

ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's



Pedalling for Parkinson's:

Jon Kenny's 51-day cross-Canada trek

Food for thought: Meeting your nutritional needs

SuperWalk 2005: Over \$1.75 million raised

PLUS

**How young-onset
affects sex**



Parkinson Society Canada
Soci t  Parkinson Canada

Ease the Burden; Find a Cure



Join in the fun!

Be part of SuperWalk for Parkinson's this September 2006!

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

Join the ranks of the SuperSTARWalkers:

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

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

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

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

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

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

Come and be part of the fun this September!



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ON OUR COVER:

Jon Kenny, from Vancouver, BC,
cycled across Canada to raise
awareness for Parkinson's disease.
Read Jon's story on page 20.

Better service, more information

All of us at Parkinson Society Canada are constantly seeking ways to improve our service to Canadians living with Parkinson's disease. So as the editor of the *Parkinson Post*, I, along with the editorial team, have been working hard over the past months to deliver an improved magazine.

Although we have had our challenges during the past year, we have been busy working to improve service, customer relations and delivery of a more timely *Parkinson Post*. Each one of us appreciates your support for the only national Canadian magazine focused on Parkinson's disease. Thank you.

I also wanted to thank and welcome new subscribers who came our way through the combined mailing we did with our regional partner, Parkinson Society Canada Central and Northern Ontario. We combined *LiveWire* with the *Parkinson Post*, and the results have been very positive.

Also, to those who answered our survey in the fall 2005 *Parkinson Post*, thank you. Your feedback has been valuable, and in our spring issue, you'll begin to see the articles that you and other readers have suggested.

In fact, in the next few issues of *Parkinson Post*, you'll find stories on the Donald Calne Lecture 2005, April Awareness, the World Parkinson Congress 2006, National Volunteer Award recipients, SuperWalk, and more profiles of courage from our "We are the Faces of Parkinson's" campaign. You'll also read more Regional Partner news, First Person stories, resource reviews, and the latest information on Parkinson's research and advocacy.

This year, due to rising postal and other costs, the *Parkinson Post* will have our first subscription increase in nearly four years. The rates will increase for those subscribers whose subscription ends with this winter 2005 issue. Watch for our new subscriber card in our spring issue and on our website in the coming months.

It is a very exciting time for the *Parkinson Post* and Parkinson Society Canada, and we want all of our stakeholders to be part of our changes and improvements.

A handwritten signature in gold ink that reads 'Peggy Yates'.

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

P.S. As spring approaches, let's not forget that Parkinson's awareness month is fast approaching. Contact the regional partner office near you and volunteer. We need your help to raise awareness and funds to further our mission: to ease the burden and find a cure.

Photo: Terry Lowe



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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

- ▶ SuperWalk was a great success and raised \$140,000 in BC.
- ▶ A three-day facilitator's conference took place in October with 28 facilitators in attendance.
- ▶ Seventy people attended the educational meeting in Vancouver, and for the first time, eight health-community organizations participated in a fair after the meeting.
- ▶ The New Diagnosis Day was held on November 12 with presentations from Dr. Martin McKeown and Susan Calne of Pacific Parkinson's Research Centre.
- ▶ The first volunteer recognition reception was held on November 30.

Victoria Epilepsy and Parkinson Centre

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

- ▶ Popular three-week early-stage PD program received wonderful feedback and resulted in many of the participants forming a lunch group.
- ▶ Clinical psychologist Nancy Reeves gave an inspiring presentation on "Finding meaning and growth through Parkinson's."
- ▶ The agency has launched a "Parkinson's Mind Body Program" that draws on research from the

fields of physiotherapy, speech therapy, cognitive therapy, yoga and kinesiology. The new group service is being led by two certified yoga instructors and includes a focus on releasing physical tension and anxiety.

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 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

- ▶ The Dr. Frank Ramsay Graduate Award in Neuroscience has been established by PSSA at the University of Calgary. The \$1,000 scholarship honours Dr. Frank Ramsay (ret. neurologist). The 2005 recipient is Krissy Doyle, a second-year Masters of Science student in medical neurosciences, who is studying deep brain stimulation in Parkinson's.
- ▶ PSC's AGM and meetings were attended in Winnipeg by PSSA Board members Dr. Jim Emmett and Mr. Dan Cooney. Marilynne Herron and Gisele Marcoux (PSSA Direct Service staff) and Judy Axelson, executive director, PSSA, also attended.
- ▶ PSSA now holds two young onset groups in Calgary, with a third planned for this year. Young onset groups also meet in Red Deer and Lethbridge.

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

- ▶ SuperWalk 2005 in Saskatoon raised approximately \$52,000. Our volunteer group is already gearing-up for SuperWalk 2006!
- ▶ The week of September 26 was Parkinson Week. Two world-renowned movement disorder experts, Dr. William J. Weiner and Dr. Lisa M. Shulman from Baltimore, Maryland, delivered excellent presentations in Saskatoon and Regina.
- ▶ Movement disorder clinics were held in Saskatoon and Regina.
- ▶ The 13th Annual Regina Curling Classic for Parkinson's Research will be held on March 31 to April 1, 2006.

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 welcomes Marc Pittet as the Regional Chair (2005-2007). Marc's expertise in governance process will benefit the organization as it continues to work towards independence and self-sufficiency.
- ▶ PSM bids a fond farewell to Terry Snell (Chair from 2003-2005). Terry will continue to support the fund development for the organization.
- ▶ Support groups continue to work towards self-directed operation with the help of Linda Rigaux, co-ordinator programs and services.
- ▶ Thanks to all those who attended the AGM on November 3-6, 2005.

continued on page 6



Parkinson Society Canada
Société Parkinson Canada

Special thanks to the AGM planning committee: Terry Snell, Shaun Hobson, Lisa Gilmour, Wayne Buchanan, and Nichola Lastella from PSM; Joyce Gordon, Melissa Adamson, Peggy Yates, and Debbie Davis from PSC.

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

- ▶ PSP/MSA Conference organized by CNOR and PSP Canada in November had 100 participants.
- ▶ Represented CNOR/PSC at the Shopper's Home Health Care annual trade show, which hosted 2,500 delegates.
- ▶ Represented CNOR at the Ontario Community Support Associations conference, which hosted 400 delegates
- ▶ Held a volunteer appreciation tea that thanked community and office volunteers for their support.
- ▶ Sandra Jones, client services and education co-ordinator, was the recipient of the Mimi Feutl award at this year's AGM.

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
- ▶ SuperWalk for Parkinson's raised over \$213,000.
- ▶ Sold 52,470 tulip bulbs, a 10 per cent raise over last year.
- ▶ Held Community Volunteer Fairs for Parkinson's in Windsor and Kitchener.
- ▶ Upcoming PEP for Community Caregivers was presented at the Community Care Worker Conference 2005, hosted by Red Cross Community Health Services.
- ▶ Support group facilitators learned about group dynamics and self-care thanks to speaker Rosita Hall, who has designated Parkinson's as her

charity of choice this year.

Parkinson Society Ottawa

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

- ▶ In early October, we participated in the annual Day of Caring program set up by Volunteer Ottawa and United Way. Three volunteers planted 1,000 James Parkinson tulip bulbs in the flower beds in front of our building.
- ▶ The Family Education Series, an informal group with panel presentations by health professionals, was held in November and attracted many newly diagnosed people and their family members.
- ▶ The annual holiday party was held in early December. Three generations of members and their families enjoyed the talent show, lunch, carol-singing with the Kiwanis Club and, of course, Santa Claus.
- ▶ A new monthly support group began in Kemptville in January 2006. It is facilitated by a social worker from Kemptville District Hospital.
- ▶ To strengthen an existing partnership with the Algonquin College public relations program, we are providing mock interviews to all second-year students in exchange for having a student for each of two seven-week placements.

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

- ▶ Conducted a thorough review of the organization's internal management and funding policy in order to develop a strategic plan.
- ▶ Prepared the Parkinson's month activities.
- ▶ Launching of a spring membership campaign.

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

- ▶ The region is incorporated and now receives CRA status as a charitable organization.
- ▶ SuperWalk set a record with a 30 per cent increase in revenue.
- ▶ Annual conference attracts delegates from six provinces and two states.
- ▶ AGM elects new Board with four directors from NS, four from NB and one from PEI.
- ▶ First regional awards presented to Art MacPhee (Volunteer), Moncton (Chapter), Banyan Tree Foundation (Leadership), Rene O'Flaherty (Health care), and Mildred Nickerson (Lifetime).
- ▶ New regional poster, brochure, and resource guide launched with a grant from Allegra Print.

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

- ▶ Regional SuperWalks raised more \$36,800.
- ▶ Volunteers sold almost 20,000 tulip bulbs.
- ▶ The first annual Anne Rutherford award was awarded to Joyce Humphries, a volunteer who has made a difference in the lives of people living with Parkinson's on the west coast of the Island.
- ▶ The VOCM Cares Foundation has supported our Parkinson's Community Education Program with a \$10,000 grant.
- ▶ Regional Board sponsored a public forum in November to offer mem-



Parkinson Society Canada
Société Parkinson Canada

Issues of interest to people with Parkinson's

Momentum is building for national advocacy efforts

By Joyce Gordon

With the federal election behind us and the 39th Parliament now in place, efforts are underway to establish relationships with newly elected Members of Parliament and their staff. At the same time, we remain committed to strengthening relations with those Members who have supported Parkinson Society Canada (PSC) over the years.

The federal election presented the opportunity for Parkinson's stakeholders across Canada to speak with one voice and to raise issues related to Parkinson's with their local candidates. This grassroots effort, supported by our election advocacy toolkit, marked a new high in working collaboratively with and sending a universal message to decision makers:

Parkinson's matters and the time to act is now! More specifically, candidates heard our call for a consistent and sustained annual investment of at least \$1 million for Parkinson's research, and the need for universal access to skilled Parkinson's care and services regardless of what province, region, city or town a person may live in.

Just prior to the election call, PSC representatives met with key decision makers at the Institute of Aging and the Department of Health in Ottawa. Our task now is to follow up with those candidates who pledged their support, with government staff, and with the various agencies and organizations where we successfully opened doors.

We also must ready ourselves for future election advocacy efforts. As we have another minority government, it won't be long before we will need to make our voices heard once again. We hope we can count on each and every Canadian with Parkinson's, their family and friends, their caregivers, and medical professionals to help us educate our communities as well as our representatives.

Advocacy requires continuous effort, not just at election time. We are actively seeking individuals across Canada who want to participate on an ongoing basis. If interested, please e-mail advocacy@parkinson.ca, and we will be sure to keep you informed and active.

Together we can make change happen.

What we want

Parkinson's stakeholders across Canada have been very clear about their priorities: research funding to find a cure, and universal access to health care, services and supports. These are both areas in need of significant improvement; areas that directly affect the 100,000 Canadians with Parkinson's, their families, friends, caregivers and communities.

To make the most impact with audiences across Canada, PSC has structured our messages around the slogan "Parkinson's disease: Act Now" both in terms of research funding and home care supports and services.



Photo: Invisicare Canada

Make your bathroom safe

Take plenty of tiles, some slippery porcelain, and add a little water, and you'll easily see why most accidents in the home occur in the bathroom. One little slip could mean a serious injury. People with Parkinson's, due to their disease and its impact on motor ability, have to be even more cautious. Following are a few tips to make your next trip to the bathroom a safe one:

- Ensure the bathroom is well lit.
- Safely secure any bathroom rugs with two-sided tape, or use non-skid bath mats.
- Preset your water heater to prevent scalding (maximum 49°C/120°F). Then, make sure the hot and cold water handles on your heater and on your taps are clearly marked.
- Install lever-type faucets in the sink and tub. These faucets require less hand strength and wrist pressure to operate.
- Place a non-skid rubber mat or self-adhesive strips on the bottom of the tub or shower stall.
- Sit on a stool in the shower if you have difficulty with balance.
- Purchase a hand-held shower head that has a flexible hose.
- Install grab bars or safety bars. Install a grab bar on the tub sidewall and another on the back of the shower or tub as well as next to the toilet. Securely mount both ends to wall studs; don't merely screw them into drywall.

An occupational therapist can provide other bathroom safety tips as well as an in-home assessment to help you identify other areas in your home where safety may be a concern. For a referral, please contact your local Parkinson Society Canada Regional Partner. You'll find a list of names and addresses on pages 5 and 6 of this issue.

Ease the Burden; Find a Cure

Food for thought: Meeting the nutritional challenges of Parkinson's

By Ian Corks

Eating a well-balanced, healthy diet can benefit anyone, but for people with Parkinson's disease (PD), good nutrition can take on added emphasis. In addition to its inherent health value, a good diet can help the person with PD meet some of the nutrition-related challenges that can be part of the disease.

"A person with PD will find that their nutritional issues will change

as the disease progresses," explains Karol Traviss, MSc, RD, a Dietetic Education Co-ordinator, Food, Nutrition and Health at the University of British Columbia (UBC). "In the early stages, it is important to emphasize the nutritional value of the diet, just like any adult of a similar age should do. Later on, as certain effects of the disease or Parkinson's medications

begin to take hold, it may become necessary to make adjustments."

Karol, who has worked with people with Parkinson's at the UBC Hospital's Movement Disorders Program and through her involvement with Parkinson Society British Columbia, advises people to adopt good eating habits as soon as possible, not only to feel better in the present but also to prepare for future challenges.

"Good nutrition is vital to staying as healthy as you can," she



says. "The goal of any meal plan should be to ensure a sufficient intake of all essential nutrients and enough calories to prevent the weight loss that can occur as the disease progresses."

What to eat

Your meal plan should feature a variety of foods from all four food groups: grain products, vegetables and fruit, milk products, and meats and alternatives. *Canada's Food Guide to Healthy Eating* is an excellent source of information on healthy eating. (Editor's note: Visit www.hc-sc.gc.ca/fn-an/food-guide-aliment/index_e.html and click on the *Canada's Food Guide* icon.)

Vitamins and minerals are key components of any healthy diet. Vitamins and minerals that are needed on a daily basis include vitamin E (an antioxidant that helps neutralize toxins in the body), calcium (essential for strong bones), vitamin D (another component of strong bones), iron (helps prevent anemia) and vitamin B complex (beneficial to brain function). Recommended daily intakes of essential vitamins and minerals vary by factors such as age, weight and sex. However, most people can achieve their daily requirements by following the food group intake recommendations of *Canada's Food Guide*.

Although most people can get the nutrients they need by making healthy food choices, Karol points out that people often fall short in their eating habits. "As such, taking a once-daily multipurpose vitamin mineral supplement is not a bad idea," she notes.

While multipurpose vitamin mineral supplements are generally safe, people with PD should be cautious about the use of high doses and herbal supplements as these

could cause unwanted side effects or interactions with medications. As such, advice from a professional such as a physician, pharmacist, or registered dietitian, can be useful.

Keeping up with PD

Sticking to a balanced diet and a regular exercise program will help to maximize your overall health and wellness during the early stages of PD. However, dietary modification may be necessary as time goes by.

"The progression of PD is associated with a number of eating-related challenges," Karol explains. "These can be related to medications or to the physical manifestations of the condition." Each of these challenges can seriously impact an individual's nutritional status. The good news is that there are a number of strategies to help people with PD and their caregivers cope.

Medications and protein: High levels of protein intake can affect the brain's uptake of levodopa, reducing its efficacy. This has led to some debate over the benefits of a protein-restricted diet. "People with PD need protein as much as anyone else," Karol remarks. "In fact, too many older individuals eat what nutritionists refer to as a 'tea and toast' diet, and don't get enough protein. In general, there is no need to drastically restrict protein intakes."

For individuals who find that protein affects medication effectiveness, solutions can be to take medications 30–45 minutes before meals and to avoid eating large amounts of protein at one time. A protein redistribution diet—a special diet that redistributes protein intake across the day—is not generally recommended and should only be used with advice and monitoring from a neurologist.

Constipation: Constipation is generally defined as having less than two bowel movements per week and/or having stool that is dry, hardened and difficult to pass. Constipation can be a problem for people with PD for a number of reasons, including PD's effects on the colon, medication side effects, low physical activity and poor intake of dietary fibre and fluid.

A starting point for anyone with constipation is to eat more dietary fibre and drink several glasses of water per day. High fibre foods include whole grain breads and cereals (particularly bran-containing), fruits and vegetables with skins, and nuts, seeds and legumes. Individuals with poor appetites or swallowing problems can have difficulty getting enough fibre. Fruit smoothies, pureed vegetable soups and fruitlax or prune butter stirred into hot cereals can be helpful in these cases.

Unfortunately, even with a good dietary fibre intake, constipation may still be a problem. "You might need to use a mild bulk-forming laxative such as Metamucil®" says Karol, adding that stronger laxatives, stool softeners, and even enemas are options that may need to be considered if the problem persists, and then only on advice from a health professional.

Osteoporosis: People with PD are prone to osteoporosis due to their lack of mobility (resulting in loss of bone density) and typically older age (risk increases with age).

"Calcium and vitamin D are the best nutritional factors which protect against osteoporosis," Karol advises. "The recommended daily intake is 1,000 to 1,500 milligrams of calcium and 10 to 15 micrograms of vitamin D. Milk and other dairy products are by far the best

dietary source, but many people don't get enough of these. If you don't, then a daily calcium and vitamin D supplement is a good idea."

Swallowing difficulties: Dysphagia, or problems with swallowing, is a serious concern for some people in the later stages of PD. Naturally, this can impact eating, due to the risk of choking or aspiration of food into the lungs (leading to pneumonia).

Dysphagia can develop gradually and requires expert intervention. "If significant swallowing problems develop, ask your physician for a referral to a swallowing professional, often a speech language pathologist (SLP), for an assessment," warns Karol. "The assessment typically includes a physical examination, swallowing tests, and radiographic studies.

"The SLP will then develop recommendations," she continues. "These could include exercises to improve swallowing technique, adjusting body position and, of course, dietary adjustments. It is important to note that each person's specific problems and solutions could be different. For example, people vary in their ability to safely swallow various food textures and fluid consistencies. Some people may need pureed diets and thickened liquids. If there are many dietary recommendations from the SLP, it can be helpful to consult with a registered dietitian. You definitely need professional assessment and advice."

As a safeguard, Karol suggests that caregivers of people with PD who have trouble swallowing should take the time to learn the Heimlich manoeuvre. This simple technique could save the life of someone who is choking.

Appetite: As people age, they tend to have less appetite at the best of times. In Parkinson's, this loss of appetite can be more pronounced due to a variety of factors. "The side effects of PD medications can affect appetite," says Karol.

Parkinson's and anti-oxidant vitamins

For many years, researchers have theorized that anti-oxidant vitamins such as vitamin E, vitamin C and beta-carotene could have neuro-protective effects and thus may have a role in preventing or delaying the progression of PD.

A team of researchers at Montreal's Royal Victoria Hospital conducted a meta-analysis study which looked at almost 40 years of studies on antioxidants and PD (see *Parkinson Post*, Spring 2005). No effects were seen for vitamin C, beta-carotene, or vitamin E taken as supplements. However, dietary vitamin E intake appeared to have a protective effect. This potential beneficial effect has not been confirmed using randomized controlled trials.

Most experts suggest that while getting your recommended daily intake of vitamin E (10–15 mg for adults) is important to overall health, supplements are generally not needed if you eat a balanced diet. Good natural sources of vitamin E include nuts, seeds, wheat germ, vegetable oils, and leafy green vegetables.

If you have any questions or concerns about vitamin intake, talk to a registered dietitian. Visit the Dietitians of Canada website at www.dietitians.ca, or ask your physician for a referral.

"Delayed gastric emptying is another issue. Food tends to move more slowly through the digestive system. This can make you feel fuller longer and contributes to heartburn and nausea, so you are less inclined to eat."

In these cases, a physician may be able to suggest various strategies, ranging from adjusting PD drug schedules and the timing of meals, to specific medications to treat gastrointestinal problems. Karol suggests that "easy-to-use food supplements, such as Boost® or Ensure®, can be useful in supplying essential nutrients for people who don't eat properly, or even regularly, due to poor appetite."

Expert advice

Ensuring that a person with PD continues to eat well is an ongoing challenge. Paying close attention to diet and seeking advice from experts is recommended.

A physician can help answer general questions about PD and its medical management, while a pharmacist can help address medication-related questions, and a registered dietitian can help with dietary advice.

American registered dietitian Kathrynne Holden has written a cookbook, *Cook Well, Stay Well with Parkinson's Disease*, specifically for people with PD. (Editor's note: Watch for the book review in the next issue of *Parkinson Post*.)

"While it is rare to find a registered dietitian who can claim special expertise in PD, many have encountered PD in their work and can help you address the eating and nutritional issues you face," notes Karol Traviss. "A dietitian's knowledge of nutrition and wellness can be a tremendous help in developing an individualized healthy eating plan and strategies for coping with some of the challenges. Ask your physician for a referral. You may find that sitting down with a registered dietitian can be very worthwhile and can help you plan the right nutritional strategy."

“I am proud of us...”

Facing up to Parkinson’s with love and patience

Micheline Savoie has become very familiar with the symptoms and treatments of Parkinson’s disease (PD) over the years. As a pharmacist with more than 30 years’ experience in the community and hospital settings, she has frequently worked with people with PD.

Living in the beautiful lower St. Lawrence region of Quebec with her husband Yves, Micheline currently works at Le Centre de santé et de services sociaux (CSSS) de La Mitis in Mont-Joli. At this long-term care and rehab centre she meets with patients, including those with PD, and their families. She also gives regular presentations to the Day Centre Out Patient exercise group for people with Parkinson’s, where she discusses symptoms of PD, medications, side effects and other important drug-related issues.

But Micheline has come to know Parkinson’s more intimately than most other health-care professionals. *Parkinson Post* (PP) chatted with Micheline (MS) about her unique perspective on PD.

PP: In addition to dealing with the disease on a professional basis, how are you personally affected by Parkinson’s?

MS: My husband, Yves, was diagnosed with PD in 1998.



Being a health professional didn’t diminish Micheline’s shock and fear when Yves was diagnosed with PD at age 43.

tration, attention and memory.

PP: How did you react to Yves’ diagnosis?

MS: Yves was only 43. The diagnosis came as a shock. It was very difficult to accept.

PP: How did Yves adjust?

MS: Yves immediately started learning about PD. He read everything he could find on the subject, he searched the Internet, he met with experts, and we talked about it profusely.

He made the decision to adapt in whatever way was needed. For example, he is right-handed but has tremors in his right hand, so he has trained himself to use his left hand to eat and to work on the computer. He felt that he was becoming slower and a little clumsy, so he reorganized his work to be as

efficient as possible.

At the beginning, he imagined that PD was only a disease of tremors. He did not know that it was so complicated, with more challenges to come... difficulties with walking, moving, getting up, turning in bed, eating, shaving, etc. It can be like being “a 150 kg teddy bear,” as Yves says in one of the talks on PD he gives to various groups.

PP: How did you cope?

MS: When I studied pharmacology at the University of Montreal I learned about the symptoms and treatments of PD. I thought that I knew all about the disease. But, wow, was I surprised!

Each day I discovered more and more about the complexity of the disease—its highs and lows, its unpredictability, its inconsistency. Nothing is as simple as it is in the textbooks. Textbooks rarely address the true “human” side. They don’t talk about the understanding, compassion and dedication, not to mention the sense of humour, that are required to provide adequate support for our loved ones.

Of course, after working in a hospital for many years, I knew—even though it was much less than I thought—about some of the difficulties. And because I knew, the

fear of what might lie ahead mixed with the shock, so it was also very difficult for me.

PP: How have you both handled Yves' treatment regimen?

MS: At first, my main fear was that Yves, who seldom went to any doctor, would not follow his physician's orders.

Fortunately, he quickly understood that now his quality of life depended on listening to the doctor and taking his medication regularly.

In the beginning we had to deal with the many problems related to side effects. Yves' neurologist, Dr. Emmanuelle Pourcher, and her nurse, Marie-Claude Fortin, in Quebec City have been great. Right now Yves is involved in a clinical trial, hoping to reduce motor fluctuations—times we refer to as his "on/off" periods.

Yves also puts his trust in me. He is very aware of the physical and

psychological effects of his medications, both positive and negative.

PP: Do you find it difficult at times?

MS: Yes, but I take time to take care of myself. I find relaxation in reading, gardening, dancing, painting and meeting with friends. I want to remain strong and brave because I know the difficult years are still ahead. Unless, of course, medical research succeeds in finding the miracle remedy, the cure for Parkinson's that is so much wished and hoped for by both people with PD and their caregivers.

PP: What are some positive things you have learned?

MS: I have been able to accept Yves as he is, over and above the changes caused by the disease. It must be love!

My admiration for his strength of character and courage continues to grow. I am very proud to be his partner. I wish that all caregivers could have as gratifying an experience.

I have even noticed some positive effects of the condition on Yves. He had been a loner; he has now developed a network of true friends. He used to think only of his work; he has now developed his artistic talents. He thought that I spent too much time volunteering, but now he has made it his personal mission to increase public awareness of PD, and he doesn't count the hours that he gives to that and to

many other causes.

I have met many extraordinary people: people with PD, their partners, caregivers, and health-care professionals. I realize that it is important for us to share our doubts and our joys with people that can understand what we feel.

PP: As a caregiver and health care professional, do you have any advice?

MS: Parkinson's is a complex disease, difficult to understand and to control. It shows up in different ways for different people. It is essential to be well informed. The more you know about your adversary, the better it is to fight it! Gather information from your neurologist, nurses, family doctor, and pharmacist in order to understand the facets of the disease, to recognize the symptoms and the ways to approach and to manage them. This will help to improve quality of life.

Get information from the people at the Parkinson Society in your province or region. They can provide all sorts of information and advice. They can help you find your way through the health care system and learn about available services and how to obtain them. They can also direct you to nearby support and exercise groups.

Even as a professional, I have never been taught to be a good caregiver. It's something you must learn for yourself, through your own experiences. Most caregivers don't realize the time and energy they spend, and too often forget about themselves. They risk depression and burnout. You will endanger your own health if you don't take care of yourself. This is basic and essential! There are limits to what our body and soul can do. We must learn to



"Even as a professional, I have never been taught to be a caregiver," says Micheline, adding "caregiving must be experienced."

recognize these limits and respect them.

PP: How are things now, and what do you think the future holds for you and Yves?

MS: Life goes on. Today, at 50, Yves is still working full-time. The only activities he has given up are cycling and participating in fitness competitions.

I encourage him to continue his work to increase awareness about PD. Together we help organize and participate in fundraising events in our region, and Yves often speaks on the challenges of PD.

Yves is not ready to throw in the towel. I allow him all the time he wants and needs for his handiwork, painting, sculpting, piano playing and writing. These hobbies allow him to express himself and find fulfillment.

We both know these times of total independence are limited so we make the most of them. As Yves puts it, "whenever anyone asks me why I take on so many projects, I tell them that I understand too well the price of immobility and the value of movement."

Certain aspects of our life together and activities that we loved to share have changed or



Micheline advises caregivers to take care of themselves to avoid depression and burnout.

have been lost and replaced by others. We maintain the closeness of our relationship by being selective in what we choose to do and by enjoying the moment.

As for anyone with Parkinson's, Yves' condition will certainly demand more and more time, attention, patience, understanding, courage, and treatment as time goes on. If I continue to work, I will modify my schedule in response to his needs. However, everything in its own time...

My own reality includes living with and supporting the man that I love while I, powerless, witness the deterioration of his physical condi-

tion. I had never foreseen it. I know that I have been mourning, as he has, and will continue to do so. But I will adapt. We are, and will continue to be, happy for what life brings us, despite PD.

We have both discovered talents that hitherto were unknown. I find him more communicative and more sharing than before he had PD. I am proud of us. We enjoy ourselves when we are together. I sometimes think that life is better than before. It is certainly more real, more important, and more spiritual.

Editor's note: A special thanks to Ginette Mayrand of Société Parkinson

DON'T MISS AN ISSUE!

Coming in the Spring 2006 issue of *Parkinson Post*

We are the Faces of Parkinson's
Parkinson Post continues to profile our faces of Parkinson's. Read about the experiences, triumphs, and challenges of those living with the disease.

April Awareness Month
April is Parkinson's disease Awareness Month. Learn about stories and events from across Canada.

2005 Donald Calne Lecture
Find out about Dr. Zbigniew Wzolek, the 2005 recipient of the Donald Calne Lecture, and his work in Parkinson's research.

2005 National Volunteer Awards and AGM Weekend
Meet the new National Board of Directors and our 2005 National

Award recipients, and read highlights of the AGM weekend held in partnership with Parkinson Society Manitoba.

Research update
We report on the latest medical research on Parkinson's disease. Read about recent findings on the neurobiological processes of the condition and much more.

Meet the “Faces of Parkinson’s”

By Ian Corks



When Parkinson Society Canada (PSC) was looking for a fresh approach to increasing the awareness of Parkinson’s among Canadians, they looked for input from across the country.

“It was important to work with our regional partners,” notes Peggy Yates, PSC’s National Director, Communications and Marketing. “We really needed to get their valu-

able perspectives and learn from their experiences. And, of course, we needed to hear from the people that really mattered, Canadians living with Parkinson’s.”

The result of this collaborative approach is the “We are the Faces of Parkinson’s” campaign, an exciting and innovative approach to raising the “profile” of Parkinson’s disease (PD) among Canadians.

A three-year campaign

The Faces of Parkinson’s is a three-year public awareness and advertising campaign. The concept and details of the campaign were worked out by the Design Working Group (DWG), the cross-Canada team formed by PSC to develop tools to help raise awareness of PD. In addition to Peggy, members of the DWG include Nichola Lastella, Executive Director, Parkinson Society Manitoba; Christopher Rawn-Kane, Executive Director, Central and Northern Ontario Region, PSC; and Paul McNair, Executive Director, Parkinson Society Maritime Region.

Together, the DWG came up with a campaign that puts people with Parkinson’s firmly in the forefront.

“Quite simply, it helps put a real ‘face’ on an abstract illness,” explains Christopher Rawn-Kane. “It allows Canadians to see the actual faces of the people who are affected by PD.”

Finding the Faces of Parkinson’s

Exactly who are the Faces of Parkinson’s? “They are people who aren’t letting PD stand in their way,” says Nichola Lastella of the Design Working Group (DWG) which helped develop the campaign. “They are mothers, fathers, sisters, brothers, business people, doll collectors, dog lovers, hockey players and even Olympians.”

The people chosen to be the Faces of Parkinson’s come from across the country. All regions were invited to identify and recommend individuals who had an inspirational story to share with other Canadians.

“We looked for people—young or old, man or woman, regardless of cultural background or the type of work they did—who were meeting the challenges of Parkinson’s to the best of their ability,” says DWG member Peggy Yates. “We looked for and found people who refused to be defined or limited by their condition. The Faces of Parkinson’s are people who we feel will get their fellow Canadians to sit up and take notice and inspire them to become involved in the fight against Parkinson’s disease.”

Editor’s note: Watch for stories on many of the inspiring individuals who make up the Faces of Parkinson’s in future issues of *Parkinson Post*.

Real stories, real images

The Faces of Parkinson's campaign will present real images and stories of people across the country who are facing and meeting the everyday challenges of PD. "It shows Canadians as real people from coast to coast—family members, neighbours, coworkers—and illustrates the impact that PD has," says Paul McNair. "It says, 'here is what the disease does to vibrant, contributing individuals.' It will create awareness, understanding and, hopefully, valuable dollars for our programs and research."

Nichola Lastella elaborates on the program's goals. "I would hope the campaign clearly says that PD is not just your 'grandpa's disease',"

she notes. "We have younger, vital people who are fighting to stay active, fighting for their lives."

As Paul explains, the input from people with Parkinson's helped to guide the DWG. "We kept hearing that the public does not associate 'real' people with Parkinson's. This campaign is an attempt to identify Canadians living with PD and present them in the context of how the condition affects their daily lives."

Increased awareness

The campaign will feature a variety of initiatives, many of which are already underway.

"The campaign was officially launched at the PSC Annual General Meeting weekend this past

November in Winnipeg, Manitoba," says Peggy. "We used people from the Faces of Parkinson's on the cover of the *Annual Report*, posters and other materials," she notes. "And there are many more elements to come, including public service announcements, book-marks, advertising materials and other media pieces. And of course, the Faces of Parkinson's will be the driving force behind this year's April Awareness campaign."

"We want to tell the stories of Canadians living with Parkinson's, their families and care partners," Peggy concludes. "These are real people with real experiences. It's the best way to show the realities of Parkinson's disease."



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

- **Advocacy Tool Kit: Advocating for Change.** Join our effort to inform federal politicians about key Parkinson's issues that require attention. **Click on Headline News to view and download English and French versions.**
- **National Clinical Program.** PSC announces the competition of our June 2006 to May 2008 National Clinical Program cycle. Applications are being accepted for Clinical Assistance and Community Outreach Grants. **Click on the Clinical Research icon on our homepage.**
- **Connect with the PSC regional partner in your area** to learn how you can help ease the burden and find a cure by supporting local events. Locate a support group in your area and get regional news. **Click on the map of Canada.**
- **Annual Report 2005.** View and download a copy of Parkinson Society Canada's 2005 *Annual Report*. The report is available in both English and French. **Click on the Annual Report icon.**

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



SuperWalk for Parkinson's hits

SuperWalk for Parkinson's continues to grow as this key fundraiser for Parkinson Society Canada and its regional partners reached new heights this September by grossing \$1.75 million!

With over 11,000 people in 78 locations taking part this year, the event now includes a growing team challenge, more incentives, great national prizes, an on-line registration system that saw a 127 per cent increase this year, and a program that highlights SuperSTARS (people who raise more than \$1,000).

Canadian musician Tom Cochrane, SuperWalk's 2005 Honorary Chairman, took part in his first SuperWalk in Toronto, Ontario. "My father lived with Parkinson's, as do nearly 100,000 Canadians," says Cochrane. "Parkinson's, a progressive neurological disorder, places extraordinary demands on affected families. Thank you to all the walkers, supporters, volunteers and sponsors who walked with me towards a cure."

Each year, our walkers get one chance to win great prizes for every \$100 they raise. On November 5, the winner's names were drawn from thousands of ballots:

- Olive Hornby from Oakville, Ontario, is the winner of the 10 day Costa Rica Rainforest Adventure, courtesy of ElderTreks.

- Mrs. Sherrill Robinson from Grand Prairie, Alberta, is the winner of two hospitality class airline tickets to any scheduled international Air Canada destination, courtesy of Air Canada.
- Lynden Evers from Sarnia, Ontario, is the winner of a Famous Players One Year Big Card, courtesy of Famous Players.
- Each member of the Happy Bums team from Manitoba wins a Banff leather bag, courtesy of Roots.
- Jean Fortier, a SuperSTARWalker from Quebec, won the Aquos Liquid Crystal Television, courtesy of SHARP.
- Frank Hogan, a SuperSTARWalker from Ontario, won a \$500 Roots gift certificate.
- Alyse Geiger, a student from Edmonton, Alberta, raised over \$9,000 to win a \$500 Roots gift certificate.

In addition to these draws, 60 walkers across Canada who raised \$2,500+ were our first SuperSTARWalker Supremes and received gift packages courtesy of Solstice Beauty. Those who raised \$5,000+ also received a pair of ZERO RH+ sunglasses from Allison Canada.

Thank you to all who participated as a volunteer, walker or a sponsor. We succeed because of you! All money raised from this event will fund the organization's

SuperSTARS



national research program and provide local support services for people living with Parkinson's and their caregivers.

Plan now to participate in SuperWalk for Parkinson's 2006. Visit www.superwalk.com to find out more. See you there!



Thanks to our national sponsors

Gold level: GlaxoSmithKline, Kohl & Frisch, Running Room, Solstice, Teva Neuroscience **Silver level:** Air Canada, ElderTreks, Novartis, Shire, Weston **Bronze Level:** Allison Canada, Astra Zeneca, CB Richard Ellis Limited, Nathan Hennick & Co. Ltd, Pure Metal Galvanizing, Rio Can **Prize sponsors:** Famous Players, SHARP, and Roots

an all-time high



Teams



Parkinson's research around the world

Research Editor: Dr. John Wherrett

Valuable insights from post-mortem studies

Although post-mortem studies have been going on for a century and a half, the location and nature of the changes in brain cells associated with Parkinson's disease (PD) were only identified about 40 years ago. As new discoveries are made and techniques developed, it becomes necessary to reassess the findings in human tissue. Two recent studies of human brains post-mortem have added to our understanding of important aspects of PD.

Understanding dementia in

Parkinson's: It is now well established that the motor disorder that we recognize as Parkinson's results from injury to the nigrostriatal system in the upper brainstem, the so-called midbrain. More recently, attention has been focused on other features of PD, such as dementia and control of automatic bodily functions, that are regulated in other parts of the brain. About 40 years ago, before properly representative groups of patients could be examined and before staining techniques using antibodies were available, isolated studies suggested that the development of dementia (decline in memory and other learned higher brain functions such as language, attention, perception, ability to plan, etc.) in PD represented the appearance of Alzheimer disease. Dementia may develop along with the motor features of PD or, more

commonly, appear much later or not at all.

A team of Norwegian and British researchers has addressed the issue of the nature of the cell and tissue pathology that may account for the dementia. This is becoming especially important because of new treatments for Alzheimer that are under development, and that might be used for people with Parkinson's showing signs of dementia if, in fact, there is a link. The researchers were able to exploit a careful epidemiologic study in which 245 people with Parkinson's in a single community were identified and then examined at regular intervals over 11 years. Many study participants were asked to consider brain donation on death, and 51 gave consent.

By 2001, autopsies had been performed on 22 individuals, most of whom (19) had developed dementia between six and 21 years after the diagnosis of PD. In none of these individuals were there sufficient changes to allow a diagnosis of Alzheimer disease. The most up-to-date techniques were used. Among multiple features tested, only the pathologic feature of PD, namely Lewy bodies, was detected widely throughout the brain. This is very strong evidence that the major pathological influence that causes the motor disorder of PD is also responsible for the later occurrence of cognitive change.

This data indicates that treatment of the dementia associated

with PD as Alzheimer disease could be inappropriate.

Tracking the cause of gait disorder:

Balance and walking ability decline with aging to the extent that up to 50 per cent of people over 85 may exhibit one of the features commonly associated with PD, such as shuffling gait, slow initiation of movement, stiffness or tremor. Until other signs have developed, it may be very difficult for the neurologist to conclude that PD is present. A recent study attempted to determine what pathological changes correlated with these isolated features, and particularly whether these features represented an incomplete form of PD.

It was part of a long-term study of aging among Catholic religious orders in Illinois, members of which altruistically consent to regular, highly standardized assessments of neurologic and cognitive functions, as well as autopsy when they die.

Over 11 years, more than 1,000 clergy had enrolled and by early 2005, 307 had died. Post-mortem studies were performed on approximately 290 individuals. Eighty-six cases that did not have the features of PD at autopsy had further sophisticated microscopic assessment. Statistical associations of the findings with the clinical signs were examined.

The salient finding was that gait disorder, but no other signs of PD, correlated closely with the presence

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.

of “neurofibrillary tangles” in the nigrostriatal system. Neurofibrillary tangles are one of the two clinical features of Alzheimer disease but are also found in a variety of other neurodegenerative disorders without the other main feature of Alzheimer: amyloid plaques. Gait disorder, and other PD features, did not correlate with dementia or the full pathologic features of Alzheimer disease or, indeed, with any other pathologies, such as small strokes.

This study shows that a pathology different from that of PD is associated with gait disorder and suggests that this pathology also causes dysfunction in the nigrostriatal system.

References: *Annals of Neurology*, November 2005 and January 2006

Dopamine, parkin function and cell protection

Dopamine, the neurotransmitter central to PD, is a highly reactive molecule, and complex mechanisms exist in brain cells to ensure that dopamine reactions are restricted to those favourable to normal brain function. One of the concerns about the therapeutic use of the dopamine precursor levodopa for control of the symptoms of PD is that unfavourable reactions might be initiated that would, in fact, accelerate damage to dopamine-producing cells.

Investigators at Harvard have been studying rat cells in culture that contain the human gene for parkin, an enzyme involved in the disposal of toxic proteins. Mutations in this gene (called PARK2) cause degeneration of dopamine nerve cells in the substantia nigra, resulting in



Focus on ...

Dr. Brian Staveley



Memorial University of Newfoundland
St. John's, Newfoundland and Labrador

Could the common fruit fly hold vital genetic clues to the treatment of Parkinson's disease in people? That question is behind a promising research project headed by Dr. Brian Staveley at Memorial University of Newfoundland in St. John's.

A native of Orangeville, Ontario, Dr. Staveley earned his BSc and MSc at the University of Guelph and his PhD at the University of Alberta en route to his current position, Associate Professor of Biology, Molecular Cell Biology and Developmental Genetics Laboratory at Memorial. On the way he spent some time at the Ontario Cancer Institute, where he became interested in cell survival mechanisms and the processes that oppose cell death. Cell death, particularly the death of dopamine-producing neurons, has been implicated in Parkinson's disease.

Originally funded by a Friedman Pilot Project Grant from the Parkinson Society Canada (PSC), Dr. Staveley's current work centres on *drosophila*, or the common fruit fly. By stimulating the gene α -synuclein in the fruit fly's nervous system, scientists have been able to produce an excellent 'model' of Parkinson's disease, which can be used to study various features of the condition.

“We know that by manipulating this gene, we can trigger Parkinson's-like symptoms in fruit flies,” Dr. Staveley explains. “We believe that by manipulating other genes we may be able to counteract this effect. In other words, we can find ways to stop the progression of, or provide protection against, Parkinson's.”

Working closely with graduate students Annika Haywood and Amy Todd, Dr. Staveley has been encouraged by initial results. “We have shown that increasing the activity of the parkin gene can alleviate the Parkinson's-like symptoms in the α -synuclein-induced model in fruit flies,” he notes. “Now we are examining how and why parkin suppresses these symptoms.”

“It's painstaking work,” Dr. Staveley concludes. “There are so many possible pathways to investigate. But only by really understanding these pathways and processes can we determine what we need to focus on in terms of finding a treatment or cure.”

an inherited form of PD. The investigators found that when they stimulated the release of dopamine in the cells, parkin molecules aggregated and became insoluble. This had occurred because the dopamine attached itself chemically to the parkin molecules and, in the process, prevented parkin from carrying out its role in the disposal of toxic proteins. They then looked at human tissue and found that concentrations of parkin combined with dopamine were elevated in the region of the nigrostriatal tract in the brain of a person with Parkinson's.

These observations (and a large

number of control experiments) strongly suggest a mechanism whereby dopamine over a long period might interfere with parkin function as well as the ability of the cell to protect itself from toxic proteins, thus leading to a progressive loss of dopamine cells. This again raises the question of whether levodopa treatment could hasten the progression of PD, an issue that continues to be studied in large clinical trials. A logical line of reasoning is that treatments that increase normal parkin in the cells would be protective.

References: *Nature Medicine*, November 2005

Fifty-one days that changed my life:

Lessons learned along the road



Kootenay, BC.

By Jon Kenny, Vancouver, BC

Day one began with an uncomfortable excitement skipping about in my stomach. I stood with my bicycle leaning between my legs; James and Stan stood next to me, the three of us dressed in blue cycling jerseys near the end of Main Mall at the University of British Columbia. We overlooked the Rose Garden that lay across the Burrard Inlet, beneath the Coast Mountains that defines the most beautiful city in Canada, Vancouver. The entire country lay before us. The three of us had decided to bicycle across Canada to raise awareness and funding for Parkinson's disease.

On June 3, 2002, James Wells, Stan Gibbs and I pedalled east, while Jessica Cullis followed in our support vehicle.

A grueling journey

The ride is hard to describe in words. It was grueling, yet wonderful. In 51 days, I experienced every emotion I had ever known thrice

over. In 51 days, I completed the greatest physical, mental and emotional challenge of my life. The monstrous Canadian Rockies, the listless Prairies, the humid Canadian Shield—these were the physical obstacles. Loneliness, isolation, exhaustion, frustration, joy, and fear—these were the mental and emotional obstacles.

Imagine being dead-tired, your toes frozen after reaching the top of the tallest road summit in Canada. It is the 120th kilometre of a 150-kilometre day, it is sleeting, and then you are zipping down the other side of this mountain at 65 km/hr on a bike. Raindrops become bee-stings, and passing automobiles become life-threatening enemies. You are pinched between thundering tractor-trailers that spray blinding mists and a two-foot high guardrail that lines a 2,000-foot cliff.

After crawling into Creston, BC, you've completed only day six of 51 days.

More than physical stamina

It took more than physical stamina to cycle 6,200 kilometres of the most diverse geography in the world. In each major city, we held fundraisers and met with hundreds of Parkinson's disease patients as well as their families and their communities. I will never forget this trip. At each stop I could see the spark of hope and gratitude in many grateful people's eyes. This is what fueled my motivation during the ride.

I first experienced this during our first rest in Lethbridge, Alberta. We were packed into a restaurant downtown. It was blistering outside, and we were exhausted from the flat, black asphalt that cooked us as we traversed Alberta. As I sat there eating quickly, I looked around the table and realized that although I had just pushed myself on a bike over the Rocky Mountains, I still had the ability to eat without travail—something many of those around me were not able to do.



Princeton, BC.



Medicine Hat, AB



Montreal, QC

Yet, the people at the lunch praised me for my dedication and courage. They expressed hope that one day others wouldn't suffer as they did, and they thanked us for our contribution.

Next, we rode into Medicine Hat; we were heat exhausted. The sun scorched our backs while we rode. We were dehydrated, and our legs wobbled beneath us as we took a picture before the sign welcoming us to the "Gas City."

However, as we posed, the daughter of a man with Parkinson's disease ran from her mini-van, grabbed Jessica, and hugged her with tears in her eyes. Her husband cycled with us into Medicine Hat with a rolling sign behind him announcing the arrival of the Ride for Parkinson's disease. They treated us like celebrities, thanked us and expressed hope that our ride would make a difference.

Chasing a mirage

Biking into Winnipeg was like chasing a mirage. We saw the city from 30 kilometres, yet as we cycled, the city seemed to never draw near. There were no shoulders in Manitoba, so we were cycling with the traffic. Tractor-trailers and cars zoomed by us in the left lane; each pass electrified me with fear. We bounced into the city over the summer road repair and were treated to dinner at The Forks. There Stan and I listened to Wayne, a person with Parkinson's, describe his passion—fishing with his sons—



Nearing the end of the ride, the team pauses to celebrate in Fredericton, NB. From left to right: Stan Gibbs; Les Hull, Mayor of Fredericton; Jessica Cullis, the support team driver; Connie MacMillan, person with Parkinson's; Randy Dickinson, from the Premier's Council on the Status of Disabled Persons; James Wells, and Jon Kenny.

and how it was slowly being taken from him by his disease. Wayne's wish was to fish with his sons for as long as possible. Stan and I were moved by Wayne's courage.

Unrelenting head winds, deer flies, tortuous terrain, and the smell of moose carcass typified our ride through the Canadian Shield. In Thunder Bay, a local newspaper reporter took pictures of us at the Terry Fox Memorial. The definition of courage and dedication to humankind was forged by Terry Fox. I was inspired by what he had accomplished, and in some way, I had a better understanding of what he had to endure while on the road. Then Elaine, a wife of a man with Parkinson's, came to us in tears and thanked us for our courage and for our contribution to Parkinson's research. She told us, "If my husband's life is made better by any new medicine or advancement, then you have had a hand in that. You're very courageous, and as a mother I would be very proud to have you as

sons." This compliment, accompanied with a mental image of the Terry Fox memorial, is indelibly stamped in my memory. It gave me hope and strength; I could push through any pain, any weather, any obstacle after that point. I was helping people with each pedal stroke.

Pride and accomplishment

Similar meetings and inspirations occurred in Toronto, Ottawa, Montreal and

Fredericton as well as many small towns across our great country. On July 23, 2002, James, Stan and I raced into Halifax, Nova Scotia. This was the proudest I had ever been. We dashed into Halifax at 60 km/hr with Roy Maguire, then the president of ADT Canada (our sponsor) driving ahead of us. Jessica drove behind us. James was ecstatic as his mom had flown there to be with him. Stan grinned with satisfaction, and I laughed to hold in a wave of emotion that swelled in my throat and behind my eyes. I had made it. We all had made it. I will never forget the lessons learned during those 51 days.

I write this as I enter my third year of medical school at the University of Toronto. Those 51 days taught me countless lessons. The people and families I met gave me confidence about my role in society: I am here to help others. They gave me a new understanding of humanity, dedication and, most importantly, hope.

Q *"I'm in my late 40s and I was recently diagnosed with young onset Parkinson's. Will the disease affect my sex life? What effect will my Parkinson's-related medications have?"*

A Your question is very important, as your sex life plays an important role in your quality of life and quality of relationships. As you probably know, sexual problems are highly prevalent in society: more than two out of five women and one out of five men experience sexual dysfunction in their lifetime. Sexual dysfunction is characterized by psycho-physiological changes associated with the sexual response cycle, including inhibited sexual desire, painful intercourse, lack of orgasm, erectile dysfunction, and rapid (premature) ejaculation.

Due to your Parkinson's, you and your partner may face a few challenges regarding your sensuality, intimacy and sexuality. People with PD experience significant physical and emotional changes, which may disturb their sensual perception and intimate communication.

To understand the effect of PD on your sex life, you must first understand normal sexual response. Normal sexual functioning demands intact anatomic structures including the autonomic, sensory and motor system; proper arterial and venous blood supply; a balanced hormonal profile, and a healthy emotional state. Age-related decline in most organ systems may cause some decline in sexual functioning. Most people start noticing these age-related changes between the ages of 40 to 50; however, this rate of decline is increased when a

person has a chronic illness.

PD impacts sexual function in all the above areas. For example, the diagnosis itself may cause an emotional crisis, resulting in a lack of desire by the person with PD and his or her partner. If you try to have sex in this tense period, you'll probably encounter some sexual dysfunction due to your and your partner's anxiety or depressed mood.



This emotional mood can make it difficult to become aroused. A man may have difficulty getting or keeping an erection, and a woman may experience vaginal dryness and painful sex. Both partners need a lot of supportive, intimate love during this period. If you encounter any sexual dysfunction, don't despair. Realize that your condition is a situational dysfunction that will improve as you learn to manage the disease.

Getting medical treatment for depression and anxiety may help you regain your previous sexual desire and function. However, one of the most frequent side-effects of anti-depressants is the difficulty to reach an orgasm.

Parkinson's-related motor symptoms such as rigidity, tremor and

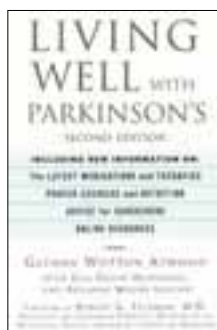
bradykinesia may influence your flexibility and cause you to become more passive, thus imposing a more active role on your healthy partner. Some couples cope well with these sexual role changes, yet others need professional support to adjust to these changes. Usually, a sex therapist can suggest some foreplay tactics and help you find a sexual position that will enable pleasurable stimulation for both of you.

As the disease progresses, sexual changes can be caused by the deteriorating dopaminergic mechanism and by treatment with anti-parkinsonian medications. Medications like Dopa-agonists might change desire. Some of the medications may induce autonomic disturbances like erectile dysfunction, mood and libido changes. If you sense an undesired effect (e.g., hypersexuality) from any medication, ask your physician about changing your dosage or type of medication.

One final note: many physicians and other health care providers find it difficult to address sexual issues. Some may have difficulties initiating a conversation on sexual health, and others may feel that they lack the proper training on sexual health counselling. Nonetheless, remember that you are entitled to receive proper medical advice that will promote your sexual health. So share your concerns, overcome your embarrassment, and seek help to improve your sexual health.

Gila Bronner, MSW, MPH

Director of the Sex Therapy Service in the Sexual Medicine Center, Sheba Medical Center, Ramat-Gan, Israel



Living well with Parkinson's, second edition

By Glenna Wotton Atwood, Lila Green Hunnewell and Roxanne Moore Saucier

Reviewed by Jennifer Watson of Premier Homecare Services Inc.

This personal, practical resource written by a Parkinson patient is a comfort for those with the disease and for family members. Atwood feels leading a satisfying life with Parkinson's means being an informed patient with a positive attitude and having proper personal care, good nutrition, and reliable support. Her book is infused with tips, resources and information on everything from lifestyle changes to hallucinations, and from current medications to caregiving.

For family and loved ones, this book effectively frames the life, needs, fears and frustrations of someone living with Parkinson's. While lacking in Canadian resources and references, this book is still an insightful, down-to-earth read.

Visit your local bookstore to order a copy.



Parkinson's Disease: Questions and Answers, fourth edition

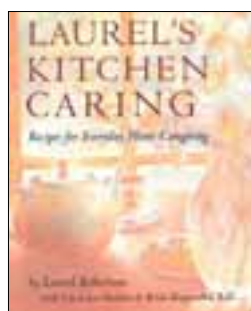
By Robert Hauser, Kelly Lyons, Rajesh Pahwa, Theresa Zesiewicz, and Lawrence Golbe

Reviewed by Barbara Snelgrove

This slim resource is an "everything-you-want-to-know" about Parkinson's disease. The book's question and answer format is an excellent way to cover the topic. Questions include How does one diagnose Parkinson's disease? What are the basic treatment strategies? and Which Parkinson patients are candidates for surgery?

The authors provide context for each answer and often include results of studies and clinical trials to support the information. Some topics, such as medications, are quite clinical with graphs and diagrams, but the detailed description on the various surgery options is most informative. The CD-Rom is an added companion feature.

Available at a bookstore near you.



Laurel's Kitchen Caring: Recipes for Everyday Home Caregiving

By Laurel Robertson, Carol Lee Flinders and Brian Ruppenthal

Reviewed by Chris Noone

Visit your local bookstore and you'll find shelves upon shelves of cookbooks. So why buy *Laurel's Kitchen Caring*? One reason only: You're caring for someone who is ill.

In her new book, Robertson turns her culinary skills to creating dishes that nourish and comfort the sick. This 150-page paperback offers up a variety of recipes in such categories as comfort foods, casseroles and treats, healing soups, simple pleasures, and care for the caregiver. The majority of recipes are written in paragraph form, so you'll need to do a bit more reading than you would with a traditional cookbook; however, the recipes are easy to make.

Although not specific to Parkinson's disease, the recipes in this book will help you create tasty dishes that are sure to soothe the sick.

Laurel's Kitchen Caring is available at your local bookstore.



Annual Report 2005 Parkinson Society Canada

Just released at the annual general meeting in November 2005, Parkinson Society Canada's *Annual Report* reviews the Society's progress during the past fiscal year at the national level and includes highlights from regional partners.

The report contains extensive information about our research program and showcases PSC-funded researchers. Also included are detailed financial statements, education accomplishments, advocacy and support program information, and recognition of donors, volunteers, corporations and foundations.

Please request a free bilingual copy of the *Annual Report 2005* by calling 1-800-565-3000 ext. 3394, or view it online at www.parkinson.ca.

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

We Need Your Support

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.

Through *The Parkinson Legacy*, there are numerous ways you can make a Planned Gift to Parkinson Society Canada or one of its Regional Partners:

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To become a part of The Parkinson Legacy, or for more information about making a Planned Gift, please contact any of the following offices:

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National Office**

To discuss a planned gift or request an information kit, please call:
(416) 227-3385
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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
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