

LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

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This year marks the 45th year that Parkinson Society Canada has been in existence. The team in the Central & Northern Ontario office is working hard on your behalf, and is moving into overdrive as April, Parkinson's Awareness Month, rapidly approaches.

The Central & Northern Ontario (CNO) region of Parkinson Society Canada contributes to the national research program while regionally offering support services, information and specialized programs to ease the burden for those living with this chronic, degenerative neurological disorder. CNO covers a large geographic area from Guelph to Niagara to Kingston and then north to include all of Northern Ontario.

Debbie Davis, the CEO, is responsible for the operations of Parkinson Society Central & Northern Ontario, and for the achievement of the goals and objectives as outlined by the Regional Board and aligned with national strategic priorities. She is proud that this past year several Trillium grants were secured, two of them in partnership with other neurological health charities, allowing us to expand our services without any cost to our donors! "Balancing my desire to provide

more services and finding the funds to do this" is the most difficult challenge of her job, Davis



Parkinson's Awareness: 365 Days a Year

states. "There is so much I want to accomplish to provide more services for people living with PD, but I need to raise more money to do that."

Helping to raise money to provide services are Lorelei Wilkinson (Major & Planned Giving, Senior Development Officer) and Melissa Campisi (SuperWalk and Special Events Coordinator). Lorelei works to connect major donors' philanthropic goals with our mission statement, while Melissa has the challenge of overseeing 17 separate SuperWalks across our region. Both are diligent in their work, knowing that without funds, we could not deliver services.

The need for service is great. Sandie Jones and Robert TerSteege, who communicate with all clients making inquiries, regularly receive upwards of 400 contacts a month, and at certain times of the year may receive closer to 600 inquiries. They are also behind coordinating major education sessions and conferences (see pg. 8), and designing and delivering education series for newly diagnosed people and for carepartners. Sandie is also regularly on the road, providing in-service education to health care professionals in the community, such as nursing staff in hospitals and long-term care facilities.

Many of our clients belong to local support groups and chapters. These groups are supported by one of our five Community Development Coordinators (CDCs): Elizabeth, Karen, Nada, Sandra, and Jon. The CDCs help local groups with programming and sustainability, helping to increase local awareness of Parkinson's disease and fundraising efforts. Jon worked hard in helping with the self-sustainability of the Vaughan group and the restarting of a group in Orillia. These areas had been underserved,

and now have a new avenue of support. Karen's awareness efforts led to a new Hope on Display in Oakville.

The work being done depends heavily on the support of volunteers. Louise LeBlanc, Coordinator of Volunteers, recruits, screens, hires, and trains volunteers for CNO. This past year, she was able to develop a Peer Support program for individuals, and she also hired a successful team of volunteers to complete the SuperWalk data entry.

Stella Recchiuti, Accounting and Administrative Coordinator, could not possibly be expected to do that volume of data entry herself. She is responsible for processing all funds and invoices for CNO, which includes all financial reporting of the chapters within the CNO. Her work also ensures that the funds that come into our office are designated and used appropriately to help people living with Parkinson's.

For each staff person, there is always more to do and one more call to return, but for all of us, there is motivation as we realize the importance of our work in the lives of people living with Parkinson's. As Elizabeth McCaw said, "Having a grandfather who lived with Parkinson's has been a major motivator for me personally and ultimately led me to CNO. He has always been a true inspiration in my life and now, with my work at CNO, I have the opportunity to honour his memory each day."

Inside this issue, you will find portraits of people whose stories motivate the staff of CNO daily in their work.

While April is Parkinson's Awareness Month across the country, the staff of CNO are very aware of the needs of the people they proudly serve, 365 days of the year.

Spring 2010



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

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MISSION STATEMENT

Parkinson Society Canada is the national voice of Canadians living with Parkinson's. Its purpose is to ease the burden and find a cure through research, education, advocacy, and support services. The Central & Northern Ontario office contributes to the national research program while offering support services, information, and specialized programs to ease the burden for those living with this chronic, degenerative neurological disorder in the region.

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Volunteer Award Nominations Wanted

Every year in May, at our Volunteer Tea in Toronto, we present three important volunteer awards.

- The Derek Curwen award is given to volunteers who exemplify Curwen's fundraising expertise, ability to inspire and lead others, and wholehearted support of Parkinson Society Central & Northern Ontario.
- The Marilyn Forbes award is presented to volunteers nominated by their peers who exemplify Forbes's dedication to their chapter, support of people living with Parkinson's, and the work of the Parkinson Society Central & Northern Ontario region.
- The Ian Davidson award is presented in recognition of volunteers who have Parkinson's disease and have been role models in providing guidance and support that improved the lives of others living with Parkinson's in Central & Northern Ontario and/or increased public understanding of their situation through such activities as leading support groups, public speaking, advocacy, volunteering, and fundraising.

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

The 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, the Coordinator of Volunteers, at 416-227-1200 ext. 3304 or louise.leblanc@parkinson.ca. Nominations for the 2010 awards are due by **March 26, 2010**.

People in Motion 2010

Canada's Largest Exhibition for
Persons with Disabilities

Queen Elizabeth Building, Exhibition Place, Toronto

Friday June 4, 2010, 10 a.m. – 5 p.m.

Saturday June 5, 2010, 10 a.m. – 5 p.m.

Website: www.people-in-motion.com

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 416-227-3372 or 1-800-565-3000 ext. 3372 or email to livewire@parkinson.ca

Next submission deadline is June 18, 2010.

PD and Technology

By Jon Collins

The Internet can be a great resource for any number of topics. Online banking, research papers, and gathering information on how to approach your individual management of Parkinson's. Certainly, there is a great wealth of information available and you are encouraged to be proactive in your approach, to adjusting to Parkinson's. However, much like the perils associated with identity theft, or issues with trusting unreliable sources for school papers, there are dangers that come from relying on the Internet in your approach to the management and treatment of Parkinson's, and people must digest all information—online and otherwise—critically, rather than just accepting it as fact. It seems that there is new information being circulated on the Internet and through other media on a daily basis proclaiming that the next great medical breakthrough has been found, and although there is legitimate reason to be excited about many of the new discoveries in Parkinson's research, treatment, and management, there is also a need to view information, particularly that found on the Internet, with a critical eye.

In many cases the evidence for treatment claims is unreliable. People living with Parkinson's, like many other chronic conditions, are hopeful that new developments will help them better manage their condition; however, unfortunately there are those who try to exploit this hope with ambiguous treatment claims based on client success stories and pseudo-science.

Using the Internet to "diagnose" oneself or gather information as a patient can be confusing. The ability to weed through the misinformation and make sense of breakthrough stories, determining which are concrete and which are concocted, is a necessary skill when seeking information on Parkinson's, including treatment, medications, and other reports on the

Internet.

There are a number of different types of research reports or online promotions to be aware of. Although it is important to critically analyze and discuss with your prescribing physician all information regarding Parkinson's treatment, there are a number of particular reports to be cautious of, including the following:

1. Incomplete research—although there is reason to be hopeful based on new clinical trials of medication, the treatment will not necessarily be effective in the long term.
2. Claims of results based on only personal stories with no research based evidence.
3. Medications for sale over the Internet—In particular, some "medications" are available without a prescription or with claims to cure Parkinson's or other diseases with the same treatment.

Claims based on personal testimonies can be moving and inspiring, but they can also be misleading. People putting hope, money, and energy into a treatment are more likely to assume that there is improvement in their condition, so they feel that their efforts are worthwhile. Thus, reports of better symptom management through a certain therapy may be inflated or imagined.

Most long-term conditions have symptoms that fluctuate. People are most likely to seek treatment when they are in a down period, and the typical improvement that follows this downswing may be mistakenly attributed to a particular therapy rather than the natural course of progression.

Also, when people take a treatment that they truly hope and believe is effective, there is a risk for a *placebo effect*; optimism about the results of a treatment can in itself sometimes make people feel better.

The routine variations in Parkinson's symptoms from day to day make it difficult to judge whether therapies supported only by personal statements are really effective in the long

term or are useful only for a short while.

The benefit of a rigorous, scientific evidence-based approach is that it can account for these typical problems associated with personal testimonies and is more effective at ensuring that treatment effects are real and safe. Although it takes time, if a medicine has gone through the process of a complete clinical trial you and your doctors have access to information about the successes and benefits of a form of therapy as well as its potential side effects. Parkinson Society Canada supports peer-reviewed information published in scientific journals. When looking at claims made on Websites selling treatments, if it sounds too good to be true—it probably is. Because there is no known cure for Parkinson's, for example, one must be highly suspicious of any testimonials claiming to be a cure.

When considering a new treatment please be sure to consult with your doctor, and look out for the following:

1. Claims are based on patient testimonials rather than evaluated clinical research.
2. Multiple diseases are treated with the same stem cells or the same approach. Different diseases, such as Parkinson's and heart disease, would be expected to have very different treatments. You want to be treated by a doctor who is a specialist in Parkinson's.
3. The source of the treatment, or how the treatment will be performed, is not clearly documented.
4. The treatment claims to have no risks.
5. High costs or hidden costs are associated with treatment. It is not customary for someone to pay to be part of a clinical trial.

There are sites of great value on the Internet; try resources available from a trusted, reliable source.

www.parkinsoncno.ca,
www.parkinson.org, www.pdf.org are some examples.

Mimi Feutl Award

Kingston resident **Suzanne Extence** received one of Parkinson Society Canada's highest volunteer service awards—the **Mimi Feutl Award** for an individual who, through compassion and provision of information and support, has made life better for individuals living with Parkinson's and their families.

The award honours Mimi Feutl, who for more than 22 years displayed unwavering commitment, energy and compassion. Mimi ensured that each person who sought help, information, and services from the then-named Parkinson Foundation of Canada was treated with dignity and respect for their individuality.

Suzanne Extence received her award at the annual festive dinner celebration hosted by the Parkinson Society Kingston chapter at the Kingston Seniors Centre. This is the seventh year this award has been granted.

Suzanne's journey with Parkinson's follows an unusual path. Although she was first diagnosed with Parkinson's disease, it was discovered several years later that she had a different condition. By that time, she was so involved in the activities of the Kingston chapter, she remained a dedicated volunteer.

Like Mimi, Suzanne's dedication to the Parkinson's cause has been without hesitation. Suzanne's roles have varied from serving as Chapter Vice President to providing information and support at a weekly local health clinic. Suzanne is also the friendly, reassuring voice on the Parkinson's information line for the Kingston area, helping others the way that she was first helped so long ago.



The Tulip... a Symbol of Hope!

Join us in April to raise awareness and provide hope for over 100,000 Canadians who live with Parkinson's disease. 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 a brighter future for Canadians living 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 8, 2010
- Parkinson Awareness Day in the TTC—April 22, 2010 (Kipling, Yonge/Bloor, Sheppard, and Eglington Stations)

Get your company involved!

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

- Administrative Professionals Day *April 21, 2010*
- Staff and/or Customer Appreciation
- Staff Order Form

For information on *Hope in Bloom*, contact Elizabeth McCaw, Community Development Coordinator, at 416-227-3377 or elizabeth.mccaw@parkinson.ca

Pitch In!

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

Jays vs. Cardinals
06.23.10
cno.parkinson.ca

Get a Free Tow to Car Heaven: Get a Tax Receipt for Donating to one of the Parkinson Societies in Ontario! (This is a collaborative initiative of Parkinson Society Central & Northern Ontario, Parkinson Society Ottawa, and Parkinson Society Southwestern Ontario)

Car Heaven is a program that helps Canadians retire higher-polluting vehicles. In the 10-year existence of the program, 46,500 tons of carbon monoxide (CO), and 4,844 tons of smog-causing emissions have been prevented from entering the atmosphere through the "retirement" of older vehicles. If you retire a car through Car Heaven, your car will be towed away free of charge and recycled in an environmentally responsible way. Plus, Parkinson Society receives up to \$65 per vehicle and you receive a charitable tax receipt for your efforts. For more information about Car Heaven, please see www.carheaven.ca or call 1-866-535-7312.



Pictured at left, Sue Extence and family

Studying to Find a Cure

Alexandra Elliott knows the effects of Parkinson's all too well. Her grandmother was diagnosed with Parkinson's when Alexandra was only one year old. However, Alexandra's family recalls her grandmother showing symptoms of Parkinson's as early as 10 years before officially being diagnosed at the age of 62.

Growing up, Alexandra never really understood the extent of Parkinson's but always knew her grandmother had a disease. At a young age, Alexandra and her family became very involved with events and fundraisers hosted by the Peterborough/Kawartha Lakes

chapter. From participating and volunteering in the annual SuperWalk for Parkinson's to organizing Parkinson Society bus trips to Toronto for Blue Jays games, Alexandra stayed involved alongside her sister and

younger brother. Her true understanding of Parkinson's, however, came much later.

"It was not until university where I learned about the molecular and cellular mechanisms which govern Parkinson's disease that I really understood the impact this disease can have," Alexandra explains. It was at this time that Alexandra and her family became more aware of not only the challenges imposed by Parkinson's disease, but also the side effects of the medication used to treat Parkinson's.

Alexandra, who recently turned 21, is in her fourth year at Trent University completing her degree in biology. "This year I have been able to focus my interest on molecular pathogenesis (molecular components as to why it's so pathogenic) of disease, and am doing an honours thesis in virology," Alexandra says. "My project is to examine the potential role of a specific gene in the disease process of Frog Virus 3. While this particular project focuses on viruses, the various lab techniques employed can be

applied to working on the molecular pathogenesis of any disease, including Parkinson's." Alexandra notes that studying similar genes in other species can have direct implications for humans with these types of diseases. "This is another reason why molecular pathogenesis research of any kind is so critical, especially to Parkinson's disease."

Emotional and community support through meetings, fundraisers, and events is the number one contribution the Peterborough/Kawartha Lakes chapter has provided for Alexandra's grandmother. "Through the Peterborough/Kawartha Lakes chapter I know my grandmother has been given a



sense of community and I am certain it has made her feel less isolated and less hopeless because she has been able to rally with others in the effort to find a cure," said Alexandra. "Emotionally, she is a very strong woman and Parkinson Society Central & Northern Ontario has helped to prolong her independence, and this has

made the progression of her disease much smoother and more bearable."

In October, 2009, Alexandra Elliott was presented with the Dr. Ted Cragg memorial award by the Peterborough/Kawartha Lakes chapter for her research into Parkinson's disease. Alexandra knows that Parkinson Society Central & Northern Ontario financially supports research grants and says she will certainly apply in the future.

Medication Class Action

Class actions are proceeding in Canada on several dopamine agonists, such as Permax, Mirapex and Requip. They seek monetary relief related to alleged compulsive/obsessive behaviours, including pathological gambling.

If you have taken these medication for Parkinson symptoms, information can be found at www.thomsonrogers.com or call the office of Thomson, Rogers at 1-888-223-0448.

That 70's Show rocks downtown!

On January 30, 2010 Your Night Out Entertainment presented an evening of 70's inspired music, delicious food, dancing and entertainment in support of Parkinson Society Central & Northern Ontario. A special thanks to Zack Bandolin (joined by the Ken Jones Trio) for headlining the musical portion of the night. Other artists included Peter Mangaser, Joshua Lopez, Angelica Breanne Tomamang, and DJ Chris Zoleta. A portion of ticket and silent auction sales were graciously donated to the Society. For future events being put on by Your Night Out Entertainment, visit their Website at www.yournightoutentertainment.com



Hope on Display

In a number of locations throughout the region during April Awareness Month, we will be showcasing the creative expressions of people living with Parkinson's.

Hope On Display started in 2007 with one show in Toronto and has continued to grow. In April, 2010, we hope to expand to four locations across the region.

For venue information, or if you are a musician, painter, jewellery maker, photographer, card designer, etc. and are interested in sharing your creative efforts with others, please call the Community Development Coordinator about Hope on Display in the following areas:

Barrie/Orillia area—Jon Collins
1-800-565-3000 ext. 3370

Toronto & Durham Region East to Kingston area—Elizabeth McCaw
1-800-565-3000 ext. 3377

Halton/Wellington area—Karen Dowell
1-800-565-3000 ext. 3376

Stuck in Slow Motion: Finding Joy Behind the Mask of Parkinson's Disease by Adele Gould



I watch my children watching me as I tread cautiously down the stairs, holding tightly onto the banister. They walk in front of me

in case I should fall, concern evident in their furtive backward glances. Slight unsteadiness has gradually crept into my new reality, and I no longer remember how it felt to scurry down the stairs.

My future was carved out by the arrival, six years ago, of Parkinson's disease, a degenerative brain disorder which leads to muscle rigidity, tremor, and slowing of movement. Many people with advanced disease have impaired balance, a stiff facial expression, shuffling gait, muffled speech, and small, cramped handwriting. Some experience memory loss, others struggle with disease-induced depression.

My memories of D-Day ("Diagnosis Day") remain vivid. "You have garden-variety Parkinson's disease," announced the neurologist casually, leaving me fighting back tears as I tried to maintain a dignified front. "Garden-variety Parkinson's disease?" I repeated to myself then, and for months after, as I tried in vain to deny my new reality. I devoured copious bits of information in the hope that knowledge would empower me. Instead, it filled my mind with images of a future truncated by rapidly-spiraling physical and mental deterioration. I was utterly devastated.

As the initial shock began to wear off I resolved to fight this strong adversary with every fibre of my being, and to uphold my joyful disposition, despite the challenges ahead.

My movements have become slow and deliberate and my fingers clumsy. My handwriting is now illegible, even to me, and I scratch my head in bewilderment as I try to decipher what I've written. But as the disease marches on, striving to gain victory over my body and mind, I have learned to see humour in unlikely places. I now use voice-activated software to type because my fingers move stiffly and slowly over the keyboard. The software insists that my name is Patel not *Adele*! My body moves slowly, like a movie stuck in slow motion... sometimes I want to yell out "*Hellooo! I'm still in here!*"

Taking charge of my couch-potato self I hired a personal trainer. *Wonderful!* I lost weight and felt energized, such that I enthusiastically began to scour travel magazines for adventure-style vacations. But my formidable opponent sneaked in and tempered my newly-acquired agility.

So I joined a dance class devoted specifically to people with Parkinson's disease. For one hour each week my inhibitions take flight as I move with rapture and abandon, momentarily forgetting what brings me there...

...until I look around at some of my fellow participants and catch a glimpse of my future. I allow my imagination to run free as I weave stories about the people behind the expressionless masks and unblinking eyes that identify the individual with more advanced Parkinson's.

This one might have been a university professor...that one an aeronautical engineer...another a classical guitarist. The expression of dazed simplicity conceals their emotional and intellectual depth as the mask freezes their once-automatic facial expressiveness.

And the Parkinson's Shuffle is still the most popular dance step among this crowd.

Hoping to delay the inevitable for as

long as possible, I ingest an impressive array of medications. I remember how I used to watch little old ladies fishing for their pillboxes in their crammed purses. *I am now one of them*—except that I am neither little (unfortunately!) nor old (though I hope to get there!).

My greatest fear is the possibility of losing my intellect—for me this would be the ultimate insult (but would I know?). Even now, simple words elude me, so I try to describe what I am trying to say when I can't find the word. It's there...on the tip of my tongue, but it doesn't come to me until (if I'm lucky) someone else figures it out. So a cardinal becomes a "red bird" and a weeping willow, "the tree that cries."

It helps to be able to laugh at myself. How else can I deal with being called "Sir" on the telephone because my voice has become deeper and softer ... or being relegated to the male section of the choir?

I may be joyful, but I am also human. There are feelings and fears that drift in and out of my psyche: the trepidation that permeates my being when I picture myself with advanced disease ... the sadness that pervades when I remind myself that my beloved grandchildren will never know the person I was ... the anger I try to suppress each time my body betrays me ... the shame I experience when passers-by assume that I'm stealing a handicapped parking spot ... the embarrassment of holding up the line in the grocery store as I fumble in my wallet ... and the terror I have of developing dementia.

When frustration builds and I need a good cry, I have a loving husband and good friends whose open arms soothe my soul. And—*always*—a visit with my wonderful grandchildren guarantees unadulterated joy.

Until recently I had shared very little of my inner world with my five children, despite the close relationships we enjoy. In part, I did not want to

Continued next page

Stuck in Slow Motion—continued

burden them, but a lesser altruistic reason was that I wanted to be viewed as strong ... brave ... uncomplaining. But then I realized how this was preventing us from achieving the intimacy that emanates from openness and authenticity. And—to be fair—there was a part of me that wanted my children to know and understand my experience.

And so we laugh together and cry together ... and I quietly thank my lucky stars for the many wonderful people in my life who walk this road with me and give me every reason to be joyful.

Adele Gould is originally from South Africa and has been in Canada for 35 years. She was diagnosed at the age of 56, in 2003. She worked as a social worker—counselling people with chronic illness—for 18 years, but is currently on long-term disability. She is married and has five children and four grandchildren.

She has many interests and hobbies—not the least of which is creative writing. Adele does woodcarving; is passionate about music: she plays the piano; loves photography and videography; and is a voracious reader. Adele says "I do not have time to feel sorry for myself—I have too much living to do!"

This essay was featured February 24 in the Globe and Mail. Reprinted with permission of the author.

PSP Research Opportunity

A research study is being conducted to learn more about the challenges, resources, and needs of people with Progressive Supranuclear Palsy and their caregivers. This information will be used to develop a new service or resource to improve support for patients and family caregivers.

People living in Ontario who have been diagnosed with PSP and their family caregivers can participate in one or more of the following: focus groups, surveys, and testing of new services. To enroll or obtain more information, please contact Theresa Moore, RN, MScN, at the Centre for Movement Disorders in Markham:

905-472-7082 ext. 234

Parkinson's Disease Clinical Trials Recruiting

Clinical trials are research studies aimed at finding better ways to detect, prevent, treat, and offer advance therapy for diseases such as Parkinson's. At the Toronto Western Hospital we are currently recruiting for a variety of clinical trials for Parkinson's disease:

- Neuroprotection for delaying disease process
- New investigational drug for wearing off symptoms
- New investigational drug for dyskinesia (involuntary movements)
- New investigational drug for symptomatic treatments

We invite you to call our research coordinators for additional study information:

Julie So at 416-603-5875 ext. 3 or

Francis Baraquo at 416-603-5875 ext. 5

Benefits and Risks of Participating in a Clinical Trial

Experiences from people living with Parkinson's who have participated in clinical trials.

Benefits

Clinical trials that are well-designed and well-executed offer excellent opportunities for eligible participants to

- Play an active role in their own health care
- Obtain referrals to a study site
- Engage care partners as companions in care
- Gain access to new research treatments before they are widely available
- Obtain expert medical, sometimes multidisciplinary, care at leading health care facilities during the trial
- Help others by contributing to medical research
- Enhance personal knowledge of a medical condition

Risks

There are risks to clinical trials

- Depending on the study design, there may be no guarantee that the participant will receive the active ingredient
- There may be unpleasant, serious or even life-threatening side effects to experimental treatment
- The experimental treatment may not be effective for the participant
- The research may require collection of data, for example, genetic information, which could potentially cause psychological or informational harm
- The research criteria may require lifestyle modifications, for example, dietary changes

Parkinson's Society of Central & Northern Ontario (CNO) does not have the resources to screen or evaluate the background, ethics or intent involved in this research proposal. CNO neither encourages nor discourages involvement in this project; however, we want to be sure that people with Parkinson's have the information they need to make an informed decision. Therefore, we share this information with the understanding that CNO assumes no liability for providing access to information and—if you are interested—encourages you to review the request and ensure it will work for you, in consultation with your health care team, before proceeding to contact the research group.

Mark Your Calendar!

2010 Education Events and Conferences

Royal Botanical Gardens Education Session

Address: 680 Plains Road West, Burlington, ON

Date: Wednesday April 7, 2010

Time: 6 p.m.–7 p.m.: Information Booths; 7 p.m.–9 p.m. Main Presentation

Description: Dr. Mandar Jog, of the London Movement Disorders Program and Dr. Mark Guttman, of the Markham Centre for Movement Disorders, will debate “**hot topics**” related to Parkinson’s!

This event is free, but space is limited so registration is required. Please contact 1-800-565-3000 ext. 3303 to RSVP.

Belleville Education Session

Address: Loyalist College—376 Wallbridge-Loyalist Road, Belleville, ON

Date: Saturday April 10, 2010

Time: 10 a.m.–3 p.m.

Description: Life after Diagnosis: Four speakers, including keynote speaker Dr. Stuart Reid from the Kingston Movement Disorder clinic. **This event is free, and lunch is included! Space is limited, so registration is required.** Please contact 1-800-565-3000 ext. 3303 to RSVP.

Northern Ontario Education Conference

Address: Best Western Hotel North Bay, 700 Lakeshore Drive.

Date: Saturday May 1, 2010

Time: 10 a.m.–3 p.m.

Description: Dr. Susan Fox, from the Movement Disorders Clinic at Toronto Western Hospital is the keynote speaker. **This event is free, and lunch is included! Space is limited, so registration is required.** Conference costs are covered by Boedeker Foundation. Please contact 1-888-237-4453 or email sandi.willock@parkinson.ca

Barrie Education Session and Hope on Display

Address: Royal Victoria Hospital, 201 Georgian Drive, Barrie

Date: Tuesday May 11, 2010

Time: 6:30 p.m.–9 p.m.

Description: Dr. Mark Guttman, Markham Centre for Movement Disorders, will present an Update on Parkinson’s. Occupational Therapist Sheri Corkum, Markham Centre for Movement Disorders, will speak on Practical Tips for Activities of Daily Living.

Niagara Education Session

Date: Saturday May 15, 2010

Address: St. Columba Church on St. Columba Dr., St Catharines

Details: To Be Announced

Description: Dr. John Adams, Markham Centre for Movement Disorders

Toronto Conference

Date: Saturday October 30, 2010

Address: BMO Institute for Learning, 3550 Pharmacy Avenue

Details: To Be Announced

Parkinson Society Central & Northern Ontario gratefully acknowledges the Boedecker Foundation for covering the costs of this year’s Northern Ontario Conference.



Living with Parkinson’s— Tammy Taylor

When Tammy Taylor’s children were little, one of the books she read to them was titled, *My Mommy has PD ...But It’s Okay!* Her daughter was two and her son not quite four when Tammy was diagnosed with Parkinson’s disease.

Now 11 and nine years old, Tammy’s children are well attuned to the ups and downs of Parkinson’s. According to Tammy, “A good day is when I can get up in the morning and feel great and my

body is not rejecting anything that I try to do. My kids know when I’m not having a good day. Sometimes they react by fighting with each other; they don’t know how else to deal with it. Other times, they will come and cuddle with me. Even if I’m dealing with exhaustion, tremor, rigidity or pain, I still try to do all the things I used to be able to.”

One exception is work. At 34, Tammy had to give up her job assembling power seat adjusters at an automotive parts factory due to frequent sleep disruption and a decline in fine motor skills. For someone with an outgoing personality and a penchant for hard work, it was a blow to lose the workplace camaraderie and feel that she wasn’t contributing to the family income. Thoughts of her children and husband helped lift her out of the dark days. “I realized, they’re still here for me, they still love me, and there is still much I can do for them.”

Tammy decided to volunteer in the breakfast program at her children’s school as a way to stay engaged in her community. The teachers love her positive spirit and the fact that she’s excellent at making cards so they invite her in to help the kids create cards for special occasions like Mother’s Day and Father’s Day. Tammy says, “It makes me feel good to go to the school and see the kids get excited about a project we’ve done and be proud of their work. It helps me feel better about the fact that I can’t work.”

Dance classes in hip hop and tap round out Tammy’s regimen for staying active and engaged, and enjoying life to the fullest.

As the youngest member of her Parkinson’s support group in Bracebridge, Ontario, Tammy values the group’s sharing of knowledge, experience, and support. She would like to see more knowledge and understanding of Parkinson’s within the general public so that, “when people see tremor in a young person, they don’t assume it is related to alcohol or drug withdrawal.”

Tammy remains fully focused on her family, as a loving wife to her husband and a great mom to her kids, “spending as much time as I can with them because one day I may not be able to do with them all the things that I’d like to do.”

Tiny But Mighty

By Jon Collins

As I sit watching Sandie Jones, Coordinator of Client Services and Education with Parkinson Society Central & Northern Ontario (CNO), and Lara Duffy chat with each other, I get the impression that these are truly kindred spirits. The two feed off each other and share a genuine respect for each other that is apparent to any observer. You could easily assume that these were simply two age-old friends getting reacquainted—and in a sense, they are.

What is surprising is that the two likely would never have known each other if not for Lara's diagnosis with Parkinson's in the year 2000 and her late husband's experiences with the struggles of Lewy body Dementia. Ten years ago Lara reached out to Sandie for some much needed support, which she has continued to receive in years since, and this chance contact has developed into a strong friendship. Another thing that is apparent when speaking with Lara is her strong positive attitude, which helps her cope with her Parkinson's and some of the daily difficulties we all must face. "How are you doing Lara?" "I'm well thanks... *I'm always well.*"

Lara, a Newmarket resident and mother of five (grandmother of 10, and great-grandmother of four and counting), stands well under five feet, but has a strength of character that belies her size. Her life story continues to develop into a tale of courage in the face of adversity. Make no mistake, beneath the small frame Lara presents lays a fighter. She has led an interesting, optimistic, take-charge kind of life—starting with the two grades she skipped in elementary school and the four-year high school career from which she graduated after two. Lara has been in a hurry to take on the world. She is a woman who has held many interesting jobs, lived many interesting experiences, and

enjoyed numerous pastimes, like painting, playing bridge, and photography, all of which she still takes pleasure in.

Around the year 2000, Lara received her diagnosis of Parkinson's while struggling with her husband Gerry's misdiagnosis of his own condition, first suggested as Parkinson's and later recognized as Lewy body Dementia. Always an eager participant in all of life's challenges, Lara began a new journey. She courageously fought to keep herself healthy while helping Gerry adjust to his diagnosis



and the changes that the rapidly advancing condition brought on. When concerns over their mutual health became too heavy to bear alone, Gerry was placed in long-term care, but the fight didn't stop there. Lara recalls being an advocate for her husband with the staff at his facility, and she also took on (and received a mayoral commendation for) city council on the issue of pesticide use in Newmarket. Pesticides, long thought to play a role in the environmental causes of Parkinson's, are no longer used in the town thanks in no small part to Lara's impassioned plea.

Her experience as a volunteer is

extensive, including contributions to Girl Guides and Boy Scouts, school organizations, intergenerational programs, and auxiliary clubs. She has also volunteered as an ESL instructor with the local seniors centre and other organizations. Now Lara continues to fight for a cause that is important to her. As one of CNO's most dedicated fundraisers, she takes on sales of tulip bulbs and Christmas cakes with an intensity that is hard to match. The logic is simple: "If it's important to me, I'll do anything," Lara explains, and that is what she has done. She approaches local churches, her neighbours, friends and family, and local seniors organizations—though she's had to butt heads with a few competitors—and it's the enthusiasm that stands out. Although she's always had a fundraising avenue, cake sales are new to Lara. In 2008, she helped offload some cakes that a friend was selling, but in 2009 she took on her own order of 50 cakes. The order, when originally placed, was so ambitious that staff support at CNO weren't entirely sure it would happen. Unfazed, Lara went on to sell through her 50 quickly and place a second order, totaling 63 Christmas cakes sold leading up to the holiday season.

She says she's always been a giving person, a virtue nurtured by parents who were "kind and giving." Although funds raised are important to contribute to education, research, advocacy, and the support that Lara knows firsthand is vital, she sees her projects more than anything as a way to raise awareness of Parkinson's. Her hope is that in response to her small request, people will not only donate, but will think more about Parkinson's and the people who face its challenges. As long-time friend Sandie Jones puts it, "Personally, I think Lara is an excellent ambassador: living well with Parkinson's and making the most of every day."

Around the Region—For more information on support groups in your area, please contact 1-800-565-3000 ext. 3372.

We are growing! The north district has added a support group in Minde-moya. On November 19, a small but enthusiastic group met under the guidance of Marilyn Proulx, RN (back row, second from left in the photo below), of the Sudbury Regional Hospital, Manitoulin Site. Speaker Karen Dowell from Parkinson Society Central & Northern Ontario brought literature and videos for future use and facilitated a discussion on the direction the group wanted to take. The meeting held on January 21 saw thirteen in attendance.



The folks from the North Bay group met recently to discuss publicity and promotion of the upcoming conference made possible by a grant from the Boedecker Foundation. Nigel Wood and the group are eager to welcome everyone on May 1 for a full day of education and support. See ad on page 8 for details.

The Sudbury group increased its visibility in the community with a booth at the Older Adult Centre on January 28. Chris Sheridan organized the volunteers and gathered the educational material. Six members of the group took turns giving out information and sharing their experience of living with Parkinson's disease.

Light of Day 3 was a huge success!

Dave Rotella and his committee had all their hard work validated when the evenings receipts totalled almost \$20,000. It was a full house on November 13, the music was great and Parkinson Society Central & Northern Ontario received over \$7,000 of the proceeds, almost triple the 2009 amount.

It is the 10th anniversary of Light of Day in New Jersey and event founder Bob Benjamin came to congratulate the Niagara Falls team for coming so

far in raising funds for Parkinson's disease in just three years. Bob was diagnosed with Parkinson's at age 40. He wanted to turn his connection with the music world into charity concerts and Light of Day was born. Bruce Springsteen played for many years in this New Jersey event.

Burlington watercolour artist Debbie Lecavalier donated one of her tulip paintings to the raffle. Since being diagnosed with Parkinson's, painting has become an important expression of her creativity.

Look for Light of Day 4 in Niagara Falls on November 12, 2010.

The Barrie chapter closed out 2009 in a very positive fashion. Our year end was an excellent potluck luncheon with 38 members in attendance. Sandra Mikulski organized printed Christmas carol sheets, and A. Lett directed the carol singing, followed by a gift exchange and a closing poem by Sandra. A great beginning to the Christmas season for all. Also in December, we received a donation of \$750 from Innisfill Lions Club as well as a donation of \$1000 from the Barrie branch of RBC. Both donations were very much appreciated.

We continue our weekly meeting every Thursday at 1 p.m., where we share our positive thoughts.

The Parkinson Society North York Peer Support Group holds meetings the 3rd Monday of each month at the Edithvale Community Centre (Yonge and Finch) from 1:30 p.m. to 3:30 p.m. If you would like an opportunity to meet other individuals living with Parkinson's and to discuss Parkinson's-related issues that matter to you, please join us.

The Haliburton PD Support Group is NEW! In April, 2008, we held an information meeting to see if there was a need in our county for a support group. The response was a resounding YES as 33 individuals attended that session and told us they were interested. We have had a range of guest speakers including a pharmacist and a yoga instructor. We have watched information videos on Park-

inson's, and generally try to take some time for "sharing and caring." Our support group meets the second Wednesday of the month from 1:30 p.m. to 3:30 p.m. at a local church. New members are always welcome. Two staff members from the Haliburton Highlands Family Health Team co-facilitate the meetings. The group is open to anyone living with, or supporting someone with, PD in our County. Contact information: Janet Bottum, R.N., or Barb Fraser, Social Worker: 705-455-9220, Haliburton Highlands Family Health Team.

Kingston Golf Tournament

Glen Lawrence Golf Club was the site of the **2nd Annual Kingston Golf Tournament for Parkinson's** on August 29, 2009. The tournament raised \$2543 which was graciously donated to Parkinson Society Central & Northern Ontario. Thank you to all the sponsors who helped the tournament reach its fundraising goal. Sponsors: Amorosa Silva, Antonio & Rosa Marques, Carlos & Dorinda Valente, Carlos & Wendy Valente, Carmelinda's Family Restaurant, Curry Original (Uptown Location), Denny's Family Restaurant (RioCan), Domingas Silva, Glen Lawrence Golf Club, Golf Town, Group 4 Security, Homecraft Brew & Wine Supplies, Jo-ann & Jack Eady at Bayridge Cask & Keg, Joanne Neilson at Scotia McLeod, Judi Lancaster at Through our Eyes Interior Decorating, Judy Doran, Carlos & Maria Silva, Mark Fisher & Shirley Lieberman (Royal LePage ProAlliance Realty), Parkinson Society Kingston Chapter, Pat Eaton (Partylite), Premier Fitness, Queen's University (Bookstore), Ramekin's Restaurant, RBC Royal Bank (Princess & Drayton Branch), Rene & Margaret Roscher, Ron Darling & Danielle Ambrose (Royal LePage ProAlliance Realty), Rosa Valente at Goodlife Fitness, Suchi Gupta at Tea Connexions, Tim Hegarty (Earl Shaw Insurance), Wendy Medeiros (RMT) at Kingston West Family Chiropractic.

Young Onset PD Online Chat

We encourage you to participate in CNO Young Onset Chats. Held on the fourth Monday of the month, these chats are designed to bring together people facing similar issues so that they can learn from one another's experiences.

Please contact Jon Collins at 1-800-565-3000 ext. 3370, or visit our Website www.parkinsoncno.ca, for more details.

Porridge for Parkinson's

Parkinson Society Central & Northern Ontario applauds the heart and commitment of the volunteer organizing committee,

chefs, presenters, and attendees to find a cure and ease the burden through Parkinson's research.

Almost 300 people gathered in one of Toronto's gracious historic homes on November 1, 2009, for the second biennial Porridge for Parkinson's event with the promise that "there is no better way to spend your morning." With over \$45,000 raised and all proceeds going to research through Parkinson Society Canada, the morning was indeed well spent!

This year's breakfast tasting welcomed four of Toronto's



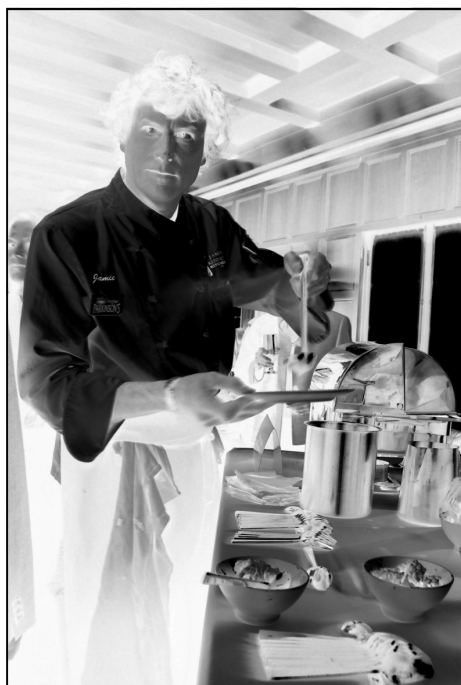
Committee and event volunteers (Photo by Paul Joe)

most celebrated chefs: Jamie Kennedy (Jamie Kennedy Kitchens), Joanne Yolles (Scaramouche), Martin Kouprie (Pangaea Restaurant), and Donna Dooher (Mildred Pierce Group). The chefs prepared porridge dishes and other breakfast treats for guests to taste.

Notable guests included fashion journalist Jeanne Beker as MC; CBC Radio 1 Metro Morning host, Andy Barrie, who shared his experiences as a person living with Parkinson's; and Michelle Leslie of CTV; Bill Coulter of Global TV; and

newscaster Robert Fisher of CBC Radio One, 99.1 FM, who welcomed the guests.

Guests participated in the breakfast-themed Silent Auction, bidding on such items as Wake Up in Cuba, Hunt Club Morning Tee-Off, and a wide assortment of "Breakfast Bling" donated by sponsors.



Jamie Kennedy (Jamie Kennedy Kitchens) serving porridge. (Photo by Joanna Dickens)

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. 3378, or 416-227-3378, or by email at info.cno@parkinson.ca

☒ **Yes**, I will help support the people affected by Parkinson's in the community.

I've enclosed my gift of ☐ \$35 ☐ \$50 ☐ \$100 ☐ \$250 ☐ Other\$ _____

☐ Cheque (payable to Parkinson Society Canada) or ☐ VISA ☐ Mastercard ☐ Amex

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.

☐ Please contact me about how I can make a gift in my will.

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

Tax receipts are issued for donations of \$10 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: ☐

***Thank you for
your support!***

SuperWalk Online Registration Begins April 7, 2010

This year, Parkinson Society Central & Northern Ontario is working to raise **\$900,000** for Parkinson's research, education, advocacy, and support services. Help us reach our goal by registering early and ensuring your eligibility for our national early bird draws!

Parkinson Society Central & Northern Ontario hosts 17 walks in locations across the region. Visit www.parkinsonsuperwalk.ca after April 7 to find out information about the walk in your community.

Questions? Contact Melissa Campisi, SuperWalk and Special Events Coordinator: melissa.campisi@parkinson.ca (416) 227-3374



Cut-a-Thon 2010

On **Sunday April 25, 2010**, join participants in **Barrie, Collingwood, Guelph, and Toronto** for a luxurious haircut at a top salon in support of Parkinson's disease. Visit www.cutathon.ca for further details and to book your appointment!



End of an Era for Hamilton Chapter

By Karen Dowell

Since before I started with CNO in 2001, Vivian Wilson and Christina Mills were the driving force behind the Hamilton chapter. I've worked with them on SuperWalk and the annual Educational Evening at the Royal Botanical Gardens and attended many of the Saturday morning meetings at St. Peter's Hospital where they provided education and a warm environment of support twice a month.

I had the privilege of giving Vivian our certificate of appreciation in person but Christina was not able to attend. The group honoured them both at their Christmas meeting, and we all wish them well as they move on to new endeavours. Earle Philips and Jim MacKenzie and a working group of four or five have now taken over responsibility of the group in their new meeting space in the hospital.



L-R: Vivian Wilson, Karen Dowell

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