Fahn

Parkinson Society Canada is pleased to announce the award of this year's Donald Calne Lectureship to Dr. Stanley Fahn, H. Houston Merritt Professor of Neurology and Director of the Center for Parkinson's Disease and Other Movement Disorders at Columbia University in New York City.

Dr. Fahn will deliver a "state of the illness" lecture on Parkinson's disease to the Parkinson community in Toronto on June 7, 2011. Details to follow at www.parkinson.ca

Light of Day Niagara

It's a bigger party every year! In just four years Dave Rotella Jr., Mike Minervini and a crew of volunteers have raised over $50,000 through Light of Day Niagara. They are part of the larger Light of Day Concert series started in New Jersey 11 years ago. Many of those original musicians team with local Niagara artists to put on a fantastic Rock 'n Roll event. To date PSC has received over $18,950 as well as terrific media exposure in the Niagara area.



Niagara Support Group's Paul Pasmore with The Soprano's *star Vincent Pastore at LOD Niagara.*

Registration Opens April , 2011

PARKINSON
SUPERWALK

www.parkinsonsuperwalk.ca

Peterborough Chapter: Yvonne Mayhew worked very hard planning our fundraising event: "Blues Jam" hosted by Red Dog Tavern; and even *sweet talked* two grocery stores into providing Parkinson themed cakes for the celebration. She raised $685 for the chapter. We have a committee working with a local doctor to set up a hospital protocol for patients to make sure people with Parkinson's get their meds on time. We enjoyed a great Christmas party; and our winter meetings included a discussion of services from "Home Instead Senior Care," Dr. Ingrid Brenner speaking on the importance of exercise and Sandie Jones from CNO who always brings useful information and enthusiasm. Plans are underway for our annual tulip sales, in locations around town and at Peterborough's Spring Garden Show at the Evinrude Centre. Call 705-749-0660 if you'd like to help.

When It's a Hard Issue to Swallow—Sandie Jones, RN

Depending on how the question is asked, 30% - 95% of people with Parkinson's say they have difficulty swallowing. Before I go further, see if you recognize any of the following symptoms:

1. Coughing or throat clearing during, or immediately after consuming food.
2. Unexplained weight loss.
3. Episodes of food going down the wrong way e.g. feeling like you are choking.
4. Food gets stuck in the back of your throat, and you need a drink to wash it down.
5. Drooling – a little or a lot.
6. An increase in saliva, or thickened mucous like saliva.
7. It takes a long time to finish eating.
8. Difficulty swallowing pills.

If you answered yes to any of these symptoms, then you have a swallowing problem that should not be ignored, as even a minor problem can become a major one as your PD progresses. It is important to understand that the same slowness and rigidity that affects the muscles in your arms and legs affects the muscles in your throat. The difference is, you can't see your throat muscles, so you may not be aware that those muscles can cause problems too, because they may not be working in a coordinated, spontaneous, smooth way. Your tongue and jaw muscles prepare food to be swallowed by chewing it and mixing it with saliva. Then, the muscles in the back of your mouth and throat start the swallow. Those same muscles seal off your windpipe and nose to keep food and liquids from backing up into them. Next, the muscles of your oesophagus propel the food into your stomach. Slow or rigid muscles during any of these steps can result in difficulty swallowing.

People with Parkinson's who have difficulty swallowing should alert their physicians immediately because of the danger of **aspiration**—a condition in which particles of food and liquid pass into the lungs instead of going down the oesophagus into the stomach. People who aspirate food are at risk of developing **aspiration pneumonia**, an infection process that makes breathing difficult. This is a very serious complication that can in some cases lead to death.

Treating the primary motor symptoms of PD—rigidity and slowness—by increasing or adjusting your levodopa, is sometimes enough to improve swallowing function. However, if your doctor suspects that your swallowing problems pose a risk of developing aspiration, he or she will usually refer you to a speech language pathologist with experience in swallowing dysfunction for assessment. In a common test called a barium swallow, individuals are asked to consume foods and liquids containing barium, with a variety of textures. An x-ray then follows the foods and liquids as they move through the swallowing process, which results in a treatment plan based on the problem area. An individual diet is often recommended, as many people with PD can swallow thick slippery textures well, but choke on thin liquids or dry crumbly foods. Sometimes eating soft foods, food cut into very small pieces or using thickening agents is the treatment of choice.

REMEMBER—everyone with Parkinson's is unique even when it comes to swallowing difficulties, so it is very important to talk to your doctor, and get referred to a speech language pathologist, so that your particular problem can be addressed as quickly as possible. For those people whose swallowing problems and weight loss are not adequately managed with conservative therapies as previously mentioned, a surgical procedure can be performed in which a tube is inserted through the abdominal wall into the stomach. This procedure, called a percutaneous endoscopic gastrostomy (PEG), is used to provide nutrition and medications to a patient who cannot swallow, or is at risk for aspiration from eating or drinking.

The insertion of a PEG tube is a serious step and all less invasive measures, including adjusting the antiparkinson medication, must have been tried first. The patient's basic quality of life should also be taken into account, as a PEG tube is most often done as a palliative measure, and not all individuals want to take this step. Though not always a comfortable topic, having a discussion with your loved ones well before these kinds of choices need to be made is important, so that your wishes are being acknowledged if this option is ever offered. It is also important to understand that while the insertion of a PEG tube allows a person to be fed, and to receive proper nutrition and medication, individuals still can and do swallow their own infected saliva, so it is still possible for people with Parkinson's to develop aspiration pneumonia even with a PEG tube.

AGAIN—please talk to your doctor and don't attempt to self-diagnose your swallowing problem. It could be a condition completely unrelated to your PD.

CNO Welcomes Naseem Jamal

It is with sadness that we say goodbye to Elizabeth McCaw, who many of you have come to know as Community Development Coordinator for Toronto and East and an exceptional coordinator of events like Pitch In! and the Hope in Bloom Tulip Campaign.

We wish Elizabeth the best of luck in her new endeavours and are happy to welcome Naseem Jamal to her role.

Naseem brings great experience to CNO. She has worked with the United Way of Greater Toronto raising funds from corporations directly by recruiting and training senior executives to make fund-raising calls on behalf of the United Way as well as orchestrating employee worksite campaigns. In addition, Naseem has a corporate marketing and sales background (most recently with Telus and WSP International) and extensive experience leading successful volunteer initiatives.

We are excited to have Naseem as part of our team and know that you will join us in welcoming her!

Online Event Manager Represents New Opportunities for Third Party Events

Through its partnership with Parkinson Society Canada, the Central & Northern Ontario Region has access to a new tool for fundraising—and it's taking off! The online Personal Event Manager (PEM) allows individual fundraisers to create, monitor, and promote their fundraising events with ease.

We've had everyone from mountain climbers, marathon runners, to a cross-Canada bicycle tour involved and the results have been great. See page 7 for the story of Jim Vlahos who used the PEM to raise over $13,000 for the Parkinson Society. Also, the Kili Conquerors have just completed their ambitious goal of climbing Mt. Kilimanjaro (stay tuned for more info on their trip in the summer edition) and raised over $35,000 for two regions. Congratulations everyone who has used PEM on your success!

Contact us at 800-565-3000 more information and for support on creating your own event page.

Cut-a-thon 2011

Save the date: Sunday April 17, 2011

Participating Cities:
Barrie, Collingwood, Guelph, Bracebridge and Toronto
Visit www.cutathon.ca for more information and to book your appointment!

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

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

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

Card No.:____________________________________ Expiry Date_______/_______ Signature:____

Please complete the following information:

☐Mr. ☐Mrs. ☐Ms. ☐Miss: ☐Other:_____ First Name:______________________ Last Name_______________________________

Address:____ City:__________________________ Province:___________

Postal Code: _____________ Telephone: ______________________ Email:____

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

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

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

Thank you for your support!

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

Tax receipts are issued for donations of $20 or more, or upon request.

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

LWIRE

2013 World Parkinson Congress to be hosted in Montreal

Montreal has been chosen as the site for the third World Parkinson Congress to be held in 2013. So, as Canada gets ready to welcome the world, we all need to get ready to send as many delegates as possible to Montreal from October 1 to 4, in 2013.

In his announcement to the media, World Parkinson Congress Co-Chair Dr. Stanley Fahn said, “We are delighted that the third World Parkinson Congress will take place in Montreal, Canada. Canada was our choice due to its outstanding history of excellence in neuroscience. This, coupled with the country’s proximity to our European friends, the accessibility of the city of Montreal and its diversity, made it a logical choice.”

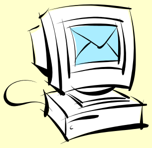
British Columbia neuroscientist and past Chair of Parkinson Society Canada’s Scientific Advisory Board, Dr. Jon Stoessl, has been named Co-Chair of the third World Parkinson Congress which is scheduled to take place October 1-4, 2013.

According to Parkinson Society Canada President & CEO Joyce Gordon, “We are thrilled that Canada was chosen for this honour for so many reasons. Canada is home to over 100,000 people with Parkinson’s. We have a world-renowned Parkinson’s research community. Parkinson Society Canada looks forward to hosting the international Parkinson’s community in 2013 in Montreal, a wonderfully vibrant city.”

The World Parkinson Congress is the only global Parkinson’s conference that brings together the entire Parkinson’s community – people with Parkinson’s disease, those who care for them, medical and health professionals and dedicated researchers working toward a cure and better treatments.

The Congress is anticipated to bring some 3,500 attendees to Montreal from over 66 countries around the world. Prior to Glasgow, Washington, D.C. hosted the first World Parkinson Congress in 2006.

If you would like to volunteer in any capacity for the World Parkinson Congress in Montreal in 2013, please contact Debbie Davis at debbie.davis@parkinson.ca



Did you know?

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

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