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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Staying on your feet
How to reduce the risk of falling

It's OK to grieve: Coping with your personal loss

Hope in Bloom: Garden Co-op members join the fight

PLUS: Getting ready for SuperWalk 2004

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

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SuperWalk for Parkinson's 2004 is just around the corner

…….so start collecting pledges now! This September over 75 walks will take place across Canada and there are various ways to get involved:

Become a SuperSTARWalker – raise over $1,000 and receive a special SuperSTARWalker hat then start collecting SuperSTAR pins to show how many years you have reached this goal!

Walk as a team – Get together a group of 4 to 10 of your friends, family members or co-workers and walk as a team. Each individual team member is still eligible for all individual prizes and incentives but the team who raises the most is collectively eligible for team prizes nationally and locally!

Register On-line – Many regions across Canada offer on-line registration. Visit www.superwalk.com to see how easy it is, send out requests to your friends and family, get immediate receipts and have a great time seeing your pledges grow!

Volunteer – Call your regional office closest to you (see pages 5 & 6 for regional office numbers) and see what you can do to help make the walk in your area successful!

Visit **www.superwalk.com** for details about the SuperWalk near you and to learn about our great prizes and incentives. **See you in September!!**

SuperWalk for Parkinson's

Reflecting a vibrant, connected, committed community

It has been my pleasure to be the Editor of *Parkinson Post* since its re-launch in December 2001, and I am consistently inspired by the people that I've encountered in the Parkinson community through e-mail, letters, phone calls and meetings.

In *Parkinson Post* the *Parkinson Post* editorial team are determined to tackle difficult issues in a thorough way, to inform and to help our readers deal with Parkinson's. We also strive to include people and experts from across Canada in our feature stories and columns. As we plan a feature story, I am often tracking down leads and lining up interviews with people with Parkinson's, family members, health care professionals and others, and I realize what a remarkably vibrant, connected, committed community this is. People are so willing to help by telling their story, reviewing a book, offering their expertise to answer a question, or suggesting story ideas.

I particularly enjoy reading the "First Person" stories that are submitted and working with the authors by phone or e-mail to prepare each story for publication. Each story highlights a different situation – and illustrates a slice of Parkinson life – in such a personal way that it helps us to expand our understanding of how others cope. Please continue to send us your personal stories, feedback and story ideas to **editor@parkinson.ca**. We need your input and we are listening!

In this issue we tackle grieving: how people living with Parkinson's cope with the small day-to-day losses which they experience as Parkinson's causes changes in their lives. The issue hit home for me recently when a reader confided, "You know, I have a very positive outlook, but I have done a lot of crying in private." I realized yet again how much more Parkinson Society Canada can do in these pages to provide practical information and to highlight hope.

I consider *Parkinson Post* my "baby," but I will be off for some months on maternity leave caring for my new daughter and my two young sons. Peggy Yates capably takes over as Editor, but I will still follow the magazine closely and look forward to returning.

Suzanne Tobin,
National Director,
Communications and Marketing;
Parkinson Society Canada
Toronto, ON

William (left) and Cameron are thrilled with their new baby sister, Gemma.

***ON OUR COVER:** Physiotherapist Janet Millar leads client Gobin Sawh through simple exercises at the Maritime Parkinson Clinic in Halifax, NS.*

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ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

Parkinson Post Vol. 4, Issue 2, Summer 2004

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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
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Toronto, ON M2P 2A9
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Toll Free: (800) 565-3000
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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

- Held our first Porridge for Parkinson's. Over 150 people attended and approximately $8,500 were raised.
- Regional Conferences have taken place in Nanaimo and Abbotsford with two more scheduled for the Sunshine Coast and Kelowna.
- Celebrating our Society's 35th Anniversary.
- Our Annual Golf Tournament with Ballet BC is scheduled for June 22.

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

- Held a number of presentations, including: "Safe Mobility," presented by a physiotherapist in January; "Speech & Swallowing Symptom Care," the focus of the Sidney presentation in February; and "Exercise for PD," presented by a kinesiologist in March.
- A financial planning session was also held in March to review the many considerations for those under 65 with PD.

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

- Potted tulips were sold across Northern Alberta to celebrate April as Parkinson's Awareness Month.
- Dr. George Turnbull of Halifax was the special guest speaker for the AGM and 25th Annie Wylie Memorial Lecture in April. He also presented telemedicine rounds on "Minimizing the Secondary Complications of Parkinson's", and anchored a discussion of "Living well with Parkinson's" on Access TV – The Learning Channel.
- "Parkinson's Golf Classic" held June 17 at Northern Bear, a Jack Nicklaus signature course.

The Parkinson's Society of Southern Alberta
480D 36th Avenue SE
Calgary, AB T2G 1W4
Ph: (403) 243-9901
Toll Free (Alberta): (800) 561-1911
Fax: (403) 243-8283
www.parkinsons-society.org

- Co-hosted special fundraiser/ awareness event, "Classic Antique Bicycles," in February with Museum of the Regiments. Event sponsored by Calgary Bow Cycle & Sports.
- Presented with cheque for $13,000 by Gord & Eva Hoffman, proceeds from their Gala Event, "Back in a Flash," with Neil Sedaka.
- New support group started in Lethbridge for the recently diagnosed. Two groups, including a young-onset group, meet regularly in Red Deer. There is a new support group in Olds.
- New session of "Brain Waves" and speech improvement classes are underway in Calgary.

Saskatchewan Parkinson's Disease Foundation
3502 Taylor St. E., Suite 108B
Saskatoon, SK S7H 5H9
Ph: (306) 477-4242
Fax: (306) 477-4243

- Regina Curling Classic for Parkinson's Research on April 2-3, 2004.
- PW Golf Classic for Parkinson's Research in Avonlea in August, 2004.
- SuperWalk 2004 on Sunday, September 26. To register, call Cindy Holmes at 306-651-2810.
- New support group in Prince Albert. Call Bernie Pellegrini at 306-764-2353.

Parkinson Society Manitoba
171 Donald Street, Suite 302
Winnipeg, MB R3C 1M4
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 975-3027

- Welcomed new Executive Director, Nichola Lastella.
- The Advisory Board welcomes Colleen Johnston (MLCC), and looks forward to her contributions in the area of human resources.
- New Winnipeg chapter in development.
- Janet Stewart, CKY News anchor, is named spokeswoman for Superwalk 2004. Our various walks are already shaping up to be successful.
- Watch for "Symposium" in April 2005.

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

PSC Central and Northern Ontario Region

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

- Completed a three-session series for people with Parkinson's who are newly diagnosed.
- Held the first Toronto chapter meeting on March 25. Thirty individuals attended.
- Eighty-five delegates attended a successful educational conference on April 3 in Thunder Bay.
- TV personality Michael Landsberg of "Off the Record" will be the honorary chair of the 15th Annual Pitch-in for Parkinson's event scheduled for June 23rd.

PSC Southwestern Ontario Region

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

- Held a pilot event, "Spell the End of Parkinson's" Scrabble® tournament. Organizers anticipate that it will be a popular winter-blues buster throughout the region in 2005!
- Involved health-care professionals and other stakeholders in the development of an "Action Plan for Parkinson Education Program" (PEP), a dynamic train-the-trainer program. PEP is designed to maximize our capacity to educate and support large numbers of people about Parkinson's in a consistent, and cost-effective manner.

Parkinson Society Ottawa

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

- As Parkinson Society Ottawa celebrated its 25th Anniversary during 2003, stories, research, profiles, coping tips and poems were collected over 25 weeks. A 60-page commemorative anniversary publication, *Celebrating 25 Years*, has been produced.
- Our outreach continues to grow. Another new support group, located at Granite Ridge Long Term Care Centre in Stittsville, has been started.
- Dr. David Grimes brought a panel of research colleagues to present our annual research update in early February.
- Parkinson Society Ottawa was highlighted in a full-page story in the *Ottawa Citizen* during a week-long series on the charity industry. The story focused on how we dealt with a sound-alike charity that was doing door-to-door solicitation, as well as our litigation with them on the issue of copyright infringement.

Parkinson Society Québec

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Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.infoparkinson.org

- The www.infoparkinson.org website is now available in English.
- Entreprise J.Walter Thomson, a communication firm in Montreal, has agreed to work *pro bono* for PSQ. They will help us raise public awareness and will develop a communication campaign for 2005.
- *The InfoParkinson Manual For People Living With Parkinson's* is now available in English. It is free for members of PSQ (excluding shipping charges).
- Research has been initiated to learn about home care services and to verify if the public health network in Quebec is able to conveniently respond to the need of people living with Parkinson's.

PSC Maritime Region

5991 Spring Garden Road, Suite 290
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 pleased to announce a $1-million gift in the form of a 25-year annuity from the Banyan Tree Foundation.
- Denise Hubley has joined the regional office as Programs & Services Officer. She will be responsible for developing education programs and support services in the Maritimes.
- A meeting of SuperWalk Coordinators was recently held in Truro. The Maritimes have planned 14 walks again for 2004.
- The Fredericton chapter has planned their second annual "Porridge for Parkinson's" with Vicki Gabereau as special guest.
- The Regional Workshop has been scheduled for October 29-30 at the Ramada Hotel in Fredericton.
- The Maritime Region is pleased to welcome its newest chapter in the Annapolis Valley.

Parkinson Society Newfoundland and Labrador

The Ashley Building
31 Peet Street, Suite 219
St. John's, NL A1B 3W8
Ph: (709) 754-4428
Toll Free (NFLD/Labrador):
(800) 567-7020 Fax: (709) 754-5868

- The College of the North Atlantic sponsored a sumptuous breakfast for the Society on March 27 at its St. John's Campus. Over 400 people purchased tickets.
- A Regional Planning Committee is developing a five-year operational plan for the Regional Society.
- The young-onset group in the St. John's area has formed a social group and will be planning activities for the upcoming year.
- Information days are planned for St. John's and Conception Bay North in April and May

Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

Embryonic stem cell research to proceed in Canada

Bill C-6, *An Act Respecting Assisted Human Reproduction and Related Research*, received Royal Assent on Monday March 29, 2004, and became law. This gives Canada one of the most comprehensive legislative frameworks in the world regarding assisted human reproduction.

The law is far-reaching and covers many areas including the regulation of fertility treatments, but the relevance to people living with Parkinson's is that the law allows embryonic stem cell research to proceed in Canada under certain restrictions. Many people in the Parkinson community have been closely following this Act over the past few years as many scientists consider embryonic stem cell research to be a very promising area of research.

A government appointed agency, the Assisted Human Reproduction Agency of Canada will be established to license, inspect and enforce activities controlled under the Act. This Agency will apply safeguards and will have the authority to approve of using embryos leftover from fertility clinics for stem cell research. The Act prohibits, among other things, human cloning and the use of reproductive material without consent.

Parkinson Society Canada (PSC) is supportive of this legislation and is very grateful to all those Canadians who made their voices heard and wrote letters of support to their Members of Parliament and Senators over the past few years. Parkinson Society Canada was one of the health charities invited to present to the Senate Committee of Social Affairs, Science and Technology on March 3, 2004. David Simmonds, former Chair of PSC, made a presentation on behalf of PSC, and his eloquent remarks can be read at www.parkinson.ca. Select What's New and scroll down to News for March 2004.

Please access the government's site referring to Bill C-6 at www.parl.gc.ca/36/2/parlbus/chambus/house/bills/government/C-6/C-6_3/C-6_cover-E.html

Parkinson patient population to double while number of doctors to decline

The best care for Parkinson's disease is through a multi-disciplinary team of medical professionals, of which neurologists play a key role. Surprisingly, access to neurologists is limited, according to a recent study.

This news comes after a 2002 study raised concerns about current access to neurological care in Ontario. The study revealed that 31 per cent of respondents with Parkinson's are going without neurological care. Of those who see a neurologist, over 50 per cent do so infrequently. With fewer neurologists to care for an increasing number of people with Parkinson's disease, concern is building about the future quality of care for Canadians with Parkinson's.

"We're raising the issue with key stakeholders to develop long-term solutions," says Barry Johnson, Chair, PSC National. "In the meantime, PSC is developing a Parkinson Society Canada Information and Support Program for Family Physicians. We expect to launch this new resource later this year."

Ease the Burden; Find a Cure

Health Tip

Ten timely tips for caregivers

By Dorothy Orr

1. Get help with tasks and chores early on in the illness: your loved one will get used to having other people around the home.
2. Involve other members of your family from the beginning of the illness, even if you are the only one who sees the changes which are taking place. Pass these on as "information only" and not as a debating issue.
3. Access all the information you can about the illness and educate yourself as much as possible about its progression. Disease-specific organizations, your doctor and the public library are sources of information.
4. Recognize and learn to accept that anger, anxiety and guilt are normal feelings given the situation you are experiencing. They come not only from being tired but also from the losses you are experiencing.
5. Join a support group as soon as you can. You do not need to be alone on this journey.
6. Every change in your loved one means more adaptation and change for you. Acknowledge that this gives you the right to feel off-balance some days.
7. Forgive yourself for not being perfect. Caring for someone with a chronic or terminal illness turns your life inside out.
8. Make friends with your family physician and ask for time to speak with her/him alone if you need to do so.
9. Get regular physical check-ups, eat a balanced diet and take time out to express sadness, anger and helplessness. Accept yourself for being human and try to do at least one thing that you enjoy every day.
10. Take one day at a time while planning for the future. Good planning means understanding and addressing any legal and financial considerations, facility placement issues or palliative care. Above all, be kind to yourself.

Reprinted with permission from Family Caregivers' Network Society, www.fcns-caregiving.org, Victoria, B.C.

Staying on your feet

Understanding and reducing the risk of falling

By Ian Corks

There are certain changes that occur with normal aging that make people more prone to the risk of falling. For example, impaired eyesight may prevent you from seeing an object in your path, a reduction in muscle strength can limit your ability to cope with obstacles, impaired reaction time means you don't react to hazards as quickly, and your balance control is affected. Then there are the effects of the multiple medications you may be taking.

It's no wonder that experts report that as many as one in three seniors have a serious fall at least once a year.

As sobering as that statistic is, keep in mind that it applies to all seniors, regardless of their overall health. Throw Parkinson's into the mix and that ratio is likely significantly higher.

Increased risk

The unfortunate fact is that the risk of falling is magnified by Parkinson's disease. Both the natural course of the condition and the medications used to treat it can increase the dangers.

Parkinson's is a neurological condition, and many of its primary symptoms – bradykinesia, rigidity and tremor – can significantly impact balance and movement. In fact, changes in balance often provide the first clue to the existence of Parkinson's. The tendency to freeze in certain situations or times can also dramatically

IMPROVE BALANCE

Physiotherapist Janet Millar leads Gobin Sawh through simple exercises designed to improve balance.

increase the risk of falling. Finally, postural instability, which occurs in advanced stages of Parkinson's, implies an increased risk of falling.

Add these together, and it's no surprise that Parkinson's experts put a lot of effort into raising awareness of the danger of falls and teaching fall prevention strategies.

Physiotherapist (PT) Diane Lyders works with the The Parkinson Society of Southern Alberta (PSSA) and has done a lot of work in the area of falls. "Of the people with Parkinson's I see in the community, almost half have some type of balance problems," she notes. "And about 15 per cent of the people who attend my regular exercise classes have difficulties."

Diane has authored a pamphlet for the PSSA on the subject, called *Information on Preventing Falls*. "Falls can occur for different reasons in people with Parkinson's," she points out. "Disturbances in the posture control system, light-headedness due to low blood pressure or side effects of medications, environment hazards and physical changes affecting vision, strength and posture are all possible causes."

Rebecca Gruber, a PT with Toronto's Baycrest Centre, has studied the risk of falls and fall intervention as part of a pilot project funded by Health Canada and agrees that falls can have many causes. "People tend to fall for multiple reasons, not just one," she notes. "But, the main factor that influences falls is mobility, or rather a lack of it."

A person's overall mobility, as Rebecca explains, is dictated by a combination of their strength, agility and balance. With aging, all of these can be affected, and with Parkinson's the impact is even greater.

Maximizing your mobility

The good news is that a person's

Fall prevention strategies

At home

- ☑ Keep a "fall diary" to help identify risks and reasons for any falls.
- ☑ Remove scatter rugs.
- ☑ Remove clutter. Ensure rooms are not too crowded and there is plenty of space for moving around.
- ☑ Install railings in hallways and on stairways inside and outside of your house.
- ☑ Install grab bars in the shower or bath and next to the toilet.
- ☑ Use non-skid strips or mats in wet floor areas, such as the shower.
- ☑ Ensure there is adequate lighting at night for trips to the bathroom.
- ☑ Sit down to dress or undress.
- ☑ If you are frail and unsteady, ask your health professional about hip pads or protectors.

When walking

- ☑ If you feel unsteady when walking, stop, place your feet wide apart with your heels on the ground and wait until you feel steady.
- ☑ If you feel dizzy when getting up from bed or a chair, stop and let the sensation pass before continuing.
- ☑ Avoid standing for long periods with your feet too close together.
- ☑ Lift your feet when walking. Falls can occur as a result of foot drag, which is common among people with Parkinson's disease.
- ☑ If you feel you are losing balance take a step to recover your stability.
- ☑ Keep your hands out of your pockets or from behind your back when walking.
- ☑ Avoid carrying objects in your hands.
- ☑ Pay extra attention on uneven/sloping ground, difficult surfaces and when stepping on/off curbs.
- ☑ Avoid loose fitting or high-heeled footwear, and avoid crepe or rubber soles that stick to surfaces, .
- ☑ When walking, focus on each step.

Sources: Diane Lyders, PT; Ken Clement

mobility can be improved, through exercise and compensation strategies.

"While some of the risk of falling is due to the neurological effects of the condition, much is related to a lack of activity," states Janet Millar, a PT who works with people with Parkinson's at the Maritime Parkinson Clinic in Halifax, NS. "The appropriate exercise can help improve mobility and thus reduce the risk of falling. In fact, if you don't exercise, the danger will only get worse."

"Exercise won't change your condition, but it will help you stay active," Janet continues. "Exercise helps keep your muscles strong and flexible and also gives your balance a workout. Balance, just like anything, responds positively to use. If you aren't active, it's only natural that it will deteriorate."

She relates the case of one of her Parkinson's patients whose wife was worried that he wouldn't give up his hobby of fly-fishing in streams. "She was worried for his safety," she recalls. "However, he told me that standing waist deep in water challenged his balance. He had to be more aware and focused all the time, and think about his movements. It actually helped him."

Not everyone is up to this type of activity, however, which is why exercise is so important.

Janet uses simple exercises, such as working out with a therapeutic ball, or leaning on a counter and lifting one leg at a time, or walking a straight line. "Naturally, the specific exercise program depends on the person's symptoms and level of physical ability," she notes. "But the goal is the same – to challenge your balance and keep you moving. You can't let yourself stop moving because of balance problems and fear of falling. You have to keep going as long as you can."

Diane Lyder's classes in Calgary employ a similar approach. Though not specifically aimed at fall prevention, her exercises naturally help improve balance and muscle tone.

Falling facts

- Falls are the leading cause of injury for people over 65 in Canada.
- Falls account for 86 per cent of all hospital admissions.
- Older women are twice as likely to fall as older men

Source: Ontario Trauma Registry

Calgary's Sheila McKenzie has had Parkinson's for about five years, and has benefited from Diane's classes. "I was an occupational therapist before I retired, so I didn't need a lot of convincing about the benefits of exercise," Sheila explains. "I had a couple of bad falls, including one that badly cut my leg. I thought Diane's balance classes would help, and they did."

The twice-weekly classes help keep Shiela limber and have provided her with practical tips. They also helped rebuild her confidence. "The classes have helped me a lot," Sheila adds. "I've even visited the zoo in winter and passed a few tricky balance tests in the slightly icy conditions. I was able to use some of the balancing tips I had learned to 'catch' myself, and avoid falling a couple of times, when I almost lost my footing."

An ounce of prevention

As Janet Millar notes, however, some risks can't be totally eliminated by exercise, especially in older patients or advanced stages of Parkinson's. "That's where prevention strategies come in," she notes. These strategies centre on changing your habits and adjusting your living space (see *Fall prevention strategies*).

"You need to be proactive," notes Ken Clements of Ottawa. "Especially in the beginning. It will save you a lot of problems later on." Ken speaks from experience. He has Parkinson's and needed a hip replacement just over two years ago, primarily as a result of a fall. He is a firm believer in using the many tools available to make life safer and easier and frequently writes on the subject for the Parkinson Society Ottawa newsletter. "If I'd been wearing hip pads for example, I'd probably have avoided the hip replacement," he notes.

Be safe at home

A safe home environment is a key contributor to preventing falls. In fact, Rebecca Gruber's study showed the environment to be the second greatest risk factor in falls. An occupational therapist can be a great source of information and practical advice in this area.

Other professionals can also help you reduce the risk of falls, including physiotherapists, your pharmacist (regarding side effects of medication) and your family doctor.

"It's always a good idea to talk to a professional," notes Janet Millar. "Don't be afraid of admitting that you aren't as steady as you used to be and asking for help. You'll find that help is available, whether it's through mobility and balance exercises or aids to daily living."

Sheila McKenzie agrees. "Getting the advice and help you need to overcome the fear and risks of falling can make you feel more secure, more confident and let you do more of the things you used to," she concludes. "It can help you take back your life."

Coming together for change

World Parkinson Day inspires and motivates the Canadian Parkinson's community

By Shannon MacDonald

The Honourable Carolyn Bennett, Minister of State (Public Health) for Canada, was on hand to help Parkinson Society Canada (PSC) host the eighth International World Parkinson Day on April 21, 2004. Together, Dr. Bennett and PSC welcomed members of the Canadian Parkinson's community and World Health Organization (WHO) representative, Dr. Mary Baker, and participated in the signing of the WHO's *Global Declaration on Parkinson's Disease*.

Signing of the global declaration. Standing, from left to right: The Honourable George Smitherman, Minister of Health and Long-Term Care for Ontario; Dr. Mary Baker, Chair of the World Health Organization's Working Group on Parkinson's Disease; The Honourable Carolyn Bennett, Minister of State for Public Health; Tom Pitfield, Master of Ceremonies. Seated, from left to right: Dr. Anthony Lang, Neurologist; Judy Hazlett; and Barry Johnson, Chair, National Board of Directors, Parkinson Society Canada.

Tom Pitfield, son of Parkinson Society Canada's Honourary Chair, Senator Michael Pitfield, spoke very honestly about his personal experience with the disease and referred to himself as, "a young foot-soldier for Parkinson's." He called on more young people to bring their energy and passion forward to work on behalf of their loved-one(s).

Barry Johnson, Chair of Parkinson Society Canada, announced Parkinson Society Canada's commitment to develop a Parkinson's Medical Education & Support Program as a preliminary measure to help family physicians enhance their knowledge and understanding of Parkinson's while all stakeholders come together to tackle much-needed long-term solutions.

This announcement was applauded by Dr. Bennett, a family physician prior to her election to the House of Commons in 1997. She went on to stress the importance of working together to find solutions and ensure that the services are in place for people with Parkinson's and their families. Her message was echoed by Judy Hazlett, who spoke on behalf of Canadians with Parkinson's. "This disorder is a burden not to be underestimated. Even though it weighs one down gradually, it impacts on everything and everyone in our lives," said Judy of her 24-year battle with Parkinson's. "Continuing research into improving treatment and into finding causes and a cure is paramount, just as training more neurologists and nurses who choose to study Parkinson's is critical to providing quality care."

Dr. Anthony Lang, Director of the Division of Neurology, Faculty of Medicine, at the University of Toronto, supported Judy's call for more medical professionals by quoting startling statistics about current access to neurological care. Dr. Lang urged Parkinson Society Canada to continue partnering with other neurological-related organizations to advocate for change at provincial and national levels.

In closing, Dr. Baker delivered an eloquent and informative talk about the work of the WHO's Working Group on Parkinson's disease and the significance of the Charter of Rights and Global Declaration. She spoke of the issues facing people with Parkinson's, and how similar the experience is for the 6.3 million people with Parkinson's disease around the world. She encouraged everyone associated with Parkinson's to engage in honest dialogue about the needs of people with Parkinson's and their families, and to educate decision makers about the benefit of providing better supports and services.

To see more photos of the event and transcripts of speakers' remarks, please visit www.parkinson.ca.

Research Report

A look at current Parkinson's research arou

Research Editor: Dr. John Wherrett

Gene mutations provide clues

Two new studies look at mutations in the gene that is the code for alpha-synuclein, the main protein that aggregates in Lewy bodies found in the injured cells in Parkinson's disease.

In a study of a Spanish-American family, Parkinson's disease occurred in members who carried two extra copies of the normal alpha-synuclein gene. This observation adds strong support to earlier findings that excessive production of alpha-synuclein results in aggregations of the protein that are toxic and disruptive to cell membranes.

The other study, of a family from Spain, demonstrated that affected members had a mutation in the gene different from those previously found. This mutation produced an altered alpha-synuclein that would behave very differently than the normal protein so that it could build up to toxic levels. One effect of toxic aggregates of the protein is to "punch holes" in membranes such as the membrane packets that normally release dopamine transmitters and the mitochondrial energy packets.

These studies indicate that injury to dopaminergic neurones in Parkinson's disease can result from actions of mutant genes that produce excessive quantities of alpha-synuclein, cause buildup because of defective disposal mechanisms or promote formation of toxic aggregates through failure to control excessive oxidation. Environmental factors such as toxins, in combination with more subtle gene influences, can be expected to generate sufficient levels of alpha-synuclein to begin damaging cells.

Reference: *Annals of Neurology*, Vol. 55.

Parkinson-linked syndrome shows atypical features

Some individuals with Parkinson's and their families will be only too aware of the difficulties that neurologists often experience in making the diagnosis in the early stages when symptoms are just beginning to be felt. In making the diagnosis, several typical conditions may need to be considered. Recently, a relatively common genetic disorder that may have some typical features, but more commonly may also present with tremor and gait atypical for Parkinson's disease, has been recognized and characterized.

This disorder is called the Fragile X-associated tremor/ataxia syndrome. The tremor that is seen in this syndrome is present when the limbs are used, in contrast to the classical Parkinson's tremor that is most prominent when the limbs are at rest. The gait disorder is due to a loss of balance, in contrast to the stiff shuffling character that may develop in people with Parkinson's.

Fragile X-associated tremor/ataxia syndrome is usually found in adult males who carry a mutation on the single X chromosome. Females have two X chromosomes and although one of their chromosomes may carry the mutation, the clinical condition usually does not develop because the other normal chromosome is protective.

The tremor/ataxia syndrome was discovered when it was noticed that the parents and ancestors of affected boys had developed an atypical neurogenerative disorder in later life.

Reference: *Journal of the American Medical Association*, Vol. 291

Polymorphisms increase susceptibility

Recent studies confirm the potential role of normal or relatively common gene variants called polymorphisms in predisposing to Parkinson's disease.

A French study looked at an enzyme called debrisoquine hydrolase in a population with a high prevalence of exposure to pesticide. Several epidemiologic and experimental studies support the possibility that pesticide exposure is associated with an increased risk of Parkinson's disease. Debrisoquine hydrolase breaks down pesticides in the human body. Between five to 10 per cent of Caucasians inherit one form of the gene that produces a very small amount of the enzyme. These individuals are referred to as "poor metabolizers." In the study population, it was found that the risk for developing Parkinson's disease was increased two fold in the poor metabolizers who were

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.

nd the world

exposed to pesticide, but was not increased in those poor metabolizers not exposed to pesticide.

In another study, conducted by a European consortium, polymorphisms in a gene for the enzyme dopamine beta-hydroylase were examined in persons with Parkinson's matched with persons without Parkinson's. This enzyme converts dopamine into noradrenalin. As such, someone who inherits a form of the enzyme that is relatively inactive will normally have higher levels of dopamine. It was found that Parkinson's disease was less likely to be found in those inheriting the low activity form of the enzyme.

These studies add to the evidence that variants of several genes that are not absolute causes of Parkinson's disease can increase the risk by acting as susceptibility factors.

References: *Annals of Neurology*, Vol. 55

Focus on ...

Dr. Michel Rathbone and Dr. Eva Werstiuk
McMaster University

It's a classic case of combining talents towards a common goal. Dr. Michel Rathbone and Dr. Eva Werstiuk each bring their own expertise and experience to the promising research project currently underway at Hamilton's McMaster University, with funding from Parkinson Society Canada.

The project involves the purine guanosine. Research has indicated that guanosine has properties that somehow interfere with apoptosis – the process of 'programmed' cell death. The McMaster team is investigating if guanosine can protect against the type of apotosis that occurs in Parkinson's disease. Currently they are working with the toxin MPP+, which has been shown to induce a Parkinson-like condition.

The work is complex and currently still at the cellular level in the laboratory.

This project is the latest in a history of collaborations between the two scientists. "Eva and I have been working together on and off virtually since the day I arrived in Canada back in the 60s," Dr. Rathbone notes. "Eva's expertise is chemistry and pharmacology, while mine is cell biology and neurology. We each have something to offer."

In fact, they both have a considerable amount to offer, having individually earned solid reputations in basic research. With a PhD in organic chemistry from the University of London, Dr. Werstiuk's résumé includes working with the late Professor Sir Derek Barton, a Chemistry Nobel Prize winner. Dr. Rathbone, who earned his medical degree from the University of Liverpool and did his neurology residency at the University of Western Ontario, has been combining basic research with clinical work for several years. It was his interest in Parkinson's disease that inspired them to apply their findings to this particular area.

"Our findings on guanosine and its potential to reduce cell death were very promising," Dr. Rathbone relates. "We then looked at what clinical uses these findings might have, and we naturally thought of Parkinson's disease."

So far the project looks promising. "The *in vitro* data have been very encouraging," says Dr. Werstiuk. "We have found that guanosine does seem to protect cells against MPP+. Now we are beginning to look at exactly how it protects them. If all goes well, we will be able to move to *in vivo* studies in animal models within two years. The ultimate goal would be to use these findings to help develop treatments that prevent cell death and thus stop the progress of Parkinson's disease."

Renowned scientist awarded Donald Calne Lectureship

Parkinson Society Canada is pleased to announce the award of the second annual *Donald Calne Lectureship* to Dr. Oleh Hornykiewicz of Vienna.

Recognized as one of the world's leading neuroscientists, Dr. Hornykiewicz's international reputation was cemented early in his career when he determined that Parkinson's results from too little of the neurotransmitter dopamine. His subsequent development of L-dopa for the treatment of Parkinson's revolutionized treatment and remains the cornerstone of therapy today.

A distinguished neuroscientist of international reputation, whose work is primarily in the area of Parkinson's disease, is awarded the Lectureship each year. Dr. Hornykiewicz, who did much of his work in Canada, will deliver a state-of-the-illness lecture on Parkinson's at the Annual General Meeting of Parkinson Society Canada on Sunday, November 7, 2004, in Toronto. Watch for more information on the Annual General Meeting and the lecture in the Fall issue of *Parkinson Post*.

New Chair of Scientific Advisory Board

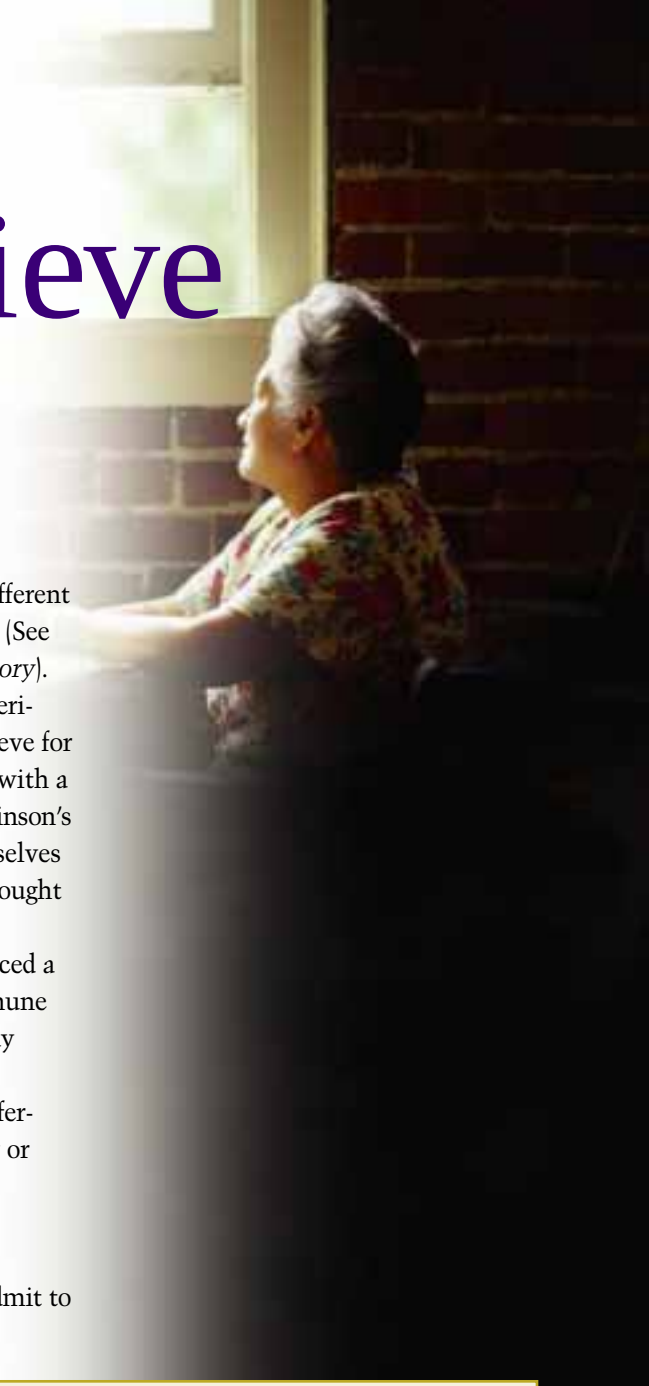
Parkinson Society Canada welcomes Dr. A. Jon Stoessl as the new Chair of its Scientific Advisory Board. Dr. Stoessl replaces Dr. Ali Rajput who recently stepped down and whose hard work was greatly appreciated.

Dr. Stoessl is the Director of the Pacific Parkinson's Research Centre at UBC and has been a professor in the Division of Neurology at UBC since 1996. Dr. Stoessl is internationally recognized for his neuropharmacological work and his leadership in PET imaging. He writes and lectures extensively on Parkinson's and other movement disorders, and has been published in over 100 publications.

It's OK to grieve

Coming to grips with your personal Parkinson's "loss"

By Ian Corks



You recently found out that you have Parkinson's disease. You've probably been warned to expect a gamut of emotions, from shock to fear. But what about grief? You are still alive, and your loved ones are still there with you. What do you have to grieve about? Lots.

Grief is about more than mourning the death of a loved one. Grief is a natural emotional response to a significant loss, and that can include the loss of abilities and sense of self that often accompanies a diagnosis of Parkinson's disease. And grief is an essential part of the process of recovering from that sense of loss and moving on with your life.

"People think that if it's not a death, they are not allowed to grieve," notes Dr. Nancy Reeves, a clinical psychologist from Victoria, BC, who has worked with trauma, grief and loss counselling for more than 20 years. "Grief over something like a diagnosis of Parkinson's is legitimate and valid."

Experts describe grief as the internal experience of loss – the thoughts, feelings and emotions that you experience within yourself at a very personal level. In a chronic disease like Parkinson's the feelings of loss can encompass many facets of your life, from physical ability, to independence, to financial security, to friends, to self-confidence, to the ability to pursue hobbies or socialize. The list is long, and each item holds different importance to each individual. (See *Charlie's story* and *Doreen's story*).

While people who have experienced a death in the family grieve for the loss of that person, people with a chronic condition such as Parkinson's can grieve for the loss of themselves – or at least the person they thought they were before the diagnosis.

"Nobody who has experienced a serious loss of this kind is immune from grief, as much as they may think they are," points out Dr. Reeves. "Everybody grieves differently, but we all do in one way or another."

Reluctant to grieve

Some people are reluctant to admit to

Doreen's story

Calgary's Doreen Lattin was diagnosed in 1998 at age 62. For her, the hardest thing was giving up her car and the independence that came with it. She also had to give up her sewing. "I'd sit in my sewing room looking at patterns and thinking, 'maybe I could try this or that'," she states. "But my head doesn't control my hands anymore. I found that very difficult. I also found that you have to come to grips with it or you'll just slip into depression."

Doreen credits greater knowledge about coping with Parkinson's and support from the sources such as the Parkinson's Society of Southern Alberta with helping her through.

She stills finds things tough, but the grieving has passed. "Now I just take a taxi or use public transit," she notes. "I still miss the car but have just learned to grin and bear it. After all, if you don't laugh it off, you'll end up crying all the time."

their grief, however. In many cases, it is simply because they may not understand what they are feeling. Other people don't acknowledge their

grief because they wrongly feel to do so would be a sign of weakness.

Society often encourages people to minimize their grief. Being 'strong' or 'moving on' is often viewed as desirable and even admirable reactions to loss. Loved ones, friends and associates unconsciously encourage this pattern because they don't want to talk about unpleasant things or face the grief that they themselves may be feeling. As a result, it is easy for a person with newly diagnosed Parkinson's to internalize feelings of grief or, if they do face up to them, to feel they have to "get it over with" quickly and quietly.

Accepting grief is the first step towards coping with it properly. And understanding the grieving process can facilitate that acceptance.

"In my clinical practice, I have come across numerous examples of people who are helped by becoming what I call 'informed consumers' of the grieving process," Dr. Reeves explains. "Acquiring information and understanding about grief and about yourself is empowering and helps you to move through the process in a healthy way."

Stages of grief

Shock and Denial: These temporarily protect you from the full reality of your loss. They serve as psychological shock absorbers until you are more able to accept the situation.

Fear: You feel helpless and afraid. Your energy is drained, and you can easily feel overwhelmed by what you are facing today as well as the uncertainties of what lies ahead.

Anger: You become very angry at life in general. You may find yourself asking "Why did this happen to me?" You may be looking around for something to blame or to fight back against.

Depression: This can be the most difficult and dangerous stage of all, and is often accompanied with sudden extreme feelings of loss, hopelessness and frustration. You may experience physical symptoms like trouble sleeping or low energy.

Acceptance: Reaching acceptance is the gateway from the negative emotions of grief. As you gain acceptance, you will be able to move on with your life, regardless of what you may have lost.

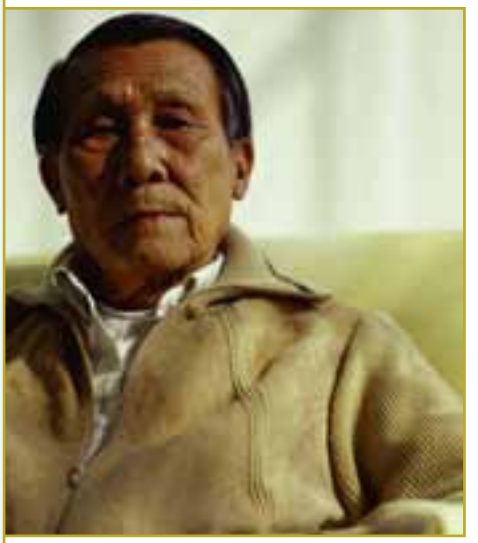
How do we grieve?

Grief is a process that we must undertake to come to terms with loss. It is a physical, emotional, spiritual and psychological response. Grief is not a single emotion, but rather a variety of feelings (Dr. Reeves calls it a "spider web"), which we express through a variety of behaviours.

Quite simply, grief is the healthiest way to accept a loss and put it into perspective. It helps us to face the realities of our loss, to recover, and to grow through the experience.

There are many ways to express grief and, as a result, many ways to resolve it. Expressions of grief may differ with each individual, yet they follow a broad common framework.

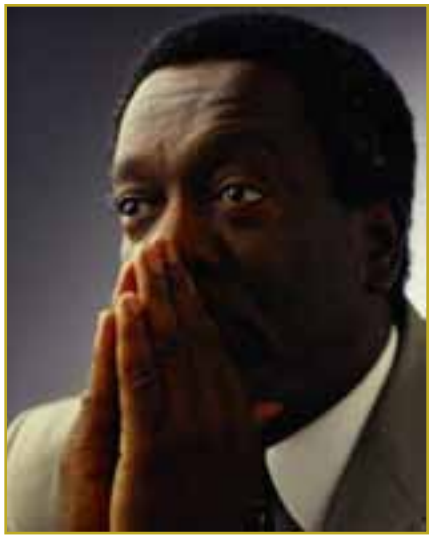
The best-known description of the grief process – the so-called *stages of grief* – was originally presented by



Swiss psychiatrist Dr. Elisabeth Kubler-Ross in 1969. Many experts use these stages extensively in grief counselling. Others view them not so much as definitive stages, but more as ways of helping people understand that each of these are common, normal and even healthy reactions. A basic understanding of these stages is very helpful in coming to terms with grief. (See *Stages of grief*).

Most people will experience all or most of these stages, although the length and intensity of the experience will differ. A person may flow back and forth between stages, with no set time limit. To reach a level of acceptance may take weeks, months or even years.

By understanding each of these stages, you can develop individual



strategies to deal with them. "We react to grief individually, but we can find clues in our general behaviour," offers Dr. Reeves. "You can get clues from how you reacted to other unpleasant events in your life, such as a job loss, a failed relationship, etc. If you didn't like the way you reacted to those, chances are you won't be happy with the way you handle your grief over Parkinson's. But knowing this will allow you to try and positively change your reaction, either by yourself or with help."

How much is too much?

Grief is typically viewed as a normal, though intense, form of sadness. However, grief can sometimes cause

Dr. Nancy Reeves points out that "nobody is immune" from feelings of grief when faced with a chronic disease like Parkinson's.

extreme or prolonged problems as the sadness evolves into serious disorders of anxiety and depression.

Dr. Reeves uses a simple checklist she calls the SOW Model as a quick indicator if the grieving process is overwhelming a person. "The SOW Model looks at relationships – how the individual is relating to, and coping with, three essential elements of their lives," she explains. "The S stands for self. Is the person suffering from low self-esteem or total lack of motivation? The O stands for others. Is the person withdrawn, antisocial and isolating his or herself from loved ones and associates? The W represents the world. Is the person having trouble with living his or her everyday life? Are they depressed or anxious?

"It's normal for someone to have problems with all three at some point," she continues. "But if there are constant problems with all three, or a continuing pattern with two of the three, I would recommend seeking professional help from a therapist. Or at least speaking with the family doctor."

Some of the physical warning signs that counselling or therapy may be needed include:

- constant feelings of panic
- feeling overwhelmed and incapacitated by fear
- an emotional "numbness" that does not go away
- intense symptoms of depression, which may include chronic insomnia, lack of appetite, loss of interest in relationships, hobbies and recreation
- thoughts of suicide.

How can therapy help?

You may find that friends and family are not able to provide the level or kinds of support you need. They may be overwhelmed with their own grief, or be unable to provide support because they themselves have fallen victim to societal myths – revolving around both grief and Parkinson's disease.

In these cases, therapy may offer the support you need. You should never be afraid to ask for help. The family doctor is a good starting point. He or she can refer you to the help you may need.

A therapist can help you understand your grieving process by providing information and support. He or she can provide a place for you to grieve fully and naturally, and help you move through your grief to find continued meaning in life.

Editor's note: In the next issue of Parkinson Post *we will look at the grieving process from the perspective of family members and friends – how you can cope with the grief of*

Charlie's story

For Charlie L. of Etobicoke, ON, who was diagnosed with Parkinson's at age 66, grief was centred on loss of control over his life and the deterioration of his physical abilities. "I'm a planner by nature," he relates. "I'm the type of person who likes to know what's going to happen next. With Parkinson's, I simply don't know anymore. All I have are questions and uncertainty."

"I was also an avid tennis player, but due to the condition and hip replacement surgery that didn't quite work out I had to give that up. The lack of activity made me feel physically worse and that made me very depressed. I wasn't able to do anything. I felt like a barnacle on the backside of society."

Time, supportive relationships (including a new marriage) and a strong will helped Charlie reach acceptance. "After about a year I felt that I wanted to carry on," he explains. "I decided I should shape up, as there was still plenty of life ahead of me."

Plan now to walk with your community

SuperWalk for Parkinson's 2003 was our most successful event ever, as we saw our national gross revenue jump to $1,518,183 – a 19% increase over 2002. To the many dedicated volunteers, staff and walkers who participated, thank you!

With our many prize sponsors returning for SuperWalk 2003, Parkinson Society Canada was thrilled to have Air Canada once again offer two hospitality class tickets to any Air Canada destination. The winner of the Air Canada prize this year was Ellen Shilton. Ellen and her husband have attended the Brantford, Ontario, walk with her parents for the past four years, as her Dad is a member of the local support group in the area. Ellen says, "they were blown away when told about their prize." Although they have never considered traveling before, they are hoping to go to Southern Europe this fall.

We have great prizes available this year again, and there are so many ways for you to get involved:

- Each walker who raises at least $1,000 becomes a **SuperSTARWalker** and receives a special hat and a pin marking each year they reach this goal. In 2004, each SuperSTARWalker gets a chance at winning a **SHARP Aquos television** in addition to being eligible for all of the national and local prizes and Roots incentives.
- Over 350 teams participated in our **National Team Challenge** last year and the winner of the team prize in 2003 was the Bearg Family Team from Toronto. Any group of four to 10 people can enter this challenge – a family, group of friends or fellow employees can join together and register as team. This makes your day more fun and you are eligible for more prizes. In addition to being eligible as individuals for all of the national and local prizes and Roots incentives, each member of the winning team in Canada wins a prize package worth over $300!

National Grand Prizes

One chance to win for every $100 raised!

Costa Rica Rainforest Adventure, courtesy of ElderTreks

Two tickets to any Air Canada scheduled destination, courtesy of Air Canada

One-year, unlimited movie access for two adults, courtesy of Famous Players

Plus, earn **ROOTS gift certificates** for every $100.00 raised

Call us to request a copy of our team challenge book.

- **Register on-line!** Have fun sending out personal requests to your friends and watch the pledges you collect grow on-line as your sponsors reply and get immediate receipts.

Join us as part of a team, become a SuperSTARWalker, volunteer and bring your family and friends. Be part of the success as SuperWalk for Parkinson's 2004 takes place in over 75 communities this September.

SuperWalk for Parkinson's 2004 will be the best yet! Contact the PSC Regional Partner near you (see pages 5 & 6) or call **1-800-565-3000** or go on-line at **www.superwalk.com** to register and get information.

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My first year with Parkinson's disease

By John Knight, St. John's, Newfoundland and Labrador.

Above: Sea kayaking, hiking and motorcycling are just a few of the activities that John enjoys.

At left: John Knight.

I am 59 years old, and I work for an oil company in St. John's, Newfoundland and Labrador, as a joint-venture subsurface manager and geoscience supervisor.

During the third week of September 2002, I came home from work one day with a tremor in my right hand. While I frequently had had a minor shake in my hands through most of my adult life, and developed the shakes from drinking some kinds of coffee, this tremor was different. It was demonstrable and persistent, stopping only when I fell asleep, according to my wife, Sherrill. It didn't go away, and it made working physically difficult and publicly uncomfortable. Its onset was like a switch had been turned on inside my body.

Lots of questions

Many thoughts went through my mind. What was going on? Was this related to the viral infection that I had been diagnosed with just three months earlier? Or was it something else, like Parkinson's disease (PD)?

With my head full of questions, I went to see my family physician, Dr. Tina Squires, in late November. She ordered a series of tests, including a CAT scan of my head. Everything checked out okay.

Nonetheless, I began to find that common, everyday activities were difficult or impossible to do. For example, writing was becoming difficult and my right hand seemed to have a mind of its own when it came to operating the mouse on a computer or when I was trying to eat soup. I couldn't control the bow to play my violin. In fact, anything that required fine motor control was becoming a challenge.

On the lighter side, knocking on doors became easier and less mechanical. I simply held out my right hand, and it automatically knocked, somehow knowing that that's what it was supposed to do.

Those around me wondered what was going on. Was I nervous about something? Was there something more serious going on? I didn't have an answer.

Finding an answer

Four months later in March 2003, I saw Dr. Mark Stefonelli, a neurologist. After running me through a thorough battery of questions and tests, his diagnosis was inconclusive. In addition to the tremor in my right hand, he also noted a minor tremor in my right foot, which I had not noticed. He believed that the tremors were related either to the viral infection that I had had during the previous spring, or more likely, to Parkinson's disease. He put me on the wait-list for an MRI and suggested that I get a second opinion.

During the next two months, I continued to work and carry on with life, all the while making adjustments to compensate for the tremor. Some activities, such as violin playing, I stopped doing. I could not control the movement of the bow, which was frustrating. To hide the tremor, I'd cross my arms and stuff my hands into my armpits, sit on them or hold them behind my back. I'd been lazy about using a tripod for photography, and I now found that I couldn't take a good picture without one.

It was clear that the tremor was not going away. I was, however, determined to keep going forward with life.

During this period, the toughest part was not having a firm diagnosis (thus not knowing what I had) and in dealing with the tremor when I was around other people, particularly at the office. While I didn't fear losing my job, I found the tremor distracting, and I worried about what others must be thinking.

I saw Dr. Alan Goodridge, a neu-

Above: Having a supportive family helps John live life to the fullest. From left to right: John; his dog; Tyr (a Norwegian Elkhound); son, Eric; wife, Sherrill; and daughter, Kara.

rologist at the Movement Disorder Clinic in St. John's in May 2003. After a thorough examination, he confirmed that I had Parkinson's disease.

Their first concern at the clinic was to help me deal with this news. The diagnosis, however, was not a surprise. I had already come to the same conclusion after reading about Parkinson's and noting my symptoms. It actually felt good just to know what it was, especially after all of the uncertainty. It was time to move forward.

Moving ahead

Dr. Goodridge talked about the characteristics of the disease, its likely progression and the possibilities to 'manage', not control, the tremor. Medication and exercise were identified as key elements of defence and mitigation. He explained that finding the right medication would be experimental.

Before leaving the clinic, I was also introduced to a great resource nurse, Denise Murphy. She provided me with more information about PD, introduced me to one of the Clinic's physiotherapists, and told me to call her anytime if I had any questions.

An important next step for me was to disclose that I had Parkinson's. I wanted the questioning looks to stop. I wanted to get on with living, and I wanted people to know that having Parkinson's was not going to stop me from enjoying life. When I started telling those around me, I didn't have a plan. I just started doing it. This was a good decision. While everyone was saddened by the news, they were happy to hear that it wasn't something more serious.

During the next few months, I tried different medications. Each impacted the tremor differently, and each had unwanted side effects. Some medications didn't seem to do anything. Others seemed to reduce the tremor a little, but I found that I couldn't stay awake. This was not only awkward at the office but quite stressful.

I found that keeping track of how I responded to each drug and staying in touch with Denise at the Clinic was important, as it gave her and Dr. Goodridge a basis for what to consider next.

With my current medication, there seems to be some management of the tremor. Although there's still a sleepiness that comes within an hour of taking the medication and lasts up to two hours, I'm able to deal with it (most days). On some days, I find that I can play some kinds of music on my violin for short periods. There are good days and bad, but to be able to play again, even a little, is great. I'm still able to work, and I still enjoy hiking, sea kayaking and motorcycling. Those around me have indicated that they don't think about my tremor, now that they know what it is.

A new path

Through my first year with Parkinson's, I've learned new things about myself and about the disease. I'm changing some of my personal expectations by defining new limits and boundaries. I'm continuing to learn and grow. Parkinson's disease has created a new path in my life; one that, I'm sure, will be just as interesting and challenging as earlier ones.

What I've learned

- Having a loving and supportive family is important.
- Letting people around you in on what's happening is a good thing.
- There are good and bad days.
- I better understand the nuance of "managing," as opposed to controlling, the tremor with medication.
- Finding the right medication through "trial and error" has its ups and downs. It can be frustrating, but stick with it until you find what works for you. And, build a good connection with your doctor and his or her resource nurse.
- Keep trying to do activities that you're used to doing.
- Experiment with different ways of doing things. For example, try using a computer mouse with your non-dominant hand, or try using a tripod with a cable release to take photographs.
- If you can't do an activity today and it's frustrating you, stop and try again tomorrow.
- Try new activities and hobbies.
- Exercise often and hard. Having a personal trainer is a worthwhile consideration.
- Smile and laugh about the humorous and challenging sides of Parkinson's, such as trying to drink your coffee or eating your soup without wearing it.

Tulip inspires Garden Centre Group Co-Op

Members support fight against Parkinson's

With the tulip blooming proudly as the international symbol of the fight against Parkinson's disease, it seems especially appropriate that the Garden Centre Group Co-Op (GCGC) chose Parkinson Society Canada as their charity of choice. And since making that choice five years ago, the members, suppliers, employees and customers of the GCGC have raised more than $100,000.

The Garden Centre Group Co-Op is a nationwide association of garden centres. Member stores are privately owned and range in size from smaller nurseries to large centres that include florists and gift shops. The GCGC has grown considerably since its inception and now has 42 members located across the country.

"Supporting the fight against Parkinson's was a natural choice for us," explains Heather Milne, Office Manager at the GCGC central office in Mississauga, ON. "Frank Reeves Jr., one of our founders and a member of the Board of Directors, had been diagnosed with Parkinson's. Fran Reeves, who worked at Reeves Florist and Nursery at the time, suggested that the Group concentrate their fundraising in this area as a way of honouring Frank, and we agreed it was a great idea."

Since kicking off their support of Parkinson Society Canada (PSC) in 1999, the response has been tremendous, both from within and outside the group, and continues to grow steadily. Funds are raised through two main programs: the annual GCGC Trade Show and the newer Hope In Bloom campaign.

A SHOW of support

Funds raised at the GCGC Trade Show

1999	$10,000
2000	$13,000
2001	$16,330
2002	$32,000
2003	$35,000

An annual tradition

Each year, the GCGC holds a trade show in Toronto, attended by members as well as wholesalers and other suppliers from the Canadian gardening industry. For the past five years, PSC has also been on hand (with a booth manned by volunteers from PSC Central and Northern Ontario Region) and funds have been raised at the show through a variety of imaginative – and fun – ways. To start off, a portion of the admission and exhibitor booth price goes directly to PSC, as does part of the cost of the closing banquet tickets. Then there is a charity casino and a 50-50 draw. Finally, there is a silent auction, with some great prizes donated by the exhibitors. Proceeds from all these events go directly to PSC.

Add these all up, and the total

Volunteers Silvia and Robert McNutt regularly attend the GCGC trade show and are always made to feel welcome by the GCGC members and exhibitors.

money raised is impressive. "The exhibitors at the show have been very supportive, and our members have done their bit as well," notes Jay McLaren of Sunset Nurseries in Pembroke, ON, who chairs the Garden Centre Group Trade Show Committee. "Last year we set a new record and raised $35,000 for PSC just from the show alone."

Grassroots efforts

Jay's Sunset Nursery is also one of the 19 GCGC members currently participating in the Hope in Bloom Campaign. Hope in Bloom is a way of taking GCGC's support of PSC from the national to the grassroots, local member level.

Now in its second year, Hope in Bloom gives employees and customers a chance to show their support for the fight against Parkinson's by "buying" a paper card bearing the Hope in Bloom tulip logo for $2 or as much as they wish to contribute. The cards are then posted on the store wall or window. One hundred per cent of the monies raised go to PSC.

"The campaign was a great success last year," Jay states. "In our centre, the staff were the first to show their support, and customers soon joined in. In fact, we had to reorder Hope in Bloom cards twice to keep up with demand. This year we will order four times as many cards as we did last year."

Roy Van Hest operates three Art Knapp Plant World locations in Richmond, Nanaimo and Victoria, BC, that all participated in Hope in Bloom for the first time this year. "The tulip symbol is cheerful and represents hope," Roy comments. "It seemed fitting for us to get involved, and further extend the Group's support of PSC. And we are happy to help."

Participating centres run their

The front window at Reeves Florist and Nursery in Woodbridge, ON, is beginning to show early results from Hope in Bloom 2004.

Hope in Bloom campaigns in April or May, depending on their busy time. Some members plan to expand the Parkinson's awareness and fundraising activities through added initiatives. Some ideas include offering raffle prizes with the cards (to encourage customers to buy more than one), May long weekend activities and having PSC volunteers on site to distribute information about Parkinson's and the society.

The enthusiasm and imagination shown by the members participating in Hope in Bloom is just another example of the tremendous support the GCGC has shown for PSC, while asking very little in return.

"It's been a great relationship," concludes Roger Ali, PSC National Director, Resource Development, who has been involved with the GCGC's fundraising efforts since their beginning in 1999. "The partnership between the Garden Centre Group Co-op and PSC is an excellent example of how one organization can use creativity and a charitable spirit to make a significant contribution to a worthy cause and society in general."

To find out more about the Hope

DON'T MISS AN ISSUE!

Coming in the Fall 2004 issue of *Parkinson Post*

Taking control

Do you ever wish you had more help, support and information at every stage? We'll give you some practical tips to help you get information from reputable sources, create a resource file, maximize the time you spend with health care professionals, make the most of local help and support, maintain an active social life and more.

The grieving process: part II

Caregivers and family members also grieve the small everyday losses caused by Parkinson's. We'll look at grieving from their perspective and cover how caregivers and family members can deal with their own grief and deal with people living with Parkinson's who are close to them. If you found the article in this issue helpful, don't miss the follow-up.

Resources

As always, we're searching the Parkinson community and beyond to recommend the best new resources: brochures, books, videos, websites, print and online magazines and newsletters, and more. Don't miss our latest selection.

Parkinson Society Canada
Société Parkinson Canada

Ask the Expert

Q ***Why do so many people with Parkinson's experience problems with their legs (cramps, pain, burning sensation, restless legs). What causes these problems, and how can I cope?***

A Burning legs and leg cramps are common problems often experienced by people with Parkinson's. People often describe these symptoms as burning, creeping, tugging, tightness or like insects crawling inside their legs. One of the most distinctive aspects of this condition is that lying down and relaxing actually seems to activate the symptoms. Just when a person gets into bed and settled, they begin to have the sensation(s). If not treated it can cause exhaustion and daytime fatigue. Their partner's sleep is often disrupted as well because the person may be up and down many times during the night. While no one is sure why it seems to occur most often at night, it may be that it becomes more apparent when you are relaxed.

Many people with Parkinson's also experience restless legs: periodic involuntary leg twitching or jerking movements during sleep. Again, this can severely disrupt sleep.

While we do not know what causes this condition, we do know that the following may contribute to the symptoms: low iron levels or anemia; chronic disease including Parkinson's, diabetes, kidney failure and peripheral neuropathy. Some medications may increase the symptoms, including anti-seizure, anti-psychotic and even some over-the-counter cold medications. Caffeine, alcohol and tobacco may also aggravate or trigger symptoms.

Can this be treated? For those suffering with mild to moderate symptoms, prevention is the key. Certain lifestyle changes – such as decreased caffeine, alcohol and tobacco use – may greatly diminish or even eliminate the symptoms. Some individuals may benefit from supplements, such as iron, folate, b12, calcium and magnesium, but it is important to discuss this with your physician first. Maintaining a regular sleep pattern may also reduce symptoms. Walking on a cold tile floor is beneficial to some. Moderate exercise helps some people to sleep better; however, some studies have shown that excessive exercise may aggravate symptoms. Taking a hot bath, massaging the legs and applying ice or heat may help decrease the discomfort. In some cases, the symptoms may be severe enough to warrant the use of medication, such as benzodiazepines, opioids and, in some cases, atypical anti-convulsants. Of course, all medications have potential side effects and the risk/benefit ratio must be carefully considered.

In summary, there is no one solution that will work for everyone. Massage, heat or cold and a healthy diet as well as limiting caffeine, alcohol and tobacco use may all reduce the symptoms. Speak to your physician. It may be something as simple as a blood test that reveals the need for a supplement.

Laura Jewell, RN
Movement Disorders Clinic
St. Peter's Hospital,
Hamilton, ON

WEBSITE HIGHLIGHTS

Visit Us On-line: www.parkinson.ca

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

- On April 21, 2004, Parkinson Society Canada hosted the eighth Annual World Parkinson Day event in cooperation with the World Health Organization. Click on the World Parkinson Day icon on our home page for news and a photo gallery.
- You can now read summaries of completed Parkinson Society Canada research projects funded from January 1, 2002, to December 31, 2003, specifically written for "non-scientists." Project topics range from genetics to the study of dyskinesias to neuron protection and regeneration. **(See Research/PSC Funded Research 2002-2003 National Research Program Awards – Final Reports)**
- Bill C-6, An Act Respecting Assisted Human Reproduction and Related Research, received Royal Assent on March 29, 2004. This gives Canada one of the most comprehensive legislative frameworks in the world regarding assisted human reproduction (AHR). **(Look in the "What's New" section)**

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

Resources

Parkinson's: Stepping Forward

By David Grimes

Reviewed by Lois Harper

What do we want? Information. What do we really want? Hope. What do we need? Practical tips and solutions. This book – an update of the popular book *One Step at a Time* – fulfills these requirements in a concise and readable presentation.

The chapter on current research in drugs and surgery provides hope for the future. Dr. Grimes gives many practical tips on coping with the "little things" that bother people with Parkinson's. He tells how Parkinson's can affect one socially and gives good advice on driving.

An index, bibliographies, glossary and drug lists are all thankfully included. This is worthwhile for a newly diagnosed person or someone who wants a lift in spirit.

This book is available at select bookstores across Canada for $19.95 paperback or to order by phone, call 416-862-7777, ext. 229.

Northwest Parkinson's Foundation – E-mail Update

Reviewed by Jill Pritchard

Searching for news about developments in the field of Parkinson's disease can be time consuming and disappointing, if the source you find isn't a credible one. The Northwest Parkinson's Foundation (NWPF), based in Washington state, offers a free weekly e-mail update that highlights the latest science and discoveries about Parkinson's.

NWPF's E-mail Update de-mystifies many of the reports that first appear in obscure scientific journals and makes new developments and avenues for research understandable. The site is archived and searchable, and is ideal for people living with Parkinson's, as well as their caregivers and loved ones.

NWPF also offers a free bi-monthly print newsletter – *The NWPF Parkinson's Post* – which is available by subscription or by downloading from their website.

To subscribe, go to www.nwpf.org and follow the links to E-mail Update.

National Research Program – Lay Final Reports Funding Period: January 1, 2002-December 31, 2003

Parkinson Society Canada (PSC)

This document offers short summaries of scientific progress, written in lay language for the non-scientist, for six Canadian Parkinson's research projects.

These research projects were funded through PSC's National Research Program during the January 1, 2002-December 31, 2003, funding cycle. Project topics range from genetics to the study of dyskinesias to neuron protection and regeneration. Recommended for those who follow research closely and are interested in seeing how funding for PSC's research program translates into scientific progress, this is also a tiny taste of the incredible diversity and range of Parkinson's research underway in Canada.

To order a free copy, call PSC at 1-800-565-3000, ext. 225 or visit www.parkinson.ca and select "Research/PSC Funded Research."

Motivating Moves for People with Parkinson's

By Janet Hamburg

Reviewed by Michelle Shilton, BHSc(PT) MEd

Author Janet Hamburg offers a unique, seated exercise program of 24 exercises for flexibility, balance, posture, vocal range and facial expressivity. It is divided into three sections: section I provides a demonstration of each exercise, section II is an actual class set to music and section III provides tips for everyday living. This program allows participants to complete the exercises at their own pace and requires no special equipment. It is a lively and upbeat presentation which would benefit the young onset or newly diagnosed Parkinson's patient.

To order, please call the Parkinson Disease Foundation at 1-800-457-6676 or visit www.pdf.org.

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

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:

Bequest in Your Will
Gift of Life Insurance
Charitable Remainder Trust
Gift of Residual Interest
Gift Annuity
Commemorative Gifts

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

Parkinson Society Canada National Office
To discuss a planned gift or request an information kit, please call:
(416) 227-9700, ext. 227
Toll Free: (800) 565-3000, ext. 227
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
Ph: (306) 477-4242

Parkinson Society Manitoba
Ph: (204) 786-2637
Toll Free: (866) 999-5558

Parkinson Society Canada Central & Northern Ontario Region
Ph: (416) 227-9700
Toll Free National: (800) 565-3000

Parkinson Society Canada Southwestern Ontario Region
Ph: (519) 652-9437
Toll Free Ontario: (888) 851-7376

Parkinson Society Ottawa
Ph: (613) 722-9238

Parkinson Society Quebec
Ph: (514) 861-4422
Toll Free: (800) 720-1307

Parkinson Society Canada Maritime Region
Ph: (902) 422-3656
Toll Free (NS, NB & PEI): (800) 663-2468

Parkinson Society Newfoundland & Labrador
Ph: (709) 754-4428
Toll Free (NFLD / Labrador): (800) 567-7020

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Ease the Burden; Find a Cure