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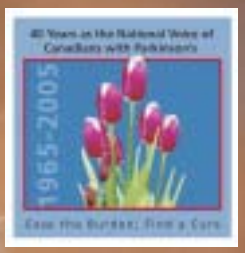
# ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's




## Tom Cochrane
## Singer signs up for SuperWalk

## Meet Maureen Matthew
## Helping people help themselves

## PLUS
## Parkinson Society Canada turns 40!

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

Sales Product Agreement No. 40624078. Photo: Mark Pineo

# SuperWalk for Parkinson's

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

Come and be part of the fun this September!

# 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.

Parkinson Society Canada
Société Parkinson Canada



***ON OUR COVER:***
***In an exclusive interview with Parkinson Post, Tom Cochrane, Honourary Chair of SuperWalk, chats about his father's life with Parkinson's and his commitment to the fight against the disease.***

# Our symbol of hope

It has been a long winter for Canadians so the blooms of spring are a most welcoming site. The warmer weather makes me think of Parkinson's disease awareness month and of tulips, the Parkinson's national and international symbol of hope, and how they first came to Canada.

Tulips have special meaning for all Canadians. During World War II, the Dutch royal family was hosted at Government House in Ottawa and Princess Margriet was born at the Ottawa Civic Hospital.

Princess Juliana, her mother, presented Ottawa with 100,000 tulip bulbs as a gift in appreciation of the safe haven which Holland's exiled royal family received during the Second World War and in recognition of the role which Canadian troops played in liberating the Netherlands. Canadians still have a sentimental spot for tulips and what they represent in our history.

So how did the tulip become the symbol of Parkinson Society Canada (PSC)? The history of the James Parkinson's tulip also has its beginnings in the Netherlands. The Parkinson tulip began in 1980 when J.W.S. Van der Wereld, a Dutch horticulturalist who had Parkinson's disease, gave the name "Dr. James Parkinson" to the red and white tulip he had developed. In 1981, he registered his prize cultivar, the "Dr James Parkinson" bulb. The name was chosen to honor Dr. James Parkinson, the English doctor who first described Parkinson's disease in his 1817 "Essay On The Shaking Palsy" and to honour the International Year of the Disabled.

This year, PSC celebrates our 40th anniversary, and our recent event on Parliament Hill in our nation's capital to mark April as Parkinson's disease awareness month and to commemorate our anniversary was again another magical thread that ties PSC to the hope that tulips represent. As I was awed by the site of all the tulips in bloom in Ottawa, I thought of how we at PSC are all truly connected by tulips, our mission and vision, and the hope that spring always brings.

Photo: Terry Lowe, Terrier Productions

Peggy Yates, CFRE
National Director,
Communications and Marketing,
Parkinson Society Canada
Toronto, ON

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**ParkinsonPost**
A quarterly magazine for Canadians living with Parkinson's

*Parkinson Post* Vol. 5, Issue 1, Spring 2005

Parkinson Society Canada
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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

- Porridge for Parkinson's was successful. Revenue from the auction increased over last year.
- Fifteen members of the Better Pharmacare Coalition, to which PSBC belongs, met with the Provincial Liberal Health Caucus to discuss the newer drugs for conditions such as asthma, diabetes, Parkinson's, and so on, that have not been approved for reimbursement by Pharmacare.
- Two education meetings were held: one for people living alone with Parkinson's and another for people with young onset.
- In the last four months, the Support Services Co-ordinator has given four in-services and visited 11 support groups.

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

- A presentation by a local psychology professor on "Enhancing memory and thinking process" provided many tips to a large audience.
- "The impact of chronic illness on personal relationships" was presented to a young onset audience by a clinical counsellor who has been living with multiple sclerosis for many years.
- Students from the local massage therapy college continue to help over 50 clients who attend a weekly Parkinson's-focused therapeutic massage clinic.
- Several PD discussion groups are incorporating progressive muscle relaxation into their monthly sessions.
- A neuro-knowledge management project is being planned and will involve clients participating in web-based tracking of symptoms, treatment and outcomes.

### 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

- Ms. Julia Hawley was awarded the Gilbert H. Krause Course Prize in Neurology, an award named in honour of one of the founders of The Parkinson's Society of Alberta.
- Alyse Geiger, 12 years old, was the top fundraising student for SuperWalk for Parkinson's 2004 and was one of 19 students honoured by Premier Ralph Klein as a recipient of a "Great Kids Award."
- Results of a survey of persons with Parkinson's are being compiled by University of Alberta faculty of nursing staff.

### 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

- Ghost River Theatre held a joint fundraiser for Ghost River and PSSA with a gala performance of the play *Mesa* in mid-December. Doug Curtis, who wrote *Mesa*, has young-onset Parkinson's.
- Dr. Anthony Lang, neurologist at Toronto Western Hospital, presented an "Update on Parkinson's" for PSSA members and guests on February 18. Over 100 people attended.
- Porridge for Parkinson's was hosted in February by Beth Carter and Bob Baker. CBC's "answer lady," Marg Meikle, was the special guest.

### 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

- Regina Curling Classic was once again a huge success.
- Movement disorder clinics are held in Saskatoon and Regina.
- Annual Golf Classic is scheduled for August.
- SuperWalk scheduled for September 25, 2005, in Saskatoon.
- Parkinson Week is September 26–30. A movement disorder expert will speak in Regina and 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

- Hope in Bloom retail card program was at nearly 100 vendor locations.
- Potted tulip sales set a new revenue record.

*Continued on page 6*

Parkinson Society Canada
Société Parkinson Canada

- Parkinson Society Manitoba celebrated World Parkinson Day on A-channel's Big Breakfast.
- Regional conference attracted hundreds of people. Dr. Colin Powel, MB, FRCP, Dalhousie University (Halifax); Dr. Jerry P. Krcek, BA, MSc, PhD (Med Sci), MD, FRCSC, Neurosurgeon, HSC Winnipeg; and Lynn Mitchell-Pederson, RN, BA, EdD, were presenters.
- Annual Golf Classic held on May 30, 2005, at Breezy Bend Golf and Country Club in Winnipeg.
- Educational grants provided by Novartis Pharmaceuticals Canada Inc., GlaxoSmithKline, and Boehringer Ingleheim.
- First regional volunteer awards presented.

### 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

- Toronto held "Everyday living strategies: A holistic approach to coping with Parkinson's disease through the use of humour, exercise and knowledge" at a conference on May 7, 2005.
- Ninth annual Granite Ridge Golf Tournament held on June 8, 2005.
- Sixteenth annual Pitch-in for Parkinson's held on June 21, 2005.

### 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

- "Spell the end of Parkinson's" was a winter-blues buster for Scrabble® gurus, raising $8,400 for client services.
- Thanks to the senior occupational therapy students of the University of Western Ontario for creating the "Falls prevention binder."
- Congratulations to Dr. Quincy Almeida for his work with Parkinson's patients at the new Movement Disorders Research Centre in Waterloo.
- Welcome to Dr. Mary Jenkins, movement disorders specialist, who joined the Movement Disorders Clinic at London Health Sciences Centre last fall.
- Thanks to volunteers who helped during April Awareness Month.

### Parkinson Society Ottawa

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

- Our fall presentation featured Dr. David Park, a neuroscientist with the Ottawa Health Research Institute and a co-chair of the newly-formed Parkinson's Research Consortium.
- Our Yuk Yuk's Comedy Night for Parkinson's raised over $14,000.
- Results of a client survey showed there are several under-serviced areas outside Ottawa. One new support group was set up, and two more are in the planning stages.
- The Masonic Foundation of Ontario donated $15,000 to purchase new equipment.

### 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

- The annual conference was held on April 29. Anxiety sleep disturbances, yoga, and physiotherapy were among the subjects discussed. Some of them will be published on the Infoparkinson website and in the *Bulletin*.
- Introducted a new service, Care-ring Voice, which provides caregivers with support through teleconferencing-based services.
- Nine SuperWalks are being organized in Abitibi-Témiscamingue, Chicoutimi, Montréal, Quebec, Rimouski, Rivière-du-Loup, Sherbooke and Trois-Rivières. For information, call Amelie Verret at the office.
- SPQ-Greater Montreal will hold their golf tournament on September 1.

### 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

- During awareness month, Jan Duff presented awareness sessions in Truro, Moncton, Charlottetown and Halifax.
- Porridge for Parkinson's was held in Fredericton and chicken wing eating challenges were held in Moncton and Saint John. All were successful.
- Plates for Parkinson's, the region's first gala dinner and auction, was held on April 25 in conjunction with a themed lotto.
- The Moncton chapter marks its 15th anniversary in June.
- Hope volleyball is scheduled for August 20 in Halifax, marking the second year of a three-year agreement with PSC.
- The 2005 golf tournament will be held August 26 in Truro.

### 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

- We moved to a larger office in December. The new office allows volunteers to work unencumbered by staff.
- In February, we held a new fundraiser: a flea market, which was fun and profitable.
- Welcomed Claudette Barnes, a well-known radio personality, as our honourary chair.

Parkinson Society Canada
Société Parkinson Canada

*Issues of interest to people with Parkinson's*

## Parliament Hill takes time for Parkinson's

Photo: Mike Heffernan, Binary Rhyme

*Joyce Gordon, President and CEO of Parkinson Society Canada (second from left), celebrates Parkinson's Disease Awareness Month with Minister of National Defence Bill Graham (far left), Senator Michael Pitfield, and Minister of Health Ujjal Dosanjh (far right).*

In April, Minister of Defence Bill Graham and Senator Michael Pitfield took time out to bring their parliamentary colleagues together to mark National Parkinson's Disease Awareness Month and the 40th anniversary of Parkinson Society Canada (PSC).

Minister of Health Ujjal Dosanjh and Minister of State (Public Health) Dr. Carolyn Bennett joined Senator Serge Joyal, Senator Wilbert Keon, Senator Jack Austin, Senator Sharon Carstairs, Senator Lillian Dyck and Senator Nancy Ruth over lunch for what Parkinson Society Canada hopes will be the beginning of a dialogue on the future approach to Parkinson's disease in Canada.

PSC was well represented by volunteers Alan Riccardi, Fran Squire, David Simmonds, William Harshaw and Gerry Kelleher and by President and CEO Joyce Gordon.

## Dr. Wszolek recognized with lectureship

Parkinson Society Canada is pleased to announce the award of the third annual Donald Calne Lectureship to Dr. Zbigniew Wszolek of the Mayo Clinic in Jacksonville, Florida.

Dr. Wszolek received his MD degree from the Silesian University in Poland in 1973 and has been consulting and teaching at the prestigious Mayo Clinic and Mayo Foundation in Jacksonville since 1998. A specialist in the neurogenetics and neurophysiology of Parkinson's disease, Dr. Wszolek has recently been involved in work on the Tau gene and on Lewy bodies.

This year's lecture will be given on Friday, November 4, 2005, in Winnipeg, Manitoba, during PSC's Annual General Meeting. Watch for updates on www.parkinson.ca.

## PSC kicks-off annual campaign

April 11 marked World Parkinson Day and the kick-off of Parkinson Society Canada's national Parkinson Disease Awareness Campaign. Efforts are underway across Canada to promote a better understanding of Parkinson's, to share accurate and up-to-date information with those living with the disease, and to raise funds for research and support programs.

One such program is the new Medical Information and Support Program, launched this past November. To date, over 18,900 family physicians have received this kit of resources and information that will enhance their understanding of Parkinson's and their ability to care for more aspects of their patients' medical needs.

Ease the Burden; Find a Cure



## Dietary vitamin E may cut risk of Parkinson's disease

Findings from a meta-analysis of study data suggest that consuming a diet high in vitamin E may help stave off Parkinson's disease. However, the authors caution that confirmatory data from a randomized trial is needed.

Oxidative stress has been theorized to play a role in the pathogenesis of Parkinson's disease. As such, treatment with antioxidants, such as vitamin E and C, could confer neuroprotection.

As reported in the June issue of *The Lancet Neurology*, Dr. Mahyar Etminan, from the Royal Victoria Hospital in Montreal, and colleagues conducted a search of studies published between 1966 and 2005 that looked at the effect of antioxidant intake on the risk of Parkinson's disease. Eight observational studies were identified.

Moderate or high intake of vitamin E reduced the risk of Parkinson's disease by about 20 per cent compared with little or no intake.

By contrast, there was no evidence that consuming diets high in vitamin C or beta carotene offered any protection against Parkinson's disease, the authors note.

"Our data suggest that diets rich in vitamin E protect against the development of Parkinson's disease," the authors state. "No definite conclusions regarding the benefits of supplemental vitamin E can be made."

*Source:* Lancet Neurol *2005;4:362-365. Reprinted with permission from Reuters Health, New York.*

Please remember that while Parkinson Society Canada provides information that may be of interest to persons living with Parkinson's, their families and caregivers, we recommend that you always check with your physician or pharmacist before taking any over-the-counter products to ensure compatibility with your Parkinson's and other prescription medications.

# Helping people help themselves

## On the job with Maureen Matthew, Parkinson Program Co-ordinator

Maureen Matthew, BSW, is a strong believer in the power of people. So it seems only fitting that much of her work is focused on helping people with Parkinson's find and utilize the power that lies within each of them.

By Ian Corks


Photos: CP Images

*Maureen Matthew, Parkinson Program Co-ordinator, welcomes visitors to the Victoria Epilepsy and Parkinson's Centre.*

As the Parkinson Program Co-ordinator for the Victoria Epilepsy and Parkinson's Centre (VEPC), Maureen is one of the many dedicated people working to provide support and services to the Canadian Parkinson's community. And, as for all of her colleagues across the country, it's a job that calls on a variety of skills and talents, not to mention a sense of compassion and a distinct desire to make a difference.

The VEPC is a not-for-profit organization, serving people living with Parkinson's and epilepsy in Victoria and the Capital Region District of Vancouver Island. The agency is unique in Canada in that it serves those whose lives are affected by either of these very different neurological conditions.

A qualified geriatric social worker, Maureen joined the VEPC in 1989, following a varied career in the Victoria health-care system. "I'd worked in a variety of health-related settings, and I found that I really enjoyed providing client services that empowered people," she recalls. "My job at the VEPC allows me to do this."

### Focus on self-determination

From its beginnings, the VEPC has adopted a focus on client self-determination and teamwork, an ideal fit for Maureen's personal and professional philosophy. "The VEPC is a very effective agency with gifted Executive Director Sandra Bitz, five dedicated staff and an amazing team of volunteers," she notes.

Maureen's role as Parkinson Program Co-ordinator is multi-faceted. On any given day, she can be involved in a number of diverse activities—all with the ultimate goal of supporting people with Parkinson's and their families.

"About half my time is spent in providing direct, personal client services," notes Maureen. "That means talking to people in person or on the phone, answering e-mails, responding to requests for information, providing referrals, etc. Our clients include anyone who is touched by Parkinson's. That can mean people with the condition, family members, health-care professionals or others."

When it comes to people with Parkinson's and their loved ones, Maureen prefers to meet face-to-face whenever possible. "About 85 per cent of the people we talk to come in for at least one sit-down visit," she says. "A face-to-face meeting puts people more at ease, especially those dealing with a new diagnosis."

Understanding exactly what the

client needs allows Maureen and the VEPC to tailor their services appropriately. This could mean providing counseling and information on issues such as symptom management strategies, treatment options, emotional reactions, family relationships or other important issues. It could also mean referring the client to another community resource or to one of the many programs co-ordinated by the VEPC. These programs currently include a short-term early stage group, exercise classes and a variety of educational initiatives. "Clients and family members are also invited to contact me as needed," Maureen states. "We get to know each other fairly well over the years."

## Enriching lives

Maureen works closely with Mary Chu, Co-ordinator of Education Services. Mary organizes the VEPC's innovative educational events. For example, she recently organized a daytime seminar on the topic "Exploring your potential," which featured Maureen as one of many presenters. This inspiring afternoon focused on some of the many creative ways that people with Parkinson's choose to maintain fulfilling, joyful lives.

Program development is another key part of Maureen's job. This can be a complex and time-consuming process, one that calls on her clinical education and background. "Financial resources are limited, so we regularly check with our clients to ensure that our services are both effective and responsive to changing needs" she notes. "For example, we are currently exploring whether our agency could partner with other community groups to offer some kind of mind-body program. We know that it is better for people with a health challenge to stay integrated into their community, but we also know that it can be magical to be with others with a common experience."

*At Victoria Epilepsy and Parkinson's Centre, caring is a team effort. Left to right are Sandra Bitz, Executive Director; Della Truitt, Office Manager; Maureen Matthew; and Jennifer Brock, Community Events Liaison.*

"Another example of our proactive stance is a stronger emphasis on inviting those who attend our educational sessions to leave with an action plan for themselves," Maureen adds. "This goal stemmed from our exploration of the Chronic Disease Self Management Program (CDSMP) developed at California's famous Stanford University."

The same level of effort is put into other programs at the VEPC. The result has been a range of practical client-oriented programs, including some innovative partnerships.

## In the community

Maureen also spends a lot of time in the community presenting in-services at the local college or at health care organizations. These are aimed at helping others to understand the subtleties of caring for people with Parkinson's.

As if that's not enough, many other activities keep Maureen busy. For example, she is the editor of the Centre's quarterly newsletter, *The Transmitter*, gathering useful materials and writing articles when needed.

Maureen's role also involves recruitment and support of the over 50 volunteers who offer their time and services to help the Centre and its clients. In addition, she is occasionally called on to help supervise practicum students, such as the two nursing students who helped out at the VEPC last year.

And, of course, there are the report writing, committee meetings, special project work and other typical day-to-day tasks of working for a not-for-profit organization.

No matter which particular task she is putting her hands to, the driving force behind Maureen's efforts is always empowerment.

"Parkinson's is a potent force, but you should never give it more power than it deserves," she says. "I try to remind everyone where the ultimate power to accomplish anything lies. It lies with them."

## By the people, for the people

Maureen Matthew admits she loves the "grassroots" nature of the work at the Victoria Epilepsy and Parkinson's Centre.

Grassroots seems a particularly apt term for the VEPC, which got its start in the early '80s during an informal living room get-together of a group of people with Parkinson's. Seeking advice on forming a support network, they were put in touch with a similar group of people dealing with the challenges of epilepsy. Sharing the same philosophy–that people who are well informed about their health condition are best able to live to their maximum potential–the two groups decided to work together. The eventual result was the VEPC, which now provides services to about 1,000 people in Victoria and the surrounding region.

*Editor's note:* For information about the VEPC, visit www.vepc.bc.ca.

Canadian rocker Tom Cochrane is supporting Parkinson Society Canada as the Honourary Chair of SuperWalk.

Photos: Mark Pineo

# In memory of Tuck:

## *Tom Cochrane talks about his father, his friends and the fight for a cure*

Tom Cochrane is a Canadian icon. Born in Lynn Lake, Manitoba, the Juno-award-winning rocker has earned his status as one of the country's best-known musicians. From his early days in the coffee houses of Toronto's Yorkville district, to the emergence of the group Red Ryder in the 1980s, to his 2003 induction into the Canadian Music Hall of Fame, Tom has made his mark on the Canadian and international music scene. His hit "Lunatic Fringe" is one of the most played songs in U.S. rock radio history. The 1991 album *Mad, Mad World* ranks among the best-selling Canadian records of all time, with the single "Life is a Highway" selling more than two million copies around the world.

Life's highway has not always been smooth for Tom. In November 2002, he lost his father, Thomas "Tuck" Cochrane, a well-known bush pilot and Second World War RCAF veteran, to Parkinson's disease. Already a supporter of Parkinson Society Canada, Tom has graciously agreed to be the Honourary Chair of SuperWalk for the next three years.

*Parkinson Post* recently talked to Tom about his late father and his commitment to the fight against Parkinson's.

**PP: Tell us a bit about your father, Tuck.**

TC: Tuck was a great guy. He was embarrassed by too much attention on the one hand, but very proud on the other. He was quick to say, "Tom, let the other guy have his say, even if you don't agree." Manners were important to him. How Canadian is that?

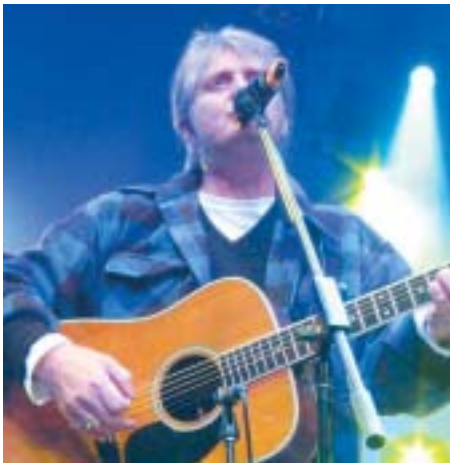
**PP: As the Honourary Chair for SuperWalk and the ambassador for the nearly 100,000 Canadians living with Parkinson's, their caregivers and families, what do you hope to achieve?**

TC: I hope that my humble contribution, in some small way, will help bring a quicker discovery of a cure. Here I am paying my dues to my dad and his memory ... and then along comes one of my good friends, at 42, who tells me he's just been diagnosed with Parkinson's. It shows it could happen to anyone.

**PP: As someone who has had a very personal experience with the debilitating effects of Parkinson's disease, can you describe how it has changed your view on life?**

TC: It made me a lot less critical of others and, perhaps, a little less intense about the stuff that really doesn't matter that much. It has taught me to get outside my ego and to respect and appreciate my friends and family a little more.

**PP: You've dedicated the proceeds of your song "Just Like Ali" to PSC. You've credited a statement by your late father—that he was, "going to fight Parkinson's, just like Ali"—as the inspiration for this moving song. Could you elaborate?**
TC: The creative process happened over a few years, but these things find their own pace and timing. In the end, the impact of a song like this has so much to do with the emotional investment … the love, the desperation and so much more attached to the way I feel about my dad and Muhammad Ali. And about how a terrible disease like Parkinson's impacts us all, yet tragically pulls



us together. It pulls even the great and strong down—but not their spirit!

**PP: PSC funds some of the best medical research in the world. What message would you like to send to the medical research community?**
TC: You are lonely soldiers on an important road to discovery and physical emancipation. You inspire us, and we salute you. Keep going … until the dawn of a cure brings light out of the darkness of this terrible disease.

**PP: Do you have any parting words for our readers?**
TC: I feel privileged ... to be able to help. All of you can as well. Please take part in the SuperWalk, and support the brave work of Parkinson Society Canada. Help them find a cure.

*Visit **www.superwalk.com** for more information.*

## Services

# Manulife supports Info Centre

Manulife Financial has made a significant commitment to Canadians with Parkinson's disease by announcing a $75,000 gift to help fund Parkinson Society Canada's National Information and Referral Centre.

"Almost 100,000 Canadians have Parkinson's today… and we expect that number to double over the next 10 years," says Joyce Gordon, President and CEO of Parkinson Society Canada (PSC). "One of the best services we can offer is access to the best information and resources that people need to manage the disease. Manulife Financial's contribution will help PSC continue this very important work and ensure that there is a compassionate and knowledgeable voice on the phone when Canadians living with Parkinson's call for help."

"Manulife Financial is committed to giving back to the communities in which we do business," says Bruce Gordon, Manulife Financial Senior Executive Vice-President and General Manager, Canada. "We applaud the work being done by PSC to raise awareness and educate the public about this disease."

In 2004, the Centre responded to more than 1,400 calls for information from people living with Parkinson's, family members, care partners and health professionals as well as providing over 19,000 Parkinson's information packages through requests to the National Information and Referral Centre. The Centre has a wealth of information, from how to contact a local support group, to details about information evenings and exercise classes, to requests for medical articles and educational brochures addressing specific aspects of Parkinson's disease.

PSC's National Information and Referral Centre can be accessed through www.parkinson.ca or by e-mailing general.info@parkinson.ca.

*For more information on Manulife Financial, visit **www.manulife.ca**.*

# Rewriting the book

## How Professor Oleh Hornykiewicz changed the lives of people with Parkinson's

By Ian Corks

Parkinson Society Canada is the proud sponsor of the prestigious Donald Calne Lecture series. Launched in 2002, this series invites the world's foremost Parkinson's researchers and clinicians to discuss their work at PSC's Annual General Meeting.

*Professor Oleh Hornykiewicz delivers the 2004 Donald Calne Lecture at Parkinson Society Canada's annual general meeting.*

This year, the *Donald Calne Lecture* was delivered by Professor Oleh Hornykiewicz, a man who forever changed our understanding and treatment of Parkinson's disease.

It was Professor Hornykiewicz who first determined the crucial role of the neurotransmitter dopamine in Parkinson's and subsequently pioneered the use of levodopa, still the mainstay of treatment.

The selection of Professor Hornykiewicz as this year's lecturer is even more appropriate due to his strong Canadian connection. He provided fascinating insight into his own accomplishments, including his years of work in Saskatoon and Toronto, and offered a hopeful look at what lies ahead in the immediate future of Parkinson's research.

The following is an overview of the 2004 *Donald Calne Lecture* given by Professor Oleh Hornykiewicz.

### Establishing the link

The presence of the neurotransmitter dopamine was first discovered in the basal ganglia of the human brain about 45 years ago by researchers in Japan.

At the time, around 1959, Professor Hornykiewicz was working in the pharmacology department of the University of Vienna. He knew that neurologists had long suspected that Parkinson's disease has something to do with the basal ganglia. Armed with this knowledge, he thought it a logical step to examine dopamine in the basal ganglia of people with Parkinson's.

This involved collecting post-mortem samples, so he asked the University's pathologist to provide the brains of deceased individuals. This was considered an unusual request at the time, but Professor Hornykiewicz persevered, and in a short time, he managed to analyze six brains of people with Parkinson's and 20 control brains, along with samples from 12 people who had non-Parkinsonian disorders of the basal ganglia.

Professor Hornykiewicz's studies confirmed the Japanese findings and provided a picture of the normal distribution of dopamine in the human brain. But they also showed something else. In examining the brains of the people with Parkinson's, Professor Hornykiewicz was the first to discover what is now common knowledge: there was a marked and even severe decrease in the amount of dopamine, compared to the control brains. Today, this loss of dopamine in Parkinson's is well established and can even be shown in live patients using floradopa PET scans.

Other non-Parkinsonian disorders involving the basal ganglia that he had studied did not have a similar loss of dopamine, so there seemed to be a real connection to the loss of this neurotransmitter and Parkinson's disease.

Even though Professor Hornykiewicz had made a major breakthrough and had the evidence of a dopamine-Parkinson's link in his hands, his work was just

beginning. He postulated that replenishing the dopamine in the brain of a Parkinson's patient would have a beneficial effect on the symptoms. The chemical levadopa suggested itself, as it is a precursor of dopamine and is able to enter the brain.

The next step was to try giving levopoda to a Parkinson's patient, an idea that many thought to be "crazy." In fact, it took almost a year for Professor Hornykiewicz to convince his colleague, neurologist Dr. Walter Birkmeyer, to inject levodopa intravenously into a few of his patients.

The results were immediate, with the patients responding in a way that was described as "miraculous." From the first patient treatment, Dr. Birkmeyer became one of the most enthusiastic supporters of the use of levodopa in clinical practice. From that point on, levodopa has been the cornerstone of Parkinson's treatment, with enhancements made to the therapy over the years.

However, in the early days, the levodopa-dopamine-Parkinson's link was not enthusiastically received by all experts, in spite of the growing evidence. This doubting, sometimes from eminent neuroscientists, continued into the 1970s.

## A Canadian connection

By that time, Professor Hornykiewicz was working in Toronto at the famous Clarke Institute. He decided to address the concerns by assigning his PhD student at the time, Ken Lloyd, to look deeply into the brains of Parkinson's patients treated with levodopa and determine the exact effect of the drug on dopamine levels.

This research showed a direct link between levodopa treatment and dopamine levels, with dopamine concentrations being nine to 15 times higher in treated patients. It also showed that patients with higher dopamine concentrations were classified as "good responders," in terms of Parkinson's symptoms, while those with lower concentrations were classified as "poor responders." The results of these Toronto studies finally silenced the critics and eliminated doubts about the specificity of levodopa treatment for Parkinson's disease.

In terms of the future of Parkinson's treatments, Professor Hornykiewicz is watching three particular areas of developing research with interest.

The first involves ways of improving the therapeutic profile of levodopa, mainly by addressing its main disadvantage, the side effects that most patients develop after long-term use. Most of the work in this area revolves around combining levodopa with other medications, such as dopamine agonists or enzyme inhibitors. Investigators hope that these will enable a reduction in the amount of levodopa required, along with a corresponding reduction in side effects.

Another area of study is the search for a biological approach to dopamine replacement. This is essentially a way of prompting the production of dopamine by the brain so that levodopa is not needed. Researchers believe this may be possible by a number of methods, including intrastriatal fetal nigral cell transplants, genetically modifying somatic cells to express dopamine synthetic enzymes or—the most recent approach—the use of human stem cells.

Finally, there are the ongoing investigations into the actual cause of Parkinson's. Professor Hornykiewicz has been involved in some of these investigations, including studies conducted in Toronto. While the potential rewards are great, he admits that this is the most complex field of all, with many avenues to be investigated and innumerable questions to be answered.

While tremendous progress has been make in the understanding and treatment of Parkinson's disease, Professor Hornykiewicz—the man behind much of that progress—believes that the really great breakthrough still lies ahead.

## The man behind the breakthroughs

Professor Oleh Hornykiewicz is one of the world's leading neuroscientists. He received his medical training at the University of Vienna in Austria. He has held full professorships concurrently at the University of Toronto, in the departments of Pharmacology and Psychiatry, and at the University of Vienna in the Department of Biochemical Pharmacology. Professor Hornykiewicz is presently Professor Emeritus at both universities. He continues to work out of the Brain Research Institute at the University of Vienna and is widely acknowledged as the leading authority on neurotransmitter function in the diseased and normal brain.

*Professor Hornykiewicz's experimental bench in the basement of the University of Vienna's Pharmacology Department circa 1959, where he conducted his ground-breaking research on dopamine and levodopa.*

# Our volunteers: The heart and soul of Parkinson Society Canada

By Peggy Yates

Canada has long enjoyed the reputation of leading the world in volunteering. For example, Canadian volunteers contributed approximately one billion hours of their time to charitable causes in the year 2000. These hours translate into the equivalent of 549,000 full-time year-round jobs!

Parkinson Society Canada's volunteers are no exception. Each year, the Parkinson's community selects recipients for the honour of being recognized by their peers. Our National Volunteer Awards recognize achievements and service to Canadians living with Parkinson's.

## The David Simmonds Award

This award honours the unique contribution and charisma of David Simmonds, the Chair of Parkinson Society Canada (PSC) from 1999–2001, who, through his exceptional vision, leadership, negotiation skills, perseverance and commitment, strengthened the voice of those living with Parkinson's. The recipient of the award is someone who has demonstrated extraordinary leadership skills that have resulted in a significant contribution to the lives of person's living with Parkinson's.

Passion and charisma describe this year's recipient, broadcast icon Vicki Gabereau. As Honourary Chair of SuperWalk for the past three years, Vicki has shown extraordinary commitment and dedication to PSC's mission over the past three years. She used her familiar face, presence and voice to encourage and promote SuperWalk, our largest national fundraiser. She added all of her own resources and led others to action to make this annual event exceed its previous records.

Vicki continues to help those living with Parkinson's and to do what she can to make a difference.

## The Mimi Feutl Award

This award was created to honour the incredible force who was the Director of Patient Services with the Parkinson Foundation of Canada for 22 years.

This award is given to an individual who, through compassion and provision of information and support, has made life better for individuals living with Parkinson's and their families. The award recipient exemplifies the same dedication and compassion for the mission and people of PSC that Mimi did.

*David Simmonds (right) presents Vicki Gabereau with the 2004 David Simmonds Award.*

The ability to respond to all requests for information and support while ensuring and respecting the dignity and individuality of all who seek support are important characteristics of the recipient.

In 2004, the Mimi Feutl Award was presented to two exceptional recipients.

*Left to right: Jan Duff, Ruth Vant, Mimi Feutl, Peggy Grey and Barry Johnson.*

**Peggy Grey** of the Parkinson's Disease and Movement Disorders Clinic at the Ottawa Hospital is known as the "person who's really in charge of the clinic since its inception in 1976 until her retirement this year." Among her accomplishments, Peggy was one of the original members of the Parkinson Study Group, an international group of individuals with the common goal of performing clinical research in the hope of developing better treatments for those suffering from Parkinson's. Peggy has taught hundreds, if not thousands, of health care professionals about Parkinson's disease, and her commitment to easing the burden has never wavered.

While Peggy has provided expertise to colleagues and health care professionals, her most important role has been providing compassionate advice to individuals and their families who contact the clinic. Peggy has shown great commitment in her work. She inspires us all, and we thank her for her commitment to PSC and to Canadians living with Parkinson's.

**Marie-Josée Fortin** from Montreal, Quebec, has been described as a steady force. A passionate and dedicated nurse, research co-ordinator, nurse clinician and patient advocate are just a few of the roles this year's second recipient of the Mimi Feutl Award fills. Her dedication and passion for her work has not lessened over the years. In the true spirit of Mimi Feutl, Marie-Josée has always made time for the direct care of her Parkinson's patients. She not only provides clients with a complete evaluation of their clinical status but also looks after their overall well-being.

She has always gone beyond the call of duty to arrange for

*Left to right: Ginette Maynard, Mimi Feutl, Marie-Josée Fortin and Barry Johnson.*

services and to identify ways to help with issues that are not necessarily addressed in a regular clinic. For example, she has been instrumental in establishing a network of consultants in physiotherapy, psychology, speech therapy, social services, and other services not directly available in a clinic setting.

Marie-Josée has inspired the Parkinson's community to assist, support and serve those living with Parkinson's and their families and caregivers.

PSC congratulates all recipients of the 2004 National Volunteer Awards.

*Please view our website (**www.parkinson.ca**) over the coming months for information about the 2005 Annual General Meeting, National Volunteer Awards and the Third Annual Donald Calne Lectureship.*

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. Some of the new materials includes**

- A map of Canada to direct you to your Parkinson Society Canada (PSC) regional partner. **Click on the map to locate the regional partner closest to you and to read the news from the regions.**
- PSC and Parliament Hill celebrate PSC's 40th Anniversary and April Awareness 2005. **Click on Headline News.**
- PSC announces 2005 Donald Calne Lectureship. **Click on Headline News.**
- Manulife Financial and PSC join forces to help Canadians with Parkinson's disease. **Click on Headline News.**

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

## 2004 Annual General Meeting

PSC's Annual General Meeting (AGM) was held on Sunday, November 5, 2004, at the Delta Meadowvale Resort and Conference Centre in Mississauga, Ontario. Participants included the National Board of Directors, Regional Board Chairs, Regional Executive Directors from regional offices across the country, national staff, PSC volunteers, donors and stakeholders.

Joyce Gordon, PSC's President and CEO, addressed the Parkinson community, highlighting accomplishments over the past year and speaking of the passion for the PSC mission that is shared by staff and volunteers alike.

***Left to right:** Joyce Gordon, President and CEO, PSC, talks to Oleh Hornykiewicz, Professor Emeritus, and Barry Johnson, National Board Chair.*

Barry Johnson, National Board Chair, called the AGM to order. PSC's Annual General Meeting was followed by the Annual National Volunteer Awards Ceremony, and then the final item on the agenda, the second annual Donald Calne Lecture. World-renowned scientist Professor Oleh Hornykiewicz, Professor Emeritus, delivered the lecture. Professor Hornykiewicz joined us from Vienna, Austria, to present a state-of-the-illness lecture and to answer questions from the audience.

The 2005 Annual General Meeting and the third annual Donald Calne Lecture will take place November 4–6, 2005 in Winnipeg, Manitoba. The meeting and lecture will be hosted by regional partner Parkinson Society Manitoba.

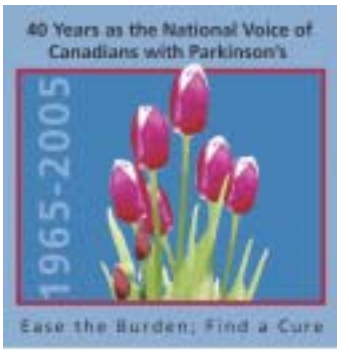
*Joyce Gordon (left), President and CEO, PSC, chats with Les Whiting, National Board member.*

***Seated left to right:** Ruth Vant, Executive Director, Parkinson Society Ottawa, and Judy Axelson, Executive Director, The Parkinson's Society of Southern Alberta.*
***Standing left to right:** Mary Jardine, former National Executive Director, PSC, and Lois Raphael, Executive Director (now retired), Parkinson Society British Columbia.*

***National Board of Directors. Back row, left to right:** Barry Johnson, Calgary, Alberta; John Parkhurst, Penetanguishene, Ontario; Bernard Lefebvre, Otterburn Park, Quebec; Lucie Lachance, Montreal, Quebec; Bruce MacGowan, Toronto, Ontario; Les Whiting, Coquitlam, British Columbia; Kelly McKay, Halifax, Nova Scotia; and Jim Emmett, Calgary, Alberta. **Front row, left to right:** Isabel Ward, Ingersoll, Ontario; Anne-Louise Lafontaine, Montreal, Quebec; Fran Squire, Ottawa, Ontario; Alan Riccardi, Ottawa, Ontario; Bob Ashuk, Winnipeg, Manitoba; Elizabeth Holloway, St. John's, Newfoundland and Labrador; Georges Allard, Sherbrooke, Quebec; and Meredith Saunderson, Toronto, Ontario. **Not pictured are** David Whittle, North Vancouver, British Columbia; Mike Harris, Toronto, Ontario; and Russell Armstrong, Ottawa, Ontario.*

***Left to right:** Meredith Saunderson, National Board member; Robert Feutl; Mimi Feutl, former National Director of Patient Services, PSC; and Marilee Weisman, volunteer.*

# 40 outstanding achievements mark our 40th anniversary




By Carol Jamieson

To celebrate our 40th anniversary, we looked back at some of the people and events that have shaped our history. We've selected 40 highlights from our hundreds of achievements to mark our special anniversary.

**1 1965**
- Creation of Canadian Parkinson's Disease Association

**2 1971**
- Name change to The Parkinson Foundation of Canada

**3 1978**
- Director Mimi Feutl identifies need for local volunteer services

**4 1980**
- Research Fellowship to Playfair Neurological Institute

**5 & 6 1981**
- First Scientific Advisory Board/National Research Program
- First research grant to Dr. Clement Young of Toronto

**7 1982**
- First operating grant (of several) to professor Oleh Hornykiewicz, international pioneer in Parkinson's research

**8 1984**
- First Parkinson Awareness Week in Canada

**9 & 10 1988**
- First national annual sale of James Parkinson tulip bulbs
- First edition of the brochure "Parkinson's Disease: The Facts"

**11 & 12 1990s**
- Volunteers successfully lobby Nova Scotia government to allow cell transplant surgery trials
- Bill Harshaw persuades Ontario government to include people with Parkinson's on the Ontario Trillium Drug Plan

**13 to 17 1990**
- First known SuperWalk
- Launch of Clinical Assistant Program
- First national annual Cut-a-Thon
- First annual Blue Jay Pitch-in for Parkinson's
- Tulip of Hope greeting card becomes part of boutique sales

**18 1992**
- Community Outreach Program begins

**19 1996**
- PSC supports development/validation of first North American scale to measure quality of life in Parkinson's

**20 to 24 2001**
- Revised mission and new name: Parkinson Society Canada
- National agreement among Canadian Parkinson's organizations
- Relaunch of *Parkinson Post*
- New logo
- Start of National Information & Referral Centre

**25 2002**
- Donald Calne Lectureship created

**26 2003**
- PSC works with Health Canada to produce first-ever economic statistics about Parkinson's disease

**27 & 28 2004**
- PSC hosts eighth International World Parkinson Day
- Family Physician Information and Resource Kit created and distributed

**29 2005**
- PSC's Joyce Gordon celebrates Parkinson's Disease Awareness Month on Parliament Hill with Senator Michael Pitfield, Minister of National Defence Bill Graham, and Minister of Health Ujjal Dosanjh.

**30 to 40 2005**
*PSC funds support:*
- UBC PET program, only one of its kind in the world devoted to Parkinson's
- World-renowned Parkinson's researchers:
  - Dr. Ali Samii
  - Dr. Peter St. George-Hyslop
  - Drs. Edith and Patrick McGeer
  - Dr. Pierre Blanchet
  - Dr. A. Jon Stoessl
  - Dr. Judes Poirier
  - Dr. Ali Rajput
  - Dr. Donald Calne
  - Dr. Rémi Quirion

Visit www.parkinson.ca and click on the 40th anniversary icon for more history.

# A look at current Parkinson's research aro

Research Editor: Dr. John Wherrett

## Parkinson's and driving

Until a few years ago, only people with Parkinson's who had advanced symptoms were thought to be at risk for unsafe driving behaviour. However, recent reports of sudden onset sleepiness, attributed to some of the anti-parkinson's drugs, have focused attention on earlier stages of Parkinson's.

An Australian team, consisting of optometrists, a kinesiologist, a neurologist, an occupational therapist (OT) and a driving instructor, compared a volunteer group of people with Parkinson's with a control group of people without the disease who had similar driving experience. The assessment considered the duration and degree of the disease as well as driving experience and habits. Performance was measured on a standardized open road course monitored by the OT and driving instructor, and scored for 147 locations along the course. The subjects also scored their own performance.

It should be noted that the people with Parkinson's who volunteered were a select group who do not necessarily represent the general Parkinson's population. For example, they may have volunteered because they were concerned about driving or were confident about their skills.

The researchers found that the people with Parkinson's were driving less than the controls but considered themselves equally safe drivers. However, the driving assessment showed that 56 per cent of the people with Parkinson's would not have met the standards of the state driving test as opposed to five per cent of the control subjects. Specific difficulties included errors in keeping to the lane, changing lanes, reversing, parking and monitoring blind spots. These difficulties were thought to result from decreased motor control, impaired visuospatial processing, controlling of sequential events, and planning. The duration of the illness was a predictor of impaired performance; however, the standard clinical scales of severity were not.

The authors concluded that implications for driving should be discussed at diagnosis of Parkinson's disease and that driving assessments should be considered earlier in the course of the disease to ascertain the need for future planning.

References: *Journal of Neurology, Neurosurgery* and *Psychiatry*, 2005.

## Advances in the genetics of Parkinson's disease

Major discoveries of the genetic causes of Parkinson's disease continue to shed light on the underlying mechanisms leading to nerve cell death.

Mutations in three genes called Parkin, DJ-1 and Pink1 cause a recessive form of the disease (autosomal recessive, where two copies of mutated gene are present). Mutations in three other genes called α-synuclein, UCHL1 and NR4A2 cause a dominant form (autosomal dominant, where a single copy of a mutated gene is sufficient to disrupt gene function). In the dominant forms, the disease is manifest in succeeding generations, whereas in the recessive forms, succeeding generations will not be affected unless a new copy of the mutated gene is introduced by an unrelated spouse.

From this knowledge of the normal and separate function of these genes, it can be postulated that cellular damage occurs because of abnormal aggregation of the protein α-synuclein. This occurs because of structural abnormalities in, or excessive amounts of, α-synuclein; dysfunction of the normal pathways for breakdown of the protein, as in Parkin and UCHL1; and the effects of excessive oxidation, as in DJ-1 and Pink1.

In 2002, a new gene link associated with autosomal dominant Parkinson's was detected in Japan. In subsequent work, the gene was identified, characterized and named leucine-rich repeat kinase-2 (LRRK2). Its protein product is called "dardarin," derived from the Basque word *dardara* for tremor. This protein has enzymatic activity (kinase activity) that adds a phosphorus atom to other proteins—a common form of molecular signaling in cells. This may give a totally new insight into the mechanisms that injure nerve cells affected in Parkinson's disease. Dardarin mutations appear to be much

**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

more common than other inherited forms, accounting for five to six per cent of familial cases and one to two per cent of sporadic cases.

Although different mutations have been encountered, one appears to predominate. Affected individuals develop typical Parkinson's disease, responsive to treatment and exhibiting the common complications of treatment. Pathological studies to-date suggest that the mutations can be associated with cellular changes characteristic of a number of neurodegenerative diseases, such as diffuse Lewy body disease, progressive supranuclear palsy, and other dementias.

Reference: *Lancet*, 2005

### Testing the placebo effect

Placebos are "dummy" medications given to patients in the course of clinical trials, which are designed to test a drug's effectiveness. They are assumed to be ineffective and are intended to serve as a comparison to the drug being tested. If the therapeutic responses in the subjects who received the drug outweigh those measured in the subjects who received the placebo, the drug is considered to be effective.

But what if the subjects are found to derive some benefit from the placebo? For some time, it has been apparent that subjects in trials of drugs for Parkinson's disease (and for other disorders) do derive benefit from placebos—the so-called "placebo effect." This response, if marked, can confuse interpretation of the trial.

Investigators at the University of British Columbia have been studying the mechanisms that underlie the placebo effect. Using metabolic imaging with positron emission tomography, they have shown that circuitry in the brain, sub-serving the unconscious perception of rewards promoting survival, is activated by placebo. These circuits are not only located close to the circuit (nigrostriatal tract) that is affected in Parkinson's disease, but also are largely dependent on dopamine. This has been supported in studies of patients undergoing electrode implantation for deep brain stimulation, where electrical activation of nerve cells in the reward circuitry was measured.

Thus, it appears that the perception of possible benefit, even if receiving an inactive drug, could activate systems mediated by dopamine and favourably affect symptoms of Parkinson's. A spontaneous example of activation of the reward circuitry may occur in the phenomenon of kinesia paradoxica (paradoxical ability to move), wherein a patient with advanced Parkinson's disease experiencing a life-threatening emergency is able to move.

References: *Biological Psychiatry*, 2004; and *Nature Neuroscience*, 2004

## Focus on ...

**Dr. Jennifer Takahashi**

**PSC Boehringer Ingelheim Clinical Movement Disorders Fellow**

Movement has always been a vital part of Dr. Jennifer Takahashi's life.

While training to be a professional ballerina at the National Ballet School in Toronto, Dr. Takahashi learned and practised the intricate movements of dance. Now, she is viewing movement from a totally different perspective at the Centre for Movement Disorders in Markham, Ontario.

"Even while I was training in ballet, it was my intention to eventually pursue a career in medicine," says Dr. Takahashi. "After I graduated, I decided I didn't want to wait."

Dr. Takahashi studied medicine at Queen's University in Kingston, Ontario, subsequently receiving her neurology training at the University of Calgary and University of Alberta. "Neurology had always interested me," she explains. "It is an intimate, personal specialty that lets you really get to know patients and their families."

She had focused on multiple sclerosis before becoming involved with Parkinson's and other movement disorders. "I had enjoyed my experiences with Parkinson's patients and wanted to learn more," recalls Dr. Takahashi. "Then I met Dr. Mark Guttman at the annual movement disorders course for neurology residents, and I was very impressed by his attitude and multidisciplinary approach."

Following a maternity leave, Dr. Takahashi was awarded the PSC Boehringer Ingelheim Clinical Movement Disorders Fellowship, giving her the opportunity to work with Dr. Guttman at the Centre for Movement Disorders.

"I am involved in some research," she notes. "For example, one of the projects involves looking at the efficacy of an interdisciplinary model of caring for people with Parkinson's. But about 80 per cent of my time is spent in the clinic, working with patients. That's the place where you really learn about treating this disease."

On completion of her Fellowship, Dr. Takahashi plans to return to her native Kamloops, British Columbia, with her husband, Dr. Anders Ganstal. "I plan to join a neurology practice with two other clinicians," she says. "My focus will be on movement disorders. The experience I will have gained from this Fellowship will be invaluable."

# Up-times and off-times: Living life with Parkinson's

By Ken Chute, Lower Sackville, NS

I remember clearly that February day in 1996 when Dr. Bahn said to me, "You already know what you have." In 1969, my dad was diagnosed with Parkinson's disease (PD). And since 1969, my mom and two of my aunts on my mother's side were told they had the condition. So in 1996, I was diagnosed as "one of them."

For several years, under Dr. Bahn's guidance, I experimented with various combinations of pills and time schedules. The objective of these ever-changing combinations was and still is to provide me with the maximum daily up-times when I am neither suffering from bradykinesia (including moments of freezing) or dyskinesia. These experiments result in various forms of fluctuations and contribute to my physical and mental state.

Since my 1996 diagnosis, I have been on an interesting ride as the disease progresses. I require more medication, experience more complicated swings from dyskinesia to bradykinesia, and see a number of strange outcomes that are increasingly hard to understand and to explain. Even so, without the medication, I would return to all of the ravages of Parkinson's disease.

## A steady state

My medication helps me deal with cyclic periods called "up-times" and "off-times." Up-times happen when the medication is doing its job. Off-times occur when the medication is either under-reacting (resulting in PD symptoms) or over-reacting (when I can't relax or stop moving).

During my off-times, thoughts about PD continuously flood my mind. I often think about the effect of the condition on my life and my family. And since the effects of PD are progressive—the average time from diagnosis to when PD medication is no longer effective is estimated to be 10 to 12 years—I become concerned. During my up-times, however, I crowd all of the activities that I value into my schedule, and I generally forget about the condition. In other words, I get on with my life. Lately, I've noticed that my off-times are slowly increasing and my up-times are decreasing.

My ideal situation is to have the medication carefully controlled so I can achieve a "steady state," where I become neither over– nor under–medicated. This in fact is the objective of the medication

*Deanna and Ken Chute with their daughter Holly.*

**During my up-times, I crowd all of the activities that I value into my schedule, and I ... forget about the condition. In other words, I get on with my life.**

selection and times. Since there is no cure for Parkinson's, the four pills that I take eight times daily control my quality of life.

### A flexible schedule

So how do I control my medication? My daily routine starts at 5:15 a.m. when I take my scheduled medication, which I prepare on the previous night. From 9:30 p.m. the night before to 5:15 a.m. the next day, my medication is kept to a minimum, so by 5:15 a.m., I am experiencing most of the Parkinson's symptoms. The morning often sends me into a dyskinetic tailspin, which may last for several hours. Of course, having a tendency towards bradykinesia is also undesirable. Both of these conditions affect my concentration. Fortunately, these swings often take place over only two (out of eight) medicated periods.

My best and longest up-times often occur in the late morning. During this time, I may attend a few 10:30 a.m. church services in a row. (Those who see me at church might believe that my health is improving; in fact, the opposite is the case.)

The rest of my day isn't as scheduled, thanks to the unpredictability of my up-times and off-times. Slipping from one state to another is not like flicking a switch. The changes, driven by medication adjustments, could take place in as little as 15 minutes or as much as two hours. In both cases, I experience various degrees of either bradykinesia or dyskinesia, so I have no fixed schedule.

### A sense of humour

These changes, although frustrating, often provide comic relief. For example, my feet may become "frozen." When I break free, I can almost run (well, trot anyways). At other times, I have difficulty walking through a door, yet I can navigate stairs.

If you don't have a sense of humour, you should develop one, particularly when it comes to your appearance. I know some of the physical changes that Parkinson's bestows: you can walk with a slow–gaited stance, and your facial expression may appear stiff. If you hold to an unkempt appearance, people will tend to feel uncomfortable around you. Showering and shaving improves your appearance and makes you feel better. The irony of looking your best results in comments from your friends and relatives ("Ken, you look great"), so it may be hard to explain how you're looking great yet the onslaught of PD continues.

As I pass my 58th birthday, I seem to reflect more on my future. On the upside, I, like many other persons with Parkinson's, have a relatively positive outlook on life. An appreciation for what one may have once taken for granted is continuously honed.

### A ray of hope

Although I've spent much effort in dealing with the symptoms of PD, my medications have provided me with a quality of life that I could only hope for a few years ago. While ideal, a cure would take as long as 10 years to help people with Parkinson's. In the meantime, a "new to me" pill has shown promise in controlling my symptoms, so there is always hope.

# Ask the Expert

***Q I've been having problems sleeping since my diagnosis with Parkinson's. Is this normal?***

A Sleep disorders are common in Parkinson's disease. A survey published in 1982 found that 74 out of 100 Parkinson's patients had significant sleep-related complaints. In addition, sleep disorders may result in an exacerbation of Parkinson's symptoms.

In general, sleep disorders are grouped under the categories of the insomnias, parasomnias and disorders associated with excessive drowsiness. Sleep disorders of interest to people with Parkinson's include the following:

**Insomnia:** Insomnia is the most commonly reported sleep disorder for people with Parkinson's. It may be the result of an underlying depression, a common accompaniment of the disease. This possibility needs to be explored. Treatment possibilities may include the use of an antidepressant.

Sleep fragmentation (where the individual falls asleep but wakes up repeatedly) is noted by 39 per cent of people with Parkinson's as compared to 12 per cent of normal elderly individuals, according to a study from Norway. These individuals may need to use sleep medication. However, the pattern of disturbance should be established and other methods of promoting sleep hygiene should be explored. If insomnia is caused by changes related to motor symptoms, management may consist of adjusting dopaminergic drugs, so that nocturnal "off" periods can be minimized.

The discomfort and fear of waking up immobile during the course of the night can be a major source of concern to people with Parkinson's. This must be weighed against some of these drugs causing sleep problems of their own, including vivid dreaming.

**REM Behaviour Disorder (RBD):** In people with this condition, the usual loss of muscle tone associated with REM sleep does not take place; therefore, the patient becomes very active, thrashing around and posing a danger to his or her bed partner. This condition is common in Parkinson's, but it may also occur in several other neurological conditions. Clonazepam has been used with considerable success in the treatment of RBD.

**Abnormal dreaming:** This may be a side-effect of dopaminergic drugs and may become worse the longer these drugs are used. Vivid dreaming is the most common manifestation, and the person may sometimes have difficulty differentiating what was real from the dream itself, upon awakening. Night terrors may be forgotten by the person upon waking, but may be a source of anxiety for the family, as he or she seems to be in a state of distress during the event. These disorders may require changes in medication regimes, particularly those taken just prior to going to sleep.

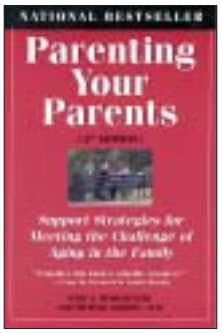
**Excessive daytime drowsiness (EDS):** In Parkinson's, this may be a result of the disease itself, or may result from some of the drugs used. For example, dopamine agonists may produce somnolence in 10 per cent to 25 per cent of individuals. If the offending drug cannot be stopped or reduced, a stimulant, such as modafinil, is sometimes added to the drug regime to counteract EDS. Some people with Parkinson's may continue to experience EDS despite manipulations in their drug regime.

**Sudden onset sleep attacks:** These consist of a sense of overwhelming sleepiness and can occur without warning. They may occur in the context of EDS or may be a separate entity. Since there is no warning, people may be unable to protect themselves during a certain activity; for example, while driving. For this reason, they pose major safety concerns, and it may be necessary to forbid driving. These attacks were first described with the dopamine agonists pramipexole and ropinirole, but subsequent studies have shown that they may occur with other dopamine agonists as well as with levodopa.

It is important to discuss any sleep-related problems frankly with the treating physician. Quality of life may be significantly improved for a person with Parkinson's by treating his or her sleep disorder.

***Tilak Mendis, MD, FRCPC, FACP***
*Director, Parkinsons and Neurodegenerative Disorders Clinic; Consulting Neurologist, Movement Disorders Clinic, The Ottawa Hospital and Kingston General Hospital.*

# Resources




**Parenting Your Parents, second edition**

*By Bart J. Mindszenthy and Michael Gordon, MD*

*Reviewed by Marilee Weisman*

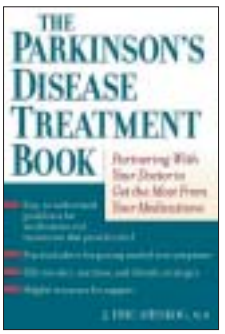
When you spot a book on aging by Michael Gordon, MD, you can be confident that it will be worth reading.

This opus presents an abundance of caregiving information, including examples of different scenarios and a comprehensive personal parenting planner, which the authors encourage you to prepare before making any drastic care decisions.

Chapter headings seem to cover every eventuality: from "Dementia and Depression: Reading the Signs" to "Siblings: In Charge and On the Attack" to this reviewer's favourite, "Breaking the Mold: The Rebellious Grandmother."

This revised second edition has new stories and an updated resource directory. I enthusiastically recommend this useful work to friends.

Visit www.parentingyourparents.ca




**The Parkinson's Disease Treatment Book**

*By J. Eric Ahlskog, MD*

*Reviewed by Gerry Kelleher*

Reading this book gives you a better understanding of Parkinson's disease and its treatments. Parkinson's is explained in detail—from changes in the brain to diagnosis—in easy to understand terminology.

Author J. Erie Ahlskog, MD, gives readers the tools to manage Parkinson's more effectively. *The Parkinson's Disease Treatment Book: Partnering With Your Doctor To Get The Most From Your Medications,* is a must-read for everyone at all stages of the disease. It will be particularly helpful to caregivers and the newly diagnosed as they gain a better understanding of this disease.

*The Parkinson's Disease Treatment Book* is published by Oxford University Press and is available at your local bookstore.


**The Official Patient's Source Book On Parkinson's**

*Edited by James N. Parker, MD, and Philip M. Parker, PhD*

*Reviewed by Marilee Weisman*

The organization of this electronic book is beautifully executed. The content is broken down into three main parts: Essentials, Additional resources and advanced materials, and Appendices.

Within seconds of opening this book, you'll easily find the topic you're searching for. For example, in the Essentials section, you'll find the question "Can diet or exercise programs help relieve symptoms?" The answer inside is "Exercises may improve body strength ... exercises also improve balance...." Under the heading "Working with your doctor" is more good advice. A wide variety of subjects are covered a consumer-friendly way.

Published by Icon Health Publications. To order, visit www.icongrouponline.com/health/.

**www.healingwell.com**

*Reviewed by Peggy Yates*

HealingWell.com is an information resource for patients, caregivers, and families coping with diseases, disorders and chronic illness. Their goal is to help people on their way to "healing well."

There is a great deal of information about Parkinson's disease on this site. It is easy to navigate and the information is straightforward and current. The chat forum is busy, and there are messages from people of different ages. For information that deals with questions from the newly diagnosed to information for families and care partners to Parkinson's research, this site provides easy access to information that will assist and inform.

Health content is contributed by reputable health organizations, including the National Institutes of Health, Healthology Inc., and Mediwire.

Visit www.healingwell.com.

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.

THE Parkinson LEGACY

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When you make a planned gift through ***The Parkinson Legacy***, you provide **Parkinson Society Canada** and its regional partners with resources to support research into a cure as well as Parkinson's support programs across Canada.

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

**Parkinson Society British Columbia**
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**
Ph: (780) 482-8993
Toll Free: (888) 873-9801

**The Parkinson's Society of Southern Alberta**
Ph: (403) 243-9901
Toll Free (Alberta): (800) 561-1911

**Saskatchewan Parkinson's Disease Foundation**
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Toll Free (NS, NB & PEI): (800) 663-2468

**Parkinson Society Newfoundland & Labrador**
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Toll Free (NFLD / Labrador): (800) 567-7020

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