

## INSIDE...

Spring 2009

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*Reprinted from E Parkinson Post,  
February 2009*

Dr. J. William Langston—founder, CEO and Scientific Director of the Parkinson's Institute in Sunnyvale, California—addressed a packed banquet hall in Calgary, Friday, January 9th at the 2008 Donald Calne Lecture, hosted by Parkinson Society Canada and Parkinson's Society of Southern Alberta (PSSA), and sponsored by Solvay Pharma. Dr. Langston brought up to date an audience of over 120, including attendees of the Parkinson Research Alliance meeting, on developments in Parkinson's disease (PD).

Earlier in the day, Dr. Langston presented Grand Rounds at Foot-hills Hospital where he talked about the latest stem cell progress in Japan. Scientists are using skin samples to generate stem cells that could one day lead to the reversal of PD.

Special thanks to John Petryshen and his wonderful staff and volunteers at PSSA for all their help in making the event run smoothly.

### Lecture highlights

#### Developments in Parkinson's

- PD is very likely a protein folding disease like ALS, Alzheimer's, and Huntington's.

Researchers now know that, in PD, the protein  $\alpha$ -synuclein becomes toxic and destroys the cells when it does not fold properly. "This represents a huge shift in the thinking about PD and makes the area of protein folding an important thera-

## Internationally Renowned Neuroscientist Highlights New Developments in Parkinson's



**Dr. Stoessl and Dr. Langston**

peutic target," said Langston.

- PD may begin in the olfactory bulb.

Dr. Langston noted that loss of smell may occur long before the onset of other symptoms, making the olfactory bulb, which governs the sense of smell, a prime target for investigation. "No matter how many people get Parkinson's, it usually begins with the loss of the sense of smell, but only 60 percent of people realize there is a problem."

- Environmental factors play an important role in PD.

Dr. Langston cited many studies showing a link between the use of pesticides and herbicides and PD.

Over 50 published studies show an inverse relationship between PD and smoking, according to Dr. Langston. "If you smoked from the time you were a teenager, your risk of getting Parkinson's is much less." However, cigarette smoke has 4,000 chemical compounds, so finding the right one poses its own challenges, he cautioned.

Coffee drinking also seems to reduce the risk of PD.

- Genetics loads the gun, but the

environment pulls the trigger.

Dr. Langston discussed the long-standing debate about genetics versus environment, and reviewed the studies of twins—both identical and fraternal—which showed that the environment plays a role. "While genetics loads the gun, the environment pulls the trigger," he said.

### New research-gathering techniques

Dr. Langston spoke about using the Internet to gather research, citing 23andMe, the company that won Time Magazine's Best Invention of the Year award, as one example. 23andMe is embarking on a genome project where you "spit in a cup," send it to a central location, and six weeks later receive a personalized genome that traces your genetics, where your ancestors came from, and whether you will ever be an Olympic sprinter. It also can tell whether you are at risk for Type 2 diabetes and which diseases are high risk for you. This study has the ability to gather massive amounts of population information and could change the future of research.

### New California Parkinson's Disease Registry

California recently passed into law new legislation that calls for all cases of PD to be reported in the State of California. According to Dr. Langston, both patients and doctors wanted this law.

### DVD coming soon

This lecture will be available soon at [www.parkinson.ca](http://www.parkinson.ca)



## Parkinson Society Central & Northern Ontario Soci t  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                              | - Newsletter                        |
| - Carepartner Workshops                 | - Personalized Information Packages |
| - Education In-services and Conferences | - Presence at Health Fairs          |
| - Fundraising Events                    | - Resource Library                  |
| - Individual Support (RN on staff)      | - Scientific Research Funding       |
| - Information Sessions                  | - Support Group Network             |
| - Newly Diagnosed Education             | - Website                           |

## FOR JAMES PARKINSON—A BELATED (254 years late!) BIRTHDAY TRIBUTE

You barely escaped oblivion—your very name forgotten except perhaps to scholarly historians of medicine. Now it is known to millions around the globe.

Not that it mattered to you—  
as long as human suffering was  
relieved and justice was done for the poor.  
Now we who carry the burden  
you described in such elegant prose  
and with such passion for alleviating human suffering  
bring this tribute of gratitude  
and proudly bear the name some of us are happy to be  
called—  
PARKINSONIANS.

— Sister Thelma-Anne, SSJD

## Pitch In for Parkinson's

Save the date! On Thursday June 25, 2009, come help us celebrate the 20th annual Pitch In for Parkinson's event at the Rogers Centre!

Join us for an exciting evening of baseball as the Toronto Blue Jays take on the Cincinnati Reds, while helping people with Parkinson's. This year will be better than ever, with special guests, great food, and a great baseball team.



For ticket information, please call Sara Lawson at 1-800-565-3000 ext. 3377 or email sara.lawson@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 the Regional Office at 416-227-3372 or 1-800-565-3000 ext. 3372 or email to livewire@parkinson.ca

**Next submission deadline is JUNE 23, 2009.**

## Brochures and Booklets

The following is a list of brochures and booklets that are currently available through Parkinson Society Central & Northern Ontario. We also have a list of recommended reading materials, available through most libraries and local bookstores. For more information, please call 1-800-565-3000, ext. 3372.



### **Parkinson's: The facts**

Contains general information about Parkinson's, including symptoms, treatment, and taking charge of your life with Parkinson's.

### **Where to get the help you need**

Take charge of your health—who should be on your health care team?

### **How you can become a supportive caregiver**

What does it mean to be a caregiver? This question and other questions about this new role in your life are answered.

### **What you need to know about the medication you take**

Provides an overview of medications currently used in the management of Parkinson's.

### **How you can get a better night's sleep**

Fatigue and lack of sleep are all too common experiences for people with Parkinson's. These simple suggestions may help!

### **What you can do to prevent and relieve constipation**

Helps readers understand what makes constipation a problem and offers ideas to eat right as well as natural ways to help.

### **Exercises for people with Parkinson's**

Offers easy-to-follow posture, flexibility, and strengthening exercises.

### **A manual for people living with Parkinson's disease**

Provides information and helpful hints that will assist people with Parkinson's to manage their challenges.

### **My mommy has PD ... but that's okay**

Assists you in talking to your child about Parkinson's.

### **Medication cards**

Allows people living with Parkinson's specifically to list current medications, dosages, times, etc.

### **What you need to know about Parkinson's: information for health care staff at long-term care facilities**

Explains key issues relevant specifically to staff at long-term care (LTC) facilities who are supporting people with Parkinson's.



## Parkinson's Carepartner Workshops

As the carepartner of a person with Parkinson's, we would like to offer you an opportunity to share your experiences with other carepartners, learn more about strategies to reduce caregiver strain, receive support from others, and develop strategies for promoting your own health and well-being.

The goal of the program is to reduce carepartner strain and improve quality of life. Discussion topics will include the following:

- Sharing your experiences and feelings
- Problem solving with others
- Learning to reach out and accept help
- Making the "system" work for you
- Stress busters/therapeutic approaches to self care
- Strategies for coping with the unpredictability of Parkinson's disease
- Coping with changes in behaviours

We are currently gathering names in order to determine where and when we can offer workshops in the coming year.

If you are interested in attending these workshops, please call 1-800-565-3000 ext. 3372.

## Hope On Display

You are cordially invited to an afternoon of Art and Awareness, presented by Parkinson Society Central & Northern Ontario.

Ten artists will share their art in a variety of media, including oil, water colour, music, photography, and jewellery.

This event happens on Tuesday April 21, 2009, between 4 p.m. and 8 p.m., at the Oakville YMCA, 410 Rebecca Street.

For more information, please call Karen at 1-800-565-3000 ext. 3376.

Barrie will also be home to a Hope on Display event on April 21, 2009.

This event will be at Barrie City Hall Rotunda from 11 a.m. to 4 p.m. For more information, please call Amanda at 1-800-565-3000, ext. 3370.



## Facilitator training in CNO—first time in 9 years!



On November 7 and 8, 2008, all chapter and support group leaders were invited to attend a training session at the Central & Northern Ontario (CNO) office conference centre. The last time the entire group of regional facilitators came together was in 1999.

On Friday evening, we were honoured to hear from guests who were involved in the advocacy efforts going on throughout Ontario and about the national research programme that CNO helps to fund.

We also received the financial statements for the region and had an opportunity to ask questions.



On Saturday morning, everyone arrived ready for a day with Spencer Brennan from the Ontario Self Help Resource Centre. The group did some role playing, learned about their roles and responsibilities as group leaders, and networked with other chapter lead-



ers. At the end of the day, everyone received a copy of the CNO Support Group Facilitator's Guide and Volunteer Policies.

Everyone, staff and volunteers included, had a real feeling of unity by the end of the day as we left feeling renewed. We met new people, met people we had only talked to on the phone, and felt energized by the whole weekend. We look forward to this session becoming an annual event and thank all who came for making it a success!



## Cut-A-Thon 2009

Coming to Salons in Toronto, Collingwood, Guelph, and Barrie on Sunday April 26, 2009. Visit [www.cut-a-thon.ca](http://www.cut-a-thon.ca) for more information and to book your haircut!



**SUPPORT**

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

**BY ATTENDING**



**Thursday May 21, 2009 at 7:30 p.m.**  
Elgin Theatre, 189 Yonge Street

**Adult Tickets: \$50 - \$65**  
Plus save 40% on tickets for children

15% of every ticket will be donated to  
Parkinson Society Central and Northern Ontario

Meet the cast following the performance!

**For bookings, please call**  
**(416) 590-0843**  
or to buy online, go to:  
**[dancaptickets.com/ps](http://dancaptickets.com/ps)**

Quote: "PS" when ordering

Service charge not included. Offer not valid with any other promotion or offer.

## Freezing and Falls

By Sandie Jones, R.N.

Those of you who know me (even if we've only met on one occasion) know that being lost for words is not usually a problem for me. In fact, it is usually quite the opposite—knowing when to be quiet is a much bigger challenge! When I was trying to decide how to start this article I felt “stuck.” It wasn't that I didn't know what I wanted to write about, I just couldn't get started ... and then it came to me! The problem I was struggling with, “start hesitation,” is the very thing many of you have difficulty with on a regular basis! So now that I've taken the first step, let's hope no one interrupts me, or I'll have to start all over again!

Normally, we don't have to think about the act of walking; our brain incorporates this activity into the task we are trying to achieve. For example, if you were off to the corner mailbox to post a card to a friend, your brain would go into autopilot: you would put on outdoor shoes, put on your coat, make sure you had your door key, and head out. Your brain would calculate the distance and speed as well as help you avoid the dips and cracks in the sidewalk, and you would be back at home before you knew it. When you have Parkinson's, the timing aspect of your walking may be affected so this sort of “normal activity” can become more difficult.

If you have noticed that you have difficulty taking the first step, this difficulty is caused by an interruption or slowing down of messages reaching the part of your brain that sequences your thoughts into action. “Start hesitation” is affected by feeling tired, anxious, or hurried, or if you are “wearing off” or coming to the end of a medication dose. Whatever the reason, initiation of gait (taking the first step) often affects only the first few steps,

and then, once you are away, you can walk with ease.

Muscle weakness in the legs as well as problems with balance and walking in addition to “freezing” are the most common reasons for falls, so it is important to have some strategies for both preventing as well as overcoming a freezing episode.

About 30% of people with Parkinson's experience a sudden feeling of being stuck in wet cement where they are frozen in one spot, unable to walk, and which no amount of



willpower can overcome. Freezing can also occur when you are initiating movements like when you want to get out of a chair, so it can occur when you want to start moving or when you are already moving. The problem can occur at any time, and some people are more prone to freezing episodes than others. It is not possible to predict when freezing will occur, which—coupled with efforts of well-meaning companions to force you to move—may cause you to lose your balance and fall.

Freezing occurs more frequently when a person with Parkinson's approaches doorways and narrow hallways; is walking on a surface that suddenly changes; is walking in

crowds; is confined in small spaces such as restroom stalls or elevators; is tired, or is in a stressful, unfamiliar situation.

Freezing is a **temporary** phenomenon but the sudden inability to move can be both frightening and frustrating. Freezing is not immediately responsive to medication and requires behavioural retraining to initiate movement.

Not being able to predict when freezing episodes will occur can leave you feeling insecure and afraid to do things on your own, so it is important to develop strategies for coping such as the following:

1. Visualize where you are going and plan your movement first.
2. If you feel yourself sticking to the ground, **stop**. Think about standing tall with your feet apart.
3. Try shifting your weight sideways from foot to foot. Rock from one foot to the other.
4. Try to take a step backwards or to the side. Once movement is initiated, try stepping forward again.
5. Step over a companion's foot placed in front of your foot, or step over a line on the ground. Shining a red-dot laser or a pocket flashlight in front of your foot can also help. Step toward the light.
6. Stick strips of coloured tape, a step length apart, in “hot spots” where you have difficulty at home, so you can step over the lines made by the tape.
7. Repeat “one, two,” or say to yourself “left, right, left, right,” as you come closer to the place where you stick so that you keep the rhythm of your steps. This type of counting can also help when you rise from a chair and have problems taking the first step after standing up. Use a marching rhythm to move—audio tapes and portable CD players are helpful.
8. Focus on something straight

*Continued next page*  
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ahead, especially when going through a doorway or getting on an elevator.

9. When approaching a chair to sit down, concentrate on walking to the arm on the far side of the chair before turning to sit down.

10. Carepartners should resist the temptation to give many instructions. Keep it short and sweet. **Do not push or pull!**

11. Keep your living area free of clutter and obstacles.

12. Focus your full attention on moving around furniture.

13. Take your time; do not rush.

14. Minimize disruptions or interruptions when executing a movement.

Freezing can also affect your ability to speak spontaneously, particularly when answering a question or trying to enter into a conversation. Sadly, this difficulty causes people with Parkinson's to withdraw from socializing and—coupled with feeling insecure and afraid to go places on their own—can lead to isolation, loneliness, and depression. When you are about to speak, **stop** and think about what you want to say before actually initiating the sentence. If you are doing other things while trying to have a conversation, stop what you are doing and concentrate on what you are trying to say. Parkinson's is associated with slowness of movement and therefore it may seem odd that I have used the word “**stop**” several times throughout this article, but it is very important to **stop**, **concentrate**, and **visualize** if you are experiencing freezing.

After all, if your computer freezes, what do you do (after you swear at it, that is)? You **stop** it by turning it off and on again and rebooting it. It's exactly the same for you if you “freeze.”



LiveWire

## Upcoming 2009 Educational Events

Throughout the year, Parkinson Society Central & Northern Ontario and supporting chapters strive to provide educational opportunities with a variety of guest speakers throughout our region.

For more details, please visit our Website, [www.cno.parkinson.ca](http://www.cno.parkinson.ca), and click on “Regional Events.” You may also call 1-800-565-3000, ext. 3372 for more details closer to the dates.

### March

#### Etobicoke Carepartner Workshop

Date: Saturday March 28, 10 a.m. to 3 p.m. Venue: St. James United Church, **CANCELLED DUE TO LACK OF INTEREST.**

Please see our Carepartner Workshop announcement on Page 4 for future opportunities.

### April

#### Burlington Educational Session

Date: April 8, 6:30 p.m. to 9 p.m. Venue: Royal Botanical Gardens, 680 Plains Road West, Burlington Details: Keynote speaker, Dr. Mandar Jog: “The Path Less Explored But Often Travelled,” including the challenges of sleep disorders, pain, apathy, anxiety, depression, decline in executive functioning (multi-tasking and verbal fluency), and memory.

#### North Bay Video Conference

Venue: satellite feeds to Sioux Lookout, Fort Frances, and Dryden Date: April 14, 5 p.m. to 7 p.m. Details: Keynote speaker, Dr. Mark Guttman: Updates on Treatment and Research

### May

#### Cobourg Educational Session

Date: May 12, 7 p.m. to 9 p.m. Venue: St. Peter's Anglican Church, 240 College Street, Cobourg Details: Keynote speaker, Dr. John Adams

### Mississauga Educational Session

Date: May 26, 7 p.m. to 9 p.m.

Venue: Senior's Life Enhancement Centre, 2041 Cliff Road, Cliffway Plaza, off North Service Road between Hurontario and Cawthra Details: Keynote speaker, Dr. John Adams

### June

#### Durham Region Conference

Date: Saturday, June 13

Venue: Ajax Convention Centre, 550 Beck Crescent Details: Family Focus—How Parkinson's impacts everyone in the family. Please call the Durham Region Chapter at 1-866-264-3345.

### October

#### Toronto Conference

Date: October 17, 9:30 a.m. to 3:30 p.m.

Venue: BMO Institute for Learning, 3550 Pharmacy Avenue, Toronto Details: Keynote speaker, Dr. John Adams



PSCNO gratefully acknowledges that some of these events were made possible through unrestricted educational grants from:

 **NOVARTIS**

and

  
**TEVA**  
**NEUROSCIENCE**

## Around the Region

### Barrie Chapter

The Barrie Chapter's *Ease the Burden, Find a Cure* 4th Annual Golf Tournament happens on May 3 at 8 a.m. sharp. The day includes continental breakfast, golf and cart (18 holes), lunch, and prizes.

**Early Bird registration and payment:** sign up and pay for a team before March 31 and pay only \$500. This sign up includes all of the above plus 2 mulligans and 2 Sands. After March 31, the cost will be \$125 per person and \$10 each for Sands and mulligans.

The tournament will be held at Innisbrook Golf Course in Barrie. For information on sponsor packages or registration, please contact Greg McGinnis at 705-735-0461 or [gjmccinnis@sympatico.ca](mailto:gjmccinnis@sympatico.ca)

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### Belleville—Quinte Chapter

2009 was off to a great start! At our first meeting, Sara Lawson gave us informative insight as to what is happening at the regional office.

In February, we hosted a luncheon seminar with Sandra Wetherby, RN of the Kingston Movement Disorder Clinic. The topic was "Sex, Drugs, and Rock and Roll." The talk was superb and we hope to have Sandra back on an annual basis.

We are gearing up for April Awareness and on April 4, we will have another gala at the Shopper's Drug Mart in the east end of Belleville. It is a fun and easy way to raise money for, as well as raise awareness of, PD.

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### Burlington Support Group

In February, 2009, the Burlington Support Group celebrated its 10th Anniversary. This group was started by a handful of people who had been affected with this "thing" called Parkinson's. With the help of

Sandie Jones (PSC) and Jane Langlotz, a group was formed. The longevity of this group can be attributed to its members and their continued support. While we have lost many friends over the years, we are pleased to say that we still have a few of the "original" members with us.

Join us on Wednesday April 8 for the "4th Annual PD Awareness Meeting" held at Royal Botanical Gardens in Burlington from 6:30 p.m. to 9 p.m. The guest speaker will be Dr. Mandar Jog, and the theme of his presentation will be "The Path Less Explored, but Often Travelled." This event is free so we hope to see everyone there.

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### Haliburton—New Group!

A new support group will be starting in the Haliburton Highlands area in Spring, 2009. If you are interested in joining, please call Sara Lawson at 1-800-565-3000 ext. 3377.

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### Mississauga Support Group

The Mississauga Support Group has found a new home! In February, the group began meeting every 3rd Wednesday of the month at the Seniors Life Enrichment Centre in the Cliffway Plaza at 2041 Cliff Road, Mississauga.

Call Karen for details at 1-800-565-3000 ext. 3376.

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### North Simcoe Chapter

We meet monthly on the 4th Thursday from 4 p.m. to 6 p.m. in the Community Room of the Superstore (Zehrs) on County Road 93 in Midland.

Spread over the year, our meet-

**FOR MORE INFORMATION ABOUT  
SUPPORT GROUP MEETINGS,  
PLEASE CALL:**

**1-800-565-3000 ext. 3372**

ings have a balance of purpose. Alan Lloyd from Revenue Canada came in February with advice to attain our best advantages on tax returns. March will bring physiotherapist Paul Love with his suggestions on posture, balance, and mobility. In April, we take time to share our own concerns and experiences, and offer support to each other. In May, Dr. Oster, a nutritionist, will speak about maintaining a healthy diet. Our annual June BBQ brings enjoyment, laughter, and great food. Fundraising rounds out our year's activities.

Please contact Elaine (705-526-3879 or [ejones@csolve.net](mailto:ejones@csolve.net)) or Penny (705-538-1377 or [penny.mcdowell@sympatico.ca](mailto:penny.mcdowell@sympatico.ca)) for more information.

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### South Muskoka (Bracebridge) and North Muskoka (Huntsville) Support Groups

Both groups enjoyed a festive pot luck luncheon and Christmas trivia games at the December meetings.

At the October meetings, we took time to brainstorm program ideas for the coming year. Lots of interesting suggestions were put forward for speakers and topics that the facilitator will organize. Already in January, we had a presentation on emergency planning for seniors and persons with disabilities. Many useful tips were shared. In February, we heard about tax preparation to gain benefits for caregivers and those with disabilities. Sandie Jones' much anticipated annual visit is already scheduled for May.

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### Peterborough/Kawartha Lakes Chapter

A SUPER SuperWalk raised a new record of over \$35,000! Thanks to the great team effort headed by Gail who counted 43 volunteers and 89 pledge sheets.



Last year they had 2 blue caps and this year, 7! A threat of rain moved the logistics inside, and we will continue holding this portion of the event inside to provide more comfort and socializing opportunities for participants.

A Young Onset group has been created with at least 8 active members who socialize on the third Sunday of the month. Thanks to Yvonne who has pulled together the group. Give her a call at 705-743-5970. Early awareness counts in many ways.

**Finding Others:** We hold a “gathering” every 3rd Tuesday at 1:30 p.m. in Peterborough. Call 705-749-0660 for more details. Caregivers meet on the 1st Thursday of each month at 1:30 p.m. Call Amy at 705-743-5479. A support group for the City of Kawartha Lakes meets at Loblaws in Lindsay on the 2nd Monday of the month at 1:30 p.m. Call Anne at 705-324-5355.

Persons with Parkinson's here—Caregivers there. Let's get together here and there, for example, a father with Parkinson's in Scarborough and a daughter in Peterborough. Join in with your local chapter and expand the network. For the many caregivers, we give thanks.

We are trying to identify and associate with other neurological “partners.” After an initial meeting with Huntington's disease groups, we would appreciate hearing about the experiences of other chapters to broaden or establish the neurological network following the initiation of the Neurological Health Charities Canada (NHCC).

Peterborough is creating T-shirts that focus on a **“Moving Experience,”** for example, “I have Parkinson's but I'm trying to shake it!” We intend to “show our stuff” with an exciting new change to our chapter name.



## Awareness at Any Age

The offices of Parkinson Society Central & Northern Ontario were recently turned into an interview studio. No, it wasn't CBC conducting the interview—it was 10-year-old Samantha Kettner.

Samantha's school is teaching about fundraising and charities and gave students a special assignment: choose a cause close to their heart, learn about it, make a presentation to the class about it, and then plan and execute a fundraiser. Samantha chose Parkinson Society Central and Northern Ontario because her grandfather has Parkinson's disease.

With the help of her dad, Miles, Samantha contacted Debbie Davis, who worked with Sara Lawson to assist Samantha with her project. On the designated day, Samantha got picked up from school early and came to the office. Her dad acted as the camera operator while Samantha interviewed her experts on Parkinson's disease.

First to be interviewed was Sandie Jones, who gave Samantha the medical aspects of the disease as well as some tips for her presentation. Next came Robert McNutt, Ellen Alban, and Marg Turner—

three people with Parkinson's who told Samantha about their histories and attitudes toward the disease, and offered their perspectives on coping. Then Samantha spoke with Sara about her role, not only as a staff person but also as the daughter of someone with Parkinson's.

Samantha then edited all the interviews into a video presentation. She showed the movie to her class this January and is planning to raise funds through the SuperWalk for Parkinson's in the fall.

We applaud Samantha's efforts to learn about Parkinson's disease and demonstrate that youthfulness is no barrier to empathy and understanding.

## Telemedicine Improves Access for People with Parkinson's

*Reprinted from E Parkinson Post, December 2008 edition*

Almost every afternoon, Dr. Mark Guttman closes his office door at the Centre for Movement Disorders in Markham and turns on the TV. The waiting room may be empty, but he still has patients to see via the Ontario Telemedicine Network.

Dr. Guttman describes how it works: “The patient and family go to a local hospital and enter one of the videoconferencing suites. The coordinator at the other end, usually a nurse, helps with the evaluation and handles the equipment. I am in my office. I can see the patient and the patient can see me. We have a conversation. Then I ask the nurse when it's time to help with the physical examination.”

Using the high-resolution camera, Dr. Guttman can zoom in for a close-up of the patient's symptoms. He says, “In Parkinson's, it's impor-

*Continued on page 10*



## Staying in Hospital: What You Need to Know

*The following article was originally featured in the Winter 2004 issue of Parkinson Post.*

By Lois Raphael, Maureen Mathew, and Susan Calne, CM, RN

When you have Parkinson's, be ready for unforeseen circumstances or emergencies. The following handy guide can help if you need to stay in the hospital because of elective surgery or an unexpected admission (e.g., hip surgery after a fall or fracture, pneumonia, infection, bowel impaction, or stroke).

### What to consider when you need surgery

Day surgery generally is not a problem for Parkinson patients. However, some procedures, such as cataract surgery or dental procedures where a person is normally awake, may pose problems if your tremor or dyskinesia creates too much movement. Ensure your general practitioner (GP), surgeon, and neurologist coordinate your hospital care.

Talk to the surgeon before the procedure date, so you can make informed choices on the following:

- Benefits and risks
- Tests and procedures (and alternatives)
- Expected outcomes and odds of success
- Potential complications
- Length of stay and alternatives

### Pre-operative medication

When surgery requires general anaesthetic, anti-Parkinson medication is often stopped the night before surgery. Some neurologists recommend an early morning dose of Sinemet (carbidopa/levodopa) with a small amount of water. Ask for early morning surgery to avoid

long unmedicated periods.

### Restarting anti-Parkinson medication after surgery

- Anti-Parkinson drugs cannot be used during surgery.
- If nothing can be taken orally, a nasogastric tube insert (prior to surgery) is recommended even if the surgeon does not normally insert one. Post surgery, crushed regular levodopa as well as other tablets and capsule contents can be administered with water through the tube.
- For stomach surgery, reintroducing Parkinson medications is more complex, requiring careful pre-planning.

### Medication timing when in hospital

- Ask your GP to send your drug regimen and schedule with admitting orders before you go to the hospital. Bring your Parkinson drugs in the original bottles, and several copies of your drug list and schedule. For example, if you take medication three times daily, include what time you take it. Otherwise hospital staff may think you take it every eight hours.
- If you are on an experimental Parkinson drug, bring your own supply and a letter describing the

study.

- Talk to your GP about getting authorization to administer your own medications if you take frequent or "as needed" doses.

### Contraindicated drugs and their side effects

- Provide the hospital with your allergy list.
- Morphine tends to be better tolerated by people with Parkinson's than Demerol for pain control. Eldepryl (selegiline) is contraindicated in combination with Demerol. Demerol, premedication, and drugs used for anaesthesia can cause severe confusion. It can take a few days or weeks to resolve the situation even with people who are not normally confused.
- For post-operative nausea, do not accept dopamine-antagonist drugs such as Reglan or Maxeran (metoclopramide hydrochloride), Compazine (prochlorperazine edisylate), or Stemetil (prochlorperazine mesylate). Gravol by mouth or injection is a practical choice. (Domperidone only prevents nausea associated with anti-Parkinson drugs.)
- Avoid conventional anti-psychotic drugs: haloperidol, resperidone, and olanzapine. Seroquel (quetiapine fumarate) is one safe anti-psychotic drug for Parkinson patients.

- For bladder or prostate problems, anticholinergic drugs often relieve muscle spasms after surgery but can cause confusion, constipation, and urine retention.

### How hospital stays and procedures can affect your Parkinson's

- Parkinson's already creates stress, so your body may be less able to cope with additional problems. Stress reduces energy re-



quired to heal and will make your symptoms worse. Use stress management skills, including breathing exercises, relaxing music on a portable music player, and a heavy dose of optimism.

- A different diet, inadequate fluid, and lack of mobility can lead to severe constipation. Bring along a bowel management protocol.
- Expect a reduced ability to hear and listen well, especially when it comes to medical jargon. Ask questions and seek clarification. Medication complications can disrupt your mobility and mental status, thus delaying your recovery. Family caregivers need a support system, and they should seek a key hospital contact person.

### **How to communicate your needs to hospital staff**

Staff may not have much experience with Parkinson's. Talk to your nurse about some of the condition's characteristics:

- Unintentional on/off fluctuations
- Importance of taking medications on time. Most hospitals allow nurses a "window" (up to an hour) in which to deliver medications, which is unacceptable for Parkinson patients.
- Significant physical and mental slowness
- Speech problems, which may affect intercom use
- Hand dexterity problems with eating and hygiene
- Assistance with bed turns, transfers, and walking
- Increased risk of falls and fractures

### **Activation and rehabilitation during hospital recovery**

- People with Parkinson's need quick re-activation to avoid complications such as pneumonia, deep vein clots, urinary tract infections,

and increased rigidity.

Your GP can order physiotherapy, such as body mobility exercises or chest therapy to ease rib cage rigidity and lung complications. Ask about geriatric programs for assessment and rehabilitation services.

### **Discharge planning**

- Ensure you understand the medical team's follow-up plans.
- Before discharge, talk to hospital staff about home nursing care, rehabilitation therapy, and caregiver respite needs.

If you require ongoing facility care, talk to the hospital social worker or community health department liaison nurse.

*Adapted by Carol Jamieson from "Hospitalization and Parkinson's," Parkinson Society British Columbia, 2004. Prepared by Lois Raphael, Parkinson Society British Columbia; Maureen Matthew, Victoria Epilepsy and Parkinson's Centre; and Susan Calne, CM, RN, Coordinator, Pacific Parkinson's Research Centre, Vancouver, BC.*

### **Telemedicine Continued from page 8**

-tant to watch somebody to observe their speed of movement, their muscle tone, and how they're walking." Also on hand are the latest tele-diagnostic instruments, such as digital stethoscopes and digital imaging facilities that transfer information to the doctor.

Videoconferencing is enabling people with Parkinson's disease in Ontario's remote communities to access neurologists, like Dr. Guttman, without the time and expense of travelling to larger urban centres. "Some people were driving from Thunder Bay to see me. That's 14 hours each way for a follow-up assessment that lasts 20 minutes," says Dr. Guttman. "Now they just go to the local hospital and it's so much easier."

Dr. Guttman sees about 12 patients a week, or 500 a year, in this manner. Over 90% of these patients have expressed satisfaction with the care they have received. The program is so successful that Dr. Guttman is installing a second videoconferencing suite in his clinic.

## **Hope Blooms!**

Do you like tulips? Would you like to help support people with Parkinson's? If so, we need your help! Volunteers are needed to help sell fresh-cut and potted tulips during the month of April. Sales will be held throughout the region on various dates. It's easy, a fun way to meet people, and a great way to support our programs helping people with Parkinson's. For local information and dates, please call

- West (Hamilton, Burlington, etc.): Karen Dowell, 1-800-565-3000 ext. 3376
- East (Peterborough, Cobourg, etc.) or City of Toronto: Sara Lawson, 1-800-565-3000 ext. 3377 or local, 416-227-3377
- North (Sudbury, Sault Ste. Marie, etc.): Donna Makela, 1-888-237-4453



# Giving Back—with Kid Power!

## Evan's Story

Evan says that helping people makes him happy. When he learned that *High School Musical: The Ice Tour* was coming to Thunder Bay, and that part of the proceeds were being donated to Parkinson Society Canada, Evan took his own initiative to help. His motivation? A couple of special people in his life who live with Parkinson's!

Throughout the summer, he set up many iced tea stands, offered to give chess lessons, and raffled off a beautiful bouquet of home grown flowers. His excitement grew as he saw how successful he was at his first fundraising effort.

He even had a sign on his picnic table that said "Iced Tea for Sale until Bedtime." Evan was pleased to present a cheque for \$250 to Parkinson Society Canada at the end of January.

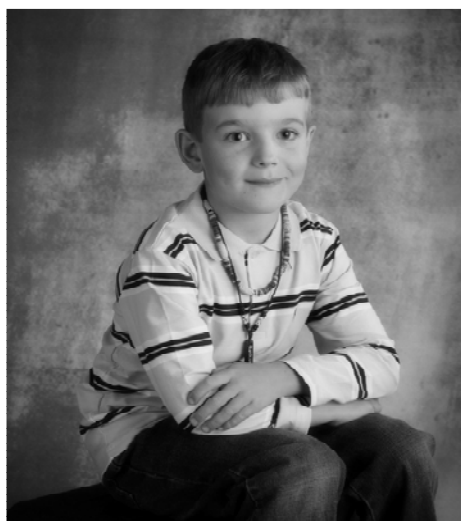
When Ryan found out that his grandfather had Parkinson's disease, he wanted more than anything for his papa Jim to get well. A friend gave his family the idea of collecting empty wine and beer bottles to raise money for SuperWalk. Ryan and his family delivered notices around their neighbourhood, and every Monday morning, Ryan went around with his wagon and the family filled their van to the rafters with empties.

## Ryan's Story

Since 2005, he has raised almost \$10,000 and has received a citizenship award from the City of Brampton and the TVOKids Super Citizen Award in 2009.

**Way to go Evan & Ryan!**

**You are demonstrating that you can give back and make a difference for people with Parkinson's, no matter what your age is!**



**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](mailto: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

Card No.: \_\_\_\_\_ Expiry Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Signature: \_\_\_\_\_

**Please complete the following information:**

☐Mr. ☐Mrs. ☐Ms. ☐Miss: ☐Other: \_\_\_\_\_ First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ Province: \_\_\_\_\_

Postal Code: \_\_\_\_\_ Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

☐ **Please sign me up as a monthly donor. I have completed the information above and understand the amount indicated will be charged to my credit card or deducted from my bank account on the 15<sup>th</sup> 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!***

# Mark Your Calendar!



## SuperWalk On-Line Registration

Register on-line and raise donations between April 1 and May 31, 2009, and you can be eligible to win one of our early bird draw prizes. Visit [superwalk.com](http://superwalk.com) for complete details.

Online registration and receipting is cost effective, making your donor dollars go further!

Check out [superwalk.com](http://superwalk.com) for updates on the walk nearest you and for exciting new information about SuperWalk 2009.

Questions? Contact Christine Kirby, SuperWalk Coordinator at 416-227-3374 or [christine.kirby@parkinson.ca](mailto:christine.kirby@parkinson.ca)

## Are you ready for the Bowl Movement?

If so, mark Sunday November 1, 2009, at 10 a.m. in your calendar for the second *Porridge for Parkinson's* fundraiser in Toronto.

This 'FUN'draiser is the brainchild of Marg Meikle in Vancouver, and it has all the ingredients for a great way to spend a Sunday morning: the best porridge and a mouth-watering array of other culinary treats created by Toronto's best-known chefs, media celebrities greeting you at the door, and a themed silent auction that will whet your appetite to get into some early holiday shopping.

The planning committee is gearing up and we are always looking for new energy and new ideas. If you are interested in being part of the team, please contact Sheila Knox at 416-482-5072 or [porridgeforparkinsons@hotmail.com](mailto:porridgeforparkinsons@hotmail.com)

All revenues will benefit Parkinson Society Central & Northern Ontario, a regional partner of Parkinson Society Canada. Please plan to join us for a bowl of gruel and more. Further details will follow in the next issue of LiveWire.

## Of Interest

People in Motion 2009

Canada's Largest Exhibition for Disabilities

Queen Elizabeth Building, Exhibition Place, Toronto

June 5 and 6, 2009

For more information, call 1-877-745-6555 or visit [www.people-in-motion.com](http://www.people-in-motion.com)

### LiveWire

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