

ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Tony's team:
Caring for
thousands
each year

SuperWalk 2005:
Be part of
the success

PLUS
Women and sexuality

Medication matters:
A quick guide to
Parkinson's drugs



Parkinson Society Canada
Soci t  Parkinson Canada

Ease the Burden; Find a Cure



Join in the fun!

Be part of SuperWalk for Parkinson's this September 2005!

Collect pledges and walk with your friends and family! You can plan now to be involved....

Join the ranks of the SuperSTARWalkers:

Raise over \$1,000 and the fun gets better! Receive a **SuperSTARWalker** hat and a pin for each year you reach this level plus enjoy the special incentives and draw prize just for these walkers.

Bring along a team: Invite your friends and family to join you for the day! Sharing the day will make it more fun so check out the extra incentives for groups of 4 to 10 walkers.

Enjoy the prizes: In addition to local prizes, for every \$100 raised, each walker gets one chance to win some great national prizes!

Volunteer to work on a committee: Call the regional office closest to you (see pages 5 & 6 for the number) and become part of the success in your region!

Register on-line: Visit www.superwalk.com and find out how easy it is to join a walk and ask your friends for their support while providing them with immediate receipts.

For details about a walk near you and prize updates visit www.superwalk.com.

Come and be part of the fun this September!

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Ontario

ON OUR COVER:

The team at the Morton and Gloria Shulman Movement Disorders Centre at Toronto Western Hospital handle more than 7,000 patient visits a year. Team members include (left to right) Dr. Jong Sam Biak, Dr. Cindy Zadikoff, Dr. Anthony Lang (Director), Dr. Christine Klein and Dr. Thamer Alkhalillah, among many others.

September means SuperWalk

September is SuperWalk for Parkinson's month. This year, I'm personally inviting each and every reader of the *Parkinson Post* to walk with us to raise awareness and funds to support our collective purpose: to ease the burden and find a cure through research, education, advocacy and support services.

The annual SuperWalk for Parkinson's has become Parkinson Society Canada's largest fundraising event, and it continues to grow. The event was founded by seven Ontario residents in 1990 as they walked to raise funds for research. In 2004, over 11,000 Canadians walked in 74 different locations and raised over \$1.69 million. This year, we hope to raise even more funds and generate greater awareness of Parkinson's disease among Canadians.

SuperWalk means many wonderful things to me. Since beginning my role as National Co-ordinator of SuperWalk in 2001, I've been privileged to work with many volunteers who have put countless hours into their local events and who have a true passion for our mission. I also have the opportunity to work with our regional partners who share my desire for success and who will put forth every effort to make the 76 local events taking place this September the best so far.

This year, we're so pleased to be working with Tom Cochrane. Tom's passion for Parkinson Society Canada (PSC) and his connection to our mandate is a personal story: one of admiration for his late father, Tuck, who struggled with Parkinson's. Tom will be walking with us this year, and we are so grateful for his support.

SuperWalk could not take place on such a grand scale without the support of our sponsors as well. We value their participation as partners with PSC and as sponsors of our largest national fundraising and awareness event.

Each year, thousands of walkers, our regional partners, our honorary chair, our valued sponsors and you all contribute to making each year more successful than the previous year.

Some day, we may all take to the streets in jubilation that a cure has been discovered for the disease. Until that day, we'll continue to SuperWalk for Parkinson's and we'll continue to help the almost 100,000 Canadians living with the disease.

So please join us! We need everyone's help to make this year's SuperWalk the best ever. Visit www.superwalk.com today to learn how you can participate.

Debbie Davis

Debbie Davis,
National Co-ordinator, SuperWalk
Parkinson Society Canada



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Parkinson Society Canada
4211 Yonge Street, Suite 316,
Toronto, ON M2P 2A9

Editor:
Peggy Yates

Publisher:
BCS Communications Ltd.

How to contact Parkinson Post:

Parkinson Post
4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
Phone: (416) 227-9700
Toll Free: (800) 565-3000
Fax: (416) 227-9600
E-mail: editor@parkinson.ca
subscriptions@parkinson.ca
Website: www.parkinson.ca

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Our mission

Parkinson Society Canada/Société Parkinson Canada is the national voice of Canadians living with Parkinson's. Our purpose is to ease the burden and find a cure through research, education, advocacy and support services.



Parkinson Society Canada
Société Parkinson Canada

National Office and Regional Partners

For information, programs and services in your area, or to make a donation, contact the following offices:

PSC National Office

4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
Ph: (416) 227-9700
Toll Free: (800) 565-3000
Fax: (416) 227-9600
www.parkinson.ca

Parkinson Society British Columbia

890 West Pender Street, Suite 600
Vancouver, BC V6C 1J9
Ph: (604) 662-3240
Toll Free (BC only): (800) 668-3330
Fax: (604) 687-1327
www.parkinson.bc.ca

- ▶ Received positive feedback from "Living single with PD" meeting.
- ▶ Held new young onset meeting with a small group. A contact list was distributed for future contact and support.
- ▶ Made presentation at "Persons with disabilities online" event, an initiative sponsored by the federal government.
- ▶ Counsellor attended meetings in Calgary with other support colleagues from across Canada.
- ▶ Responded in the first quarter of 2005 to 417 information requests.
- ▶ Second annual Porridge for Parkinson's introduced works of local artists living with Parkinson's and raised close to \$10,000.

Victoria Epilepsy and Parkinson Centre

813 Darwin Avenue
Victoria, BC V8X 2X7
Ph: (250) 475-6677
Fax: (250) 475-6619
www.vepc.bc.ca

- ▶ Held two education events: "Exploring your potential: Turning can't do's into can do's" and "Chronic disease self-management strategies."
- ▶ With good sponsorship support, the annual golf tournament netted \$44,000.
- ▶ Redesigning exercise services to

include new mind-body program that offers stretching, balance enhancement, deep breathing practise and other stress-reducing techniques.

- ▶ Working with community groups to develop a voice for seniors in government health care policy and practices.
- ▶ Launching new logo and key messages in fall.

The Parkinson's Society of Alberta

Edmonton General, Room 3Y18
11111 Jasper Avenue
Edmonton, AB T5K 0L4
Ph: (780) 482-8993
Toll Free: (888) 873-9801
Fax: (780) 482-8969
www.parkinsonalberta.ca

- ▶ Held AGM and 27th Annie Wyley Memorial Lecture featuring guest speaker Susan Calne, RN, UBC Pacific Parkinson's Clinic Coordinator, on "Living well with Parkinson's."
- ▶ Presented workshop to 200 health care providers via telemedicine (17 sites in Alberta and Saskatchewan) by Susan Calne on "Managing late-stage Parkinson's disease."
- ▶ Held educational meeting with Dr. Wayne Martin, Director, Movement Disorders Clinic in Edmonton, on "Identifying complications associated with medical treatment in Parkinson's disease."
- ▶ Planning for two SuperWalks: The 10th annual walk in Edmonton and the fourth annual walk in Grande Prairie.

The Parkinson's Society of Southern Alberta

102-5636 Burbank Crescent SE
Calgary, AB T2H 1Z6
Ph: (403) 243-9901
Toll Free (Alberta): (800) 561-1911
Fax: (403) 243-8283
www.parkinsons-society.org

- ▶ Offered a series of classes from

March through June on speech improvement, exercise, and brainwaves.

- ▶ Held 23 monthly support groups in the region.
- ▶ Held a two-day casino fundraiser on the May long weekend.
- ▶ Fourteenth annual Tulip Tournament for Parkinson's, a golf tournament, took place in July.

Saskatchewan

Parkinson's Disease Foundation

103 Hospital Drive, Box 102
Saskatoon, SK S7N 0W8
Ph: (306) 966-1348
Fax: (306) 966-8030
E-mail: spdf@sasktel.net

- ▶ Held movement disorder clinics in Saskatoon and Regina.
- ▶ Holding Parkinson Week in Saskatchewan in early fall.
- ▶ Planning for 13th annual PrintWest Golf Classic for Parkinson's in Regina and the fourth annual SuperWalk in Saskatoon.

Parkinson Society Manitoba

171 Donald Street, Suite 302
Winnipeg, MB R3C 1M4
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 786-2327

- ▶ PSC clinical assistance/outreach grant awarded to Dr. D. Hobson, who announced the opening of the first multidisciplinary movement disorder clinic in spring 2006.
- ▶ Adopted support group guidelines to offer clear direction to over 14 support groups. Facilitator training to start in fall.
- ▶ Our Executive Director completed the Certified Association Executive designation through

Continued on page 6



Parkinson Society Canada
Soci t  Parkinson Canada

the Canadian Society of Association Executives.

- ▶ New Regional Advisory Board: Chair Terry Snell, Vice-Chair G. Thomas Hodgson, Secretary-Treasurer Marc Pittet, and Board members Shaun Hobson, RN, Adrienne Toews, Colleen Johnston, Don Dietrich, Louis L. Maric, Jean Wright, Wayne Buchanan, and National Representative Bob Ashuk.
- ▶ Seventh annual Golf Classic raised almost \$70,000 for support services.

PSC Central and Northern Ontario Region

4211 Yonge Street, Suite 321
Toronto, ON M2P 2A9
Ph: (416) 227-1200
Toll Free National: (800) 565-3000
Fax: (416) 227-1520

- ▶ Held conference in Toronto in May with over 210 participants.
- ▶ Ninth annual Parkinson's Golf Classic raised \$12,000.
- ▶ Sixteenth annual Pitch In for Parkinson's raised \$26,530, including in-kind donations.

PSC Southwestern Ontario

4500 Blakie Road, Unit #117
London, ON N6L 1G5
Ph: (519) 652-9437
Toll Free Ontario: (888) 851-7376
Fax: (519) 652-9267
www3.sympatico.ca/pf.swo

- ▶ Inaugural meeting of first Parkinson's Club, formed by students from the University of Western Ontario, to take place in early fall.
- ▶ Held successful regional conference with 240 participants—an all-time high—and a waiting list of 25.
- ▶ Donations to "PEP for Community Caregivers" reached \$50,000. Recognition of need for more knowledge among health care professionals working with people with advanced Parkinson's. Teaching tools will be completed by fall. Pilot programs announced for Strathroy, Tillsonburg, and St. Thomas areas.

Parkinson Society Ottawa

1712 Carling Avenue
Ottawa, ON K1Y 4E9
Ph: (613) 722-9238
Fax: (613) 722-3241
www.parkinsons.ca

- ▶ Held presentation featuring Dr. Mendis Tilak on "Sleep and Parkinson's" and a workshop-panel discussion on "Fatigue and Parkinson's."
- ▶ Dr. David Grimes and Dr. David Park, co-chairs of Parkinson's Research Consortium in Ottawa, spoke at our Annual General Meeting. The AGM was followed by an annual Strawberry Social.
- ▶ Net proceeds from benefit concert featuring Paul Anka to Parkinson research. Teamed with Assaly Charitable Foundation to raise substantial funds at gala event for 250 guests.
- ▶ We were the recipient charity for the second year of the HOPE Volleyball SummerFest, the world's largest beach volleyball tournament, which attracted 25,000 people.
- ▶ Annual golf tournament, which celebrated the first day of spring and "national laughter day," attracted a record number of golfers and raised \$30,000.

Société Parkinson du Québec

1253 McGill College, Suite 402
Montreal, QC H3B 2Y5
Ph: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.infoparkinson.org

- ▶ Welcomed two new employees: Diane De Chevigny, Customer Service Co-ordinator, and Jocelyne Leroux, Director of Development.
- ▶ North Safety Products donated \$50,000 from its Golf Classic held in May.
- ▶ Fifth edition of PSQ Golf Open in the Greater Montreal Region to be held in the early fall.
- ▶ SuperWalk planning underway for Chicoutimi, Gatineau, Montreal, Quebec City, Repentigny, Rimouski, Rivière-du-Loup, Sherbrooke and Trois-Rivières.

PSC Maritime Region

5991 Spring Garden Road, Suite 830
Halifax, NS B3H 1Y6
Ph: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468 Fax: (902) 422-3797
www.parkinsonsocietymaritimes.ca

- ▶ Incorporated and established a working capital fund of \$200,000 (equal to six months operating).
- ▶ Welcomed Bob Shaw, professional planner and marketing expert, to the Board.
- ▶ Organizing annual East Coast Parkinson Conference (sponsored by Novartis and Medtronic) for October in Halifax. Speakers expected from Florida, Washington, Toronto, Fredericton and Halifax.
- ▶ Recognized the Moncton chapter's 15 years of serving community at a dinner where outstanding volunteers received certificates.
- ▶ First-ever corporate walk to be held in Halifax as part of the SuperWalk weekend. Event will be sponsored by Medivie Blue Cross.

Parkinson Society Newfoundland and Labrador

The Viking Building
136 Crosbie Road, Suite 305
St. John's, NL A1B 3K3
Ph: (709) 754-4428
Toll Free (NFLD/Labrador):
(800) 567-7020
Fax: (709) 754-5868

- ▶ Held presentations in St. John's, Grand Falls-Windsor and Corner Brook with video conferences in Port-aux-Basques and Stephenville featuring Janet Millar, a physiotherapist from Nova Scotia, who uses music to encourage exercise.
- ▶ Presented lecture on "Can stem cells be used to repair the damaged brain?" by Dr. Dale Corbett, Professor of Neurosciences at Memorial University's Faculty of Medicine.
- ▶ Opened new regional office on World Parkinson Day.
- ▶ Took part in a one-hour phone-in show on Parkinson's on CBC Radio.



Parkinson Society Canada
Société Parkinson Canada

Issues of interest to people with Parkinson's

Working together to effect change

Recently, the National Board of Directors of Parkinson Society Canada (PSC) reconstituted the Advocacy Committee. The Committee's new purpose is to position PSC to have a greater impact on national policy issues that affect Canadians living with Parkinson's disease.

Long-term advocacy

The new Advocacy Committee, chaired by Yvon Trepanier (Victoria, BC) and consisting of 10 volunteer members plus PSC President and CEO Joyce Gordon, met by teleconference on June 23. Very quickly, the committee agreed to begin work to address immediate government-relations issues and to identify and develop long-term national advocacy positions.

Priorities include requesting Health Canada to form a joint departmental committee with PSC to uncover all of the data and information currently available about Parkinson's in Canada, and applying to the federal government for funding to undertake an epidemiological study that would supply missing information. These two critical steps will result in an accurate, up-to-date understanding of Parkinson's disease in Canada and will better position PSC to garner much-needed attention and support.

Two key questions

The Advocacy Committee will meet in September for a two-day think-tank focused on two key questions that relate directly to PSC's mission to "ease the burden":

1. What are the major issues affecting Canadians with Parkinson's?
2. What is the most meaningful change that can be accomplished for Canadians with Parkinson's within the next two years?

This discussion will enable the committee to clearly identify and prioritize the key issues on which to build a national advocacy strategy. Insight on these questions is being sought across Canada from people with Parkinson's, caregivers, medical professionals, and other members of the Parkinson's community. Readers are encouraged to submit their thoughts on these fundamental questions by e-mailing advocacy@parkinson.ca by September 1, 2005.



Joyce Gordon, President and CEO, PSC, says the Advocacy Committee is now seeking insight on the prevalence of Parkinson's disease from people with the condition, caregivers and medical professionals.

Parkinson's disease and complementary therapy

Massage therapy has been proven to greatly benefit the lives of those living with Parkinson's disease (PD). The many signs and symptoms of PD can make even the smallest of tasks seem very difficult. With muscle rigidity, resting tremors, difficulty breathing, fatigue, postural changes, altered balance and gait (walking), sensory changes, constipation and depression being only some of the many changes the PD patient may be experiencing, any decrease in signs or symptoms may come as a relief.

In a recent study conducted at The Touch Research Institution in Miami, Florida, researchers concluded that those Parkinson's patients receiving massage therapy two times per week for five weeks received higher physician scores on daily living activities. Participants also rated themselves as showing improvement with daily functioning and having more effective, less disturbed sleep.

The increasing stiffness and tremors caused by PD can lead to muscle exhaustion, similar to what athletes may experience after competition. However, unlike athletes, those with PD have no recovery period and over time suffer permanent musculoskeletal changes leading to postural dysfunction, aching muscles and decreased range of motion. With massage therapy, the part of the nervous system responsible for calming the body, decreasing the heart and respiratory rate, and increasing gastrointestinal motility, is enhanced. With specific techniques, massage can greatly reduce muscle rigidity, increase the range of motion and encourage the production of synovial fluid, which lubricates the joints and results in easier movements. And the relaxation a patient may experience through massage may alleviate the patient's anxiety.

Massage therapy treatments designed to meet the specific needs of each patient with Parkinson's disease is vital for optimal function, both physically and mentally.

Adapted with permission from Back to Wellness Centre Inc., Burnaby, BC.

Ease the Burden; Find a Cure

Catching up with Tony:

Dr. Lang sets the pace at Canada's largest Parkinson's clinic

By Ian Corks

There is no time to ease into the working day for Dr. Anthony Lang.

The day begins early, at 8:00 a.m., and like everyone else at the Toronto Western Hospital's Morton and Gloria Shulman Movement Disorders Centre (MDC)—the largest active movement disorders clinic in Canada—Dr. Lang has to hit the ground running.

From executive committee meetings, to journal clubs, to neuroscience rounds, the mornings are hectic. And it doesn't get any easier for the Centre's Director. Research projects, administrative tasks, teaching duties and, of course, seeing patients fill the rest of the busy working day.

An international leader

Dr. Anthony (Tony) Lang is recognized as one of Canada's leading experts in Parkinson's disease and

is equally renowned on the international stage for his research into various aspects of the condition. A graduate of the University of Toronto (U of T), he first became interested in Parkinson's disease while training with Dr. Marotta at St. Michael's Hospital.

Following a clinical research fellowship at King's College Hospital in London, U.K., he returned to Toronto.

In the 1980s he became intimately involved in the development of a state-of-the-art movement disorders clinic at Toronto Western Hospital. When the Morton and Gloria Shulman Movement Disorders Centre was finally established, Dr. Lang was the natural choice for Director. Since then, the MDC has established itself as one of the leading



Dr. Tony Lang rarely has time to slow down during a typical busy day at the Morton and Gloria Shulman Movement Disorders Clinic.

Photos: Terry Lowe

centres for the treatment of movement disorders in North America.

Dr. Lang oversees a staff of movement disorder specialists. Faculty members include Dr. Elena Moro, Dr. Susan Fox, Dr. Robert Chen, Dr. Connie Marras and Associate Director Dr. Janis Miyasaki. Other staff include four specialized nurses, a research coordinator and numerous researchers and lab technicians. In addition, there are usually six or seven clinical fellows honing their treatment skills at the Centre.

Treating thousands

Together, this team handles over 7,000 patient visits each year, including a steadily increasing number of surgical cases. At the same time, it continues to build on its international reputation for research and innovation in Parkinson's disease.

"We are the biggest movement disorders treatment centre in the country and one of the largest in North America," notes Dr. Lang. "While we deal with all forms of movement disorders, Parkinson's disease is our main focus. We combine patient care with teaching and leading-edge research."

Teaching is an important aspect of the Centre. With its strong reputation and the most active fellowship program in Canada, the MDC attracts physicians from across Canada and around the world. "Currently we have fellows from the U.S., Saudi Arabia, Korea, Germany and Qatar," says Dr. Lang. "We also regularly have physicians from various countries observing."

The MDC's research department is world renowned, and its researchers are pushing the frontiers of almost all aspects of Parkinson's treatment. Each faculty member is involved in at least one ongoing research project. Among the studies currently underway are projects investigating new neuroprotective agents to slow the disease's progression, medications to reduce the side-effects of the motor fluctuations associated with levodopa treatment, new anti-dyskinesia treatments, more effective targeting of deep brain stimulation, and other improved surgical protocols.

A full calendar

The pace never slows at the Morton and Gloria Shulman Movement Disorders Centre (MDC). Here is a look at a typical week in the life of Dr. Tony Lang.

Monday

- The day begins (like all others) at 8:00 a.m. with a meeting of staff and neurology residents to review and discuss videos of interesting or complicated cases. These can come from the Centre, across Canada or around the world.
- Next up is a faculty meeting to review the Centre's ongoing research studies. It also serves as a reminder to all staff to watch for potential recruits for ongoing studies.
- The rest of the day is spent on administrative tasks and work on Dr. Lang's own research projects.

Tuesday

- First up is the weekly university-wide Executive Committee meeting, which Dr. Lang attends as the Director of the Division of Neurology of U of T. There are also Executive Committee meetings for the Division.
- The balance of the day is taken up by one of two weekly clinic days. Regular and new patients visit the Centre for treatment. Each fellow on duty presents the case to Dr. Lang, who offers his wealth of experience and expertise. Following the discussion, which is often bolstered by the input of other faculty members, Dr. Lang and the attending fellow see the patient. Clinic days can be very busy with a variety of patients, many with complex problems.

Wednesday

- The day opens with the "journal club." All faculty, fellows and residents meet to review two or three recently published clinical papers and discuss their relevance and potential impact on practice or on their own research.
- Administrative and academic work take up the rest of the day, with Dr. Lang fulfilling the role not only as Director of the MDC but also of the Division of Neurology at the University of Toronto (U of T).

Thursday

- Dr. Lang begins the day with neuroscience rounds, trying to fit some research work into the remainder of the morning.
- The week's second clinic day dominates the afternoon, with a number of patients to be seen.

Friday

- As a professor in the Department of Medicine at U of T, Dr. Lang devotes the day to various teaching-related tasks, including professor's rounds with the university's neurology residents.

In addition to this regular schedule, Dr. Lang is often on the road travelling to international conferences or serving as a visiting professor at other universities.

Patient care the priority

However, patient care is the MDC's priority and the common thread that runs through all of its efforts. "All of our faculty and fellows provide direct patient care," Dr. Lang explains. "We all see patients on a regular basis. In fact, there are many patients and family members who I have been seeing for so long that we are almost like friends. We chat about all sorts of things during our consultations. This socialization is an important part of the treatment. It helps both the doctor and the patient."

The Centre's patients also play a key role in its research activities. "We have a high volume of patients. Most are from southern Ontario, but many are referred from other parts of Canada and the

U.S.," Dr. Lang says. "They come to us with various stages of Parkinson's, and many fulfill the criteria of some of our research trials. All staff members are constantly on the lookout for potential study recruits." These studies are mutually beneficial. They allow the MDC's researchers to push ahead with important research and offer patients the possibility of benefiting from a potentially improved treatment.

One of the Centre's key areas of expertise is the surgical management of Parkinson's disease. Under the direction of renowned neurosurgeon Dr. Andres Lozano, the Centre specializes in deep brain stimulation procedures. In 2004, the Centre handled 25 surgical cases, a number that they expect to



Dr. Lang discusses a case with Dr. Christine Klein, a clinical fellow from Germany currently training at the world-renowned Centre.

double this year. In fact, this increasing demand has led to the recent addition of a second neurosurgeon, Dr. Mojgan Hodaie.

Simply keeping the whole Centre running smoothly—with its large faculty, multiple research projects and thousands of patients—would be a full-time job for most people. For Dr. Tony Lang, however, it's just one of the many roles he fulfills. And, in spite of the heavy responsibility it entails, running the Centre is very much a secondary role to those of researcher, medical educator and, above all, physician.

Clinical fellows Dr. Thamer Alkhairallah from Saudi Arabia (left) and Dr. Jong Sam Baik from Korea present their patient histories to Dr. Lang during Tuesday's clinic day.



The Morton and Gloria Shulman Movement Disorders Centre

The Morton and Gloria Shulman Movement Disorders Centre at Toronto Western Hospital was named in 1993 in honour of the generous support of Dr. Morton Shulman, a prominent Toronto resident who suffered from Parkinson's disease, and his family.

A designated National Parkinson

Foundation Centre of Excellence, the Centre has earned international respect for its proactive role in new drug trials and for its innovations in the treatment and surgical management of Parkinson's and other movement disorders.

The Centre's clinicians are actively involved in research at Toronto Western

Research Institute, a major player in the global search for a Parkinson's cure. Research and clinical achievements in movement disorders have earned the Centre's scientists prestigious grants, including awards from the Michael J. Fox Foundation for Parkinson's Research and from Parkinson Society Canada.

Through this commitment to clinical research, thousands of patients in Canada and abroad are receiving the latest treatments for disabling neurodegenerative diseases.



The remarkable Millar family:

Meeting life's challenges one step at a time

When Greg Millar got a call last year telling him he had won the Air Canada trip in the SuperWalk National Grand Prize draw, he couldn't believe it. "I was shocked to get something for donating money," he says. He and his wife, Danielle, have almost decided where they're going with the prize—most likely Italy—but when they leave depends on Greg's health.

At 25, Greg takes part in SuperWalk despite suffering from chronic renal insufficiency (kidney failure). Since March, he goes three times a week for chemo dialysis, a treatment to clean his blood and remove wastes and excess water from his body. The process, which takes about 15 hours each week, shouldn't leave Greg with much spare time, yet he and Danielle still manage to operate two successful businesses in Gravenhurst, Ontario: a Mr. Sub and a Little Red Barn Frozen Treats.

A change of plans

About 15 years ago, the Millar family's lives were changed forever. Greg's father, Gary, was diagnosed with Parkinson's disease at age 37. A close family, the Millars began participating in SuperWalk. They raised about \$1,000 in pledges

each year. Greg's sister Brittany, 18-years-old, helped with Greg's fundraising initiatives. Before she went to school in the fall, she spent some quality time with Greg while he underwent a kidney transplant. In fact, Brittany donated the kidney to Greg. He was now ready to become even more involved in raising money for SuperWalk.

But Greg wanted to do more than SuperWalk, so he decided to hold a golf tournament, calling it Par 4 Parkinson's. The first tournament, held last September, attracted 128 golfers and raised \$10,000.

This year, Greg's goal is to raise \$15,000. How will he do it? "I don't like the indirect approach," he says. "So I pound the pavement and personally visit all the businesses in the area." Everything is donated, including the welcome prize that each golfer receives (worth up to \$70). There's a car to be won for a hole-in-one. In 2004, Greg was closest to the hole, "about 18 inches away."

A community effort

Greg gets help from family and friends, including the high school students who work at his businesses.

Greg also credits George

Heathwood for playing a major role in the golf tournament's success. George, who has Parkinson's, runs the SuperWalk in Orillia. When he heard about Greg's fundraising efforts, he pitched in and became one of the tournament's major supporters.

Even Danielle's parents get into the act by bringing friends together for a bocci ball tournament. Last year, the group raised \$500.

All in the family

A while back, Gary Millar took part in a study offering experimental surgery for people with Parkinson's, and he is scheduled for deep brain stimulation later this year. (The Mr. Sub that Greg runs once belonged to Gary.)

For Greg Millar and his family, it all started with a Parkinson diagnosis years ago. It has blossomed into an extraordinary family effort to make a huge difference in the fight against Parkinson's.

Greg Millar and Parkinson Society Canada would like to thank Air Canada for extending the deadline on Greg's trip. We know Greg and Danielle will enjoy their vacation in Europe next year.

Each year, for every \$100 a person collects in pledges, he or she gets a chance to win two Hospitality Class airline tickets to any scheduled international Air Canada destination.

SuperWalk 2005

SuperWalk for Parkinson's

Be part of the success!



Team challenge: We encourage and welcome walkers to involve their co-workers, friends and family and walk as a team. Since our first team challenge, the number of teams participating each year has doubled.

On-line registration: For the third year, we are offering on-line registration whereby walkers can register on-line and send invitations to their friends to join them and pledge them. In 2004, we saw a 117 per cent increase in on-line registration with a 145 per cent increase in on-line donations. Visit www.superwalk.com and join in the fun, the easy way!

SuperSTARWalkers: In 2003, we began highlighting some of our **STARWalkers** who work so hard to raise money for research and support services. In 2004, 216 walkers across Canada raised over \$1,000 each, totaling **close to half a million dollars** from this group alone.

Each September, over 10,000 people across Canada join together and walk to raise funds for Parkinson's. Thanks to the support of these many volunteers, each September, SuperWalk raises more than the year before—and we plan to increase our revenue once again in 2005!

In 2000, we raised \$641,191 with 38 walks. Four years later, in 2004, we had 76 walks and raised almost \$1.7 million.

Along with the support of our walkers and volunteers, Parkinson Society Canada has been fortunate to have many corporate sponsors who consistently give to SuperWalk. All of our sponsors, many of whom return year after year, want to make a difference in

the fight against Parkinson's. Through their cash and prize donations, they make our event exciting and our success a reality!

This September, SuperWalk will once again be taking place in your community. For 2005, we are challenging all walkers to keep the momentum going by raising at least 10 per cent more than last year. So bring your family and friends and walk alongside

all of us and honorary chair, Tom Cochrane, as we "walk towards a cure." Be eligible for prizes and Roots gift certificates while enjoying a great time raising funds for Parkinson's.

***We need you to help us grow.
See you at the walk!***



FIFTH-YEAR SPONSORS



GlaxoSmithKline
Gold level sponsor 2005

GlaxoSmithKline has consistently supported Parkinson Society Canada and specifically SuperWalk for Parkinson's. Their aim is to help PSC succeed in easing the burden for those with Parkinson's. They hope that their commitment will provide more funds to improve support services and research.



Air Canada
Silver level sponsor 2005

PSC is most fortunate to receive Air Canada's support through the annual donation of two international tickets to any scheduled destination—an exceptional prize given to only a select group! Returning as a National Grand Prize Sponsor for the fifth time, Air Canada is a major player in SuperWalk's remarkable growth.

FOURTH-YEAR SPONSORS



WWW.ELDERTREKS.COM

ElderTrekS
Silver level sponsor 2005

ElderTrekS, the customized travel agency for people aged 50 and over, continues to demonstrate its community mindedness as it returns for the fourth consecutive year as a national grand prize sponsor. Their donation of a 10-day trip for two to Costa Rica has been a great incentive, solidly driving pledges upward each year!



THIRD-YEAR SPONSOR



SECOND-YEAR SPONSORS



Kohl & Frisch Limited

Kohl & Frisch
Gold level sponsor 2005

“We are very pleased to support PSC and SuperWalk again this year. We hope through our support that we will be able to raise awareness of Parkinson's and its effects on not just those afflicted with this disease but also those families who bear a very heavy burden. A cure is the ultimate goal. We hope to make a difference in reaching that goal.”

Ron Frisch, President and CEO
Kohl & Frisch Limited



Teva Neuroscience
Gold level sponsor 2005

“Teva Neuroscience is committed to research and development of new products in neurology, particularly in multiple sclerosis and Parkinson's disease. We are privileged to work together with Parkinson Society Canada to achieve their mission to ease the burden and find a cure. To this end, we are proud to continue our support of the Parkinson's SuperWalk in 2005.”

Alison Russell, Marketing Manager,
Parkinson's Disease Market,
Teva Neuroscience

FIRST-YEAR SPONSOR



Solstice
Gold level sponsor 2005

“It is our hope that Solstice's participation in SuperWalk will help encourage everyone to give just that little bit extra—whether it is their time or their money. We will view our participation in this event as a huge success if we know that in some way we have helped SuperWalk have its best year ever.”

Derek Johnson, General Manager, Solstice Beauty



PURE METAL GALVANIZING



Medication matters:

A quick guide to Parkinson's drugs

By Chee Chiu, BSc Pharm

Research has shown that people with Parkinson's disease (PD) do not produce enough dopamine, a chemical that acts as a "messenger" in the brain thus helping to control movement. Since the introduction of the drug levodopa in the early 1970s, medications have been the mainstay of PD treatment.

Over the past few years, the development of new drugs and formulations has continued to improve treatment. However, drug therapy can be complex. For example, PD patients often need to take more than one medication to improve their mobility, to treat other symptoms of their condition, and even to counter adverse reactions caused by their main medication. As a result, people receiving drug treatment for PD need to be aware of a number of medication-related concerns, including compliance issues, possible drug interactions, and contraindications.

Drugs used to treat Parkinson's disease

Levodopa: This is the most commonly used medication in PD and remains the most efficacious treatment. The body converts levodopa

into dopamine in the brain, helping to control some of the main mobility-related symptoms. Levodopa is always administered in combination with carbidopa or benserazide. It has a relatively short duration of action in the brain, so patients often need frequent dosing to maintain optimal therapeutic benefit.



Since 1989, a controlled-release formulation of levodopa/carbidopa (Sinemet-CR) has been available in Canada. Initially, most patients respond favourably to levodopa therapy. However, with disease progression and chronic levodopa therapy, a majority of patients will eventually experience fluctuation in drug response. In these cases, levodopa is usually supplemented with other antiparkinsonian drugs.

There are no relevant interactions between levodopa and other antiparkinsonian agents. However, foods with high protein content can interfere with the release of levodopa in the brain. It is recommended that levodopa medications be taken between 30 minutes to an hour prior to meals, or between one to two hours after a meal. Iron

supplements can decrease levodopa absorption from the intestine and should thus be taken at a different time from the medication.

Dopamine agonists: These medications (bromocriptine, pergolide, ropinirole, pramipexole) mimic the effects of dopamine and act directly on dopamine receptors in the brain. These agents may be used to treat patients with early PD or combined with levodopa for patients in more advanced stages. Most dopamine agonists have a longer duration of response than standard formulations of levodopa. Studies suggest that these agents may be less likely than levodopa therapy alone to provoke involuntary movement. However, they are more likely to cause postural hypotension and hallucination.

Dopamine agonists rarely provide symptom relief at the lowest dose levels. People often require several weeks, or even months, of gradual dose escalation before benefits can be observed. People taking ropinirole need to be aware that some commonly used drugs, such as ciprofloxacin, ranitidine or high doses of estrogens, might increase the amount of ropinirole in the blood by decreasing its breakdown in the liver.

COMT inhibitor (entacapone): This medication restricts the peripheral

metabolism of levodopa, thus enhancing the availability of levodopa in the brain. Entacapone should always be taken with levodopa, as is not effective when used alone. As an adjunct to levodopa, it provides reduced off-times, increased on-times, and enhanced motor function. Diarrhea has been reported as a side effect.

Amantadine: This agent may have a modest effect on the motor symptoms of PD. It can help lessen levodopa-induced motor fluctuation. Side effects include ankle edema, red skin blotches on the legs, hallucination and mental confusion.

Selegiline: This drug may provide mild symptomatic benefit in some patients. It is usually taken once or twice daily, in the morning and no later than noon, to avoid nighttime sleep disruption. Common adverse effects include hallucination and mental confusion. Selegiline should never be given with meperidin (Demerol). Concomitant use of selegiline and antidepressants should also be avoided.

Anticholinergic agents: These agents (trihexyphenidyl, benzotropine) may be beneficial in treating tremor, but patients, especially the elderly, may experience cognitive changes. Many over-the-counter preparations (allergy product, cold and cough products, sleeping aids) have anticholinergic side effects. They are best avoided in older patients.

Drugs contraindicated in Parkinson's disease

Some medications used to treat other conditions block dopamine in the brain. As such, they can induce or worsen the primary features of PD and need to be avoided. These medications include

- some drugs used to treat hallucination and confusion, such as haloperidol, chlorpromazine, thioridazine, perphenazine, thiothixene and flufenazine
- some drugs for gastrointestinal symptoms, including metoclopramide and prochlorperazine
- some drugs for hypertension, including reserpine and alpha-methyl dopa
- flunarizine, used for the prophylaxis of migraine

Medication management

Some people with Parkinson's have to take medications more than eight times a day. The precise timing of when the medication is taken is as important as what medication is taken. An individual dosing schedule should be designed based on daily activity and drug response to manage daily medications easily and effectively.

It is important that you buy all medications at the same drug store and tell all doctors (specialists and family physicians) about all medications being taken, including over-the-counter products.

Above all, if you or a loved one have any questions or concerns regarding medications, consult the doctor and pharmacist immediately.

This article contains general information only. It is not intended to be exhaustive and should not be considered as advice on any particular situation or to replace the advice of a doctor and pharmacist.

Chee Chiu, BSc Pharm, is the co-ordinator of the Living Well with Parkinson's program in Toronto, Ontario.

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca

Our website is constantly being updated. Some of the new material includes the following:

- We have refreshed and updated many pages, and we are working to provide more timely information and to improve the website's look and navigation.
- Read information on local chapters, their support groups and events, and their newsletters. **Click on the map of Canada on our home page and select a region.**
- Nominate your favourite volunteer for the 2005 National Volunteer Awards. New forms are now on-line. **Click on Volunteering.**
- Check out our on-line resources and articles that you can download and print. **Click on Parkinson's and then view the resources listing on the right side of the new page.**
- Order a video copy of the first and second Donald Calne Lecture. **Click on Research and then look for the Donald Calne Lectureship link.**
- Register today to walk with us in September and help us ease the burden and find a cure! **Visit www.superwalk.com.**

Send your comments and general suggestions for our website to general.info@parkinson.ca



In the footsteps of Darwin: My journey to the Galapagos Islands



The blue-footed booby, named for its intense bright blue feet.

Situated 650 miles off the western coast of Ecuador, the Galapagos Islands are officially known as the Archipiélago de Colón in honour of the 400th anniversary of Christopher Columbus' discovery of the Americas. Over 1,900 species of plants and animals are found exclusively in the Galapagos including pioneer plants, lava cacti, Galapagos penguins and flightless cormorants. The most famous visitor to the islands was Charles Darwin, whose theory of evolution was inspired by his 1835 voyage aboard the *HMS Beagle*. Few human residents were in the Galapagos when Darwin arrived; now, more than 20,000 people call it home.

A call to adventure

A glossy brochure, "Celebrity Cruises Introduces the Galapagos," promised me the opportunity to see what Darwin had observed 170 years ago. Cruise activities were at three levels of intensity: high, medium and low. Low was the clincher. I could envision myself on low-intensity rides in upscale Zodiacs (an inflatable rubber boat powered with an outboard motor) in calm Pacific waters.



Carole and Carl at the top of Bartolomé Island.

Ready for the trip

Inexperienced in the ways of Parkinson's, I naively assumed I would feel as well in March on the trip as I did in the previous July when I booked the cruise. Such was not the case. In the intervening months, I became more rigid and less stable. Morning walks, a home gym workout, and senior fitness and Tai Chi classes were my antidote to this decreased mobility. I also used hip protectors to guard against fractures.

Having made the commitment, I was determined to experience the Galapagos first-hand rather than from the vantage point my neurologist preferred: watching the Discovery Channel at home with a glass of fine wine. Nevertheless, I would revisit my decision to go many times.

But what exactly were my limitations? According to the

brochure, the cruise line's key concern was whether I was medically and physically fit for travel so I would neither endanger myself nor others. Physically, I thought I qualified. Early Parkinson's and osteoporosis were my only medical conditions. Psychologically, though, I was somewhat shaky. Along with less mobility had come less self-confidence.

An inauspicious beginning

Finally, on Sunday, March 13, 2005, my husband, Carl, and I arrived in the Galapagos at the airport in Baltra. We had lunch on board the ship and were soon ready for our first activity. Carl encouraged me to accompany him on a medium-level activity: a Zodiac ride along the coastline with a dry landing at North Seymour Island. I agreed.

Twelve passengers donned life jackets and boarded the Zodiac. Our

Ecuadorian driver and guide headed for North Seymour for the anticipated dry landing. But rough seas, the worst in one guide's experience of 25 years, had transformed this dry landing into a wet and slippery one from a rocking, rolling Zodiac.

As I watched my fellow travellers disembark with difficulty, I concluded the best course of action was to stay on the Zodiac. In the end, I was assisted by our excellent guide, and I landed without a scratch, albeit somewhat shaken. What an inauspicious beginning to our Galapagos journey.



A giant tortoise on Española Island.

Once on dry land, our guide apologized for not having noticed my distress earlier. I explained I had Parkinson's and was somewhat unsteady and unsure of my abilities. "Don't worry," she said, "I'll spread the word to the other guides. Speak to us in Spanish (which I

could) so that you can speak openly and with greater privacy." What reassuring words!

Moving along the small boulder terrain of North Seymour, I soon spotted blue-footed boobies, Galapagos sea lions, marine iguanas, frigate birds and swallowtail gulls. This is what I'd come to see.

A whole new world

In the days that followed, we circumnavigated Kicker Rock, the Galapagos version of Gibraltar; swam at a small beach on San Cristóbal, the oldest island in the archipelago; visited giant tortoises on Española; and observed sea lions and Galapagos hawks at Suarez Point. On Santa Cruz Island's Porto Ayora, we visited the Charles Darwin Research Station with its tortoise rearing and island-preservation initiatives.

Low-intensity Zodiac rides and another medium-intensity tricky landing preceded day four of our cruise and the famed high-intensity 113-metre hike/379-step climb to the top of Bartolomé Island. With my husband's encouragement, I hiked, climbed and panted my way up to the summit of the central volcano to the most



A male frigate bird displaying himself to attract a mate.

photographed vista in the Galapagos.

More Zodiac cruising, an almost vertical landing at Tagus Cove on Isabela Island, and a hike along rocks etched with pirate graffiti were also on the itinerary. On Rábida Island, we watched flamingoes in a saltwater lagoon. On Floreana, the last island on our tour, we placed postcards in a postbox—a modern-day version of the barrel used by sailors of yesteryear—to be collected by other visitors and hand-delivered to folks back home.

A once-in-a-lifetime trip

When I'm asked about my journey to the Galapagos, I respond with a certain confidence and pride that I got on with life after my diagnosis, stretched myself beyond my perceived limits, and survived the Galapagos without a scratch.

DON'T MISS AN ISSUE!

Coming in the Fall 2005 issue of *Parkinson Post*

International Congress on Parkinson's Disease

Dr. O. Suchowersky, Lorelei Derwent, RN, and Carol Pantella, RN, give a first-hand account of the 16th International Congress on Parkinson's Disease and Related Disorders, held in Berlin, Germany. More than 3,000 participants, including many Canadian doctors and scientists, from 73 countries took part.

Donald Calne Lecture and 2005 AGM

Read about the third annual Donald Calne Lecture and the 2005 Annual General Meeting to be held in Winnipeg, Manitoba.

Young-Onset

A practical and personal look at Parkinson's disease, as experienced by individuals under the age of 40. As the implications of Parkinson's

are very different, we will explore the complex issues and latest developments in the field of Young-Onset Parkinson's.

Subscriber survey

We want to know what you think about *Parkinson Post*. Please take a moment to complete and return the survey that will be included in the Fall 2005 *Parkinson Post*.

A look at current Parkinson's research around the world

Research Editor: Dr. John Wherrett

The Parkinson Society of the United Kingdom classifies research into four categories:

1. **Clinical:** Neurology and clinical trials, surgical therapy, clinical psychology, genetic studies, medical imaging, gene therapy, pathological studies, epidemiologic studies, health services research, technological developments for clinical care, etc.
2. **Pharmacology:** Medications and drug therapies, etc.
3. **Models and new therapies:** Stem cells, molecular biology, animal models, etc.
4. **Care:** Health care, social care, social policy, etc.

In this issue, recent interesting work in the first three areas is summarized.

Improving function through learning

Experts believe that with properly directed training, improved function can be maintained in people with motor and cognitive impairments, such as those caused by Parkinson's.

Researchers from the National Institutes of Health in Bethesda used the technique of functional magnetic resonance imaging (fMRI) to assess patterns of brain activation during learning of a simple skill, as well as a more complex motor skill equivalent to learning tunes of four and 12 notes on a piano. Normally, learning these sequences of finger movements become automatic, even to the point that an individual can continue the sequences while carrying out another activity, such as visually counting letters (as in this particular study).

In the study, the control subjects learned to perform the simple and complex tasks automatically, compared to only 25 per cent of the people with Parkinson's. These motor learning tasks are associated with activation of multiple distributed regions in the brain as observed with fMRI. When the task becomes automatic, the degree of activation

in these areas is diminished indicating that the brain has become more efficient and is actually working less. In the Parkinson's group, it was found that although tasks had become automatic, areas of the brain that had been activated did not show a reduction in activation. This indicates that people with Parkinson's learn to perform new motor sequences automatically, but their brains have to work harder to compensate for the dysfunction in the basal ganglia. It offers further evidence that training and fitness can improve motor function for people with Parkinson's.

Researchers from New Zealand took a different approach to studying forms of learning. The group used neuropsychologic test methods to assess what is referred to as "implicit memory," a form of memory and learning that is automatic in the sense that the person gaining the skill is unaware that they have gained a new ability.

Subjects (people with Parkinson's and controls) were seated in front of a computer screen where they were presented with different pictures in different locations on the screen,

which they were asked to identify and locate. The subjects were unaware that the objects and locations were presented in recurring sequences. It became apparent that the subjects subconsciously learned these underlying sequences, because they responded more quickly than they would have if the presentation were random. The Parkinson's subjects who participated in this study automatically learned sequences of either the pictures or their locations but had more difficulty than controls in automatically learning sequences integrating both pictures and locations. Thus, this study shows that the basal ganglia affected in Parkinson's are important for automatic cognitive functions as well as motor activities.

References: *Brain* 2005, *Neuropsychologia* 2005

The promise of immunization

Since scientists have recognized that human neurodegenerative diseases result from the build-up of proteins that are toxic to nerve cells, evidence has accumulated that immunization might be used to boost the capacity of brain cells to dispose or destroy the injurious proteins.

EDITOR'S NOTE: Please remember that clinical studies, research findings and other information featured in *Research Report* are often of a preliminary or investigative nature. Results may not be applicable to all cases and actual treatments resulting from findings can take time to be developed. The information contained here is for interest only and should not be construed as advice or recommendations.

und the world

Much interest was generated by initial studies using mice with an experimental form of Alzheimer disease resulting from implantation of a human Alzheimer gene.

Immunization of these mice with the protein β -amyloid that accumulates in Alzheimer disease resulted in a striking reduction of this toxic protein and an improvement in memory tests for the mice.

As a result, a trial was carried out with patients with Alzheimer disease—ultimately demonstrating important reductions in the β -amyloid in brain. Unfortunately, there was a strong inflammatory reaction in some patients and the trial had to be stopped. However, the investigators believe the inflammatory reactions can be circumvented by altering the immunization procedures, and the work in Alzheimer disease continues.

Similar approaches are now being undertaken in other neurodegenerative diseases where proteins thought to be toxic accumulate. This includes Parkinson's disease, where the toxic protein is thought to be α -synuclein. In June of this year, the investigators who carried out the studies in Alzheimer disease reported their results with immunizations in a mouse genetic model of Parkinson's disease. A reduction in α -synuclein accumulation was found, whether the antigenic protein itself, or an antibody to it, was used.

This work strongly suggests that the technique could be effective. Further development of this approach to treatment of Parkinson's disease to delay progression should be pursued.

Reference: *Neuron* June 2005.



Focus on ...



Dr. Connie Marras

**Morton and Gloria Shulman
Movement Disorders Centre,
Toronto Western Hospital**

As a neurology resident at the University of Toronto (U of T), Dr. Connie Marras received a first-hand look at the challenges of treating Parkinson's disease at the renowned Morton and Gloria Shulman Movement

Disorders Centre (MDC) at Toronto Western Hospital.

"We all had to do a research project as part of our training, and mine was on movement disorders," she recalls. "With a history of Parkinson's disease in my own family, it seemed particularly appropriate to focus on this important area."

Dr. Marras has since done exactly that, completing a fellowship at the MDC and undertaking epidemiology (the study of the incidence and distribution of diseases in populations) and research training at the U of T and at the Parkinson's Institute in California. Now, after recently completing her PhD (with funding from Parkinson Society Canada), she has joined Dr. Tony Lang's team as the newest member of the MDC faculty (see page 8).

"As a neurologist and epidemiologist, I am able to combine my training at the Centre," says Dr. Marras. "I am involved in the clinical side, providing patient care. And I am also participating in research that may help provide valuable information on the causes and treatment of the disease."

One of her research projects involves the study of two families with genetic mutations that make them susceptible to an inherited form of Parkinson's disease. "Using this as a model for the more common form of Parkinson's, we might be able to find ways of predicting who may or may not develop the disease."

Since she only joined the faculty on July 1, Dr. Marras is just getting started and will be involved in many more crucial research projects. "Research, particularly in the field of epidemiology, can be painstaking and time-consuming," Dr. Marras notes. However, the data from these kinds of studies provide essential pieces of the Parkinson's puzzle.

Editor's note: Dr. Marras was the recipient of a \$90,000 PSC Clinical Research Fellowship for the 2003–2005 cycle for her project, "Parkinson's disease prognosis."

Finding more clues

For some time it has been recognized that Parkinson's disease has many features in addition to the motor disorder originally recognized by Dr. James Parkinson.

Although disturbances in control of blood pressure, namely a reduction on standing up (orthostatic hypertension), have been observed for a very long time, the extent of the potential involvement of the autonomic nervous system that controls the body's automatic functions has recently begun to receive particular attention.

New studies have suggested that there is loss of adrenalin-containing nerve fibres in the heart,

which can be detected by an isotope scanning method. Loss of these fibres appears to be characteristic of Parkinson syndromes with Lewy bodies and can be used to distinguish these forms from other Parkinson-like disorders, such as progressive supranuclear palsy, multiple system atrophy and, sometimes, Alzheimer disease.

A recent pathological study from Japan has confirmed these findings in post-mortem heart tissue using special staining techniques. This loss of the so-called sympathetic (adrenalin) nerve fibres from the heart appears to be an early development in Parkinson's disease.

Reference: *Acta Neuropathologica* June 2005.

National Research Program Awards for 2005–2007 cycle

Granting period July 1, 2005, to June 30, 2007.

Parkinson Society Canada (PSC) is pleased to announce the recipients of its 2005–2007 Funding Awards for the National Research Program. For full descriptions of these and other current PSC-funded research awards, please visit www.parkinson.ca/research.

Researcher	Name of project	Institution	Total award over two years
Pilot Project Grants (one year grant)			
Mark G. Carpenter	Trunk control and balance impairment in Parkinson's disease.	University of British Columbia	\$45,000
Friedman Pilot Project Grant David S. Park	Mechanism of DJ-1 induced neuroprotection: Involvement of the AKT pathway.	University of Ottawa	\$45,000
George S. Robertson and Murray Hong	Improved survival and function of fetal dopaminergic xenografts by XIAP.	Dalhousie University	\$44,554
Claude Rouillard and Daniel Levesque	Nurr77, a natural born killer or a neuroprotector for midbrain dopamine neurons?	Laval University Hospital Centre (CHUL)	\$45,000
Jean A. Saint-Cyr and Mary-Pat McAndrews	Activation of compensatory cognitive circuits in PD as shown by fMRI.	Toronto Western Hospital	\$45,000
Anurag Tandon	Development of a genetic model of PD pathobiology in cultured human cells.	Centre for Research in Neurodegenerative Diseases University of Toronto	\$45,000
John Woulfe and David Munoz	Neuronal intranuclear rodlets in Parkinson's disease.	Ottawa Health Research Institute	\$45,000
New Investigator Grant			
Lesley Fellows	Dopamine and prefrontal cognition: Dissecting the contributions of disease and treatment to disordered reward processing in Parkinson's disease.	McGill University	\$89,100
Shucui Jiang	Effect of guanosine on proteasome inhibitor-induced Parkinson's disease in rats.	McMaster University	\$89,840
Ekaterina Rogaeva	Comprehensive genetic analysis of LRRK2: A novel causative Parkinson's disease gene.	University of Toronto	\$90,000
Vince Tropepe	Dopaminergic neuronal maintenance through recurrent transcriptional regulation.	University of Toronto	\$64,900
Fellow	Field of training	Institution	Total award over two years
Basic Research Fellowships			
Emdadul Haque	Role of PINK1 in models of Parkinson's disease.	University of Ottawa	\$95,000
Qiang Nai	Selective modulation of NMDA receptor-mediated neurotoxicity: A new approach in the treatment of Parkinson's disease.	University of Toronto	\$95,000
Martin Parent	Role of Pitx3 in survival of the subset of dopaminergic neurons affected in Parkinson's disease.	Montreal Neurological Institute and Hospital	\$76,000
The Margaret Galloway Basic Research Fellowship Gang Zhang	The role of Pitx3 in specifying neural stem cells toward a dopaminergic neuronal identity.	University of Toronto	\$76,000
Clinical Movement Disorders Fellowship (one year fellowship)			
Boehringer Ingelheim CMD Fellowship Teri R. Thomsen	Diagnosis and management of Parkinson's disease.	Morton and Gloria Shulman Movement Disorder Clinic–Toronto Western Hospital	\$45,000
Clinical Research Fellowship			
Nicolas Jodoin	Mechanisms of action in deep brain stimulation for Parkinson's.	Centre hospitalier universitaire Pitié-Salpêtrière in Paris, France	\$90,000
Total funds awarded			\$1,125,394

National Clinical Assistance and Community Outreach Program Grant Awards for 2005–2006 cycle

Granting period June 1, 2005, to May 31, 2006.

Parkinson Society Canada (PSC) provides financial support through our Clinical Assistance and Community Outreach Grant Programs (CACOP) to support the provision of health care services to people with Parkinson's across the country. PSC is proud to acknowledge these clinics and programs as valuable partners working to ease the burden and find a cure. For more information about the CACOP programs, please visit our website at www.parkinson.ca/support/clinics.html.

Clinical Assistance Grants		
Neurologist	Clinic/Centre	Location
RBC Foundation Clinical Assistance Grant Dr. Sylvain Chouinard, Dr. Michel Panisset	Andre Barbeau Movement Disorders Clinic, Hotel Dieu - CHUM	Montreal, QC
Dr. Alan Goodridge	Movement Disorder Clinic, Health Sciences Centre, Memorial University of Newfoundland	St. John's, NL
K. Bearg Clinical Assistance Grant Dr. David Grimes	Parkinson's Disease and Movement Disorders Clinic, University of Ottawa, Ottawa Hospital - Civic Campus	Ottawa, ON
Dr. Doug Hobson	Movement Disorder Program, St. Boniface Clinic, University of Manitoba	Winnipeg, MB
Dr. Mandar Jog	Movement Disorders Clinic, London Health Sciences Centre	London, ON
Dr. Anne-Louise Lafontaine	McGill Movement Disorders Clinic, McGill University, Montreal Neurological Hospital	Montreal, QC
Dr. Anthony Lang	Movement Disorders Centre, Toronto Western Hospital	Toronto, ON
"The Donors from Agincourt" Clinical Assistance Grant Dr. Wayne Martin	Movement Disorders Clinic, Glenrose Rehabilitation Hospital	Edmonton, AB
K. Bearg Clinical Assistance Grant Dr. Calvin Melmed	Department of Neurosciences, Jewish General Hospital	Montreal, QC
Dr. Giovanna Pari	Movement Disorder Clinic, Kingston General Hospital	Kingston, ON
Dr. Emmanuelle Pourcher	Quebec Memory and Motor Skills Disorders Clinic, Laval University	Quebec City, QC
Dr. Jean Rivest	Movement Disorders Clinic, CHUS	Fleurimont, QC
K. Bearg Clinical Assistance Grant Dr. Jon Stoessel	Neurodegenerative Disorders Clinic, Pacific Parkinson's Research Centre, University of British Columbia	Vancouver, BC
Dr. Oksana Suchowersky	The Movement Disorders Program of Southern Alberta, Foothills Medical Centre, University of Calgary	Calgary, AB
Community Outreach Grants		
Applicant	Clinic/Centre	Location
Bonnie Bereskin	The Parkinson's Speech Group	Toronto, ON
RBC Foundation Community Outreach Grant Chee Chiu	North York General Hospital Seniors Health Centre	North York, ON
TD Bank Financial Group Community Outreach Grant Dr. Mandar Jog	Movement Disorders Program, London Health Sciences Centre	London, ON
Bonnie McInnes	Community Services and Outreach, St. Peter's Hospital	Hamilton, ON
CIBC Community Outreach Grant Mary Narrowmore	VON St. John Inc.	Saint John, NB
"The Donors from Agincourt" Community Outreach Grant Roseanne Norton	VON Niagara Inc.	Thorold, ON
"The Donors from Agincourt" Community Outreach Grant Dr. George Turnbull	School of Physiotherapy, Dalhousie University	Halifax, NS

Q *I'm a young onset woman with Parkinson's. Are there any special issues that I need to know of?*

A Younger and middle-aged women diagnosed with Parkinson's disease face a number of special challenges. These can include adjustment disorder, sexuality issues, menstruation and menopause, pregnancy and breast-feeding.

Sexuality

One of the most important issues you may face is sexuality. Experts have identified myths regarding women with a serious medical condition (e.g., Parkinson's) and sexuality. For example, many wrongly believe that

- women with a medical condition are asexual
- only independently functioning women can handle sexual relationships
- women with a medical condition are celibate
- women with a medical condition cannot be mothers
- all women with a medical condition are heterosexual.

These myths need to be dispelled. Parkinson's disease should not diminish your overall sexuality. However, your condition may present certain challenges.



Sexual dysfunction can accompany Parkinson's and be devastating for a woman used to a sexually fulfilling relationship.

Fatigue, inadequate symptom control, hypotension, poor self-image, depression—all issues associated with Parkinson's disease—can contribute to sexual failure. The need to time sex to coincide with being well rested and when medications are working can reduce spontaneity, and some partners feel the desire is only driven by the drugs and is therefore artificial.

In addition, some women may not achieve orgasm if their drugs are not working or if the drugs wear off during sex. Manual stimulation or the use of a small battery powered vibrator before or after intercourse can help. There can also be an increase in tremor during intercourse, which may interrupt the sexual act. Creative "positioning" can eliminate this challenge.

Don't be afraid to talk about any sexual problems with your health professional, even though you may not be used to discussing such intimate matters. With professional help, many sexuality-related problems can be resolved.

If your physician or health professional recommends referral to a therapist or other expert in sexuality and a sexual regular partner (e.g., spouse) is involved, you should both attend any consultation or counselling together.

Menstruation and menopause

Many younger women report an increase in symptoms (tremor) or drug side-effects, such as dyskinesia, if they have premenstrual syndrome (PMS). This increase can also occur during menstruation.

Women with regular cycles can talk to their physician about increasing or decreasing their medications as their PMS time approaches.

Peri-menopausal women may also have difficulties with symptoms that exacerbate their Parkinson's. Hormone replacement therapy (HRT) has fluctuated between being considered a "miracle drug" and being a "poison" over the last decade, but if carefully screened and fully informed, many women can benefit from HRT if menopausal symptoms are negatively affecting their Parkinson's and their relationships.

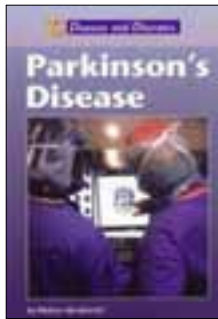
If you are experiencing vaginal dryness and do not want to take oral HRT, a sub-therapeutic dose of vaginal HRT cream used twice a week reduces the need for external lubricants. Any treatment (exercise, antidepressants, etc.) that helps unwanted effects of menopause will help Parkinson's symptoms by removing exacerbating factors.

Again, if you have any concerns about menstruation or menopause, speak to the appropriate health professional.

Editor's note: Ask the Expert will address pregnancy and breast-feeding in an upcoming issue of Parkinson Post.

Susan M. Calne, CM, RN, NPF,
Co-ordinator, Pacific Parkinson's Research Centre, Vancouver Hospital and Health Sciences Centre, Vancouver, BC.

Adapted from "What problems do women with PD face?" in the Spring 2005 issue of the EPNN Journal, the journal of the European Parkinson's Nurses Network.



Parkinson's Disease

By Melissa Abramovitz

*Reviewed by
Marilee Weisman*

For her work on *Parkinson's Disease*, Author Melissa Abramovitz deserves full marks for her writing skills. Packing so much dry material into more than 100 pages in a compact book (6" x 9") is not an easy task. The small book size leaves too little time for the subtle nuances that give a book a sense of reality.

Although the writing is strong, the choice of photos could be better. There are too many unnecessary pictures of doctors writing prescriptions or staring at computer monitors. One picture features a man in a white lab coat dissecting the brains of deceased Parkinson patients.

This book looks like a textbook yet delivers "just the facts ma'am, just the facts."

Parkinson's Disease, published by Lucent Books, is available at your local bookstore.



I'll Hold Your Hand So You Won't Fall: A Child's Guide to Parkinson's Disease

By Rasheda Ali

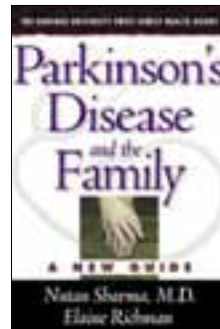
*Reviewed by
Gerry and Jia Kelleher*

This book, written by the daughter of Muhammad Ali, will help children understand the causes and symptoms of Parkinson's disease. Every page has facts that give children a better grasp of what their loved ones are coping with.

If we are not careful, however, children can misunderstand what they are reading, so it's important that you sit and read this book with your child. For example, as we read along together, my eight-year-old daughter had more questions about Parkinson's which led to longer discussions about the disease.

This book takes the disease one step at a time and gets the child interested, making it more comfortable for him or her to pose more questions.

I'll Hold Your Hand ... is available at your local bookstore.



Parkinson's Disease and the Family: A New Guide

*By Nutan Sharma, MD,
and Elaine Richman*

Reviewed by Gerry Kelleher

This is by far the best book on Parkinson's disease that I've read. The authors provide information not only on the diagnosis and treatment of the disease but also on its effects on family dynamics.

The book was written in simple terms with no big phrases or words. Once you start to read it, you are enticed to read on. The chapter titled "The Wedding" is wonderful and brings home the reality of that special day where those of us with daughters wonder if we'll be able to walk them down the aisle and dance at their weddings.

Enjoy this book; it is a must read.

Available at your local bookstore.



<http://chealth.canoe.ca>

Reviewed by Peggy Yates

C-Health contains information on a variety of health topics, and it has an array of material specific to Parkinson's disease. Type in the word "Parkinson's" in the search engine, and you'll be connected to a variety of sub-topics. Categories include Drug Fact Sheets, Condition Fact Sheets, Recommended Articles, Information on Community Support Groups, and Health News.

The Health News section is particularly informative as it contains articles specifically relating to medication, depression and pain relief.

Inside C-Health contains general health material in other informative sections, including Health Poll, Health Videos, and an Alternative Health Directory.

To learn more, visit <http://chealth.canoe.ca>.

Please remember that while Parkinson Society Canada provides information about the availability of new resources in this section, this does not necessarily imply recommendation or endorsement of the contents.

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National Office**

To discuss a planned gift or request an information kit, please call:
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www.parkinson.ca/donating/theparkinsonlegacy.html

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Ph: (604) 662-3240
Toll Free (BC only):
(800) 668-3330

**Victoria Epilepsy and
Parkinson's Centre Society**

Ph: (250) 475-6677

**The Parkinson's Society of
Alberta**

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Toll Free: (888) 873-9801

**The Parkinson's Society of
Southern Alberta**

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