Summer 2007 • Volume 7 • Issue 2
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Best of Research

ParkinsonPost

A magazine for Canadians living with Parkinson's

Robo doc:

How Dr. Ivar Mendez is changing patient care

Advances in research:

- Progress reports on PSC-funded projects
- First Psychosocial Research Grant awarded

PLUS

SuperWalk takes one step closer to a cure

Parkinson Society Canada
Société Parkinson Canada
Ease the Burden; Find a Cure

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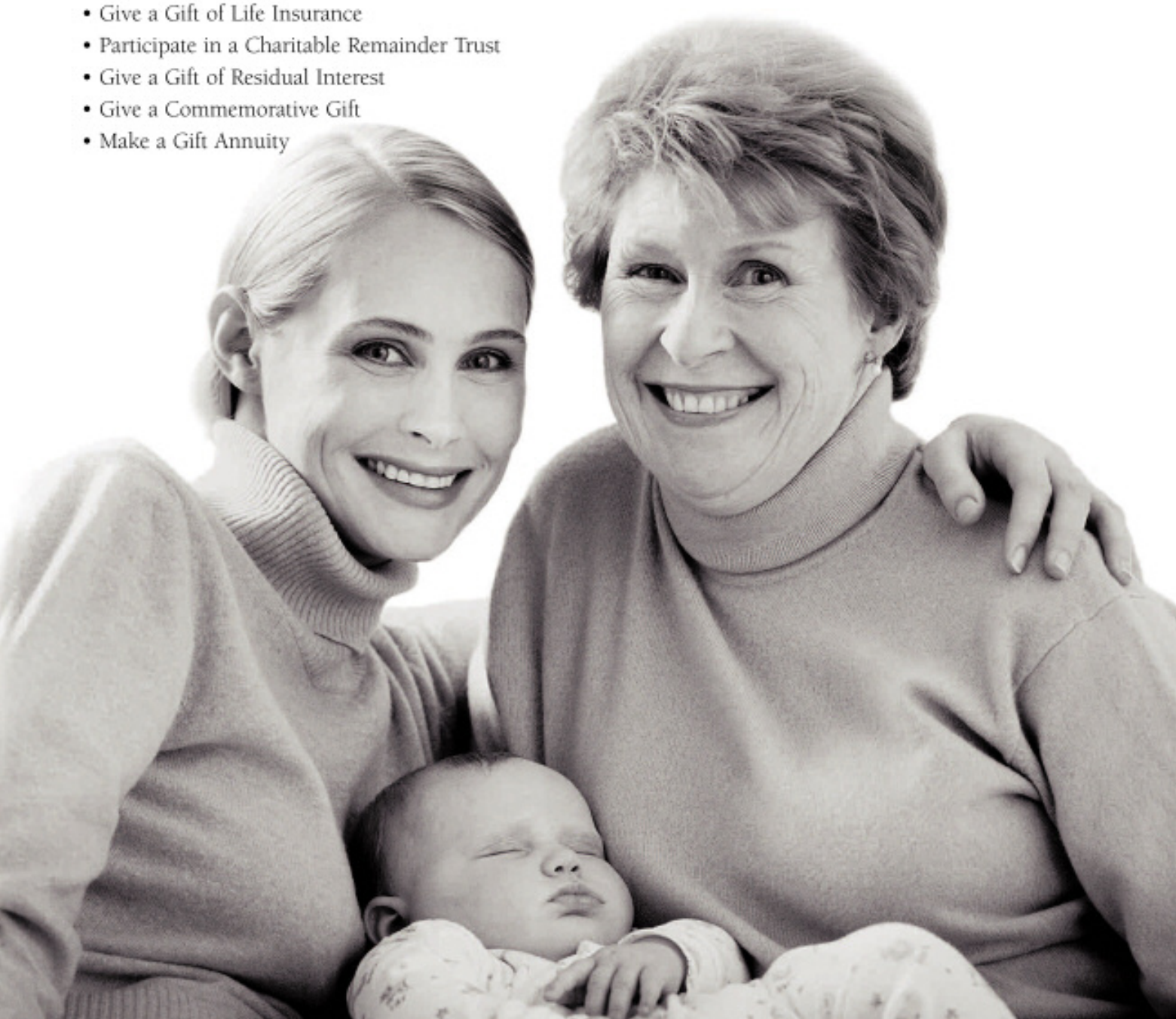

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ON OUR COVER:
Howard Bonnell poses with Canada's first-ever remote-presence robot. The robot allows Dr. Ivar Mendez, shown on the robot's screen, to interact with patients while being at a remote location. Read more on this robot on page 8.

Together, we're better

Parkinson Society Canada (PSC) has recently been brainstorming ways to further engage the research, education and service communities to help people living with Parkinson's disease (PD). There is ample evidence for successful strategic alliances between researchers in other fields and their communities.

How can those in the academic research arena work with PSC? The academic research community and PSC met in Calgary on April 18th to discuss this question. Leading Canadian researchers met with eight PSC representatives. The theme of the meeting and the conversation was "think big; think partnerships."

During the meeting, many ideas emerged about how to meet the growing needs of people with Parkinson's in Canada. Attendees reached a general consensus that organized co-operation between PD research and care is needed. As a result, the Academic Research Alliance was born. Such an alliance would attract medical residents and fellows to PD. It would communicate to trainees the job opportunities in movement disorders and increase the number of potential future neurologists and movement disorder specialists.

Marketing and public education about PD and movement disorders must remain a priority, and PSC must and will continue to be an invaluable resource to carry out this role.

Working to develop clinical practice guidelines for PD and thinking about creating alliance guidelines that will cover advocacy and social actions would provide an integrated and co-ordinated effort.

Attendees of the meeting came away with a commitment for academic institutions to work together with PSC to help position PD as a priority health issue on both national and provincial health agendas.

We will work together to get the ears of all government representatives and to increase funds for research and care. And we must continue to foster individual innovations to encourage discovery.

There is a world of possibilities, and there appears to be an opportunity for PSC and the academic researchers to become greater than the sum of our parts. Stay tuned for an upcoming Academic Research Alliance meeting early in 2008.

Joyce Gordon,
President and CEO,
Parkinson Society Canada

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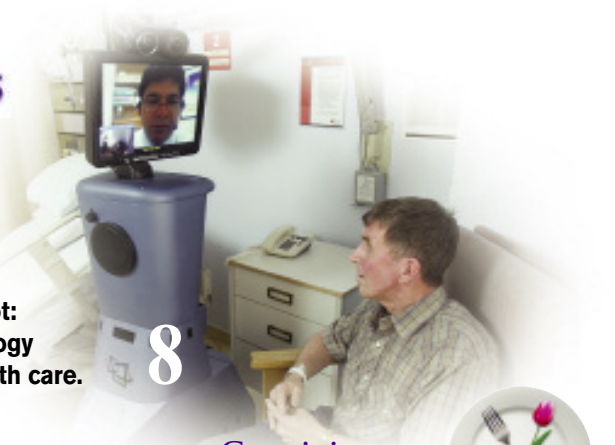

COLUMNS

ParkinsonPost
A magazine for Canadians living with Parkinson's

Parkinson Post Vol. 7, Issue 2, Summer 2007

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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:

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Toronto, ON M2P 2A9
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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

- As part of their April Awareness campaign, Parkinson Society British Columbia held its second annual "An Affair to Remember." The Tango Argentino Gala was attended by 280 guests and raised $40,000 for research and support services.
- Three new support groups have been started in the lower mainland of Vancouver.
- The Director of Support Services made 20 visits to support groups across the province.
- PSBC has planned its first three-day conference called, "Parkinson's: The Journey." This educational forum features prominent speakers. Registration details are at www.parkinson.bc.ca.

Victoria Epilepsy and Parkinson Centre

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

- Educational events will now focus on an interactive workshop model that supports clients in developing specific health and emotional action plans.
- The popular stress-management program has been successfully expanded to serve those with epilepsy.
- The annual golf tournament raised $50,000.
- Plans are underway for the September SuperWalk and Parkinson's Festival.
- The agency is in a strong financial position to continue increasing client service staffing levels.

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

- The Annual General Meeting and Annie Wyley Memorial Lecture was held on April 21, 2007.
- Two new Board Members, Ken Grimes and Dave Fraser, have been appointed to the Board of Directors. Gord Green has retired.
- PSA hosted a volunteer appreciation event as part of its April Awareness activities.

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

- In June, four eager participants spent a stimulating and challenging day of media training offered by PSC national office.
- Lethbridge and Red Deer held a successful one-day conference with Geriatric Psychologist Dr. John Kennedy, who spoke about the links between Parkinson's disease and depression.
- On June 1, 2007, Dr. Colin Powell spoke to members of PSSA on his work, *When the Pills Stop Working*.
- Long time Executive Director Judy Axelson said goodbye in May. We wish her all the best and thank her for her leadership and excellent service.

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

- The Regina Curling Classic for Parkinson's Research in Saskatchewan was a resounding success. Thank you to all the volunteers and participants.
- The PW Golf Classic is completely sold out and will be held on August 22, 2007.
- The 2007 Saskatoon SuperWalk will be held on September 9, 2007.

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

- PSM will be celebrating the 10th anniversary of the Manitoba SuperWalk this September. For more information, visit www.superwalk.com.
- In June, Parkinson Society Manitoba welcomed Howard Koks as the new Executive Director. Howard can be reached at 1-866-999-5558 or 204-786-2637.
- The Winnipeg Foundation's Youth in Philanthropy Committee from Tec Voc High School awarded Parkinson Society Manitoba a $1,000 grant.

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Parkinson Society Canada
Société Parkinson Canada

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

- Twenty-one SuperWalks will be held in communities across CNOR this September. Visit www.superwalk.com to participate.
- The 17th annual Pitch-in-for Parkinson's with the Toronto Blue Jays was held on June 21, and the 11th Annual Golf Classic was held on June 6.
- There were two winners of the Marilyn Forbes Volunteer Award: Jill Bethune-Williams from Toronto and Ian Pearson from Mississauga.
- The second annual Derek Curwen Volunteer Award winner was Bill Heinmiller from Peterborough.
- Debbie Davis is the new Executive Director. She takes over from Chris Rawn-Kane.

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

- The final pilot of "PEP for Community Caregivers: A Workshop for Trainers" was held on May 2. Sixteen health care professionals have been trained, and representatives from BC, the Maritimes and the national organization audited the workshop.
- SWO participated in a provincial advocacy day at Queen's Park on March 28, 2007.
- Thank you to the volunteers who made the April Awareness Celebrations successful. SWO held a Tulip Benefit, Cut-A-Thon, Fresh Cut Tulip Sales, Regional Raffle and a media blitz.

Parkinson Society Ottawa

1053 Carling Avenue
Ottawa, ON K1Y 4E9
Ph: (613) 722-9238
Fax: (613) 722-3241
www.parkinsons.ca

- On June 16, 2007, the Embassy of the Czech Republic and Bittersweet Gallery held an exhibition of paintings by Hugh Malcolm. Proceeds of the "Activities of the Mind" exhibit benefited both Artwell and Parkinson Society Ottawa.
- On April 25, 2007, Dr. Jackalina Van Kampen addressed a full house on her continuing work on brain cell regeneration.
- Dennise Taylor-Gilhen has been hired as the new Executive Director for Parkinson Society Ottawa.

Parkinson Society Quebec

550 Sherbrooke Street West
Office 1470, Tower West
Montreal, QC H3A 1B9
Ph: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.parkinsonquebec.ca

- Parkinson Society Quebec hosted the second annual Cyclo Parkinson 2007 on June 16.
- Charles Andre Bordeleau is the new Director of Operations and Corporate Development.

Parkinson Society 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.parkinsonmaritimes.ca

- The Rasheda Ali visit to Halifax received widespread regional media coverage and sold out the fundraising dinner.
- Plates for Parkinson's, a collection of celebrity-designed and autographed plates, raised more than $15,000 in its first year, in support of support services and education.
- Porridge for Parkinson's marked its fifth anniversary in Fredericton, raising more than $10,000.
- Janet Millar, winner of the 2006 Mimi Feutl Award, participated in April Awareness Month lecture series in Moncton, Charlottetown, Truro and Halifax.
- A successful advertising campaign featuring Rita MacNeil, Colleen Jones and Terry Kelly was launched.

Parkinson Society Newfoundland and Labrador

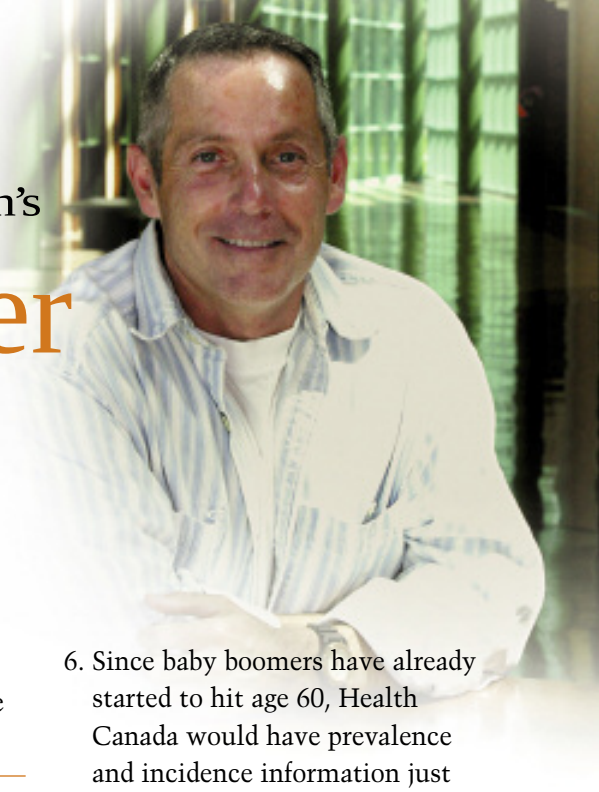
The Viking Building
136 Crosbie Road, Suite 305
St. John's, NL A1B 3K3
Ph: (709) 754-4428
Toll Free (NL): (800) 567-7020
Fax: (709) 754-5868

- PSNL is a recipient of funds from the PharaChoice Golf Tournament in August.
- The Parkinson Community Education Program has been held in five sites across the Island.
- PSNL recognized PSC's research program at Memorial University on April 12, 2007. Guest speakers included the Honourable Ross Wiseman, the Minister of Health and Community Services, and Joyce Gordon, Parkinson Society Canada President and CEO.
- PSNL surveyed northern Newfoundland to determine the area's educational needs.
- Dr. Jon Stoessl will be visiting the region in September.

Parkinson Society Canada
Société Parkinson Canada

Issues of interest to people with Parkinson's

Your letters matter



By Yvon Trepanier, Chair, National Advocacy Committee

I recently received a copy of the following letter which was sent to the federal Minister of Health by one of my fellow PSC board members, Shirley Roberts. I was struck by how well Shirley captured our message so I wanted to share it with you.

If you have not already done so, please write a similar letter to your Member of Parliament and the federal Minister of Health—and encourage your family and friends to do the same. Your letters really do matter!

Dear Minister Clement:

This letter is a follow-up to your letter of December 15, 2006, to Joyce Gordon, President and CEO, and to Yvon Trepanier, Board Member, Parkinson Society Canada. The purpose of this letter is to "fast forward to 2008 and beyond" to let you know the monumental achievements that are possible if you grant Parkinson Society Canada's request for $5 million to conduct an epidemiological study of Parkinson's disease.

Possible achievements from the Parkinson's epidemiological study:

1. The study could identify environmental, demographic, lifestyle/behavioural and medical risk factors for Parkinson's disease, by region. This would give health professionals and researchers new insights into the causes of the disease.

2. Canadians who develop Parkinson's disease could receive an earlier diagnosis and better care because risk factors would be better understood. Therefore, they could stay independent longer, and they and their caregivers could continue to work longer. The Canadian government would therefore obtain higher tax revenues and make substantial savings in health care costs.

3. The study could identify demographic groups that have a high incidence of early onset Parkinson's disease. This would likely lead to new and more specific medical research initiatives.

4. Media seeks opportunities to publish new medical research findings. Widespread publicity about the prevalence and incidence of Parkinson's disease could attract more donations to find a cure from both corporations and the public.

5. Parkinson Society Canada could allocate greater education and counselling resources to regions with the highest prevalence of Parkinson's disease.

6. Since baby boomers have already started to hit age 60, Health Canada would have prevalence and incidence information just in time to make better decisions about health care services needed for this progressive, neurodegenerative, age-related disease.

7. More medical students would be attracted to neurology because they would be aware of the increasing demand for this specialty and would have a better understanding of the disease. Wait times to see neurologists may therefore go down, or at least not increase, for people living with Parkinson's.

Mr. Clement, you have the ability to change the course of this devastating disease in Canada. The ramifications of your decision to fund a Parkinson's epidemiological study will be extensive and long lasting. Thank you for your serious consideration of this request.

Yours truly,
Shirley Roberts

To receive an electronic version of this letter, please e-mail advocacy@parkinson.ca.

Not your average robot:

Leading-edge technology is revolutionizing health care

Dr. Ivar Mendez, Chief of Neurosurgery at the Queen Elizabeth II Health Science Centre in Halifax, can provide follow-up care for his patients via the robot.

By Shannon MacDonald

Dr. Ivar Mendez, chief of neurosurgery at the Queen Elizabeth II Health Science Centre in Halifax and chair of the Brain Repair Centre, is taking the concept of universal access to specialized care to new heights with the introduction of Canada's first-ever remote-presence robot.

"In 2002, we were dealing with very long waiting lists for neurosurgery," recalls Dr. Mendez. And, with the only team of specialized neurosurgeons in the region, patients requiring specialized neurosurgical procedures were required to travel to Halifax for consultations, surgery and follow-up. The issue was compounded by a reduction in operating time in Halifax. The only solution: find a way to deliver expert neurosurgical care in community-based hospitals throughout the region.

The robot, operated by Dr. Mendez from his office, travels through the hospital's corridor to visit each patient with Parkinson's.

Changing neurosurgical care

Five years later, Dr. Mendez and his team have revolutionized neurosurgical care in Atlantic Canada by developing leading-edge technological tools to deliver expert care to patients, regardless of where they live or where their physician happens to be.

"The program developed in stages," says Dr. Mendez. "Our first solution was the introduction of a robotic arm that neurosurgeons in local hospitals would use with assis-

tance from specialists in Halifax." This allowed the team to treat patients closer to home and to support very competent neurosurgeons in performing complex procedures, but the applications were limited.

The second phase focused on movement disorders, specifically on people with Parkinson's disease. Waiting lists were growing while operating room time was being reduced. "For example, people with Parkinson's were waiting three years for deep brain stimulation (DBS) surgery. We needed to find a new way of working," says Dr. Mendez. But the problem was about more than simply transporting the human expertise. Highly specialized procedures like DBS require sophisticated technology and infrastructure, neither of which was available in community-based hospitals.

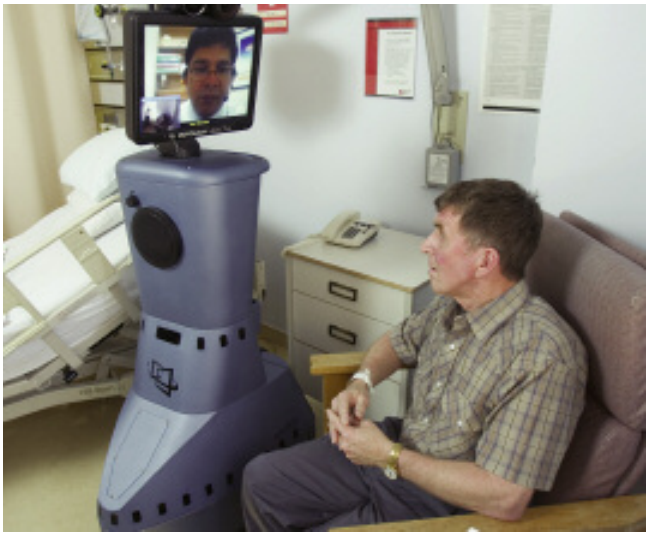
Making care portable

So, Dr. Mendez began working on the idea of being fully portable. "If we were going to perform DBS in a local hospital, we needed a stand-alone computer system capable of doing electrophysiological recordings during the procedure." The result fit into a briefcase and travelled with the team to St. John, New Brunswick, where they significantly reduced the waiting list for DBS. Patients were still required to travel to Halifax for their follow-up programming appointment.

"Our goal was always to care for people close to home, so although we had found a way to perform the surgery locally, we were not satisfied because they still needed to travel for follow-up," recalls Mendez. The team began working with In Touch Health, a California-based technology company, to develop Canada's first-ever remote-presence robot. Already, Dr. Mendez can see the day when a fleet of at least five robots are working throughout the region.

Interacting in real time

With the body mass of a small adult, the robot resembles a large vacuum cleaner with a flat screen on top (where the physician appears in real time when operational). It's not nearly as fancy as R2D2 from *Star Wars*, but don't be fooled: this machine houses state-of-the-art technology that allows for a seamless, real-time interface between doctor and patient. Its camera delivers a 180-degree view, with full 360-degree rotation and tilting of the screen. Its small stature was designed intentionally to allow for better eye contact with patients.



Howard Bonnell (seated) chats with Dr. Mendez (on screen), who is working from his office.

"I can examine a wound, speak to patients, residents and nurses, and proceed with the best course of action, just as if I was there," says Dr. Mendez. "Just last week I was delivering lectures in Geneva and London, but with the robot, I was able to do rounds with my patients every day."

One of the technological highlights is that the robot does not require advanced telecommunications infrastructure; instead, it uses a regular broadband Internet connection accessed via a laptop. And, according to Dr. Mendez, it takes just 15 minutes to learn how to operate the robot, so anyone can use it.

Following-up close to home

For people with Parkinson's, the robot now offers the capacity to do follow-up programming and care close to home. Dr. Mendez simply logs on to activate the robot and works with a local technician to perform the procedure. "I can see the programmer and how the patient is responding in real-time. The programmer responds to my instructions. The next logical step is to develop a direct interface connection to the robot so that I can do the programming remotely."

Testing is underway to measure the responsiveness of patients to the robot, as well as its efficiency and effectiveness. Approximately 30 Parkinson's patients in Cape Breton are taking part in remote DBS programming this summer.

Dr. Mendez is excited about the technology and the wide range of applications the robot has across all fields. However, it is the impact that this technology has on care delivery that Dr. Mendez speaks about most passionately. "This innovation allows us to live our values as Canadians: to deliver the best standard of care, when needed, regardless of the patient's location, in real time."

Of mice and dice:

New PSC-grants cover diverse research projects

By Ian Corks

This year, Parkinson Society Canada (PSC) awarded 17 research grants in a wide variety of promising areas. Here are a few highlights of the work now underway with PSC funding:

Dr. Stan Floresco

University of British Columbia, Vancouver, BC
Pilot Project Grant

Project: Dopamine agonist modulation of risky decision-making

Born in Toronto and raised in Vancouver, Dr. Stan Floresco is involved in research into an area of Parkinson's disease that has recently been attracting a lot of publicity.

"I was watching a news report on TV that described how a number of people with Parkinson's on certain dopamine-based medications had developed pathological gambling tendencies," he recalls. "I was amazed at how these individuals would stop gambling compulsively once they stopped taking the medication. Based on some initial research, I saw a unique opportunity to model the increase in gambling behaviour—a type of impulse control disorder—in Parkinson's patients in order to better understand exactly how anti-Parkinson's drugs may be affecting the brain to promote these behaviours.

"We hope that by unravelling the specific mechanisms through which these drugs are inducing these side effects, we can help refine treatments for the motor symptoms of PD and reduce the emergence of these types of impulse control disorders," says Dr. Floresco.

Dr. Wenjing Ruan

McGill University, Montreal, QC
Basic Research Fellowship

Project: Study of the molecular mechanisms of Parkinson's disease (PD) in mouse models

Dr. Wenjing Ruan's career has taken him from a hospital in western China to McGill University and a subsequent research-based post-doctoral Fellowship Award from the Canadian Institutes of Health Research. His research results led him towards PD—research he is now continuing through a PSC Basic Research Fellowship Award.

"MPTP is a recently discovered neurotoxin that appears to be selectively toxic to the cells in the substantia nigra of the brain, and it is capable of producing all the signs and symptoms of idiopathic PD," explains Dr. Ruan. "Our studies have shown that mice deficient in the protein Fas are susceptible to MPTP-induced PD. My research goal is to study the molecular mechanisms of Fas-mediated neuroprotective function in PD.

"These experiments will help define what could be an entirely new way of protecting degenerating neurons, and may lead to the design of small molecules that are able to slow neuronal degeneration in PD," says Dr. Ruan.

Dr. Armen Saghatelyan

Laval University, Quebec City, QC
New Investigator Award

Project: Migration of new neurons in the adult Parkinson's brain

During his PhD research, Dr. Saghatelyan started to gain a deeper understanding of the different processes controlling the development and function of the brain's inhibitory circuits. His progressive work in this area eventually earned him a Canada Research Chair (junior) in postnatal neurogenesis, and led to his current position as Assistant Professor at Laval. He is continuing to follow this promising line of research, with the help of PSC's New Investigator Award.

"Throughout my research

career, I have been interested in developmental neurobiology," comments Dr. Saghatelyan. "Our knowledge of the organization of the nervous system relies on a proper understanding of how neurons are produced, how they migrate and how they develop their chemical makeup.

"The objective of our research is to understand the basic mechanisms of new neuron generation and maturation in the adult brain," he continues. "We hope to understand the different processes that control this migration. Our goal is to then develop new strategies for cell-replacement therapies that will cure devastating neuro-degenerative diseases such as PD," says Dr. Saghatelyan.

Dr. Susan Fox
and
Dr. Antonio Strafella
Movement Disorders Clinic, Toronto Western Hospital, Toronto, ON
Pilot Project Grant

Project: Investigating 5HT2A receptor binding in Parkinson's patients with visual hallucinations: A PET study.

Dr. Susan Fox was always intrigued by the fact that visual hallucinations—seeing things that weren't there, especially at night—are a common feature of Parkinson's disease. Not much is known about the neural mechanisms underlying these hallucinations, so when Dr. Antonio Strafella, an expert in Parkinson's imaging, joined the Toronto Western team, Dr. Fox jumped at the chance to investigate this problem using positron emission tomography (PET) scanning.

"There is evidence from some pathological studies that changes in serotonin (5HT) may be involved with these hallucinations," Dr. Fox notes. "Using PET scanning, we will investigate changes in this chemical in the brains of people with Parkinson's, including some who experience hallucinations and some who don't.

"We hope to gain a greater understanding of this common problem and gain insights that may lead to better treatments," adds Dr. Fox.

First Psychosocial Research Grant awarded

Parkinson Society Canada (PSC) is pleased to announce the results of its first PSC/CIHR Psychosocial Doctoral Training Award. University of Toronto doctoral candidate Raluca Petrican is the recipient of the two-year grant of $44,000 for her project, "Perception and memory for neutral and emotional event sequences in Parkinson's disease."

Raluca Petrican

Petrican, studying under the supervision of Dr. Morris Moscovitch in the department of psychology, will investigate the relationship between memory and difficulty in social interactions in people with Parkinson's. Are these difficulties entirely due to cognitive deficits (poor memory for the order and content of social interactions) or is there an additional impairment to producing and "reading" the language of social interaction?

Using movie clips of social and solitary daily activities which have previously proven useful in studying normal perception and interpretation of ordinary events and social interactions, Petrican hopes to identify the difficulties experienced by people with Parkinson's when perceiving and later remembering social interactions.

This research may enable clinicians to better advise patients and their families about the social and cognitive consequences of PD. It may also serve as a springboard for testing the effectiveness of drug treatments to alleviate cognitive and social deficits.

About Raluca Petrican

Born in Bucharest, Romania, Raluca Petrican's interest in Parkinson's grew out of her broader interest in how non-verbal communications contribute to building a sense of "shared reality" with another individual or with a whole group. She hopes her research will be useful in developing and evaluating social-cognitive intervention programs for people with PD, fronto-temporal dementia, traumatic brain injury and Huntington's disease.

For more information on the Psychosocial Research Program, contact Ivy Lim-Carter at Ivy.lim-carter@parkinson.ca or by phone at 416-227-3382 or 1-800-565-3000 ext 3382.

Research update:

Keeping track of PSC-funded initiatives

By Ian Corks

Each year Parkinson Society Canada (PSC) funds many of the country's leading young researchers, with their stories frequently appearing in *Parkinson Post*. In this issue, we check in on a few of these researchers for an update on their research and their careers.

Dr. Connie Marras

Background: In 2003, Dr. Connie Marras was the recipient of a PSC Clinical Research Fellowship, which allowed her to receive epidemiology and research training at the University of Toronto and the Parkinson's Institute in California, followed by an ongoing term at the Morton and Gloria Shulman Movement Disorders Centre (MDC) at Toronto Western Hospital.

With a history of Parkinson's disease (PD) in her own family, Dr. Marras wanted to combine patient care with research into the treatment and causes of PD. One of the research projects she became involved with at MDC involved the study of two families with genetic mutations that make them susceptible to an inherited form of PD. In the summer 2005 issue of *Parkinson Post*, Dr. Marras explained the goals of this project. "Using this model for the more common forms of Parkinson's disease, we might be able to find ways of predicting who may or may not develop the disease," she noted.

Update: Today, Dr. Marras continues to work with Dr. Tony Lang at the MDC as a clinical scientist.

"It's a very rich environment," Dr. Marras notes. "I have the opportunity to work with seven movement-disorder specialists, each with his or her own area of expertise. I continue to benefit tremendously from this experience, plus the opportunity for research collaborations is very exciting."

And she is continuing her original research project. She comments, "We have expanded the project to include other patients with the same genetic mutation. We have seen six unrelated people here at the clinic, five of whom have introduced us to their family members. All in all, we have interviewed over 50 people.

"Another exciting development is that our work has attracted the attention of two other centres: the Parkinson's Institute in California and the Catholic University of Parana in Curitiba, Brazil. They have used the protocol we designed to independently evaluate patients. We have been sharing data, so now it is an international collaborative project."

Dr. Marras is also involved in another spin-off international collaboration, this time looking at environmental risk factors and their possible link to this particular genetic form of PD. "The protocol developed by Dr. Tony Lang, Dr. Caroline Tanner and me is being used in a project involving 14 international centres," she says. "So far, we have been able to collect data from over 100 patients with this genetic form of PD, something we couldn't have done ourselves. It provides greater amounts of data and, therefore, much more statistical power to work with."

Dr. Ratan Bhardwaj

Background: PSC funding in 2004 provided Dr. Ratan Bhardwaj with the exciting opportunity to further his research in Stockholm, Sweden.

At the Frisen Laboratory at the renowned Nobel Medical Institute at Karolinska, Dr. Bhardwaj pursued a novel line of research: investigating whether or not the adult human brain was capable of making new neurons, or brain cells. Knowledge of this type is invaluable in the development of potential treatments for Parkinson's.

"This work involves the use of a technique that allows us to determine when a population of brain cells was born," stated Dr. Bhardwaj in the winter 2004 issue of *Parkinson Post*. "The technique is similar to radiocarbon dating, best known for its use in dating fossils."

Update: Dr. Bhardwaj's two-year fellowship in Sweden is now over, an experience that he translated into a PhD in cell and molecular biology.

"The research skills and knowledge I gained will have life-long benefits," he notes. "I'm really grateful to PSC for this opportunity to expand my skills."

Dr. Bhardwaj credits the research project he was involved in with helping to create a new field in medical research: cytoarchaeology.

"Our investigations showed that, in the cortex at least, all the neurons are as old as the person themselves," he explains. "There is no turnover occurring—no new neurons are being produced after birth despite recent interesting reports in other systems. There may be turnover in other regions of the brain, but only time and further experiments will tell."

The lessons learned will help investigators looking into ways to slow, treat or reverse the effects of PD.

"Molecular or cellular research at this level is something like running around in a big maze," says Dr. Bhardwaj. "And there is no more complicated maze than the human brain. But unlike a maze, there are no dead-ends. Even if something seems like a blind alley at first glance, there is still so much you can learn. The mere fact that you investigate it provides greater insight into the way the brain is made. It helps everyone researching Parkinson's everywhere."

Dr. Anurag Tandon

Background: Featured in the cover story of the fall 2004 issue of *Parkinson Post*, Dr. Anurag Tandon had just received the Canadian Institutes of Health Research's New Investigator Award for 2004.

Working at the University of Toronto's Centre for Research in Neurodegenerative Disease, Dr. Tandon was involved in a PSC-funded project on the organization and disassembly of alpha-synuclein complexes in human cells.

"What we are looking for exists at the cellular level," Dr. Tandon explains. "We know that the protein alpha-synuclein is involved in familial Parkinson's disease, particularly in its interaction with other proteins in dopaminergic cells. We are trying to determine the 'hows' and 'whys'."

Update: Dr. Tandon's research has subsequently moved well beyond the initial stage of this long-term project. In laymen's terms, Dr. Tandon and his team have gained valuable insight into the role that the protein alpha-synuclein plays in PD—an understanding that may lead to the development of therapies to counteract the potentially damaging effect of this protein.

Of course, the actual science is much more complex. "Last year we reported some of our findings in the *Journal of Biological Chemistry*," Dr. Tandon reports. "Importantly, from a therapeutic perspective, we now have a handle on factors that modulate alpha-synuclein behaviour. Through further investigation, we may be able to develop new therapeutic tools to reduce the toxic effects of alpha-synuclein aggregation in Parkinson's brains.

"Our findings are exciting and daunting. We have good leads for investigation and a lot of work ahead. But the final goal remains, as always, to find a cure for Parkinson's disease."

National Research Program Recommended Awards, 2007–2009

Granting period July 1, 2007, to June 30, 2009

Researcher	Name of project	Institution	Amount year 1	Amount year 2	Total award
Pilot Project Grants (one-year grant)					
Dr. Stan B. Floresco	Dopamine agonist modulation of risky decision-making	University of British Columbia	$45,000	N/A	$45,000
Dr. Susan Fox & Dr. Antonio Strafella	Investigating 5HT2A receptor binding in PD patients with Visual Hallucinations: A PET study	Toronto Western Hospital	$45,000	N/A	$45,000
Dr. David S. Park	Mechanism of DJ-1 induced neuroprotection: Modulation of the antioxidant enzyme PON2	University of Ottawa	$45,000	N/A	$45,000
Dr. Qi Wan	Regulation of NMDA receptors by PTEN-induced kinase 1	Toronto Western Research Institute	$45,000	N/A	$45,000
New Investigator Awards					
Dr. Michel Cyr	Role of cytoskeleton-associated proteins in Parkinson's disease and L-Dopa-induced dyskinesia	Université du Québec à Trois-Rivieres	$45,000	$45,000	$90,000
Dr. Shawn Hayley	Neuroprotective effects of the cytokines interleukin-6 and interleukin-10 in a paraquat model of Parkinson's disease: Inhibition of motor and neuropsychiatric symptoms through the JAK-STAT signalling pathway	Carleton University	$45,000	$45,000	$90,000
Dr. Thibault Mayor	Proteomic analysis of parkin ubiquitin-ligase substrates	University of British Columbia	$45,000	$45,000	$90,000
Dr. Armen Saghatelyan	Migration of new neurons in the adult parkinsonian brain	Laval University	$45,000	$45,000	$90,000

Fellow	Field of training	Institution	Amount year 1	Amount year 2	Total award
Basic Research Fellowships					
Mr. Thomas Durcan	Neurobiology	Montreal Neurological Institute	$40,000	$40,000	$80,000
Dr. En Huang	The role of apurinic/apyrimidinic endonuclease 1(APE1) phosphorylation by CDK5 in in vitro and in vivo models of Parkinson's disease	Ottawa Health Research Institute	$40,000	$50,000	$90,000
Ms. Anne M. Landau	Evaluation of the role of monoamines in electroconvulsive therapy in an animal model of Parkinson's disease	University of British Columbia	$40,000	$40,000	$80,000
Ms. Melissa Perreault	The induction of the D1-D2 heterooligomer by L-dopa and dopamine agonists: Implications for the symptomatic treatment of Parkinson's disease	University of Toronto	$40,000	$40,000	$80,000
Dr. Wenjing Ruan	Study of the molecular mechanisms of Parkinson's disease (PD) in mouse model	McGill University	$50,000	$50,000	$100,000
Dr. Damian Shin	High-frequency stimulation depresses rat output basal ganglia nuclei activity by increasing K^+_e and enhancing activity of the hyperpolarization-activated (I_h) channel: A proposed novel mechanism underlying the inhibitory action of deep brain stimulation	Toronto Western Hospital	$50,000	$50,000	$100,000
Dr. Satoshi Suo	Genetic screen for suppressors of α-synuclein-mediated death of dopaminergic neurons	Mount Sinai Hospital	$50,000	$50,000	$100,000
Clinical Movement Disorders Fellowship (one-year fellowship) Novartis Pharmaceuticals Canada CMD Fellowship					
Dr. Rosalind Chuang	Clinical movement disorders training	Morton & Gloria Schulman Movement Disorders Centre, Toronto Western Hospital	$45,000	n/a	$45,000
Psychosocial Doctoral Training Award Parkinson Society Canada / CIHR–Institute of Neurosciences Mental Health and Addiction					
Ms. Raluca Petrican	Perception and memory for neutral and emotional event sequences in Parkinson's disease	University of Toronto	$22,000	$22,000	$44,000
Total			**$737,000**	**$522,000**	**$1,259,000**

One researcher says thanks

By David Park, PhD

I have always been astounded by the commitment and support of the Parkinson's community. Everywhere I turn, I am greeted by enthusiastic volunteers generously donating their time and by patients and families displaying an incredible outlook on life, belying the nature of their disease. I know because in my relatively short time working in Parkinson's research (nine years), I have been supported by this community and have had many wonderful opportunities to be inspired by the many volunteers, patients and caregivers. What has always impressed me is the unending encouragement that the community provides with the unyielding but educated demand for progress.

Dr. David Park

My research, understanding how dopamine neurons misfunction and die, would not proceed without the generous financial support of the Parkinson's community. Due to your support, we have been able to find specific molecular pathways that we can explore therapeutically for Parkinson's. For example, we have identified specific proteins that soak up dangerous free radical molecules in the brain. These free radicals are thought to contribute to Parkinson's.

This research is only made possible with support from organizations like Parkinson Society Canada—support that is essential to continue to initiate the exploration of innovative ideas in Parkinson's research.

If there is one thing we have learned, it is that the disease is incredibly complicated. Parkinson's is a multi-headed hydra, and trying to treat the disease by focusing on one aspect alone is unlikely to succeed. We have to know and sever all the heads of this monster, which requires attacking it from different angles and gaining a more comprehensive and holistic understanding of the disease.

This multiple approach can be frustrating to both researchers and the Parkinson's community, because comprehensive knowledge is slow in coming. It also means that many missteps and misunderstandings will occur along the way. However, I remain incredibly encouraged, because we have made amazing strides in understanding Parkinson's in the past 10 years. This progress needs to march forward unabated. We can do so, but only with the continued support from the Parkinson's community.

As a researcher, I sincerely thank those who have supported the cause. I cannot give you a time by which we will strike down this disease, but I can promise that it will occur.

Nominate a volunteer for a PSC Award

Each year, PSC recognizes a few select volunteers by awarding three distinguished awards:

David Simmonds Parkinson's Leadership Award

- recognizes achievements of the former Chair of PSC (from 1999–2001) who, through exceptional vision, leadership and commitment, has strengthened the voice of people living with Parkinson's
- acknowledges the perseverance and negotiation skills required to make a significant contribution to Canadian society

Mimi Feutl Award

- honours the former Director of Patient Services for 22 years with the Parkinson Foundation of Canada (now PSC) for compassion, energy and unwavering commitment to make life better for people with Parkinson's and their families
- acknowledges the ability to respond to requests for information and support while ensuring and respecting the client's dignity and individuality

Dr. Morton Shulman Award

- memorializes Dr. Shulman who used unorthodox, often controversial methods and innovative approaches to solving problems and easing the burden of those living with Parkinson's
- acknowledges how one person can make a difference with creativity, tenacity and energy

Nominations are being accepted until Friday, September 14, 2007. For nomination forms, visit **www.parkinson.ca**.

The power of artistic expression:

More tales of creativity from Canada's Parkinson's community

By Ian Corks

Hope on Display

In a true celebration of hope, 11 Canadians with Parkinson's showed the therapeutic power of art at the recent *Hope on Display* exhibition, held in Toronto.

Organized by PSC Central and Northern Ontario Region, *Hope on Display* featured diverse examples of creative expression from members of the Parkinson's community, sometimes with a little help from family and friends.

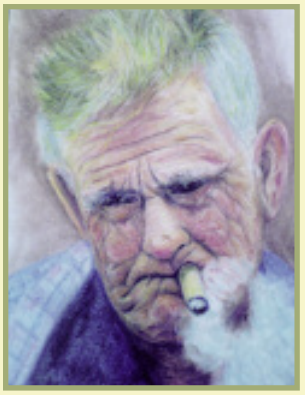
Among the established and beginner "artists" displaying their efforts were

- Dr. Gordon Hardacre: a humorous collection of tongue-twisting limericks
- Peter Thompson: vocal performance
- Nancy Antonacci and her sister Carol Birch: music on keyboards and piano
- Judy Hazlett and dance partner Cynthia Croker: a moving interpretive dance
- Peter Calvert: George Dingman's new book, *And the Walls … Come Tumbling Down*
- Colin Edwards: a large screen presentation on the art of land sailing
- John Scaini: watercolour paintings
- Jamshid Azarian: oil paintings
- Ellen Alban: beaded jewellery
- Linda McKenzie: photographs and cards
- Bruce Hal: sand-blasted stained-glass work

The event was a terrific success, and plans are already underway for an expanded *Hope on Display* next year!

New to the world of painting since his diagnosis with Parkinson's, John Sciani displayed his lovely watercolours.

Jamshid Azarian's stunning oil paintings were one of the exhibit's highlights.



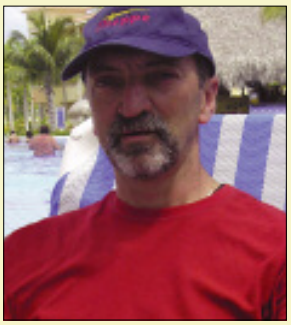
"Lonely," an original pastel painting by Grace Kwon.

"I was lucky that, throughout my life, my hobby was my profession. I always loved drawing and playing the piano as a child, and I was able to translate that into a career as an art and music teacher in Hong Kong and, subsequently in Calgary.

"I still love art. When I do it, I am totally absorbed. I actually have to set the alarm to remind me to take my pills; I can't paint or do much without my medications. But when my medications are working and I am focused on my art, I feel as normal as I used to.

"When I do something creative and it comes out the way I wanted, I get a great feeling of satisfaction. I will do it for as long as I can."

Grace Kwon, amateur artist and musician,
Calgary, Alberta



"It was about five years after my diagnosis. I awoke early on Father's Day. It was the first without my father, who had passed away the previous winter. I was very emotional, so I sat at the computer and wrote what I was feeling. I wrote in rhymes and found great satisfaction in doing this. From that day, I have continued to write about different things in my life, such as living with Parkinson's.

"Writing takes me away from my problems for a while and is a good outlet for expressing my thoughts and feelings. It keeps me focused on being positive and reminds me of the real treasures of my life: my wife, children, family and friends."

Paul Mazzerole, poet
Dieppe, New Brunswick

One button at a time

There used to be a time
I could just jump out of bed.
In just a few short minutes
I would be washed and dressed and fed.

Now I'm not so fast.
In fact, I'm very slow.
But it doesn't really matter
As long as I get up and go.

It's not easy getting dressed
And I must focus my attention.
When I'm putting on my shirt
I fight with each and every button.
It can be very frustrating
But I do not want to stop.
Until my shirt is buttoned up from
The bottom to the top.

This is how it is and
It's how my life's defined.
I take each and every day
Just one button at a time.

Paul Mazzerole

Creativity, celebrity style!

Artwork by Prime Minister Stephen Harper and singer Celine Dion were featured on the plates.

Creativity can also be used to help raise funds, as illustrated by the Plates for Parkinson's project.

Celine Dion, Stephen Harper, Sidney Crosby and other celebrities lent their artistic talents to the eBay's charity auction held in May in support of the Parkinson Society Maritime Region. Other celebrity contributors included Tom Hanks, Bette Midler, the cast of *CSI*, Martha Stewart, Dr. Phil, and more.

Each plate featured a hand-drawn interpretation of the tulip, the symbol of Parkinson Society Canada, and was signed.

Proceeds from the auction went to support services, education and research.

Tales of inspiration

A few years ago, Gord Carley's mother was diagnosed at the age of 78 with Parkinson's. Carley's new book, *Surviving Adversity*, is his tribute to his mother and their relationship.

Canadians and Americans with the disease share their personal stories through 28 creative essays. Readers will hear of each person's challenges and triumphs as the contributors share their stories through the therapeutic process of writing.

Visit www.SurvivingAdversity.com.

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca

Our website has a new look and is being updated regularly! Please watch for more changes in the months ahead.

- Visit our new website at **www.parkinson.ca** to read about the latest goings-on at Parkinson Society Canada (PSC).
- **New for health care professionals.** If you're a health care professional, join the new Health Care Professionals' Discussion Forum.
- Visit the **What's New?** section and nominate a special person for the 2007 PSC Volunteer Awards.
- Click on the **Research** section to view the latest PSC research award recipients.

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

Taking one step closer to a cure

This year's goal is $2.2 million!

During September, be sure to watch for thousands of people on the nearby streets and in parks walking for Parkinson's. They'll be easy to spot: they'll be walking with a mission—one to raise money to fight Parkinson's, a disease that affects more than 100,000 Canadians and their families. And they'll be wearing SuperWalk T-shirts as well as a look of determination and pride.

And they should be proud. In 2000, SuperWalk raised $641,000. Last year, just six years later, that amount was tripled. This year, our goal is to raise $2.2 million! With more than 80 walks taking place coast to coast, we will reach our goal—with your help, of course.

We do hope you will join us. Put on your walking shoes and help us raise money as we walk toward a cure. Here are three ways you can get involved:

• **Sign up on-line to become a walker.** You can set your own fundraising goal and invite your friends to sponsor you. Our website enables you to easily put up your own web page to explain why you are walking and to track your fundraising progress. Just go to www.superwalk.com to get started.

• **Become a SuperSTARWalker.** Raise over $1,000 and join our club of special walkers who have put their best foot forward to raise money for research and support services. You'll be recognized as a SuperSTARWalker with a special hat and a pin, and you'll be eligible for a draw to win a 42" AQUOS TV, courtesy of SHARP.

• **Join as a team.** Invite your friends and family to join you and help raise money together. Your group will have a chance to win some great team prizes, and you'll have the satisfaction of raising money for Parkinson's.

SuperWalk is our largest national fundraising event, yet it wouldn't be successful without the help of our corporate sponsors who have consistently supported the event. Check out our website for a listing of the sponsors that so generously give cash and prizes to help us run the event and make it so much fun.

Researchers say a cure for Parkinson's is possible—if only there was enough money dedicated to research. So join us this year, and help us reach our goal of not only raising $2.2 million but also of finding a cure.

Go to **www.superwalk.com** to sign up for the walk nearest you. See you in September!

Parkinson Society Canada thanks our sponsors who generously give each year!

Platinum:	Burnbrae Farms
Gold:	K&F, Novartis, Teva
Silver:	Air Canada, Alcoa, ElderTreks
Bronze:	CB Richard Ellis, RioCan, MindFit

Meet Leslee Wills,
our on-line early bird prize winner

When we launched our on-line registration in April, we offered an early bird prize to those who registered and had raised more than $100 by May 15. Leslee Wills was thrilled to have been chosen. She won a 32" AQUOS TV, courtesy of SHARP.

Why does Leslee think it's so important to take part in SuperWalk?

"My dad was diagnosed on Thanksgiving of 2005. This was obviously a massive blow to our whole family. Not knowing anything about the disease, I was hungry for information, so I was committed to learning as much as I could about the disease so that I could share this with my family.

"While searching for information, I came across the Parkinson's website. When I saw the Superwalk section, I knew that this was something I wanted and needed to do. My dad has always been the rock of our family, and to see him dealt this kind of news having truly *never* been sick or *ever* having to take medication a day in his life was devastating to me. I knew I had to do something to rally our family around this for two reasons: (1) to let him know that he's not alone and (2) any monies raised would go to research, development and infrastructure, which he could benefit from. As Dad has done so much for our family, I knew I needed to do as much as I could to help him out.

"So in 2006, my husband and I, my parents and a handful of friends (both two-legged and four-legged) participated in the Durham region SuperWalk. And my brother, his wife, and his two daughters (now four and 11) participated in the Kingston SuperWalk.

"This September, our gang will be out in force again—along with whomever else I can get to join us!"

Musician and the beast

By Robbie Tucker, Montreal, Quebec

Musician Robbie Tucker was diagnosed with young-onset Parkinson's at age 28. In spite of the condition, he continues to write music and perform, and he has now recorded 35 songs.

In 2003, I was doing what I was born to do: playing music and making people laugh. I had just recorded and released my first album, *The Ledden Street Sessions*, which landed me a summer gig doing theatre in Charlottetown. Life was good.

Not knowing what to do after the summer, I moved to Toronto where I was able to book an appearance on the *Toronto Show*—a big deal for me, as it was my very first opportunity to be on television. But I had a terrible rehearsal: I had no power in my voice and had no fluidity of movement. My television appearance ended even before it started.

Deteriorating abilities

Devastated, I decided to return home to the Maritimes where I began to write more music. I toyed with the idea of starting my own band. After making a few calls, I formed the group Robbie Tucker and the Band. We toured a bit, playing to local crowds. During our sets, we liked to switch instruments to show how versatile we were, but I soon found out that I could no longer play other instruments as well as I could my guitar.

During this time, I also worked at a local restaurant. But even things that always came easily to me became more and more difficult. At work, my knack of making drinks and rolling the forks and knives into napkins became more challenging. In fact, my ability to perform simple tasks failed to a point where I just couldn't function. I felt awkward, out of place and utterly useless. I also began to get frequent back pains, which I attributed to me constantly moving stage equipment. My voice continued to falter, and my ability to play the piano got worse; it soon became so bad that I had to hide my musical inadequacies behind my guitar.

Looking for answers

Fed up, in 2004 I decided to visit a doctor to discuss the troubles I was having. I hoped that some pill somewhere would make all of my symptoms go away. At my first visit to the local medical clinic, I met an intern who took blood. He asked if anyone in my family had Parkinson's, a word I heard for the first time but one that I wouldn't

hear again until almost a year later.

My situation worsened, so I eventually had to quit my job at the restaurant. I couldn't hold on to my data entry position either. Next, I auditioned for a theatre company where my friend was performing, but I didn't get the part. Everything was falling apart. The only ray of light in my life was that I fell in love and moved to Montreal.

Facing new challenges

Moving to Quebec would prove to be the biggest challenge of my life. Over the next few months, I began to notice a serious decline in my ability to walk, talk and perform on stage. My posture was stooped. I couldn't tie my shoes, button my pants, or play the guitar. My speech was weak, and I had lost my once-powerful singing voice. I had constant back pain, moved slowly, had trouble walking and had a tremor in one of my arms.

I was starting to feel a touch crazy when I kept going to the doctor over and over again without getting any answers. The doctors took blood work, brain scans and urine samples, but couldn't find anything. In the meantime, my health was deteriorating. One of the scariest moments of my life occurred when my right leg became so limp that when I walked, I dragged it so much that I wore out the side of my sneaker.

To keep my sanity, I began work on a new album, *Songs from Apartment #12*. I decided to show off my new material at Brutopia, a small Montreal pub where new artists get to play original music on Sundays. While on stage, I performed horribly. The fast-paced vocal and guitar I had arranged was so out of sync with my body and mind that I didn't even finish the first song.

That moment was the most disappointing of my life. I dealt with a lot of things—failed relationships, lost loved ones, even doctors telling me I was crazy (they thought my condition was a reaction to my mother's death when I was 12)—but now something was tearing my soul out. It was killing me; it was taking my gift of music away from me.

Facing the breaking point

My breaking point finally came in summer 2005. I was working as a salesperson that season, and one day, it was raining hard. After trying to make a sale, I felt lousy so I took shelter in a mall. I felt as though I would pass out if I didn't sit down. My hands were shaking. At that point, I realized I just couldn't do it any more. I quit my job that same day and went home. I sat down with my head in my hands and began to cry.

I decided I would go to the doctor one more time. Alone, crying, and walking in the rain, I once again entered the local health clinic that had become so familiar to me during the past few years. There were a lot of people there, and just like so many times before, I waited. When I finally reached the reception desk, all I could say was, "Please help me."

Finding an answer

Finally, after two years of frustration and after three visits to my current neurologist, I was diagnosed with Parkinson's disease at age 28. I was happy and sad at the same time: sad for obvious reasons yet happy to realize that I was not crazy after all.

The days that followed taking my first medication were amazing! I felt better than I had in years. I promised myself that while I had my health, I would make the most of it. With all that extra dopamine, I kicked my songwriting into high gear! I penned the song "PD Groove (L-dopa shakedown)," an abbreviated melodic version of the story you are now reading.

I'm not sure if anyone is on earth for a reason, but I know that while I am here, I'll be making music. Music wakes me up and music pulls me through. Sometimes, something might get in my way, but nothing will ever stop me. Now, I feel like I'm just like everyone else. The only difference is that when I wake up, I need to take some medication to help me function throughout the day. Life these days is once again great!

Clarification

"Making life better for people with Parkinson's," spring 2007

Janet Millar, recipient of the Mimi Feutl Award, is also a physiotherapist at the Maritime Parkinson Clinic in Halifax, NS.

The Disability Tax Credit: You could be eligible

By Carolyn Forbes

After helping several family members apply for the federal Disability Tax Credit (DTC), I wanted to share what I learned with others. To find out if you may be eligible for the DTC, begin by reading all the information on the Canada Revenue Agency (CRA) website at www.cra.gc.ca.

The DTC is a "non-refundable tax credit" that reduces the amount of tax you owe by decreasing your "tax payable" amount. If the total of your tax credit is more than the amount of federal tax you would owe without the credit, you do not get a refund. A "non-refundable tax credit" works only by reducing the amount of tax you owe until you reach zero.

Where to begin

The first step is to ask a qualified practitioner to complete Form T2201, The Disability Tax Credit Certificate. This Form can be found at www.cra-arc.gc.ca/E/pbg/tf/t2201/. A list of qualified practitioners is included on this page.

The qualified practitioner will review your medical condition to determine that you have "a prolonged impairment, and that the effects of the impairment are such that at least one of the following criteria applies":

- You are blind, even with the use of corrective lenses or medication, or
- You are markedly restricted in any one of the following basic activities of daily living: speaking, hearing, walking, elimination (bowel or bladder functions), eating, dressing, or performing the mental functions necessary for everyday life, or
- You need and must dedicate a certain amount of time specifically for life-sustaining therapy to support a vital function.

Recent changes to the criteria have broadened the requirements as follows: for the year 2005 and later years, if you do not quite meet the criteria for blind or markedly restricted, but the following conditions apply, then you could qualify if

- (a) because of your impairment, you are significantly restricted in two or more of these basic activities of daily living: speaking, hearing, walking, elimination (bowel or bladder functions), eating, dressing, or performing the mental functions necessary for everyday life, or
- (b) you are significantly restricted in vision, and at least one of the basic activities of daily living [see (a) above], even with appropriate therapy, medication, and devices, and
- these significant restrictions exist together, all or substantially all the time,
- such that the cumulative or overall effect of these significant restrictions is equivalent to being markedly restricted in a single basic activity of daily living.

Ensure the date on the form for the onset of any medical condition is the year in which the marked restriction began. If you are eligible for the credit, you can request amendment of your prior years' tax returns by CRA to the date of onset of the disability. Send the completed form to the same address where you send your tax return. It can take three months to receive the decision on your application.

Author's note: For further information, please read the CRA Guide RC4064, *Medical and Disability-Related Information, 2006*.

Qualified practitioner	Can certify ...
medical doctors	all sections on the DTC certificate
optometrists	vision
audiologists	hearing
occupational therapists	walking, eating, dressing, and the cumulative effect for these activities
physiotherapists	walking
psychologists	mental functions necessary for everyday life
speech-language pathologists	speaking

Ask the Expert

Q ***If I want to participate in a clinical trial, what should I know?***

A Clinical trials are an important step in bringing new drugs to the market. They are designed to test the safety and effectiveness of medications, before they are made available to the public. The clinical trial (also called clinical research) involves human volunteers and helps pharmaceutical companies find treatments for various diseases that improve health and quality of life.

Before drugs are available for public use through pharmacies and other providers, they must go through several phases in the drug development process. The entire process takes 10 to 15 years and can cost the pharmaceutical companies over $1 billion for a single new drug. The phases of the process are as follows:

1. **Research discovery.** This involves the Preclinical Testing Phase. In this step, scientists evaluate the toxicology (chemical effects) and biological activity of the drug in the laboratory and in animal studies. If this phase is successful, the company can file an Investigational New Drug (IND) application with Health Canada or the U.S. Food and Drug Administration (FDA).
2. **Clinical trials.** There are three phases involved in the clinical trials step. Before starting a new phase, the pharmaceutical company must send a progress report to Health Canada or the FDA.
   - **Phase One** requires 20-100 healthy volunteers, and assesses the safety and dosage of the medication.
   - **Phase Two** requires 100-500 patient volunteers, and observes the effectiveness and the side effects of the medication.
   - **Phase Three** requires 500-10,000 patient volunteers, and again observes the effectiveness and the side effects of the medication over a longer period of time.
3. **Health Canada or FDA Review Process.** After the pharmaceutical company has completed the clinical trials and the drug is proven to be safe and effective, a New Drug Application (NDA) is filed with Health Canada or the FDA. Sometimes these government agencies will require the company to do additional testing on the drug. This is conducted through a Phase Four trial.

Q ***How are clinical trials monitored?***

A Clinical trials are closely monitored at every stage by Health Canada or the FDA. The trials are also monitored by Research Ethics Boards (REB) or Institutional Review Boards (IRB). These boards ensure that the trial is conducted by qualified physicians and that the safety of the participant is not at risk. REBs and IRBs follow guidelines set out in the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans. These guidelines were released in 1998 by the Medical Research Council of Canada, the Natural Sciences and Engineering Research Council and the Social Sciences and Humanities Research Council. For more information, visit http://pre.ethics.gc.ca/english/policystatement/policystatement.cfm.

Q ***Why should I participate?***

A Participating in clinical trials allows persons who are affected by disease to access some of the newest, most innovative drugs and products available. Although there is no guarantee that the treatment will work, many participate in research in the hope of helping others and contributing to drug development. It is also important for ethnic groups to participate, in order to have a patient sample that is reflective of the Canadian population. It is always recommended that you speak to your doctor and be sure to ask a lot of questions before participating in clinical trials.

Q ***What questions should I ask if I want to participate?***

A It is important to ask about the purpose of the trial, any known side effects of the medication, how long you will be required to participate, and the chances you will get the actual drug or a placebo (an inactive pill). Although most of this information will be provided through the "informed consent process," it is important to have these and any other questions answered before agreeing to participate.

Rayonne Caesar-Chavannes, BSc, MBA,
Founder and CEO,
ReSolve Research Solutions Inc.

Parkinson Society Canada
Société Parkinson Canada

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