Winter 2004 ▪ Volume 4 ▪ Issue 4
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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

On the frontlines
The active life of Denise Murphy

Staying in hospital
What you need to know

SuperWalk success
A record-breaking year

PLUS
Meet our volunteer award-winners

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

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www.parkinson.ca

Parkinson Society Canada
Société Parkinson Canada

What affects 1 in 300 Canadians?

Parkinson’s Disease

Parkinson’s is a progressive neurological disorder that affects movement and slowly leads to disability

Symptoms may include:

- A resting tremor
- Slowness of movement
- Rigidity and stiffness of muscles
- Difficulty with balance and walking
- Loss of volume and clarity of speech
- Tendency to shuffle when walking
- Handwriting difficulty

We offer information, support and hope for people with Parkinson’s

Parkinson Society Canada is the national voice of Canadian’s living with Parkinson’s. Our purpose is to ease the burden and find a cure through research, education, advocacy and support services. We share a common vision with Regional Partners from coast to coast ….. to improve the quality of life for all those affected by Parkinson’s.

Call us toll free for more information:
1-800-565-3000

Ease the Burden; Find a Cure

Letter from Parkinson Society Canada

From humble beginnings…

On April 21, 2005, Parkinson Society Canada (PSC) will celebrate our 40th anniversary, and we have much to be proud of. From our humble beginnings in 1965, PSC has grown to include 12 regional partners who directly serve and support Canadians living with Parkinson's from coast-to-coast.

Our largest single fundraising event, SuperWalk has grown from a few determined volunteers to an event that has a presence in 74 communities across Canada and that has revenue totalling in the millions, all directed in support of research, education, advocacy and support services.

Our National Research Program has grown into one of the premier programs for Parkinson's research in Canada, and as a result, we attract the best and the brightest researchers to help us ease the burden and find a cure.

In response to the growing need for family physicians to access information regarding the diagnosis and treatment of Parkinson's, we have successfully launched the Medical Information and Support Program. We applaud the volunteers and medical professionals who were the backbone of this new initiative.

We are also very proud of the establishment of the Donald Calne Lecture as part of our yearly Annual General Meeting. This prestigious award, established in 2003 by Dr. Donald Calne and the national board of directors, has awarded this honour to Dr. Yoshikuni Mizuno who, along with his team, discovered the parkin gene, and to Professor Oleh Hornykiewicz, who proposed dopamine deficiency as the pharmacological hallmark of Parkinson's.

As we plan to celebrate April Awareness 2005 and our 40th anniversary, we will also celebrate the birthday of Dr. James Parkinson (April 11, 1755). James Parkinson was a London doctor whose famous essay, "An Essay on the Shaking Palsy," was published in 1817 and established Parkinson's disease as a recognized medical condition.

As we prepare to celebrate, there is still much work ahead. As our President and CEO Joyce Gordon says, "We are laying the groundwork for the next 40 years through a consultative process to amend the national agreement, which forms the foundation of the partnership among the national and regional representative organizations. Our work will ensure a seamless national organization that will focus our efforts on the four pillars of our mission statement: research, education, advocacy, and support services."

Since 1965, PSC has accomplished much. This year is our year to celebrate our accomplishments and to plan ahead, for we recognize our need to grow and our need to deliver superior services to our stakeholders, supporters and the Canadian public.

Peggy Yates

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

ON OUR COVER:* *Denise Murphy, RN, reads the latest medical journal article on Parkinson's disease at the Health Science Centre's Movement Disorder Clinic in St. John's, Newfoundland.

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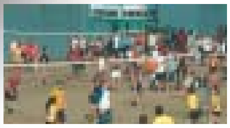

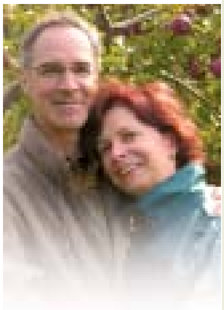

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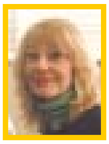

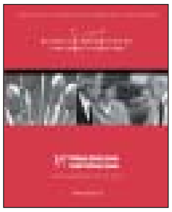

ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

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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

- Our newly diagnosed day took place with Dr. Jon Stoessl as the featured speaker.
- SuperWalk raised $140,500.
- Year-end donations are up in 2004 over 2003.

Victoria Epilepsy and Parkinson Centre

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

- Evaluation results from graduates of our annual three-week early stage Parkinson's disease program were very positive.
- The agency is adding some action planning strategies from the chronic disease self-management program to our service delivery.
- Advanced students from the local therapeutic massage college will be offering massage to over 40 people with Parkinson's and their family members for a fee.
- Various educational events, strategic communications, the annual fundraising campaign, SuperWalk for Parkinson's, and an agency website update and logo redesign are recent projects.

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

- Significant increase in participation and revenue for the Edmonton and Grande Prairie SuperWalks.
- The fourth annual "Speech Education in Action," an educational program offered in partnership with the University of Alberta speech-language department, had full participation from September to December.
- Lee Silverman Voice Training workshop conducted in Grande Prairie in October resulted in 20 speech-language pathologists certified to offer the program.
- A survey of people with Parkinson's was conducted in co-operation with the University of Alberta faculty of nursing. Results are expected in Spring 2005.

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

- Over 125 attended an "Update on Parkinson's therapy" forum sponsored by Novartis Pharma Canada Inc. The speaker was Dr. Oksana Suchowersky.
- A four-part education and support series was held in October for newly diagnosed individuals aged between 30 and 50 years.
- The SuperWalks held in Calgary, Red Deer, Medicine Hat and Lethbridge were successful.
- A "Porridge For Parkinson's" event hosted on November 27 by PSSA members. The McLaren and Schreiner families raised over $7,000!
- PSC meetings and Annual General Meeting in Toronto from November 4 to 7 was attended by PSSA's Dr. Jim Emmett, who is also a PSC board member; Barry Johnson, PSSA past president and current PSC board chair; Dan Cooney, PSSA board president; and Judy Axelson, executive director.

Saskatchewan Parkinson's Disease Foundation

Office location in transition
Ph: (306) 966-8007
Fax: (306) 966-8030

- Exceeded our goal of $60,000 at the Saskatoon SuperWalk.
- The Regina Curling Classic and auction will be held on April 1 and 2, 2005.
- Movement Disorder Clinics are held in Saskatoon and Regina.

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

- Developing support groups and partnerships across the region. New groups include North Winnipeg exercise group, Hamiota support group and the Roblin support group.
- Jim Hearne, CA (retired), was welcomed as the new Treasurer to the Regional Advisory Board.
- A new event, "Tracking the cure for Parkinson's" is a great train robbery ride and dinner on the nostalgic Prairie Dog Central.
- The strategic plan for Parkinson Society Manitoba is complete.

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

PSC Central and Northern Ontario Region

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

- Superwalk raised over $523,000 in 20 communities across the region. This is an increase of 10% above the funds raised last year.
- Dr. Janis Miyasaki from The Movement Disorders Centre at the University of Toronto presented "Identifying the signs and symptoms of wearing-off in Parkinson's disease" at an educational session sponsored by Novartis Pharmaceuticals Canada. The event was attended by 117 people.
- The Toronto chapter held an educational session which featured Dr. Nora Pope speaking on "Parkinson's and naturopathic medicine." Over 35 people attended the session.
- The newly diagnosed information and educational sessions were completed. From these sessions, two new support groups were created in Toronto and Markham.

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

- Two-hundred people attended a session with Dr. Mandar Jog on "Identifying the signs and symptoms of medication wearing off in Parkinson's" sponsored by Novartis Pharmaceuticals.
- SuperWalk for Parkinson's was another success, raising over $246,000 for Parkinson's research in seven cities: Brantford, Chatham, Kincardine, Kitchener, London, Sarnia and Windsor.
- Over 46,400 tulip bulbs were sold in Southwestern Ontario.

Parkinson Society Ottawa

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

- SuperWalk 2004 was a great success: over 340 people raised approximately $78,000.
- One hundred people attended the Novartis patient forum in which Dr. David Grimes presented "Identifying signs and symptoms of medication wearing off in Parkinson's disease."
- A grant application for funding from the Ontario Trillium Foundation has enabled Parkinson Society Ottawa to expand its client service program.
- An awareness survey is being distributed by the movement disorders clinic to determine awareness of PSO and to identify areas in need of service.
- Parkinson Society Ottawa was recognized for its founding contribution to the Parkinson's Research Consortium, a team of 14 scientists whose diverse fields of investigation have applications in Parkinson's research.
- Monthly workshops continued to attract interest: Update on changes at the Parkinson's clinic (August), Music therapy (September), Making informed choices when considering the retirement residence option (October), and Sleep and Parkinson's disease (November).

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

- More than 150 people attended "Understanding fluctuations in Parkinson's Disease," which was organized by PSQ in collaboration with Novartis.
- The Society participated in three specialized exhibitions in the fall to raise awareness of Parkinson's disease with health care professionals.
- PSQ 2005 Congress will be held April 29 in Longueil.

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

- Dr. George Turnbull Award for graduate-level student research has been established in recognition of service.
- The Maritime conference was held in Fredericton with 90 participants.
- MacDonald Foundation funding received for two library book collections.
- A golf tournament sponsored by Gammon Lake Resources raised $10,000.
- Novartis Forum with Dr. David King attracted 90 people.
- Kelly MacKay has been elected Board Chair for 2004–2006.

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

- Five successful SuperWalks in the Region raised more than $35,000, a 57% increase over last year.
- Volunteers sold almost 20,000 tulip bulbs.
- The annual "Information and education cross-island tour" held day-long sessions in Corner Brook, Gander and Port Rexton.
- In September, Dr. Brian Stavely and Annika Heywood presented their findings on curing Parkinson's in fruit flies.

Parkinson Society Canada
Société Parkinson Canada

Issues of interest to people with Parkinson's

Support program eases the burden

A key objective of Parkinson Society Canada (PSC) is to enhance our profile and credibility among medical professionals, which is why we developed the Parkinson's Resource and Information Kit as part of our Medical Information and Support Program. We are very proud of the volunteer committees who were instrumental in developing this program and the Parkinson's Resource and Information Kit.

By delivering this kit and by communicating our progress to the Parkinson's community, we strategically position PSC as the national leader on Parkinson's disease.

For more information about the Medical Information and Support Program, visit www.parkinson.ca or call 1-800-565-3000 ext. 3381.

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Hornykiewicz delivers second annual Donald Calne Lecture

As the 2004 awardee of the Donald Calne Lecture, Professor Oleh Hornykiewicz is an extraordinary pioneer in Parkinson's research. His achievements can be described in a few words: He showed, for the first time, that lack of the biogenic substance dopamine in the brain causes the symptoms of Parkinson's disease and that this substance is an important neurotransmitter in the human brain. He concluded that substitution of dopamine should improve the condition of patients, which he proved by suggesting treatment with L-Dopa, the biological precursor of dopamine. Professor Hornykiewicz was also the first to show that lack of a well-defined chemical substance causes a specific brain disease, a discovery that stimulated worldwide investigations into analogous connections between biogenic substances and neurological and psychiatric diseases.

A full excerpt of Professor Hornykeiwicz's address will be published in the Spring 2005 *Parkinson Post*. For more information, visit www.parkinson.ca

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National Volunteer Award winners

PSC is pleased to announce the winners of its 2004 National Volunteer Awards, presented at the recent annual general meeting in November.

David Simmonds Leadership Award—Leadership Volunteer

Vicki Gabereau has served as the Honourary Chair for PSC's SuperWalk for the last three years.

Mimi Feutl Award—Patient Services Volunteers

Peggy Gray (Ontario) was the first Parkinson's disease nurse co-ordinator in Ottawa and served the community for 24 years until her "retirement" in 2004.
Marie-Josée Fortin (Quebec) is a nurse, research co-ordinator, nurse clinician and patient advocate who has tirelessly contributed to the lives of those living with Parkinson's in the greater Montreal area.

Ease the Burden; Find a Cure

Use natural health products safely

By Peggy Yates

Natural health products can have positive health effects, but they can also have side effects; therefore, before you take any over-the-counter product, including a natural health product, you should ensure that the product is right for you. Start by asking yourself the following questions:

- Why would I take this product?
- What are the results I'm seeking from taking this product?
- Is this the best approach to achieve those results? Are there better alternatives?
- What evidence supports this product's safety and effectiveness?
- What risks are associated with this product?

If you are unsure of the answers, talk to a health care professional, such as your doctor, pharmacist, or complementary/alternative health care provider.

You can reduce your risk of adverse effects by taking the following steps:

- Tell your doctor what product you are taking and why you are taking it.
- Use products that are approved. Look for a Drug Identification Number-Homeopathic Medicine (DIN-HM) on the label.
- Be skeptical about health-related claims for potentially serious conditions. Do not rely on package information, and consult your doctor about a product's appropriate use.
- Be aware of any interactions with other drugs you are taking. Report any adverse reaction to your doctor.
- Consult your health care provider before taking a product if you are pregnant, are breastfeeding, are scheduled for an operation, are a senior, or have been diagnosed with a serious disease or significant previously diagnosed medical condition.

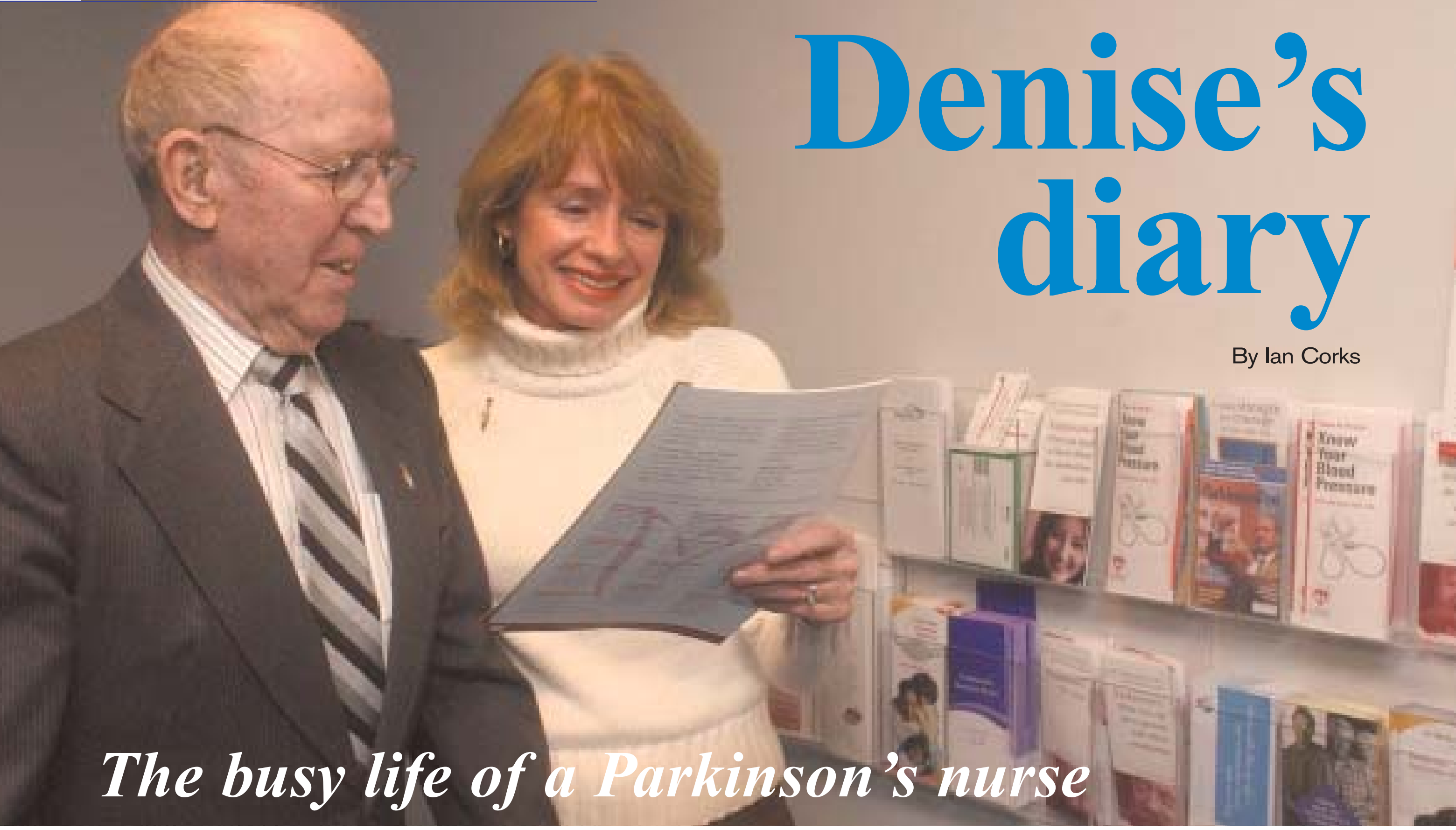
For more information on natural health products, please visit www.hc-sc.gc.ca/hpfb-dgpsa/nhpd-dpsn/index_e.html.

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

Denise's diary

The busy life of a Parkinson's nurse

By Ian Corks



Denise Murphy, RN, selects some take-home information for Leonard Abbott at the Health Science Centre's Movement Disorder Clinic in St. John's, Newfoundland.

Ask Denise Murphy, RN, what inspires her to devote so much time and energy to the fight against Parkinson's disease, and she doesn't stop to think. "It's the people," she answers, without hesitation. "The people I meet constantly amaze me with their strength and what they achieve. They are wonderful, and they provide all the inspiration I need to keep going."

And "keep going" is exactly what Denise Murphy does, tirelessly working on behalf of the Parkinson's community in her native Newfoundland. There's no such thing as an eight-hour workday or a 40-hour workweek in Denise's world.

As the Nurse Co-ordinator and Neurology Research Co-ordinator at the Health Science Centre's Movement Disorder Clinic in her hometown of St. John's, Denise has earned considerable respect among patients and colleagues for her understanding of Parkinson's and the complex challenges faced by the people it effects.

But it is her personal commitment and devotion to her job that defines Denise to the many who have encountered her over the years.

"Regardless of personal or work schedule, regardless of the demands on her time, regardless of the person, Denise is always there," notes one of the many people who supported Denise's successful nomination for Parkinson Society Canada's *Mimi Feutl Award 2003*.

In fact, Denise has been there for people with Parkinson's and their families since 1992, when she first joined the staff of the Movement Disorder Clinic. "Following my basic training, I decided to specialize in neuroscience and took a job as a staff nurse in the neurosurgery department at St. John's General Hospital," she recalls. "I really enjoyed working in this field, and it sparked my interest in Parkinson's disease. Joining the team at the Movement Disorder Clinic was a natural step for me."

Keeping busy

Trying to pin Denise down on what a typical day on the job involves is difficult. "Each day is different," she says. "It can involve so many varied activities, some that are scheduled and some that just seem to come up."

Here's a look at just some of the tasks that keep Denise busy throughout the week.

Care in the clinic: If any day is more structured than others, it's Thursday, the main clinic day. Every Thursday, Denise joins

Memorial University's Chief of Neurology Dr. Alan Goodridge and other health professionals at the Miller Centre in St. John's.

The Movement Disorder Clinic is the only one of its kind in the province, and so it can be very busy. "Most of the people we see are local, but we do get referrals from all over the province," Denise explains. "They can be new patients or people we have seen for a number of years."

On a typical clinic day, the team will see 10 to 12 patients. Consultation can cover anything from symptoms and medications to exercise and nutrition. The clinic has a physiotherapist on staff to help with exercise and mobility programs. "It's a great team to work with," Denise says with pride. "Dr. Goodridge has tremendous expertise and a great way with people. And we all believe in what we are doing."

In addition to the Thursday clinic, the team sees other patients at various times throughout the week.

Answer the call: If people can't see Denise in person, they know they can always reach her by phone, and that's exactly what they do. "Some days it feels like the receiver is glued to my ear," she laughs. "I couldn't even begin to calculate how many hours I spend on the phone on the average day.

Denise walks Leonard through some exercises at the Miller Centre in St. John's. Leonard is just one of up to 12 patients who will be helped on a typical clinical day.

"Most calls come from patients or family members who are experiencing difficulty with Parkinson's symptoms," she continues. "A typical call may be a question about the side effects of a medication. Or it might concern a change in symptoms. Patients are usually seen in the clinic every six months, but there can be many changes during that period. We encourage them to call if they experience difficulties."

Others may be first-time callers. "Parkinson Society Newfoundland and Labrador (PSNL) will often refer calls from individuals who have medical questions," Denise states. "Caregivers also call with their concerns. These calls come from all over Newfoundland and Labrador, and they can come at any time of day."

Make connections: One of Denise's least glamorous but most important roles is to co-ordinate patients' referrals to the appropriate resources. "It's my job to put people with Parkinson's and their families in touch with whom or what they need," she explains. "It can be a practitioner such as a physiotherapist, occupational therapist or speech pathologist, or a support such as home care. Luckily, we have a great network to call on, which makes [my] job easier."

Co-ordinate clinical trials: Ongoing clinical research holds the key to improving the lives of people with Parkinson's, and Denise is happy to play her part, even if it's a small one. "Part of the challenge of developing new, more effective treatments is to test them on patients when they reach the appropriate stage," she notes. "Dr. Goodridge and I are involved in recruiting individuals and co-ordinating clinical trials for promising new medications, such as new neuroprotective agents, if we believe they may be of some benefit."

Share expertise: Over the years, Denise has developed an expertise in Parkinson's that only comes from the unique combination of knowledge and experience. As a result, she spends a fair amount of time sharing that expertise with others. She is con-

A rewarding career

Denise Murphy will tell you that she doesn't deserve any awards or special recognition for what she has done. Her peers, however, disagree. To date, Denise has received two prestigious honours for her contributions to the fight against Parkinson's disease.

Queen's Jubilee Medal 2002: Presented by the Office of the Governor General of Canada "in recognition of a significant achievement or distinguished service to her fellow citizens, her community or to Canada."

Mimi Feutl Award 2003: Presented by Parkinson Society Canada "to honour an individual who through compassion and provision of information and support, has made life better for individuals living with Parkinson's and their families."

stantly called on to speak to a variety of audiences, ranging from families to fellow nurses and other health professionals.

For example, Denise, along with the PSNL's Executive Director, Patricia Morrissey, and the Vice-Chair of the Regional Advisory Board, Beth Holloway, recently spent three days on the road travelling to Corner Brook, Gander and Grand Falls, as well as the small rural community of Port Rexton. Denise spoke at information sessions for people with Parkinson's and their families. She also visited nursing homes in the community and spoke to their staff.

Visit the hospital: Whether she is in St. John's or in one of the other centres across the province, Denise tries to visit Parkinson's patients and their caregivers in hospitals. "Being in a hospital can be a difficult time for everyone," she explains. "It can also be hard for nurses providing the care. For example, medication regimens can be very complicated and you need to educate staff on the importance of maintaining the right schedule. It's not like other conditions. Being even five minutes late with a Parkinson's medication can make a huge difference in symptom control. Sharing this kind of information with staff is in everyone's best interest."

Keep current: Of course, being able to educate others on Parkinson's means you have to keep up with the latest developments yourself. For Denise, this means constantly searching Parkinson's specific sites on the web, reading clinical journals like *Neurology* and participating in professional continuing medical education programs. "Sure, it can be time consuming, but our understanding of Parkinson's is advancing so rapidly these days, you really have to make an effort to keep up," she says. The Movement Disorder Nursing Group is one program that Denise finds particularly useful. "We meet once a year, usually around the PSC annual general meeting," she says. "It's great to share experiences and expertise with other professionals doing similar work across Canada."

Spread the word: In addition to the considerable demands of her professional life as a Parkinson's nurse, Denise spends considerable time volunteering for—you guessed it—PSNL.

She regularly promotes the work of the Society in its education and awareness programs by appearing as a guest on radio talk shows and by participating in information sessions held throughout the province for health care professionals.

Denise served for many years as the Secretary for the St. John's Support Group and has recently become a member of the PSNL's Regional Advisory Board in the role of medical advisor. She is also a member of the PSNL Outreach Committee, which is dedicated to providing information and support to remote rural communities. In addition, Denise can be seen at virtually every Parkinson fundraiser, from SuperWalk down to local events.

Life beyond Parkinson's

Does Denise have any time left for a life beyond Parkinson's? "Of course," she smiles, proudly naming her three children: Shelley (25), a social worker; Stephen (21), currently working in Edmonton; and Andrew (17), a high school student in St. John's. As for her husband, Joe? "He's an accountant," she notes. "He also does volunteer work...on the Financial Committee of the PSNL."

Denise Murphy's involvement with Parkinson's disease is more than just a family affair; it even goes beyond her professional and personal commitment to easing the suffering of people with this condition. In fact, her involvement is probably best summed up in Denise's own words.

"It's a labour of love," she says.

On the Frontlines is a series of articles focusing on the dedicated Canadians who are fighting the war against Parkinson's disease in their own special ways.

A personal tribute

"I met Denise in 1994 when my dad became a patient at the Movement Disorder Clinic in St. John's. My family felt very special because we would receive answers to our questions at any time, often after hours and even through late night telephone calls. Little did we realize that we were just one of many families that Denise responded to on her personal time. These late night phone calls exemplify a characteristic of Denise: her compassion.

"My family was also witness to Denise's unfaltering patience and kindness. During the last year of my dad's life when his speech and strength failed, Denise would sit next to him, quietly ask questions, and patiently wait for him to struggle with his voice to answer. Her respect for my father as a person was overwhelmingly evident.

"I have since watched Denise in numerous similar circumstances, and I am always struck by her patience and attention, which exemplify her dedication to nursing."

Patricia Morrissey, Executive Director,
Parkinson Society Newfoundland and Labrador

Excerpted from the *Mimi Feutl Award 2003* presentation

Beach volleyball brings HOPE

More than 20 years ago, a group of friends watched Terry Fox in his quest to run across Canada. Inspired by Fox's courage and determination, the group formed HOPE, an Ottawa-based, volunteer-driven, non-profit organization dedicated to supporting local charities through community fundraising events.

HOPE created an innovative and successful way to raise funds: a beach volleyball tournament at Mooney's Bay. The annual event has since grown into the largest of its kind in the world. This year's event featured 1,000 volunteers, 35 corporate sponsors, a day-long line-up of big bands, 10,000 volleyball players and 20,000 spectators.

Life is a beach! Participants soak up the sun and splash in the sand during the annual HOPE beach volleyball tournament that raised over $4.5 million.

HOPE's BeachFest has raised over $4.5 million for more than 100 Ottawa charities including Parkinson Society Ottawa. Parkinson Society Canada (PSC) is proud to be selected as the first national charity partner of BeachFest proceeds.

HOPE members shared its philosophy of social entrepreneurship with Halifax-based volunteers this past summer, helping organize the first volleyball tournament and rock concert at Citadel Hill. Based on the Ottawa model, the event featured 100 teams in a variety of divisions, including recreational, competitive, corporate and wheelchair. Proving that "giving is a day at the beach," this first annual HOPE BeachFest supported three local charities, including PSC, Maritimes Region.

Roger Ali, PSC's National Director, Resource Development, says, "HOPE funds ensure we continue to help every member of the Parkinson community."

SuperWalk for Parkinson's

Another record-breaking year!

Thanks to those who walked, donated and volunteered in September, a new record was set as we raised almost $1.7 million! SuperWalk for Parkinson's, the single most important national awareness and fundraising event for Parkinson Society Canada (PSC), took place in 74 communities across Canada.

PSC is grateful to Vicki Gabereau who has been our Honorary Chair since 2001. Over the past four years, Vicki has attended many walks across Canada and has taken every opportunity to support our event. From all of us, thank you Vicki!

The much anticipated draw for our SuperWalk National Grand Prize draw took place on November 6 with a new prize draw for SuperSTARWalkers (those raising over $1,000).

The walk begins at Sherbrooke, Quebec. The walkers helped double the revenue from last year!

Here are our lucky winners:

- **Rose and John Scaini** from Maple, Ontario, are the winners of the Costa Rica Rainforest Adventure, courtesy of Eldertreks.
- **Greg Millar** from Orillia, Ontario, is the winner of two Air Canada tickets, courtesy of Air Canada.
- **Sandy Hugo** from Cambridge, Ontario, is the winner of the Famous Players Big Card, courtesy of Famous Players.
- The SuperSTARWalker winner of the Aquos Liquid Crystal Television, courtesy of SHARP, is **Florence Trudel** from Manitoba.
- **Dolores Runnalls** from Alliston, Ontario, is the winner of the Roots Banff leather Bag, courtesy of Roots Canada.
- **The Bearg Family Team** from Toronto is the National Team Challenge winner after raising over $23,000!
- **Alyse Geiger** from Edmonton is the student who raised the most in Canada with an individual total of $8,741. She is the winner of a $500 gift from Roots Canada.

Planning is already underway for SuperWalk for Parkinson's 2005! Get involved and take part in our continuing success. Become a SuperSTARWalker, gather a team of friends for some added fun, or call your local office and volunteer your time. For more information, visit **www.superwalk.com**.

Enthusiastic walkers at the starting line in Saskatoon, Saskatchewan.

Vicki Gabereau, in her last year as the SuperWalk honorary chair, cuts the starting ribbon for the Edmonton, Alberta, walk.

A new SuperWalk begins at Elliot Lake, Ontario.

Parkinson Society Canada gratefully acknowledges the support of many sponsors who contributed to this year's successful event: GlaxoSmithKline, Kohl & Frisch Ltd, The Running Room, Air Canada, Astra Zeneca, ElderTreks, Novartis, Shire, Teva Neuroscience, George Weston Limited, Allison Canada, CB Richard Ellis, Nathan Hennick & Co. Ltd, Pure Metal Galvanizing, RioCan, and We Care.

Young walkers enjoying the walk in St. John's, Newfoundland.

The organizing committee of the Sudbury, Ontario, walk.

SuperWalk
for Parkinson's

Two participants get ready for the Fraser Valley, British Columbia, walk.

Kelly MacKay, Chair of the Maritime Regional Board, and her family at the Halifax, Nova Scotia, walk.

The Blackie's Angels team from Brant-Norfolk, Ontario. Left to right is Sherry Shrubb and SuperSTARWalkers Fred Black, Alona Black and Brian Black.

A young walker helps out at the Ottawa, Ontario, SuperWalk.

Katie Strachan and her brother lead the way for the first walk in Brandon, Manitoba.

Staying in hospital:

What you need to know

By Lois Raphael, Maureen Matthew and Susan Calne, CM, RN.

When you have Parkinson's, be ready for unforeseen circumstances or emergencies. Following is a handy guide if you need to stay in hospital because of elective surgery or an unexpected admission (e.g., hip surgery after a fall/fracture, pneumonia, infection, bowel impaction or stroke).

What to consider when you need surgery

Day surgery generally is not a problem for Parkinson's patients. However, some procedures, such as cataract surgery or dental procedures where a person is normally awake, may pose problems if your tremor or dyskinesia creates too much movement. Ensure your general practitioner, surgeon and neurologist co-ordinate your hospital care.

Talk to the surgeon before the procedure date, so you can make informed choices on

- benefits and risks
- tests and procedures (and alternatives)
- expected outcomes and odds of success
- potential complications
- length of stay and alternatives

Pre-operative medication

When surgery requires general anaesthetic, anti-Parkinson medication is often stopped the night before surgery. Some neurologists recommend an early morning dose of Sinemet (carbidopa/levodopa) with a small amount of water. Ask for early morning surgery to avoid long unmedicated periods.

Restarting anti-Parkinson medication after surgery

- Anti-Parkinson drugs cannot be used during surgery.
- If nothing can be taken orally, a nasogastric tube insert (prior to surgery) is recommended even if the surgeon does not normally insert one. Post surgery, crushed regular levodopa, other tablets and capsule contents can be administered with water through the tube.

- For stomach surgery, reintroducing Parkinson medications is more complex, requiring careful pre-planning.

Medication timing when in hospital

- Ask your general practitioner (GP) to send your drug regimen and schedule with admitting orders before you go to the hospital. Bring your Parkinson drugs in the original bottles, and several copies of your drug list and schedule. For example, if you take medication three times daily, include what time you take it. Otherwise hospital staff may think you take it every eight hours.
- If you are on an experimental Parkinson drug, bring your own supply and a letter describing the study.
- Talk to your GP about getting authorization to administer your own medications if you take frequent or "as needed" doses.

Contraindicated drugs and their side effects

- Provide the hospital with your allergy list.
- Morphine tends to be better tolerated by people with Parkinson's than Demerol for pain control. Eldepryl (Selegiline) is contra-inedicated in combination with Demerol. Demerol, premedication and drugs used for anaesthesia can cause severe confusion. It can take a few days or weeks to resolve the situation even with people not normally confused.
- For post-operative nausea, do not accept dopamine-antagonist drugs such as Reglan or Maxeran (metoclopramide hydrochloride), Compazine (prochlorperazine edistylate) or Stemetil (prochlorperazine mesylate). Gravol by mouth or injection is a practical choice. (Domperidone only prevents nausea associated with anti-Parkinson drugs.)
- Avoid conventional anti-psychotic drugs: haloperidol, respiridone and olanzapine. Seroquel (quetiapine fumurate) is one safe anti-psychotic drug for Parkinson patients.
- For bladder or prostate problems, anticholinergic drugs often relieve muscle spasms after surgery but can cause confusion, constipation and urine retention.

How hospital stays and procedures can affect your Parkinson's

- Parkinson's already creates stress, so your body may be less able to cope with additional problems.
- Stress reduces energy required to heal and will make your symptoms worse. Use stress management skills, including breathing exercises, relaxing music on a walkman and a heavy dose of optimism.
- A different diet, inadequate fluid and lack of mobility can lead to severe constipation. Bring along a bowel management protocol (available from Parkinson Society Canada).
- Expect a reduced ability to hear and listen well, especially when it comes to medical jargon. Ask questions and seek clarification.
- Medication complications can disrupt your mobility and mental status thus delaying your recovery. Family caregivers need a support system, and they should seek a key hospital contact person.

How to communicate your needs to hospital staff

Staff may not have much experience with Parkinson's. Talk to your nurse about some of the condition's characteristics:

- unintentional on/off fluctuations
- importance of taking medications on time since most hospitals allow nurses a "window" (up to an hour) in which to deliver medications, which is unacceptable for Parkinson patients
- significant physical and mental slowness
- speech problems, which may affect intercom use
- hand dexterity problems with eating and hygiene
- assistance with bed turns, transfers and walking
- increased risk of falls and fractures

Activation and rehabilitation during hospital recovery

- People with Parkinson's need quick re-activation to avoid complications such as pneumonia, deep vein clots, urinary tract infections and increased rigidity.
- Your GP can order physiotherapy, such as body mobility exercises or chest therapy to ease rib cage rigidity and lung complications. Ask about geriatric programs for assessment and rehabilitation services.

Discharge planning

- Ensure you understand the medical team's follow-up plans.
- Before discharge, talk to hospital staff about home nursing care, rehabilitation therapy and caregiver respite needs.
- If you require ongoing facility care, talk to the hospital social worker or community health department liaison nurse.

Adapted by Carol Jamieson from "Hospitalization and Parkinson's," Parkinson Society British Columbia, 2004. Prepared by Lois Raphael, Parkinson Society British Columbia, Maureen Matthew, Victoria Epilepsy and Parkinson's Centre Society, and Susan Calne, CM, RN, Coordinator, Pacific Parkinson's Research Centre, Vancouver, BC.

Research Report

A look at current Parkinson's research arou

Research Editor: Dr. John Wherrett

Parkinson's and family members

People with Parkinson's and their relatives often ask about the likelihood of other family members being affected by the condition.

This is a very important issue from a number of perspectives. These include not only heredity and genetics, but also the role of common environmental factors that family members may have been exposed to.

Thus, epidemiological studies of Parkinson's are important. These studies look at the incidence (development of the disease in a group of people over time) and prevalence (numbers of cases in a group at any particular time) of Parkinson's.

The Mayo Clinic acknowledged the value of epidemiologic studies many years ago, when neurologist Dr. Leonard Kurland set up a system for capturing coded medical data from the entire population of Olmstead County, Minnesota, where the Clinic is located. This database is now being utilized for studies of Parkinson's disease.

In a recent study, data on the incidence of Parkinson's disease among first-degree relatives (parents, siblings, children) of Parkinson patients in Olmstead County between 1976 and 1995 was collected. The incidence of disease among relatives of patients with Parkinson's referred to the Clinic from five adjacent states was also included, as was the incidence in spouses (not blood related). This study was particularly interesting due to the attention given to the examination of suspected patients by movement disorder specialists.

Analysis showed that relatives of patients who had developed the disease before the age of 66, had about two-and-a-half times the risk of developing Parkinson's than relatives of individuals without Parkinson's had. However, for those who developed their Parkinson's after the age of 66, there was no increased risk for Parkinson's among their first-degree relatives.

Reference: *Annals of Neurology*, October 2004

Reduced sense of smell a warning sign

Approximately 25 years ago, researchers first detected a weakened sense of smell among people with Parkinson's. Subsequent studies have confirmed this to be a characteristic of the disease.

Special standardized testing of people with the condition has revealed a reduced sensitivity in the detection of odours, in the identification of odours, and in discrimination between odours. In addition, microscopic examination of post-mortem brains has shown that there is a loss of the brain cells involved in the appreciation of odours. These cells can, in fact, be lost before the loss of cells involved in motor function. It is not clear if the cells affected in the loss of smell are those that use dopamine as a neurotransmitter, but it seems quite likely.

Therefore, the decreased ability to smell may be one of the earliest signs of Parkinson's disease, and investigations in this area are important. Because we are on the threshold of new treatments to delay the disease's progress, it is important to detect Parkinson's early so brain functions can be protected before serious damage occurs.

Dutch investigators assessed the sense of smell (olfaction) in 361 relatives of Parkinson patients who were unaffected by the disease. The subjects were re-examined after two years. Of the 40 relatives who had the weakest sense of smell, four had developed Parkinson's. Of the 38 relatives who had the strongest sense of smell, none had developed Parkinson's.

The investigators also conducted β-CIT SPECT scanning, a form of metabolic imaging that identifies loss of cells in the nigrostriatal system that underlies the motor symptoms of Parkinson's. These scans demonstrated a greater decline in the nigrostriatal system in subjects with a weak sense of smell than in those with a strong sense of smell. This was noted not only among subjects with a weak sense of smell who developed Parkinson's but also in all of the subjects with a weak sense of smell.

These preliminary findings indicate that a diminished sense of smell is associated with a risk of developing Parkinson's disease as high as 10 per cent.

Reference: *Annals of Neurology*, August 2004

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

Two new concepts important to Parkinson's research

There are two new concepts that seem likely to play important roles in Parkinson research: "neuroproteomics" and "proteasome."

Neuroproteomics: The Genome Project delineated all the genes characteristic of the human cell. Genes "code" for the cell's proteins, and the very large complement of cell proteins specified by the genome are referred to as the proteome. So-called high-throughput protein profiling technologies have been developed to identify and characterize large numbers of proteins. The human genome has about 30,000–36,000 genes, and each gene may yield 10 or more protein variants, called isoforms. The ability to identify these proteins and their amounts at any one time provides useful information on the normal and abnormal functioning of the cells from which they are obtained. This already represents a major approach to studying the abnormal metabolism of cells in a number of chronic diseases, and its application to Parkinson's disease has just begun.

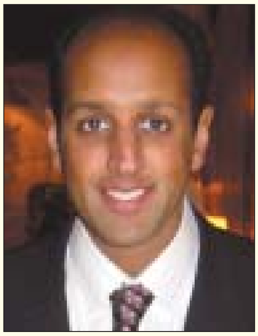
Proteasome: A machinery in cells defined over the last 25 years has become a focus of intense interest among Parkinson researchers in the last three years. Termed the proteasome, this is an elaborate structure that is able to recognize specific proteins for disassembly. These proteins are structurally normal proteins involved in various cell processes that are no longer required or, more importantly, damaged or toxic proteins that are injurious to cells.

Studies on the recently discovered rare genetic forms of Parkinson's have indicated that the function of the proteasome is affected in different ways in different genetic forms of the disease. Since genetic mutations that impair the proteasome's function can result in Parkinson's disease, it is logical to ask if environmental factors could do the same thing.

With this in mind, American investigators studied the effects of treating rats with naturally occurring and synthetic substances that block the protein-shredding function of the proteasome. The treated rats developed a condition that closely resembles human Parkinson's disease, with impaired movement (but not paralysis), selective loss of neurons, and protein accumulations in brain cells very similar to those found in humans (Lewy bodies). In addition, the condition showed response to drugs that have been successful in reversing some of the symptoms of Parkinson's in people. This animal model not only appears to reproduce the features of the human disease more faithfully than any previous model but also strongly directs investigators to a class of substances in the environment.

These proteasome-inhibiting substances need to be assessed for their role in Parkinson's disease. We anticipate a lot of work in this area in the near future.

References: *Neurochemical Research*, June 2004; *Annals of Neurology*, July 2004



Focus on …

Dr. Ratan Bhardwaj
Karolinska Institute, Sweden

"The fight against Parkinson's disease knows no borders," notes Dr. Ratan Bhardwaj.

So when the London, Ontario-born researcher was presented with the opportunity to further his research at the renowned Karolinska Institute, he jumped at the chance–even though it meant moving to Stockholm, Sweden.

"The Frisen Laboratory at the Nobel Medical Institute at Karolinska has an outstanding and innovative reputation in neural stem cell research," explains Dr. Bhardwaj. "It was the ideal place to pursue this promising line of research."

Dr. Bhardwaj's research is focused on the neurons in the human brain and their potential role in treating Parkinson's.

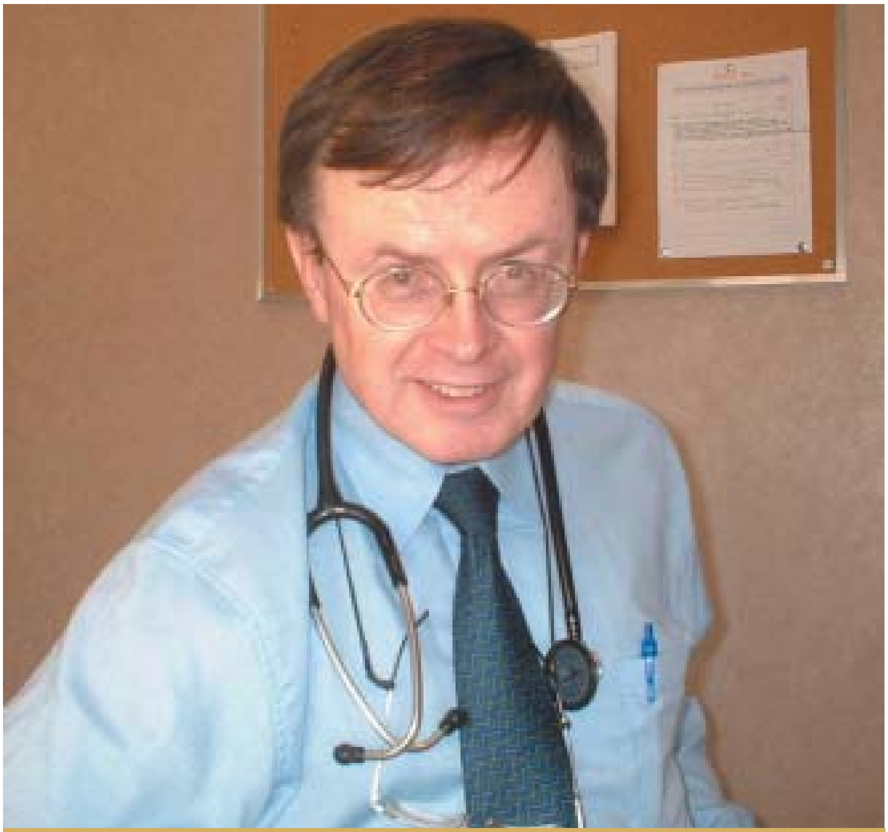
"We used to believe that the adult human brain was incapable of making new neurons, or brain cells," he explains. "Now some studies have found that specific brain regions may be able to make new neurons. We are working on a technique that will allow us to determine when a population of brain cells was born. Our technique involves radiocarbon dating, best known for its use in dating fossils and relics. It's the beginning of a new field: neuroarcheology."

"The first step is to find a population of brain cells that are 'younger' than the person, thus implying that they were born after the initial development of the brain," Dr. Bhardwaj continues. "We'll then characterize the extent of this neurogenesis. The ultimate goal is to find a source of new brain cells that could be studied and even employed to somehow allow the brain to 'cure' itself. If one's own brain could cure itself, then an effective treatment for a condition like Parkinson's disease may be within reach."

Dr. Bhardwaj credits Parkinson Society Canada with providing him with this research opportunity. "Their support is instrumental in allowing people like me to pursue our ideas," he says. "They know that what I learn here, I'll bring back to Canada."

An attitude of gratitude

By Gordon D. Hardacre, MD, CCFP, FCFP



Frustrating, invigorating, tiring, humanizing, depressing and rewarding are a few of the words that Dr. Hardacre uses to describe life with Parkinson's.

As is often the case in the life of a patient, disclosing one's own fear can be as daunting a task as bearing the burden of the fear itself. So it was that one memorable Saturday evening some years ago, having returned home from a birthday dinner for my now late mother-in-law, I abruptly switched off the television in mid-program and paused lengthily, struggling for the words to express my fear to a quizzical spouse and step-son ensconced with me in our comfortable den. Announcing with voice aquiver that, despite appearing to be in good health, I feared that I might be seriously ill—with ALS no less. I described the recent but creeping subtle stiffness in the fingers of my left hand, in the knowledge that a patient of my identical age had presented similarly and was strongly suspected to have that disease (she did indeed, and died within an all-too-common three years of diagnosis).

"Parkinson's? We'll take it!"

Family reassurance and support being immediately forthcoming, I self-monitored any symptomatic progression, and shortly thereafter, I proceeded to do exactly what I discourage my patients from doing: taking a time-saving and distance expedient bypass of my own family physician and self-referring, in my case, to a friendly general neurologist at nearby Toronto General Hospital, Dr. Vern MacMillan. Awkward chatter with him, seated on the same shuttlebus from the Toronto Western Hospital to his office for the consult, was followed by his history-taking and detailed neuro exam (remembered to this day—finger-tapping was indeed slow and fatigued early) and by his speculation about Parkinson's disease and further referral, for confirmation, to his esteemed movement disorders colleague, Dr. Anthony Lang.

Immediately following Dr. MacMillan's opinion, I hurried from his office to my car. Homeward-bound, I excitedly rang Enid, my wife, from a pay phone and in the same adrenalized moment locked myself out of the idling vehicle. Her unforgettable response? "Parkinson's? We'll take it!" which of course echoed my own relief.

Quite the voyage

Well, "taking it" has so far been quite the "voyage." At times, it has been frustrating, invigorating, tiring, humanizing, depressing, self-realizing, discouraging, rewarding and certainly demanding of me to re-examine life's priorities. A two-year period of just symptomatic monitoring plus lifestyle changes was followed by the introduction of Amantadine, one year later by the addition of Ropinirole with Domperidone, and in another two years by the further addition of carefully titrated Levodopa. This

"Parkinson's? We'll take it!" said my wife. Her comments echoed my own relief.

is a common enough pyramid regimen for a fiftyish-year-old person with idiopathic PD, not withstanding its attendant side effects (mainly leg edema and my nightly "technicolour adventure movie"). Dr. Lang has always given me as much leeway in drug and dose selection as I can prudently handle. How's that for "patient-centred" care?

But what of this frustration, invigoration, fatigue, humanization, anxiety, self-realization, discouragement and reward? Over the same period of time, my life has become otherwise "computerized," "re-hospitalized," and probably more other-"ized" than I am aware of. It has not, to my great fortune, as yet been "de-teacherized," "de-patientized," or "de-sportized," despite an irksome bradykinesia, the occasional tremor or dyskinesia, and an occasionally eventful disclosure as I gradually "come out of my closet."

Recently, a veteran colleague, in graciously congratulating me on one of those "Family Physician of the Year" awards (from the U of T), wisely commented that we middle-aged male physicians should not be so taken aback by such a turn in our own lives, given that much of the world (women in particular) has forever been such a frequent and expected bearer of great suffering. She's right—who, after all, is "guaranteed" three-score-and-ten (or less) or a clean bill of health into one's sixth decade?

One unpredictable day at a time

Life really is one unpredictable day at a time both viscerally and spiritually, and you make many small adjustments, if only to prevail. There must be another mad, word-loving medical-limerick-ist out there hiding in the interstices of the Internet. And for this retired ballplayer, for whom singing now presents the challenge of tonality and skiing the challenge of balance, my passions for top-level sports, classical and choral music, and a good golf game thrive as ever!

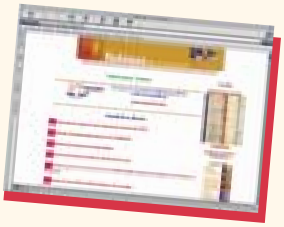
I now feel emotionally closer to a long-deceased, late-onset PD granddad and to his niece who is alive today. A misplaced concern that led to my delaying disclosure to a fretting mother was met with immeasurable support from both parents, my spouse, a married stepson and his wife, a sister, a niece, and friends. And to be honest, other family lows and highs, from the grief of a baby lost at term to the excitement of a wedding and the expectations of a budding journalism career, deserve and do occupy much of my head-space. Dr. Lang and his team motivate me to lecture, to speak to small groups and to consume the latest research paper. The resource-rich Parkinson Society Canada is nothing short of a polished gem. The generous and unqualified encouragement and "extra space" from patients and from my wonderful colleagues have also been sustaining. I mean, PD is the second most common and most treatable neurodegenerative condition, and luckily, so far for me, it has been modestly handicapping but not disabling.

Somewhere I hear a reassuring spouse blurt, "We'll take it!" and a golfing buddy advise, as he tees up his ball and points his driver earthward, "Sniff the fresh outdoor air… it's better than being on the other side of the grass !"

Just being here and alive is surely that.

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca



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

- Parkinson Society Canada celebrates our 40th anniversary. **Click on the 40th anniversary icon to learn about our history, milestones and celebrations.**
- Highlights of the 2004 Annual General Meeting and National Volunteer Awards. **Click on Headline News for details and pictures.**
- Learn about our regional partners and the services they offer. **Click on The Society and then on Regional Partners.**
- Launch of Parkinson Society Canada's Medical Information and Support Program. **Click on the icon in Headline News for details.**

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

A new motivation:
Thriving with Parkinson's

By Diane Patenaude, Montreal, QC

Diane found the support of her two daughters and her husband, Pierre, helped her adjust to the changes brought about by Parkinson's.

"I have good news and bad news," said the neurologist. Previously, he had asked me to stomp on the ground and tap my fingers on his desk, while he tried to knock me off balance. "Let's start with the bad news. You have Parkinson's disease."

Do I look so awful this morning that he thinks I'm 80 years old instead of 36? I must have misunderstood. There must be some mistake. Yes, of course, this is what's known as a wrong diagnosis. After all, my only symptom is a hand that won't do what I want.

"So what's the good news?" I asked. He told me there's a study showing that when you have Parkinson's, your health is "good" and that patients with Parkinson's don't usually get other diseases throughout their lives. Aren't I lucky! Later, when I got home, I told my husband, "no more gastroenteritis, cancer or flu. I'll shake a bit, and that'll be that!"

Challenges ahead

After my diagnosis, I ignored the disease and went on with my daily affairs—not that my affairs were that small. I worked in a large hospital where I supervised 360 employees and 19 managers, oversaw a $13-million budget (which, of course, was insufficient), and had three labour unions at my heels. In other words, stress and I were old friends. I've always enjoyed stress and found it stimulating. I was exhausted yet filled with passion.

One day, my right leg went on strike, and I began to feel increasingly tense. Then, I become not tired but ultra tired at work. It's not easy to direct your staff with your eyes closed. So I went back to see the doctor. (Maybe I am 80 years old after all!) When I mentioned that my right hand was hurting in solidarity with my right leg, the word "medication" was uttered. Catastrophe! Above all, I wanted to avoid taking pills. I didn't really need them. Besides, how much would they cost? I left with a prescription that I took to the pharmacist.

My experience at the drug store was another shock. In front of me, an older man was making a fuss because his prescription cost $12. When it was my turn, my bill came to $359. I turned to the other client and said, "My medication is expensive! Not yours."

A change of scene

The year 2002 got off to a good start. I had decided to change jobs and was offered my dream job: director of a Centre Locaux de Services Communautaires. The change made me happy. That year, I had also decided to ask my partner to marry me. After 15 years together and three children, I finally felt ready. And since I wanted to be a beautiful bride not too changed by illness, it was now or never.

Since we were making changes, we also moved closer to downtown and closer to where the action was. Getting around by bus did not suit me at all. City buses aren't exactly luxurious. Whenever the driver braked, there was always someone losing her balance and that someone was me. Parkinson's and buses don't go well together.

Things turned sour in the fall of 2002. At work, I would forget meetings, lose files and become bogged down in an extraordinary mess of papers, because I no longer knew how to keep organized. I had arguments to make yet couldn't find the words; people around me couldn't understand me; I made countless mistakes, and my image suffered. People thought I was "incompetent." But that's not the end of the story.

A new direction

In December, I made the wise but difficult choice of ending my career. I gave myself the luxury of crying for a week, then I took stock of my life. When I wiped the fog from my glasses, I saw I could be proud of what I'd accomplished, and I said to myself, "It's time to find a new source of motivation."

That's when I visited Parkinson Society Quebec to see if I could help with anything. My help was welcome and I quickly chose fundraising. After all, I have experience in this area and in communications and volunteering. I have plenty of ideas and enough energy to do it, so why not? Besides, I still have a network of contacts on my desk, so why not use them? This cause is easy to sell: after all, I am the cause. To raise funds for Parkinson's, no one is more convincing than a person with the condition. And since unity is strength, I felt I could convince other people living with the disease to lend a hand.

After all, we're fundraising for ourselves—for our own future and for the future of other people who will hear the "good news" and "bad news" from their neurologist.


Diane's enjoyment of gardening allows her to relax and keep her condition in perspective.

Author's note: If you're motivated and can give a few hours per week (no minimum; maximum 35 hours), the Society needs you. To do what? To work as part of a team (without any stress) on fundraising projects, to speak in public about your experience, to talk to other people who have the disease, and other activities. Of course, spouses are welcome to volunteer as well.

DON'T MISS AN ISSUE!

Coming in the Spring 2005 issue of *Parkinson Post*

A day in the life of a program co-ordinator

Follow Maureen Matthew, a social worker and program co-ordinator working with Parkinson Society Canada's regional partner in Victoria, British Columbia. From presenting workshops for professionals to helping families avoid burnout to providing support to the newly diagnosed, Maureen is guaranteed to have a busy day.

Parkinson Society Canada celebrates our 40th anniversary

Parkinson Society Canada celebrates 40 years of a commitment to ease the burden and find a cure. Read about our humble beginnings, highlights of the past 40 years, the growth of Parkinson Society Canada through our regional partners, and the commitment of our volunteers, stakeholders, donors, and corporate partners.

2004 Donald Calne Lectureship

A detailed overview of Professor Oleh Hornykiewicz' address to the Parkinson community. The 2004 recipient of the Donald Calne Lecture provided Parkinson Society Canada stakeholders with an overview of his work and research.

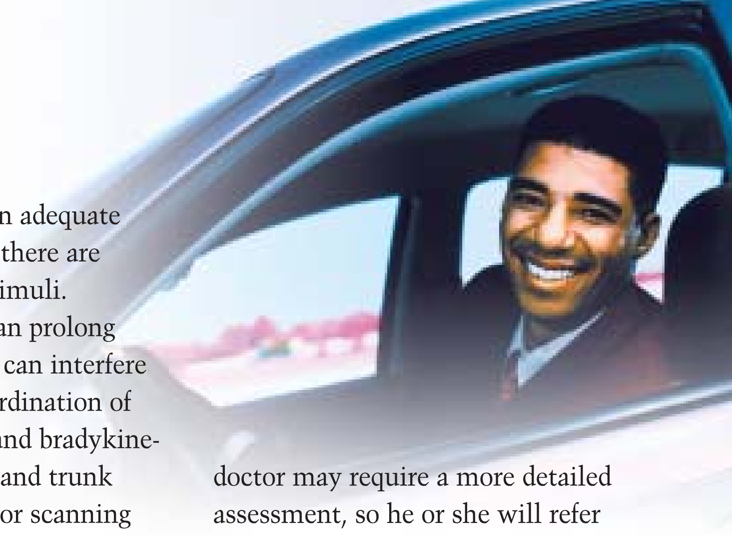
2004 Annual General Meeting and National Volunteer Awards

See highlights from the 2004 Annual General Meeting and National Volunteer Awards. More information will also be available on our website, **www.parkinson.ca**

SuperWalk 2005

Read about our plans for SuperWalk 2005 and get inspired to once again help Parkinson Society Canada ease the burden and find a cure. Our new national SuperWalk spokesperson, Canadian music legend Tom Cochrane, will be profiled.

Ask the Expert



***Q** My family has asked me to stop driving, because they feel my Parkinson's limits my ability to drive, yet I still feel safe on the road. What should I do?*

A Parkinson's affects your ability to drive in many ways. As you know, the disease progressively weakens motor skills and can impair thought processes. Some persons with Parkinson's have trouble concentrating and may have slower reaction times. Research shows that persons with Parkinson's who underwent a driver evaluation had reduced grip strength, reduced speed of movement and made more serious driving errors.

Medications for Parkinson's may also limit your ability behind the wheel. Dopamine agonists in particular can cause the sudden onset of sleep. In one Austrian study, one in three persons with Parkinson's suffered from medication-caused attacks that caused them to suddenly fall asleep. However, the Parkinson Disease Foundation in London, England, reports that such cases are rare, and that taking Parkinson's drugs should not lead to "the automatic cessation of driving."

As Parkinson's is progressive, the disease will affect people differently. Possible deficits include the following:

Visual: Eye movement abnormalities are common in patients with Parkinson's disease, potentially affecting the person's ability to scan and track objects in the environment. Muscle rigidity, limited range of motion and bradykinesia may compound the problem by affecting associated head movement.

Cognitive: A person with cognitive deficits may be unable to process an unexpected stimulus in adequate time, especially when there are multiple distracting stimuli.

Motor: Bradykinesia can prolong reaction time. Tremor can interfere with the required co-ordination of movements. Rigidity and bradykinesia can limit the neck and trunk movement necessary for scanning the environment.

International studies on the safety of Parkinson's drivers show an increase in the number of accidents among persons with the disease. In one U.S. study, persons with Parkinson's who were tested on a driving simulator were found to have more collisions than a controlled study group, and the number of collisions increased based on the disease's severity. A Finnish study of 20 men with Parkinson's showed that the participants had an increase in "risky" driving errors, notably turning across traffic and driving in city conditions.

However, most people with Parkinson's are responsible and limit their time behind the wheel. In one study, 40 per cent of people with Parkinson's who had been diagnosed five years ago were still driving; the people who had stopped driving did so due to concerns about their own safety or their family's safety. Those who had limited their driving stopped driving at night or during busy times of the day or drove only in familiar areas.

Again, Parkinson's is a progressive disease, and it can affect your ability to react quickly to a road hazard, turn the steering wheel, or operate the gas and brake pedals. You should speak with your family doctor, who will examine your physical, mental and emotional abilities to drive. However, your doctor may require a more detailed assessment, so he or she will refer you to a driver assessment centre in your area.

A driver evaluation assesses driving skills with cognitive and perceptual testing, vision testing, reaction time testing and on-road evaluation. Evaluation staff may provide training-based assessment results to improve your driving skills and recommend modifications on your vehicle to help you drive more safely.

You may be concerned that seeing your doctor will automatically result in you losing your license. Doctors are ethically and in some provinces legally obligated to report unsafe drivers to the vehicle licensing authority. In all cases, however, the doctor will first inform you of his or her opinion and reasons.

Driving is a sign of independence and freedom, and limiting or losing your ability to drive may be difficult to accept, but being responsible is important. Listen to what your family has to say and follow-up with your doctor. Having a driver evaluation will help you identify what you can and cannot do behind the wheel and ensure your safety and others' safety for the road ahead.

Shirley Rolin, BSc (OT)
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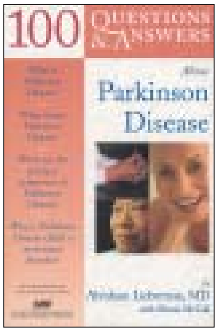
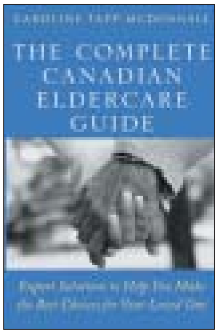
Resources





100 Questions and Answers About Parkinson's Disease

By Abraham Lieberman, MD

Reviewed by Ross Fleming, MD

This excellent book will be useful to people with PD and their families and caregivers. The information is up-to-date, accurate, clearly presented and easily understood. The 100 questions are grouped into nine chapters. A reader can peruse the book from cover to cover or learn from reading individual questions or chapters, although a reader may need to turn to several different parts of the book when seeking information on a specific topic.

The sections on symptoms, drug treatment, activities, exercise, diet, and "Making the Most of Life with PD" are especially good and contain valuable material that was new to this experienced care-partner.

Abraham Lieberman, a highly qualified neurologist, has a keen sense of what people want to know and how to present it.

Visit www.jbpub.com

Annual Report 2004

Parkinson Society Canada

Just released at the annual general meeting in November 2004, Parkinson Society Canada's *Annual Report* reviews the Society's progress during the past fiscal year at the national level and includes highlights of accomplishments from regional partners.

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

Please request a free bilingual copy of the *Annual Report 2004* by calling 1-800-565-3000, ext. 3394, or view it on-line at www.parkinson.ca.

Resource Information Kit for Family Physicians

Parkinson Society Canada

PSC's *Resource Information Kit for Family Physicians*, which will help physicians diagnose and treat Parkinson's, is full of resources and tools to help ease the burden and deliver quality information to professionals. The kit contains a listing of resources available through PSC and other reputable sources, a Parkinson's physician fact sheet, a referral pad to connect clients with PSC's Information and Referral Centre, a medication card for patients to track their medications, and one voucher to receive a free copy of the "Therapeutics of Parkinson's: State of the Art," a symposium delivered by movement disorders specialists at the Family Medicine Forum.

Physicians in Canada can request a free French or English copy by calling the Information and Referral Centre at 1-800-565-3000 ext. 3381.

The Complete Canadian Eldercare Guide

By Caroline Tapp-McDougall

Reviewed by Marilee Weisman

A journey through *The Complete Canadian Eldercare Guide* is imposing, but so is the ever-expanding number of caregivers.

This comprehensive guide by Caroline Tapp-McDougall is an encyclopaedic treasure filled with practical suggestions and an encouraging voice that keeps you reading. She speaks with the authority of someone who has walked the caregiving road when she cared for her mother (who suffered a stroke) and while she struggled to fulfill her family and career obligations.

Read the welcoming "Author's note" first, then the chapter that deals with the biggest challenge you are facing, then the next.

Available at your local bookstore.

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) 227-3385
Toll Free: (800) 565-3000, ext. 3385
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) 966-8007

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

Parkinson Society Canada Central & Northern Ontario District
Ph: (416) 227-1200
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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