livewire
A Newsletter Uniting Central & Northern Ontario

The Central & Northern Ontario Region of the Parkinson Society Canada is the voice of all those living with Parkinson's throughout Central & Northern Ontario. Our purpose is to ease the burden and find a cure through support services, education, advocacy and research.

Winter 2007

PARKINSON VOLUNTEER AWARDED ORDER OF ONTARIO

Parkinson's disease advocate Bill Harshaw was named to the Order of Ontario. The Order of Ontario recognizes the highest level of individual excellence and achievement for an Ontario resident, and is the most prestigious official honour in the province. The investiture took place at Queen's Park on Wednesday December 20, 2006.

A tireless volunteer and fundraiser for the Toronto Chapter of the Parkinson Society Canada, Bill was instrumental in the creation and implementation of the Trillium Drug Plan, a resource for those who have high prescription drug costs in relation to their household income. Bill has written countless papers, a booklet for people with Parkinson's who are considering neurosurgery, and a book about his experiences entitled, *"My Second Life: Living with Parkinson's Disease".*

Diagnosed with Parkinson's at the early age of 36, Bill quickly discovered the debilitating effects of the disease. He was one of the first patients in Canada to undergo a pallidotomy, and the first to have Deep Brain Stimulation surgery, both brain surgery treatments for people living with Parkinson's. "Receiving the Order of Ontario is particularly gratifying because it is a 'peer-reviewed' award," said Bill. "The many nominees are reviewed by an Advisory Council comprised of Members of the Order."

"We are very privileged to have such a dedicated volunteer in Bill Harshaw. It is a pleasure to work with him and we look forward to continuing our work with Bill as we address our goal of easing the burden and finding a cure", said Christopher Rawn-Kane, Executive Director of Parkinson Society Canada, Central and Northern Ontario Region.

Ian D. Davidson Award

livewire is pleased to be reporting that the 2006 Ian D. Davidson Award has been awarded to **Ian Russell**.

This award was established in memory of Ian Davidson by his daughter, Monica, to recognize significant contributions made by a person with Parkinson's in the Toronto Area. The late Mr. Davidson was himself a person with Parkinson's and long time volunteer.

continued on page 2...

Ian Russell being presented with the Ian D. Davidson Award at the CNOR office.

...continued from page 1

This year's award recognizes Ian Russell's volunteering with the Parkinson's Society in a number of areas over the last seven years, since shortly after his being diagnosed. In the early years he helped out with various tasks in the office. These included speaking to people phoning the office for information on Parkinson's, sometimes themselves newly diagnosed, staffing Parkinson's public information tables, helping to develop new information pieces, and serving on committees responsible for the planning of services to the Parkinson community. Currently his major involvement is with **live***wire*; since early last year he has played a lead role in the editorial group that pulls the publication together.

Congratulations and thanks to Ian Russell for the contribution he has made to the benefit of others who live with this disease.

April is Parkinson's Awareness Month

Second Annual Agro Talk – April 4

The second annual Agro Talk will take place at the Royal Botanical Gardens in Burlington on Wednesday April 4th 6:30pm till 9:00pm. We are thrilled to have Dr. Quincy Almeida and Dr. Dwight Stewart speak on their work at the Movement Disorders Research Centre at Wilfrid Laurier University. There will be numerous display booths to review from 6:30pm-7:00pm and during the break. From 7:00pm-9:00pm the doctors will speak and answer your questions. No charge, but you pay to park.

Hope on Display April 11 – 1:00pm-4:00pm

This will be the first of many opportunities for people with Parkinson's to display their talent and for those wishing to learn more about Parkinson's to get information. We have painters, poets and photographers and dancers. These artists will share their work and their Parkinson story. The Performing Arts Lodge (PAL) is located at 110 the Esplanade and there is lots of parking to the east at St. Lawrence Market or just west of the building. Join us from 1:00pm as we celebrate wonderful talent and Dr. James Parkinson's birthday. Admission by donation. For information contact Karen Dowell at 416-227-3376.

Hike with the Turners at the Kortright Centre! April 15

Celebrate spring and Parkinson's Awareness Month by joining Don and Margaret Turner on Sunday April 15, 2007 for a guided hike. The Turners are famous for generating interest in the SuperWalk by walking around the perimeter of Toronto in 2005 and from Oshawa to Hamilton in 2006. They will be your hosts on guided hikes at 11:00am and 1:00pm on Sunday April 15 at the Kortright Centre near Woodbridge. For more information, please contact Marg Turner at margaret.turner@sympatico.ca or Sara Lawson at 416-227-3377 or 1-800-565-3000 x 3377.

Cut-a-thon is set for April 29th

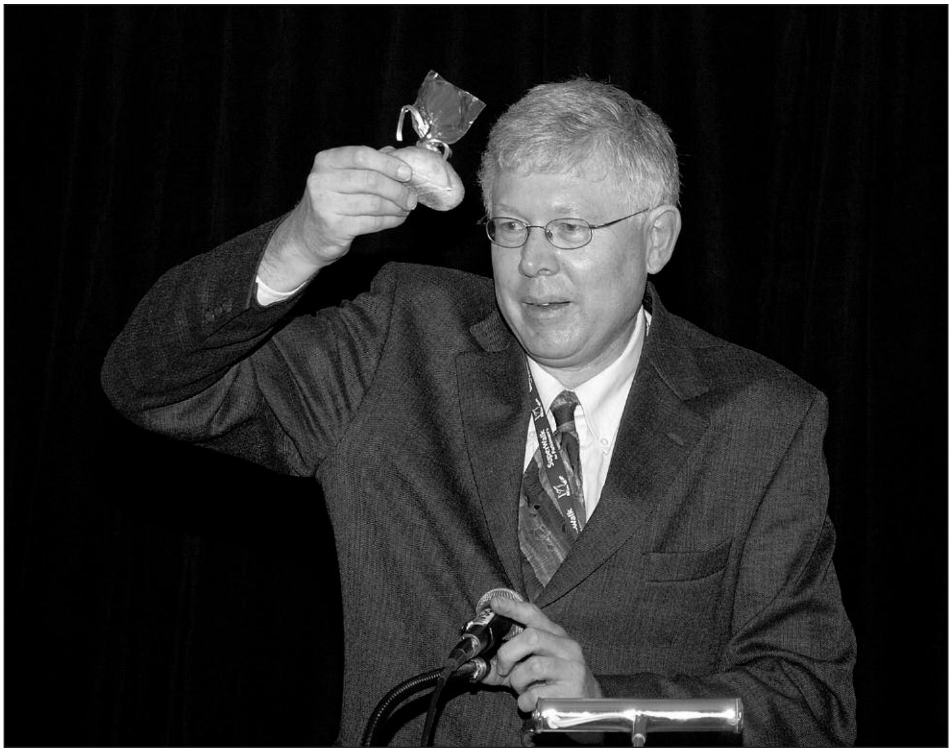
There will be Cut-a-thons in Barrie, Collingwood and Guelph. For information on Barrie call Carol Jackson at 705-737-2655, in Collingwood Jeannine Kraus at 705-444-9973, and in Guelph contact Nick or June Kaethler at 519-827-0806. A great cut and all proceeds go to education, advocacy, and support services.

Toronto will have several shops again after nearly 5 years. Come out and support this great event. Call Sara Lawson at 416-227-3377 for details.

Marilyn Forbes Award

There is still time to nominate someone for the Marilyn Forbes Award. Remember this is to honour someone at the chapter level who works tirelessly to promote the Parkinson Society and support those living with the disease. We will be accepting nominations until **March 2**. The recipient will be named in April. Mail them to the office to the attention of Karen Dowell or send by email to karen.dowell@parkinson.ca

Parkinson Society Canada Annual General Meeting



David Simmonds symbolizes Parkinson Society Canada on The Roll

Over 200 members of the Parkinson community from all over Canada attended the Parkinson Society Canada's AGM in Ottawa. The meeting incorporated within its framework a Parkinson Society of Ottawa regional meeting on the last day. Among the attendees were staff from the national office, members of the national Board of Directors, and representatives from the regional organizations. There were health professionals, volunteers, and of course people with Parkinson's themselves on their own or with their caregivers.

Many issues important to the Parkinson's community were addressed.

The national Board of Directors held a number of meetings dealing with ongoing business and planning for the future. Included was a meeting with the Implementation Team which was set up a little less than two years ago with the mandate of increasing revenue for the Regions while looking at alternative methods of seeking a more collaborative approach in the way the Parkinson Society Canada and the Regions function. Dan Cooney, chair of the Team was excited about the work that has been completed over the past year and a half and confident about the direction in which the Implemenattion Team is going.

Dr. Jon Stroessl touched on a wide variety of aspects of Parkinson's in the annual Donald Calne Lecture. In his talk on the state of Parkinson's he used his extensive expertise and wonderful sense of humour, and kept a packed house enthralled.

The national advocacy team held 45 meetings with Members of Parliament and senior civil servants. The committee was confident that it had increased the profile of Parkinson's disease, and made some progress on engaging decision-makers in issues important to Canadians with Parkinson's. The team is now working at getting written support for the request to the federal government for $5 million to fund a national epidemiology study.

Support services staff from regions across the country had a number of useful sessions, sharing

continued on next page...

Joyce Gordon - President & CEO and Alan Riccardi - Chairman National Board of Directors

...AGM continued

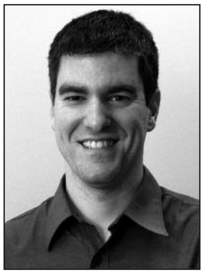
information on current activities and discussing future plans.

In her address at the National Press Club, Dr. Jackalina Van Kampen spoke of her ground-breaking discovery that adult brain cells can actually regenerate. Dr. Van Kampen is a Canadian, who is now conducting her research at the Mayo Clinic in Florida. Her message was very clear that to do this kind of work in this country more funding is needed for Canadian researchers.

The Ottawa regional conference was held on the final day. Focussing on “building bridges across generations”, it proved to be a real hit with the staff from other regions who had come for the national meeting.

Joyce Gordon, President & CEO of the national society, spoke at the windup dinner. As part of her remarks, she expressed the views of the vast majority of the participants that the meeting had been most successful. She thanked Ottawa Society for its help organizing the meeting and all others who worked so hard on it.

New Staff Member



My name is **Brandon Jopko** and I'm very excited to be joining the Parkinson Society Canada. I have over four years professional sales experience in various industries. This experience has enabled me to build a very valuable skill set to utilize in my role of Central and Northern Ontario Region’s Resource Development Coordinator. Mostly, I will be working on developing corporate sponsorship, participation, and funding for all of CNOR’s events and activities throughout the year. I will be looking at establishing new partnerships and building on existing relationships with our donors. In my spare time, I am active in Toastmasters, and am an avid baseball fan. I also enjoy creating tasty recipes in the kitchen. I welcome, everyone in the PSC community to drop me a line and introduce themselves at 416-227-3374. I look forward to working with all of you.

William Shatner was right!

Janis M. Miyasaki, MD, MEd, FRCPC, FAAN

At popular request, the New Year's column is on Bowel Function. This is probably the commonest problem among PWP regardless of illness stage. A significant amount of my time consists of giving this advice, reinforcing it and ensuring that patients are having the best bowel function possible. Why does a neurologist spend so much time on bowels? As readers are now aware, Parkinson disease (PD) is a multi-system illness. In addition to motor, mood and sleep problems, the autonomic nervous system is also affected. The autonomic nervous system controls "automatic" function such as heart rate, blood pressure, bladder and bowel control to a certain extent and sexual function.

Constipation is a common non-motor symptom in PD. In fact, having less frequent bowel movements can be an early marker of PD. As the illness progresses, this can be more problematic. Poor bowel motility results in less effective delivery of medication resulting in poor absorption. Patients will notice variable response to medication or dose failures. Prolonged constipation can distend the bowels to the extent that proper bowel motility can not be regained. In the extreme, severe constipation results in bowel obstruction. This means the bowels are completely blocked. This damages the bowels and may require surgery. If left undiagnosed, bowel obstruction is fatal that is, can cause death.

I should begin with this statement: Normal bowel function is a bowel movement that is not effortful every day or every other day. Yes, I know what you're saying – "but I'm different. I've always had less frequent bowel movements." It's not normal. Even patients with PD can have bowel movements every day if they follow a bowel care regimen.

Initial treatment should be conservative. Although good fluid intake for dietary purposes can include many liquids, for the purposes of bowel function, water or flavoured water with Crystal Light is best. An average person requires eight 8 ounce glasses of water each day – more if there is physical exertion or sweating. Next, minimizing white/refined starch products and increasing bran in natural forms is helpful. Be cautious since if you do not drink enough water after a certain point, increasing dietary bulk is not helpful. Moreover this can result in a large concrete-like collection of the fibre in your bowels, requiring surgery for removal. Therefore, I advise patients not to overdo the fibre – simply replace whole wheat for white bread, brown rice for white. Brown rice is available in long and short-grain varieties. Physical activity is also key to normal bowel function. The more active you are, the more active your bowels will be. Several yoga postures have excellent effects on core muscles and also abdominal organs.

Janis M. Miyasaki

By nature, the largest bowel peristalsis (or muscular wave) is in the morning. Take advantage of this timing and enhance the reflex. Drink hot coffee first thing in the morning and have hot oatmeal for breakfast. My patients have also shared that dried figs are fibre-full and dynamite with oatmeal – literally and figuratively. When trying to have a bowel movement – don't rush it. This is a common factor in constipation in nursing home patients. Abdominal muscles are important to help with bowel function. Many PWP have poor abdominal muscle tone. Working on core muscle strength is helpful.

These are general tips for good nutrition to this point. The goal is to have a bowel movement every day that is soft and not effortful. Every other day is acceptable but if you have a disrupted schedule or diet, for example while traveling, every other day can change to every 4 days – very unpleasant.

If the above are not successful at establishing normal bowel function, then start with docusate (a stool softener) two capsules at bedtime increasing to two capsules twice a day. If this does not establish a bowel movement every day, change to Senokot-S. This has a stool softener and Senokot to stimulate bowel function. Take two tablets twice a day.

By now, if this hasn't worked and you haven't had a bowel movement for three to four days, take one bottle of Magnesium Citrate (citro-mag). Do not take this if you have kidney disease or impaired kidney function. Instead take a fleet enema – do not use if you take Coumadin to prevent clots. I have seen patients prescribed bowel preparation; however, this should not be used daily for maintenance.

Some patients who are very constipated will have hard stools alternating with loose stools or diarrhea. This is called overflow diarrhea. When constipation is long standing, the softer stool simply flows by the hard stools (fecoliths).

Finally, if you haven't had a bowel movement for 5 days or longer, you should go to your family physician or emergency department for assistance to avoid serious complications.

For maintenance function, most patients require regular senokot S from two tablets at bedtime to two tablets twice a day. Stopping the routine results in constipation.

Remember, too, that bowel function is a barometer of what's going on in your life. Stress, change in diet, change in routines can throw the routine off. Take greater care during these times to maintain bowel function – and in effect, your health.

A Parkinson Paradox

Recent discoveries reveal that Parkinson's is more complex than previously believed. We had thought that slowness of movement, bradykinesia, was restricted to just the body's voluntary muscles, that just one part of the brain, the substantia nigra, was involved, and that the condition was due to a deficiency of just one chemical, dopamine.

The incorrectness of the first belief, that only the voluntary muscles were involved in bradykinesia, was dealt with by Dr. Mandar Jog in his webcast carried on the Parkinson Society Canada web site (see last issue of livewire). I will not address it here.

Regarding the second belief, there have been recent discoveries that Parkinson's involves more than just the substantia nigra part of the brain. Other nearby parts of the brain are now shown to be involved. So also are some more distant parts such as the large lobe at the back, the cerebellum, which is primarily responsible for balance.

As to the third belief, discoveries have shown that insufficient dopamine is not the only culprit in Parkinson's. Other brain molecules which deliver chemical signals along nerve pathways have recently been found to play a role in Parkinson's. For example, the neurotransmitter, serotonin, thought to be involved with depression, likely has a role.

Parkinson's Disease might well be the combined effect of many chemical effects in many different regions of the brain, dopamine and the substantia nigra being only the most thoroughly researched so far.

A straightforward observation of Parkinsonian features reveals what I've often thought to be a paradox of sorts. In the same individual, one may see a combination of the involuntary abnormal movements of dyskinesia, the rapidity of tremor, and the slowness of bradykinesia. How can one person exhibit such disparate features?

Dr.Gordon Hardace

Regarding tremor, we now know that tremor may involve basal ganglia structures other than the substantia nigra. So also, but indirectly, may be other brain locales that which contribute to the control of body movements. However, we do not as yet have a clear chemical explanation of tremor.

Dyskinesias or involuntary abnormal movements most often result from an excess, not a deficiency, of dopamine-like chemicals in the body. Why this is so also remains unclear.

Lastly, the slow and usually stiff movement or bradykinesia similarly involves more than just dopamine. In fact, dopamine out-of-balance with yet another neurotransmitter named glutamate seems to be the crucial factor. Normally, glutamate is associated with usual, regular, body movements. But in various forms of "excess" compared to one's available dopamine, glutamate can lead to the wrong kind of muscle activity. Its presence in such excess is said to be overly excitatory and can damage brain cell neurons. Unfortunately, we do not as yet have methods for someone to modify their own glutamate, although another group of Parkinson's – modify drugs called Glutamate Antagonists is being actively developed.

In his 1817 "*Essay on the Shaking Palsy*" Dr. James Parkinson meticulously described visible features of what was later to be known as Parkinson's Disease without himself understanding what the body's root imbalances were. The great neuroscientists of today have undoubtedly not finished discovering the intricacies of this perplexing and somewhat paradoxical movement disorder.

Win a SuperWalk Early Bird Prize from SHARP!

Visit www.superwalk.com Register online for **SuperWalk for Parkinson's** between April 1st and May 15th, 2007 and be eligible to win!

Online registration opens April 1st, 2007. Every walker who registers online with a minimum online pledge total of $100 – either self pledge or from friends – by May 15th will be included in a draw for a 32" AQUOS TV courtesy of SHARP (retail value $1,799.95).

**Winner will be announced on the website on May 18th. Contest is not open to employees of PSC and its regional partners or to any member of their immediate families.

Clinical Trials

Clinical trials test new drugs, new ways of giving drugs, new approaches to surgery, and new methods such as gene therapy. Each trial attempts to answer specific questions that will ultimately lead to better treatment. All trials are strictly monitored to ensure that the participant receives the best available care.

Participating in a clinical trial is voluntary. You should know the purpose of the trial. Is the intent to find a cure, or simply a treatment, or perhaps preventive measures or a diagnostic test?

What are the known risks and benefits of the experimental treatment? Is it a completely new approach? Is this a placebo controlled trial? Is there a chance you will receive the placebo and if so, how much risk does this represent?

If pre-clinical studies have shown that a drug seems to be safe and useful in animals, the drug company will ask the Health Protection Branch (HPB) of Health Canada, for permission to test the drug on humans.

Phase I of the study usually involves healthy people or people with the condition that the medication is intended for. In this phase investigators are trying to find the best way to give the study treatment and to determine the safest dose.

Phase II looks closely at how well the appropriate treatment is working with a small group of patients, over a longer period of time.

Phase III further tests how safe and effective the drug is, often involving thousands of people.

Phase IV trials are conducted after the treatment has been approved. This phase also looks at possible new uses of the treatment.

Coordinators will see and examine participants at every study visit. They will complete all assessments and monitor vital signs. Blood pressure, temperature, heart rate, and weight may be measured. Blood and urine samples may be collected. Steps may be taken to determine how the drug is distributed in the body, how the body eliminates it and how rapidly the drug reaches and maintains a therapeutic level. These data, when analyzed will help to determine the safest and most effective dosing regimen.

New drugs and treatments may have risks or side effects unknown to doctors. However, the ethical and legal codes that doctors and nurses follow in medical practice also apply to clinical trials.

You will be asked to sign a consent form. This is part of the process of taking part in a clinical trial. Informed consent is there for your protection. This process includes a review of why the study is being done, what will be done during the trial and for how long, what are the risks and benefits of participating and other treatments that are available to you. Review this with your family and your family doctor before you decide to participate in the clinical trial.

You must be sure you understand the rules of the study. You must be able to make yourself available for the study. However, you may stop participation in the study whenever you wish, for any reason.

You should tell the study coordinator about the medications you are currently taking and any changes to those medications.

Only you can decide whether or not to participate in a clinical trial. Before you make your decision you should learn as much as you can about your condition and the treatment options currently available. You should discuss this information with your family, friends, nurse and/or doctor, to help you determine what is right for you.

Research involving human subjects has, in recent years, become more than just a way to test new medical compounds; it provides access to new, experimental, potentially lifesaving medications to patients who would otherwise have no access to these drugs. Clinical trials continue to be the link between basic research and patient care. The questions they answer are vital to the search for better treatment and to better ways of helping people with Parkinson's attain the best possible quality of life as they live longer with their condition.

My Involvement With Clinical Trials

Many of today's treatments for Parkinson's are based on the results of past clinical studies. I have been involved in a number of clinical trials. The first one was about seven years ago when a study was done with the Rotigitone patch. I had been recently diagnosed with Parkinson's but was not on any drugs as yet. Schwartz Pharmaceutical had at that time spent over $500 million on the study of this agonist conducted in 27 cities around the world. When I last checked with my pharmacist if Rotigitone was on the market yet, she scanned the computer and replied, “Nope.” I imagine the costs must be over a billion by now. And you wonder why drugs are so expensive.

Other studies I have been involved with: a study to determine the influence sinemet has on the homocysteine levels of blood, a study to attempt to determine the influence Mirapex has on compulsive behaviours such as gambling, obsession with sex, compulsive shopping and other compulsions; testing a new drug for sialhorrea (drooling); a study on …what was it again? Oh, yeah, a study about memory and dementia. “Count backwards from 100 subtracting seven each time,” is a favorite of the neurologists. Another: “Name the days of the week backwards.” Some of these trials go on for many weeks. My girlfriend, Gloria, asks, “Why do you do it?” Well, someone has to do it and it’s a chance to make a contribution to Parkinson’s research.

Clinical trials are necessary to determine the validity of new drugs, new ways of giving drugs and other related scientific questions. Participation in a clinical trial is voluntary. The trials I was involved with were usually double blind in that no one knew who was getting what. It could be a mild dose, a medium dose, a large dose or a placebo. These trials are first tested with animals to ensure their safety.

If you decide to be a participant in a study you will be asked to sign a consent form. You must be sure you understand the rules of the study and that you are able to carry out those rules. You must make yourself available for frequent appointments. Some studies will pay you for your time. $25.00 cash is often the amount paid. You will be asked for a list of drugs you are currently on which may preclude you being involved. Further, you should inform your family doctor of the study and the drugs involved.

I will continue to make myself available for any future clinical studies. Maybe the next study I’m in will involve embryonic, adult or amniotic fluid-derived stem cells. Who knows?

Ron Penwarden
A person with Parkinson’s

Volunteer Tea Party

On Wednesday, December 6, 2006, CNOR said “thank you” to its volunteers with a tea party. Volunteers from all levels of the Region – from the SuperWalk to Executive Committee members – were treated to tea and delicious pastries.

It was a wonderful opportunity for the volunteers to meet each other, and for the staff to thank everyone for all their hard work throughout the year. National staff helped out in the kitchen and poured tea – although our enthusiastic volunteers kept jumping up to help!

Two special people were honoured at the tea: William Harshaw, who has recently been awarded the Order of Ontario, and Ian Russell, winner of the Ian D. Davidson Volunteer Award for 2006.

CNOR is very fortunate to have such generous, dedicated volunteers!

Around the Region

Alliston Support Group

Our small group strives to remain independent, despite falling attendance at meetings. We meet in Simcoe Manor in Beeton at 7:00pm on the first Tuesday of each month, except in winter. The area covered includes Cookstown, Tottenham and Schomberg. Our coordinator is Bob Nicholls who can be contacted at 705-435-6835.

We are trying to start a Tai Chi class in Beeton. If anyone is interested in joining us, please contact Les Stevens at 905-936-5644 or les.stevens@sympatico.ca. Our meetings have included Sandie Jones from PSC CNOR, a pharmacist, and a Tai Chi demonstration. We also raise funds for PSC by holding a SuperWalk, selling Christmas Cakes, tulip bulbs, and gift cash cards.

The cash cards could be a significant contributor. Our group gets 3% (on average) of our personal everyday purchases at no cost to us. We will be donating that to PSC on a regular basis. One family could easily raise $180 in a year. We have just started this program as a test, so we will report on progress later.

Belleville- Quinte Chapter

Contact: Bev Hanna-Jones 613-968-3359

bevhj@sympatico.ca

Monthly meetings Monday afternoons at 2:00pm (dates vary each month). Our meetings include: care and share, guest speakers and social events.

A new year begins and our group is going strong. Over 35 people attend our monthly meetings. In January, Bev Hanna-Jones will present information learned from the November Conference in Ottawa. Dr Grimes and Dr Stoessl were both informative and positive in their presentations. In February there will be a care and share meeting and in March, Gord Carley - author of "*Surviving Adversity*" - will be a guest speaker at our meeting. Bev met him at the November Conference as well.

Hamilton Chapter

We had our lovely annual Christmas luncheon on Saturday, December 16, 2006. Around 60 members and family attended. Everyone had a great time talking and enjoying the sandwiches and desserts with a background of Christmas music.

Some presentations for 2007:

Feb. 10 – Michelle Shilton, BHSc(PT), MEd, ORCS Assistant Clinical Professor, McMaster University Dept of Community Services, St. Peter's Hospital

Mar.24 – Jim Greenwood (Senior's Support Police Officer)

Apr. 28 – Sandie Jones(CNOR)

Sep. 23 – SuperWalk (9:00am–1:30pm)

We look forward to bringing in some other exciting speakers; these are open to the community as a lot of the topics are generic, for example; *The Benefits of Laughter, Arm Chair Exercise*, all presentations we were able to enjoy in 2006.

Our membership is growing with a support group of widowers and widows, members newly diagnosed with Parkinson, caregivers and family members.

The North

The Centre for Movement Disorders will be holding "Taking the Parkinson's Challenge" in Sault Ste. Marie this April. Dr. Adams will help attendees understand Parkinson's disease and help them learn ways that can make a difference in managing their condition. Please look for a date and time for this event in local newspapers or contact Donna at 1-888-237-4453 or by email donna@alsont.ca

---

Leaside Support Group

We ended the year with a Christmas party attended by 30 members. Our guest speaker was an "ex" heroin addict. Nothing to do with Parkinson's but an interesting person to listen to. He has personally established a needle exchange program in a community centre and works with a registered 750 addicts. He also works tirelessly to encourage them to get off the drugs and stay off. He and his girlfriend once spent $400 a day on H. He obtained this money through dealing. He has kept "clean" for over four years with a daily shot of methadone. One man's triumph over adversity!

We don't have too many professional speakers. Our two hour meetings every second Monday of the month start off at 1:00pm with a "Round Robin" where the members introduce themselves and tell the group a bit about their lives and experiences with Parkinson's. They may decide to pass if they wish. With about 25 to 30 in attendance this usually takes most of the first hour. We break for 10 minutes for tea and

continued on next page ...

cookies and follow this with a 10 minute exercise period given by Peter Allen, a long time member. I'll have something prepared to present to the group and usually have a question and answer period. Anyone and everyone is welcome to attend if they wish.

A special thanks to Lenore Roan, Marg Seal and Reverend Nick Athanasiadis for their continuing support at our group meetings. Without these three generous individuals our meetings at their beautiful church would not be possible.

Ron Penwarden
Facilitator

Toronto Chapter

2007 is starting out with a bang for the Toronto Chapter! With a new and dynamic Executive Committee (Ralph Karthein, Chair; John Martin, Vice Chair; Dan Drown, Past Chair; Mary Martin, Treasurer; Jan Duff, Director at Large), and with new staff (Sara Lawson, Community Development Coordinator - GTA), there promise to be productive and energizing times ahead!

The Executive Committee has adopted a business plan for 2007 that includes the following strategic goals:

- Create a strong Chapter Organization capable of executing the Chapter's Strategic Goals.
- Grow and develop the membership of the Toronto Chapter by providing learning opportunities and social opportunities supported by a strong communications program.
- Increase fundraising opportunities in the Toronto Chapter to support the Chapter's program initiatives and those of Parkinson Society Canada.

These initiatives will be carried out by a new Fundraising Committee and a new Membership Committee, and will be focused on people living with Parkinson's, their caregivers and family, and anyone who has an interest in Parkinson Society Canada and Parkinson's disease. If you are interested in taking part in any of these Committees, or want information about any of these new initiatives, please call Sara Lawson at 416-227-3377 or email sara.lawson@parkinson.ca.

In addition, the Membership Committee will be developing a quarterly newsletter specifically for people in the GTA. This will be available by e-mail or print, depending upon your preference. If you would like to receive this newsletter with updates on events and news in the Toronto Chapter, please contact Sara Lawson at 416-227-3377 or email sara.lawson@parkinson.ca.

It's an exciting time to be part of the Toronto Chapter! Watch for new developments here!

TORONTO PARKINSON'S CHOIR
Toronto Chapter is piloting a new project – a choir for people with Parkinson's and their loved ones. Based on the *Tremble Clefs* choir in San Diego, California, the choir will combine vocal therapy with music and a wonderful social opportunity. If this idea intrigues you, please let Sara Lawson know you are interested by calling 416-227-3377 or emailing sara.lawson@parkinson.ca. Watch future **live***wires* for updates!

Central and Northern Ontario Region Office Updates

The staff of the CNOR Office will be busy over the next four months.

A major task will be to continue with the Chapter Guideline process. Up to now, when chapters or support groups were set up in various communities across Canada, they usually were left largely to fend for themselves. There were no guidelines for such things as holding meetings, governance, fund-raising, bank accounts or other administrative or support activities.

Recently, the Parkinson Society Canada has developed a set of Chapter Guidelines. A chapter or support group which conforms to the Guidelines will qualify as a Charter Member of the Society. In the coming months the Office will be working with the Region's many chapters and support groups to help them to make any changes in the way they do things that will be needed to conform to the guidelines and, thus, to become Charter Members. We hope to become the first region in Canada to have our regions and support groups qualified.

As some of you may know, the Toronto Chapter has developed a comprehensive Facilitator's Guide which has been well received by others around the Region. The Office will continue to disseminate this guide so that other chapters and support groups can benefit from the Toronto Chapter's efforts.

CNOR staff will be studying the report of the Parkinson Society Canada's Implementation Team on the way in which the national Society works with its regional partners, including how fund-raising is carried out at each level and how revenues are shared. (See report on Annual General

continued on next page ...

Meeting on page 2 of this issue.) CNOR, as well as the other regions, will be meeting with a group of representatives from the Implementation Team to discuss its findings and recommendations. This is part of the process for developing a five-year plan for revenue-sharing for the organization as a whole.

Finally, the Office must give high priority to the many activities and events which are part of the Parkinson Society's April Awareness Month. One of the larger ones, the Agro Speakers Series taking place in Hamilton at the Royal Botanical Gardens, is expected to draw over 5000 participants. (Other activities are listed in the article on April Awareness on page 2 of this newsletter.) During April, the Office will also be organizing the Annual Pitch-in for Parkinson's and the 11th Annual Granite Ridge Golf Tournament both of which will take place early in May. It is important for every one of these events to be successful.

It's a busy time for the CNOR.

Parkinson's and the Mind

The initial complaints of Parkinson's disease could include the inability to walk normally, loss of arm swing on the affected side, handwriting that has become micrographic and drooling.

Sometime later a new symptom arrives. At least it did in my case. This one is more ominous. Disease driven or consequence of medications, it does not matter, sinister thoughts began to occupy my mind. My machinations concerned my wife and the young man next door. My wife loves me I am sure and after 46 years married I should feel secure. But there it was occupying a front and centre lobe of my brain.

Conversations became conspiratorial, hushed not in deference to me napping, in my mind they were talking about me. It was real as were the mice I continually saw out of the corner of my eye. I would tell myself I was seeing things but I would get up and look really expecting to see a mouse crouching in a corner.

After consulting with Dr. Jog, the drug Seroquel was added to my burgeoning regimen. The effects of the drug were immediate. I no longer harbour suspicious thoughts and the Pied Pier must have looked after the mice because they too are gone.

James W. Forbes, Thunder Bay,
Ontario Diagnosed 11 years ago.

Parkinson Quiz # 2

The following terms are often heard while discussing Parkinson's disease Can you match the following words on the left with the meanings on the right?

1	**Agonist**	a)	Short, shuffling steps
2	**Sialorrhea**	b)	Small, cramped handwriting
3	**Bradykinesia**	c)	Increased resistance noted to the passive movement of a limb
4	**Dyskinesia**	d)	Involuntary spasms of muscle contraction which cause abnormal movements and postures
5	**Neurotransmitter**	e)	Slowness of movement
6	**Rigidity**	f)	Drooling, increased salivation
7	**Dystonia**	g)	Abnormal, involuntary body movements that can appear as fidgeting, twisting, and turning; frequently induced by meds taken by Parkinson patients
8	**Festination**	h)	A chemical or drug that enhances the activity of neurotransmitters such as dopamine
9	**Freezing**	i)	A specialized chemical produced in nerve cells that permits the transmission of information between cells
10	**Micrographia**	j)	Temporary, involuntary inability to take a step or initiate movement

Answers on next page

live*wire* is published four times a year. The objective is to provide people with Parkinson's and their caregivers information which will be useful to them. **live***wire* would like to hear from its readers. Comments, suggestions, jokes, cartoons, and articles related to Parkinson's are welcome. Submitted material may be edited. The **live***wire* Editorial Advisory Group is made up of volunteers, Ian Russell and Ron Penwarden and staff member, Sarah Roojee. Contact the regional office by phone at 416-227-3372 or 1-800-565-3000 ext.3372 or by email to livewire@parkinson.ca

Material required by		**Issue delivered by**
Winter	23 Jan	28 Feb
Spring	23 Apr	31 May
Summer	23 Jul	31 Aug
Fall	23 Oct	30 Nov

Answers to Parkinson Quiz # 2

1–h, 2–f, 3–e, 4–g, 5–i, 6–c, 7–d, 8–a, 9–j, 10-b

Provincially Speaking

This report from Ontario Coordinating Council is the first of what we hope will be a regular series in **live***wire* and other Parkinson Society newsletters in the Province. It will report on Parkinson Society activities that are taking place across the Province.

The Coordinating Council was set up by the regional Parkinson's organizations in Ontario (Central and Northern Ontario, Southwestern Ontario and Ottawa). It is a virtual group in that its quarterly meetings are held by phone. It is made up of the Executive Directors, the National Board Representatives, and a few other individuals, from each region.

This first report is about recent work of the Ontario Advocacy Committee. This group has been hard at it over the last few weeks to finalize the plan and strategy for the next 6 -12 months. Highlights of the plan are:

- an Ontario Advocacy Information document which highlights the advocacy strategy over the next six months, the support required from the regions and the resources that will be provided to help everyone.
- a roles and responsibilities profile re the Community Advocacy Ambassadors (individuals appointed to assist with advocacy work at the community level)
- a detailed information list of Ontario MPPs.
- the hiring of Shannon MacDonald, principal owner of Bliss Communications, to work with us regarding the advocacy strategy and our activity at Queen's Park.
- the recruitment of a small group of key high level Provincial (not Community as above) Advocacy Ambassadors to work with the committee at Queen's Park meetings.

Copies of the Ontario Advocacy Plan are available in each region. If you have any questions, please contact the office at 416-227-1200. extension 3373

---

live*wire*
Parkinson Society of Canada
Central and Northern Ontario Region
321, 4211 Yonge St.
Toronto ON M2P 2A9

Canada Post
Canadian Publications Mail
Sale Product agreement
No. 40624078