LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Fall 2009

INSIDE...

When YOU think of a HERO, what comes to mind?

A superhero posed on top of a tall building?

A firefighter rushing out of a burning building with a child in his or her arms?

When I think of a hero, I think of a person like you!

Being a hero doesn't always mean putting your life in jeopardy for one moment in time. Sometimes being a hero means simply being ready, willing, and able to make a difference in your world. That's what being a SuperWalker is all about.

When you register, set a goal, and raise the funds, every step of the way you are making a difference for people with Parkinson's disease—most likely for someone you know and care about!

One family walks in honour of their mom. They said, "You give us strength every day and we are giving strength back to you. We love you!"

A grandson walks to honour his grandfather. He said, "No matter what my grandfather has, I will be there for him through good and bad times."

You can be a hero by going to www.superwalk.com and registering. Please see page 2 of this newsletter to find a walk near you.

Can't make it to SuperWalk? No problem!

If you live too far away from a walk or have other commitments on the date of the SuperWalk, you can still register and collect pledges on-line. We know you'll be with us in spirit, and the funds you raise will be included in the SuperWalk total for the local walk you register with on-line.

What we do is so essential! ***Together,*** we can fund community support and innovative research projects. We will bring a brighter future to those with Parkinson's disease.

So, who will you walk for in SuperWalk 2009?

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 and Northern Ontario Region of the Society 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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SUPPORT AND SERVICES

- Advocacy
- Carepartner Workshops
- Education In-services and Conferences
- Fundraising Events
- Individual Support (RN on staff)
- Information Sessions
- Newsletter
- Personalized Information Packages
- Presence at Health Fairs
- Resource Library
- Scientific Research Funding
- Support Group Network
- Website

Central & Northern Ontario SuperWalks

- Alliston — Saturday September 12, 2009
- Barrie — Sunday September 13, 2009
- Bracebridge — Saturday September 12, 2009
- Burlington — Sunday September 13, 2009
- Durham Region — Sunday September 27, 2009
- Georgetown — Saturday September 12, 2009
- Guelph — Saturday September 12, 2009
- Hamilton — Saturday September 19, 2009
- Kingston — Saturday September 12, 2009
- Midland-Orillia — Sunday September 13, 2009
- Newmarket/Aurora — Sunday September 13, 2009
- Niagara Region — Sunday September 13, 2009
- Peel Region: Mississauga/Brampton & Area — Sunday September 13, 2009
- Peterborough — Sunday September 13, 2009
- Sudbury — Saturday September 26, 2009
- Thunder Bay — Saturday September 12, 2009
- Toronto/Markham/Vaughan — Sunday September 13, 2009

For more details on any of these events, please contact Melissa Campisi at 416-227-3374, or 1-800-565-3000 ext. 3374.

Green Inquiries

Thank you to those who expressed a concern regarding the plastic bag that LiveWire is mailed in. This has—to date—been the most cost-effective method of sending out LiveWire; however, we are currently exploring new mailing options. To those who would prefer an electronic version of LiveWire, please send an email to livewire@parkinson.ca

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

Next submission deadline is October 16, 2009.

Heroism—Not Far from Home

Gordon D. Hardacre, MD

My November, 2008, column, outlining the management of PD with conventional drugs, was entirely medical science. By contrast, in August, 2008, I portrayed the mini-heroes of my own "Parkinson Community." Today's article, a segue from August, is yet more personal as it is about my own family. But I surmise that my family's experience might parallel one or more events in your own life. I have long believed that we can learn, even a little, from each other's struggles, be they related to Parkinson's or to subjects of another nature completely.

In 2007, my father was diagnosed with inoperable cancer of his lower esophagus. Following much thought, my parents decided that he would remain in their home until the end. Dad valiantly endured palliative laser treatments (attempts merely to contain the tumour) and blood transfusions, likewise of a palliative nature. He received multi-disciplinary home-care from his Community Care Access Centre (CCAC), attention from the family doctor and his nurse, and regular visits from friends and our small family. A proud World War 2 vet, my dad passed away quietly in our presence on, oh-so-fittingly, Remembrance Day, November 11, 2008.

Throughout that last year, my mother diligently bore the heaviest load of care. She was required to alter his diet and eating circumstances in response to weight loss plus a narrowing esophagus. To deal with specific symptoms or issues, Mom made innumerable treks upstairs and down, often carrying heavy objects. She attended tirelessly to Dad's increased needs as weakness progressively restricted him. At the age of 84, with a tiny frame, and bravely coping with hearing loss and her own diabetes, Mother began to manifest exhaustion and near-burnout during the latter weeks. Not surprisingly, the days surrounding Dad's death, visitation, solemn funeral, and cremation proved emotionally taxing and tiring. Married in 1944, my parents had been each other's best friends for decades; final separation was not easy.

However, read on. I want to tell you in this sad narrative of an admiration whose expression is overdue. The "Parkinson Community" article barely alluded to my family; it mainly paid tribute to others who have supported me over the years. Time has come to laud the "heroism" shown by my close relatives throughout the trials of Dad and me—time to confirm that "blood is indeed thicker than water." The details are hardly unique; folks with Parkinson's, like myself— and their caregivers—know similar scenarios well.

Many of my wife's efforts, including those she made daily over 18 months nursing my troublesome leg, together with the keen attention she gives to countless domestic essentials are, in my estimation, deserving of the term "heroic," or a word close to it. I simply couldn't manage as well with Parkinson's were it not for all that she does. Similarly, I view as near-heroic the sustained help my sister has given to our mother—domestic, medical, and financial assistance. I treasure deeply the support and affections shown to me by my sports-loving niece, even as I athletically decline, and I'm acutely aware of the love she felt for her grandfather. Lastly, my dear stepson came from London to be a pall-bearer for Dad's funeral, and brought with him the condolences of his wife and family.

But today's award of grandest hero goes to my mother. Not only has she stood by her son through 13 years of Parkinson's (well…it's really 63 years of "mothering"!), and not only did she gallantly sustain Dad through his most difficult final year (well, that of course was really 64 years of "marital mothering!"), but she is showing, to my relief and admiration, an amazing widowhood resilience and capacity for self-care. I'd guess that since November, her own form of relief and rest accompany her grief. I praise her for her demonstrations of survival and self-renewal. Having a secure financial status and a now-improved phone system, she is more self-confident and is ably pursuing a productive life, even while rattling around by herself inside a not-tiny house. Whatever feeling of domestic "hero" I once harboured toward my father, I can tell you that my son-to-**mother** bond feels markedly strengthened. Undoubtedly, Mom is at present my truest hero; may she enjoy this designation for a long time to come.

As a youngster at the age of 10, I proclaimed my hero a certain Mickey Mantle, the esteemed and glamorous but distant and inaccessible Yankee ball player. A half century later, I have judged as "heroic" people who are nearby, people who live ordinary lives, people who are just familiar. Perhaps you have made your own discovery that a given day's most deserving hero resides nearby and—who knows—might share with you those features which are among life's most precious traits…genes.

New Literature Available

Progression of Parkinson's disease
This document is designed to answer questions about Parkinson's and how it might progress. Included are some suggestions on how to prepare for the Parkinson's journey.

National Research Program
A summary of the current year's projects, and how PSC supports research

Taking control: 10 steps to help you cope with a recent diagnosis of Parkinson's disease
Steps to start thinking about a plan to get information and support to help make informed decisions about your future

To order, please call 1-800-565-3000 ext. 3372.

Parkinson's and Wiihabilitation with the Nintendo Wii™

The Nintendo Wii™ video entertainment system represents a revolution in the video entertainment industry. Since the system was introduced to the market in 2006, consumers have vigorously pursued it as a preferred form of video entertainment. If Ben Herz, Associate Professor of Occupational Therapy at Georgia Medical College, has his way, Parkinson's patients will soon be joining the line to buy a Wii™. While Nintendo Corporation did not anticipate this effect, nor are they claiming that their product is specifically useful for Parkinson's or any other specific condition, Herz—among other researchers—is leading the way in demonstrating the system's utility for people with Parkinson's.

With motion-sensitive, wireless controllers, the Wii™ allows for a unique user experience that other gaming systems do not offer. The gaming experience is built around the user's ability to perform tasks in virtual reality; requiring functional movement in order to receive the desirable result. Nintendo is pleased to state that the Wii's™ ease of use and interactivity allow for a unique gaming experience for players of all ages and levels of ability.

For people living with Parkinson's, staying active is one of the most important things that can be done to maintain physical and mental well-being. Studies continually indicate that people with Parkinson's who exercise can significantly delay the onset of acute Parkinson's symptoms.

Moving, stretching, and exercising can help slow down the progression of Parkinson's and the development of issues related to decreased range of movement, muscle strength, endurance, and balance.

The Nintendo Wii™ creates an environment where game players can keep up their level of activity, in a safe, comfortable, and fun environment. Implementing the Wii™ as part of your daily exercise routine helps take away excuses related to exercise: you can play on a rainy day without worrying about getting wet or slipping and falling, you can play on your own time, and you can participate in the safety and comfort of your own home.

Dr. Ben Herz

Specifically related to Parkinson's, it has been demonstrated that exercise helps to stimulate dopamine production, and because the exercises related to the use of the Wii™ are necessarily functional and random movements, users tend to see a decrease in muscle stiffness/ rigidity and an increase in range of movement. In addition to the physical benefits, users typically see positive enhancements in cognitive ability, visual ability, endurance, and balance as a result of this game-playing exercise. These enhancements come from the necessity of hand-eye coordination, sequenced movement, timing, and control of movement required to succeed at the game. Perhaps the most important thing about the Wii™ experience is that it takes traditional exercise and makes it fun. Users can compete against one another or play against a computerized opponent that improves to match the game player's skill level, meaning that the game will never get old.

The Nintendo Wii™ retails for around $250 and is available from most major department stores and video game retailers. Some research is being done by Dr. Herz and others regarding the potential benefits of Wii Fit™—a new game and add-on to the system which uses balance and motion as key game controls. The original study showed improvements in the ability of the person with Parkinson's to perform activities of daily living from using just the original gaming system. The game comes with one controller and a copy of Wii Sports™, which offers users the opportunity to play interactive games of golf, bowling, boxing,

Peer Support Volunteers

Are you interested in making a difference in people's lives?

PSCNO has re-activated the Peer Support Volunteer Program in Toronto. Trained and screened volunteers will provide support to persons with Parkinson's, members of their families, and/or their caregivers in dealing with the challenges of living with the condition using their own experience and the resources available in the Regional Office. They will also refer those needing medical advice to the appropriate medical professionals.

A new 21 hour training session will start in the fall. It will be held during regular business hours. If you are interested, please contact Louise LeBlanc, Coordinator of Volunteers, at 416 227-1200 ext 3304, or louise.leblanc@parkinson.ca

Restless Leg Syndrome

By Sandie Jones, RN

For most people, night is a time of rest and renewal; however, for many people with Parkinson's, night all too often brings anything but. The reasons for nighttime difficulties are multiple and complex. While some difficulties are related to Parkinson's, we can't blame Parkinson's for everything. Today, my topic is Restless Leg Syndrome (RLS)—the most common disorder you've never heard of.

RLS is very common for people with Parkinson's (although it also affects people who don't have Parkinson's), and is seen in approximately 10 percent of the population. My experience in speaking to people with Parkinson's is that they are not aware that they have RLS. Like Parkinson's, RLS is a neurologic disorder that involves movement of the legs, so folks think what they are experiencing is yet another Parkinson's symptom; therefore, they don't mention it to their doctor.

The symptoms of RLS

1. Include a strong urge to move your legs, or to walk, which you may not be able to resist
2. May be accompanied by uncomfortable sensations that I have heard described as creeping, itching, pulling, creepy-crawly, tugging, or gnawing
3. May be associated with numbness, aches, and cramps
4. Start or become worse when you are resting
5. Are worse in the evening, especially when you are lying down, so you may have difficulty getting to sleep, or you may wake up multiple times during the night
6. Can be serious enough to disrupt sleep, resulting in sleep deficiency and daytime drowsiness. This may cause major problems in the home, as well as in your social and work life.
7. May get better when you move your legs. Relief starts very soon after starting an activity (like walking), lasting as long as the motor activity continues and beyond ending the activity, allowing you to relax and get back to sleep.

Some people who have RLS also experience periodic limb movements during sleep. These are jerks or jumping movements that occur every 20–30 seconds on and off during the night. (These jerks/jumping movements should not be confused with the sudden, usually single jerk that sometimes happens as our muscles are relaxing just prior to falling asleep.) These movements are not harmful but can be frightening—especially to your bed partner.

Just like Parkinson's, research into the cause of RLS is occurring worldwide, but so far no one single unifying cause has been identified. There are no lab tests available to confirm or deny the presence of RLS. Diagnosis is based on your medical history and a thorough physical examination.

Anemia (a low red blood-cell count) and/or low levels of iron in the blood frequently contribute to a worsening of RLS, so anyone with this diagnosis needs to have his or her blood checked, as these problems can be easily reversed.

There are over-the-counter and prescription pharmaceutical therapies available to ease the symptoms of RLS, so it is important to talk to your doctor about your symptoms.

How to live with RLS

1. DON'T FIGHT IT! Don't suppress the urge to move. Get out of bed and find an activity to get your mind off your restless legs.
2. Find physical activities that help you deal with the symptoms and create an exercise schedule.
3. Eat a healthy, balanced diet.
4. Start a sleep diary. Keep track of your sleep/wake cycle to help the doctor determine what is causing your sleep disturbance. Dictate into an audio recorder if writing is illegible.
5. Sometimes a hot, soothing bath helps.
6. The dopamine agonists Mirapex and Requip are effective in the treatment for some individuals with Parkinson's and RLS, which is why it is important to talk about your symptoms with your doctor.

Sleep is an essential part of life that most people can take for granted, and any condition that causes sleep disturbances can greatly reduce your ability to function. Being well rested means you will be better able to manage your symptoms.

The first step to treatment of sleep disturbances is recognition of the problem. Help your doctor by keeping a record of your nighttime activities (well, maybe not ALL of them!) so you can give accurate information during your appointment.

Seeking Professional Advisors

Parkinson Society Central and Northern Ontario's development office assists people and their professional advisors with the facilitation of planned and major gifts to the Society. We are currently expanding our donor advisor list—a list of professional advisors, such as lawyers, financial advisors, insurance and stock brokers, trust officers, and accountants, who can help our supporters create tax-smart giving plans.

If you or someone you know would like to be included in this expanded list, please contact Felicia Migliore, Major and Planned Giving Associate, at 1-800-565-3000 ext. 3378 or 416-227-3378 or via email at felicia.migliore@parkinson.ca

2009 PSCNO Volunteer Awards

On May 6, 2009, we held a Volunteer Tea, where we came together to celebrate all of the contributions of our volunteers. Our annual Volunteer Awards were presented, and it was so nice that all of the award winners could be present.

The Ian Davidson award is presented in recognition of individuals who have Parkinson's disease and who have been role models in providing guidance and support that improved the lives of others living with Parkinson's in Central and Northern Ontario. These individuals also increased public understanding of their situation through such activities as leading support groups, public speaking, advocacy, volunteering, and fundraising. The 2009 award was presented to Lynda McKenzie. It was a special treat to have Ian's daughter, Monica, present the award in memory of her father.

Monica Davidson, Lynda McKenzie, Debbie Davis

The Derek Curwen Volunteer Award is presented in Derek's memory to volunteers who exemplify his fundraising expertise, ability to inspire and lead others, and whole-hearted support of Parkinson Society Central and Northern Ontario. The 2009 award was presented to Maria D'Andrea.

Judy Hazlett, Maria D'Andrea, Debbie Davis

The Marilyn Forbes Volunteer Award is presented in Marilyn's name to volunteers nominated by their peers who exemplify Marilyn's dedication to their chapter, the support of people living with Parkinson's, and the work of the Parkinson Society Central and Northern Ontario office. The 2009 award was presented to Paul Pasmore.

Paul Pasmore, Karen Dowell

There was also a Special Recognition Volunteer Award presented with appreciation from the staff at PSCNO to thank Val Elliott for her many years of dedication and reliability, which has been an integral part of the support and service we provide to people with Parkinson's.

Sandie Jones, Val Elliott

THANK YOU to all our many volunteers, for all the tireless work that you do to help improve the lives of those living with Parkinson's disease!

Porridge for Parkinson's

Porridge for Parkinson's is shaping up to be the must-attend event of the fall 2009 season, so mark Sunday November 1, 2009, at 10 a.m., in your calendar.

A breakfast tasting of culinary treats is being prepared and served by four of Toronto's best known and most respected chefs: Jamie Kennedy (Jamie Kennedy Kitchens), Joanne Yolles (Scaramouche), Martin Kouprie (Pangaea), and Donna Dooher (Mildred Pierce Group), all of whom are generously donating their time.

Come and mingle with MC and fashionista Jeanne Beker**,** speaker Andy Barrie of CBC Radio One, 99.1, and other media celebrities dedicated to this cause. A fantastic array of breakfast-themed silent auction items has been assembled including bed and breakfast packages, a one-week all-inclusive trip to Cuba, and "Breakfast with a Ron and a Cherry on Top" (a Hockey Night in Canada sweater signed by Ron MacLean and Don Cherry!).

The brainchild of Marg Meikle in Vancouver, *Porridge for Parkinson's* is a wonderful way to spend a weekend morning. The event is wheelchair accessible.

Advance tickets are on sale through www.porridgeforparkinsons.ca. If you have ideas for the silent auction or would like to volunteer at the event, please let us know by calling Sheila Knox at 416-482-5072 or by emailing porridgeforparkinsons@hotmail.com

All revenues will benefit Parkinson Society Central and Northern Ontario, a regional partner of Parkinson Society Canada.

Around the Region

Burlington

Wow, where has the time gone? We are halfway through 2009 and in Burlington we continue to celebrate our 10th Anniversary as a support group. We've been fortunate enough to have a number of great guest speakers and we are already getting things geared up for SuperWalk on Sunday September 13. We are very excited this year to be participating with the Rotary Club of Burlington in the infamous Ribfest, which will be held on Labour Day weekend. Annually we've seen this venue have 150,000 visitors pass through, so we look forward to continuing our goal of spreading awareness and education throughout our community. We want to wish everyone a safe and happy summer and we will regroup our members in September.

Collingwood & Region

Collingwood & Region Support Group held their annual Cut-A-Thon on April 26. It was well attended by both Collingwood salon stylists and clients. One young lady donated her tresses for children with cancer, and this is the second time she has done so. Everyone had a good time, and it was a nice "social" for our small group.

North Simcoe

Our meetings are held on the fourth Thursday of the month, from 4 to 6 p.m. in the 2nd floor meeting room, of the Real Canadian Superstore, (Zehrs), 9292 County Rd. 93, in Midland.

On Sept 13, we will hold our 3rd annual Midland-Orillia SuperWalk at the Midland Town Docks. Our next three meetings will feature interesting speakers: Sept 24: Rebecca Swift-Wier, BISS and Jon Collins, PSC. Oct 22: Sandie Jones, PSC, regarding Parkinson's and Depression. Nov 26: Bonnie Breadner, Speech Therapist, followed by a potluck social

Contacts: Elaine Jones at 705-526-3879 and Penny McDowell at 705-538-1377

Northumberland

Support group members enjoyed a very busy April Awareness Month this year. In addition to the successful tulip sales held in four towns, we held our first annual Buttermilk Café Day in support of Parkinson's research.

The owners of the Buttermilk Café, a well known café in downtown Cobourg, offered a percentage of a day's profits to be donated toward research. They chose Thursday April 23, which coincided with the Cobourg tulip sales. We received good media coverage for the event and flyers were distributed throughout the area. Word-of-mouth invitations by members and supporters were very effective. Reservations were recommended and proved to be very necessary. The restaurant had to turn away many people at lunch hour and the owner said that it was their busiest Thursday, with sales up 25 percent.

On April 23, we had the new pull-up poster, a display outlining the Parkinson's Canada research program, and a table in the restaurant with flyers and a donation box. Outside the restaurant we successfully sold cut and potted tulips. The Buttermilk hummed with activity from their opening at 7 a.m., when 17 staff arrived from a neighbouring bank, to closing at 9 p.m. Support group members sat at the information table, dispensing pamphlets, answering questions, and accepting many generous donations.

Everyone felt exhilarated by day's end and felt that we had met our three goals of awareness, education, and fundraising. We raised $2,035 dollars, with $1,335 going to research and $700 going to tulip sales. Our expenses of $129 were for printing the flyers. Happily, the Buttermilk owners have informed us that they want it to become an annual event.

FOR MORE INFORMATION ABOUT SUPPORT GROUP MEETINGS, PLEASE CALL:

1-800-565-3000 ext. 3372

Oakville

The Oakville Group had their Potluck Luncheon on June 30. Our group will resume September 8, 2009, St. Jude's Anglican Church, Thomas and William streets, at 10 a.m.

Peterborough/Kawartha Lakes

The Peterborough/Kawartha Lakes Chapter is selling bright red T-shirts with "I'VE GOT PARKINSON'S BUT I'M TRYING TO SHAKE IT" in white lettering. We are taking orders from around the region at $10 per shirt plus shipping. Wearing this T-shirt is a great way to tell people you have Parkinson's and start a conversation. Unfortunately, we can't guarantee that you will attract people as lovely as those shown in our photo. Please contact Bill Heinmiller at (705) 743-4628 or billhein@nexicom.net for more information.

The Young Onset Group recently had a BBQ at a member's home on Buckhorn Lake. The group has only been together for about a year and has 10 active members. Last year

Continued on Page 8

Golf for Two Causes at Once!

The 19th Annual
RMC Club of Canada Foundation
Charity Golf Tournament
Tuesday September 8, 2009
Supporting

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

Support the college that trains those who will lead our troops in Canada's Global Military.

Lunch: 12 p.m.
Shotgun: 1 p.m.

Your cost of *$175*
includes

18 holes of golf
Lunch
Steak dinner
Wine
Silent auction
Prizes !!!!

For info or to Register, email pfos1@rogers.com
for an application
or phone
Peter Fosbery at
416-769-8842.
Royal Military College
Reg. Charity #119129296RR

Bring your company's foursome! Mixed foursomes are welcome! Donate auction items! Sponsor a hole!

Richmond Hill Golf Club
8755 Bathurst Street
Richmond Hill, ON L4C 0H4
905-889-4653
www.rhgolf.com

Donations are tax-deductible. Golf participation and certain prize donations will not be eligible for a receipt.

Around the Region, cont'd

at the same BBQ there were five people in total; this year there were 13 people! Everybody had a good time and enjoyed the lovely setting on Buckhorn Lake as well as some good conversation and lots of laughs.

Thank you to Steve Legros and Christy Pendlebury for a dynamic way to launch your new life together and to aid Parkinson Society. They pledged to donate 50 percent of the net proceeds of their Stag & Doe reception to Parkinson Society. On March 26 they presented a cheque for $1,073.35. Thank you!

Thunder Bay

Thunder Bay's "Go To" man, Dan Balacko, has been a member of our Parkinson's Support Group for the past five years. In spite of having Parkinson's himself, Dan continues to give his time and energy doing many things for the benefit of the group. If there is anything that needs doing, Dan is right there selling the most Christmas cakes, selling tickets, and running errands. He and his wife, Lorna, are in charge of the food for our two yearly luncheons. We don't know what we would do without him.

Dan is also a member of our Board of Directors, gives his time to the Kettle Drive for the Salvation Army, and he is involved with Lodge activities. In order to show our appreciation to Dan, he was nominated and was accepted to receive the coveted City of Thunder Bay Citizen of Exceptional Achievement Award at a function in Thunder Bay on April 28, 2009.

As of the end of May, we have had our luncheon to wind-up our year. We don't meet again until September. However, some of us get together at the nearby mall every Thursday morning for coffee and a bit of a walk...exercise is good, you know!

Last April we had our annual Banquet of Hope, and it was a roaring success this year, with the most people and most money raised ever! Monies are distributed to PSC research, Dr. M. Jog's research clinic, and Dr. Lang's research clinic.

We will be meeting again at the end of September, and our local SuperWalk and fundraiser spaghetti dinner will be held also in September. Our best wishes to all the support groups and to PSCNO for their special help to us.

Toronto Leaside

The Leaside Group is active and continues to meet the second Monday of every month, September to June.

Information & Referral: Carepartner Basics

Robert TerSteege, CIRS-CAN

For the better part of a decade, Friday night after work is the time I have met up with my best friend at the local pub for a pint or two. It is a weekly ritual that both of us hate to miss, because when we do, the week feels somehow incomplete. I need that time to relax.

Virtually nothing is allowed to disrupt my Fridays. I have worked very hard this past year at ensuring that I get my bit of fun in every week. That may sound a bit odd at first, but a year ago my fiancée was diagnosed with a terminal form of cancer, and has been steadily dying at home. I am a full-time carepartner. I do not just "talk the talk," but I "walk the walk."

Being a carepartner

You may have seen before in our literature the term "carepartner" instead of "caregiver." While both terms are almost interchangeable, there are a few slight differences. Especially at the outset of a diagnosis of any serious or chronic health condition, there may not be very much caregiving done by the spouse/family/friend of the person diagnosed. That said, the partner is still there for the journey ahead. As the journey progresses, the person doing the caring will have specific needs, concerns, and stresses that need to be realized. In addition to dealing with symptoms of the illness, it is often left to the partner to deal with professionals (e.g., doctors, physiotherapists, social workers), not to mention the family and friends who want to know what's going on.

You're number one!

If you've researched at all about caregiving, you will hear time and again people telling you from professional and personal experience one very important message: take care of yourself first. If you do not take care of yourself, and you get ill and/or you burn yourself out, what will happen to your loved one? Find those few minutes a day, or hours a week, to take a break, and do something nice just for you!

Rally the troops

People are often surprised that the majority of those folks in their lives who say, "If there's anything I can do, please call me" really do mean it! Other folks are more than happy to help in some way, if they are just asked. It's up to you to let them know how they can help: a meal here, a ride there; or visiting with your loved one for an hour, so you can get out. If you do not have family living nearby, it may be time to meet the neighbours, or chat with someone from your place of worship.

Do the paperwork

Get your paperwork in order: the will, power of attorney, financial records, etc. If it is done, make sure you know where the paperwork is kept. Too often people do not do this kind of work, because they do not want to think about death. Also, many people have always had their spouse take care of these details, and do not know where the documents are kept. Do it now, so you don't have to worry about it later.

"You're not dead yet"

My future father-in-law and brother-in-law visited one day. After I finished serving tea, and finally sat down, my fiancée piped up, "Honey, can I have a glass of water?" to which I replied, "You're not dead yet. Get it yourself." We laughed; they didn't. The point of this is, let your partner do as much for himself or herself as possible; there will be enough of those times where you will have to do more. Encourage your partner to maintain his or her independence. It will be satisfying for your partner, as well as easier on you in the long run.

Choose to laugh

A chronic illness is not a choice that anyone willingly makes. A sense of humour is something you can choose to have. Having one can make the day-to-day routine of caregiving a lot easier to manage. As you can probably tell from earlier, my fiancée and I have a unique sense of humour in dealing with our situation. We also caution all visitors on our policy of "tears of laughter only." You will have stressful days, but you'll have more if you don't learn to laugh things off.

Learn everything you can

What do you know? What don't you know? What do you need to know? I'm lucky: having been in the social/medical field for some time, I knew most questions I needed to ask healthcare staff, CCAC staff, and whomever else we came in contact with. Even so, there has been a steep learning curve. Often, the carepartner is the one who has to do the learning, while the other partner struggles to deal with the diagnosis. Ask questions. Being informed can help you deal with things more easily, or at the very least, help you understand what is going on.

Carepartner workshops

The J.P. Bickell Foundation supported the pilot of our Carepartner Workshops with a grant in Fall, 2008. The J.P. Bickell Foundation was established in 1951 to enrich society and serve the community. The foundation supports every aspect of the community, from medicine to education, health and social welfare, and cultural expression, and Parkinson Society Canada has benefited from the foundation's support for a number of years.

Cont'd on pg 10

13th Parkinson's Golf Classic

Left to right: Jon Colins, Karen Dowell, Stan Fujarczuk, Ed Fujarczuk, and Susie Klamut

The Fujarczuk family hosted the 13th annual Parkinson's Golf Classic at Granite Ridge on June 10. The weather was perfect as over 130 golfers "hit the links." They anticipate a net donation to Parkinson Society CNO of approximately $20,000. Congratulations to all the organizers and those who took part!

Non-medical Research Studies Recruiting

Two research studies are currently looking for participants.

The first is from Parkinson's Victoria (Australia), and is an on-line survey, looking for international input. This investigation may help to improve the lives of both caregivers and patients by enabling a greater understanding of the factors contributing to Parkinson's disease caregiver and patient well-being. The researchers are seeking English-speaking Parkinson's disease patients or caregivers over the age of 18. Participation involves completing an on-line questionnaire, which will take about 30 minutes. The questionnaires can be accessed directly via the following Websites:

(Patients with Parkinson's disease)
http://opinio.online.swin.edu.au/s?s=5946

(Caregivers of Parkinson's patients)
http://opinio.online.swin.edu.au/s?s=6063

Or it can be found on the Parkinson's Victoria Website:
http://www.parkinsonsvic.org.au/

The second research study is from the University of Toronto, and is investigating emotions and social interaction on well-being in Parkinson's disease. It will explore a person's ability to interact emotionally with their partners. The research will also examine how a person and his or her partner's quality of life and relationship are affected by Parkinson's. The study is taking place in Toronto and seeks people with Parkinson's and their partners who are both willing to participate in the research. Each participant should have normal or corrected-to-normal vision. Anyone with several cognitive impairment or psychiatric conditions will not be eligible to participate.

To participate in the study, or for more information, please contact Elizabeth Olszewska at elizabeth.olszewska@yahoo.ca or 416-252-4195. The principal investigator is Dr. Morris Moscovitch, University of Toronto.

This notice is for information purposes only and does not represent endorsement or recommendation by Parkinson Society Canada.

Cont'd from pg 9

Currently, the Carepartner Workshop is offered twice a year at our office. The six bimonthly sessions last two hours an evening, and are designed to reduce carepartner stress, improve coping mechanisms, and empower advocacy and resource knowledge. We are hoping to train facilitators across the region, in order to deliver this program further. For more information, or to register, please contact 1-800-565-3000 ext. 3372.

PSC Update

PSC has met with the Michael J. Fox Foundation with regard to their arrival in Canada this fall. There is a MJFF event planned at the McEwan Centre for Regenerative Medicine in Toronto in September.

PSC and MJFF both recognize that we have our respective areas of focus and distinctness.

Michael J. Fox is a very well known public figure who will continue to help promote awareness for Parkinson's from which we can all benefit.

PSC supports Canadians living with Parkinson's and their families. It helps improve their quality of life through services, research, education, and advocacy.

CREATE A GARDEN OF HOPE

Purchase the traditional "Parkinson" tulip, which is red with white tips, in bags of 10 bulbs for $6 or a box of 100 for $50. Shipping charges may apply. With every order of 100 bulbs, you will receive a sign that reads "Parkinson's Garden of Hope" for free! It's a beautiful way to show your commitment to *easing the burden and finding a cure*. Call 1-800-565-3000 ext. 3376.

Giving Back—Sharing Hope and Inspiration in the Community

When Jenny Davidson learned that her local Royal Canadian Legion—Scarborough Branch 13—planned to give money to various charities, Parkinson Society immediately came to mind.

"Parkinson's disease touches many lives, at many different stages of life," Jenny says. "My son Andy was afflicted 11 years ago at the young age of 41. It came as a devastating blow to him and his young family."

Despite this devastating blow, with a supportive family including his wife, Lynda (his "number one"), and son Drew; Tai Chi to stay mobile; and his sense of humour, Andy approaches each day with a positive attitude.

It's because of her son that Jenny believes she needs to invest in research for Parkinson's disease. That's why she's been a member of *Partners for Parkinson's*, Parkinson Society's monthly giving club, since 2004.

For Jenny, supporting Parkinson Society on a monthly basis is an easy way to provide continual financial support and honour her son, whom she has learned so much from: "He greets every day with a positive approach. He has taught me time and again to look at the positive side, that the glass is half full, that every person has a cross to bear; his just happens to be Parkinson's."


Debbie Davis, CEO, Parkinson Society Central and Northern Ontario (far right), proudly presented Mr. Alfred Beese, President of The Royal Canadian Legion, Scarborough Branch 13, and Jenny Davidson, a long-time Parkinson Society monthly donor, with a certificate of appreciation at the Legion's annual general meeting in April.

Jenny put forward the motion to try and get Parkinson Society a gift from her local Legion, where she and her husband, Sid, have been members for 30 years. When Jenny and Sid immigrated to Canada, they joined their local Legion to help build their social network. The Royal Canadian Legion's mission is to serve veterans and their dependants, promote remembrance, and act in the service of Canada and its communities. It's a mission that Jenny is especially pleased to be a part of.

"I'm very proud to say that Branch 13 donated $14,000 to Parkinson Society Central and Northern Ontario in support of all the members who may be afflicted by this disease. It's with their help I am hopeful that with time and continued research, a cure will be found for all the wonderful people who bravely walk hand-in-hand with this disease."

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.cnor@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.

Thank you for your support!

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: ☐

LF10C

Thanks to everyone who made Cut-A-Thon For Parkinson’s 2009 a fabulous success in Barrie, Collingwood, Guelph, and Toronto!

Toronto Conference—Parkinson Society Central & Northern Ontario

Saturday October 17, 2009; 9 a.m. – 3 p.m.

BMO Financial Group Institute for Learning

“Making Connections”—A ‘Whole’isitic Approach to Coping Well with Parkinson’s

Keynote addresses include a movement disorder specialist, physiotherapist, social worker, researcher, and more!

The objective of this year’s conference is to expand your understanding of “The Problem”—why it is taking so long to find the cause of PD, what you can do to combat the challenges of Parkinson’s disease, and more!

There will be a concurrent Carepartner Workshop for carepartners only, in the afternoon, giving you an opportunity to meet others who are “Walking the Walk” and “Talking Your Talk”!

Due to space limitations, early registration will be strongly recommended. Walk-in registrations may be accepted on October 17, only if space is available. Watch for the upcoming registration brochure for additional details!

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