Winter 2003 ▪ Volume 3 ▪ Issue 4
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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Support groups:

Sister Thelma-Anne and others discover there's strength in numbers

The challenges of young onset Parkinson's

Why your pharmacist is crucial to your care

PLUS:

SuperWalk 2003 sets a new record

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

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Letter from Parkinson Society Canada

Parkinson Society Canada
Société Parkinson Canada

ON OUR COVER:
Sister Thelma-Anne McLeod of St. Lambert, Quebec, started her own support group after her diagnosis (see page 8).

Committed to making a difference

I only joined Parkinson Society Canada as National Executive Director in September but I am already tremendously impressed by the work and the people of this organization.

I attended my first SuperWalk for Parkinson's in Mississauga, Ontario, just one of 74 walks held across Canada this fall. The enthusiasm and dedication exhibited by the volunteers and hundreds of walkers was remarkable. They came together in a spirit of camaraderie with a mutual goal and commitment to making a difference and I know that same spirit was felt right across the country. We are thrilled to announce that we exceeded our goal and raised $1.46 million this year – a 15% increase over last year! Thanks to all of you who were involved!

I have visited the 12 regional partner organizations that collectively comprise Parkinson Society Canada. As I traveled, I learned of the wonderful educational and support programs delivered throughout the country by local regions, chapters and support groups. I realize how much the national office and the regions can gain by working closely together and I will strive to ensure we maximize that potential.

In mid-June 2003, a Five Year Strategic Plan was adopted by the National Board of Directors. It contains ambitious and meaningful objectives that will move the organization to the next level of service for people living with Parkinson's as well as raise additional dollars to fund focused research. I will focus on steering Parkinson Society Canada in the right direction so that we reach those objectives.

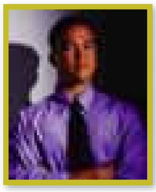
Most importantly, I have been meeting people. Courageous people living with Parkinson's, researchers striving diligently for breakthroughs in treatment and ultimately a cure, and volunteers and staff who are working tirelessly to further our mission. They all have the same vision: to ease the burden and find a cure. A vision that I embrace and am fully committed to. I am honoured to be among you!

Wendy Horton

Wendy Horton, CAE
National Executive Director,
Parkinson Society Canada
Toronto, ON

Contents

FEATURES



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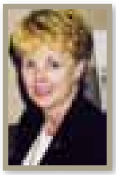

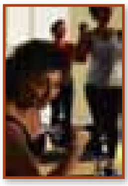

ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

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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

Regional Partners/Roundup

National Office and Regional Partners

For information, programs and services in your area, or to make a donation, contact the following offices:

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

Parkinson Society British Columbia
890 West Pender Street, Suite 600
Vancouver, BC V6C 1J9
Ph: (604) 662-3240
Toll Free (BC only): (800) 668-3330
Fax: (604) 687-1327
www.parkinson.bc.ca

- SuperWalk raised $117,000 at 11 walks.
- Held an education meeting in October with speakers giving helpful hints on traveling with PD and discussing transportation options in BC for people with disabilities.
- Held second annual conference for the newly diagnosed in November with Susan Calne CM, RN; and Sharon Yardley from UBC; along with experts in speech therapy, financial planning and physiotherapy.
- Carmen Dyck, our new Support Services Coordinator, has begun planning for regional conferences.

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

- Daytime education forums have included topics such as 'Essential Nutritional Information for Living Well with Parkinson's' presented by a registered dietitian and a naturopathic physician, and a 'Parkinson's Treatment Update' presented by a local neurologist.
- An upcoming education forum will focus on 'New Developments in Parkinson's' and will be presented by Dr. Jon Stoessl, director of the Pacific Parkinson's Research Centre at UBC.
- The four-times-weekly specialized exercise program continues to be fully booked and in high demand.
- SuperWalk for Parkinson's was well attended. Plans are already underway for next year's event.

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

- Grande Prairie SuperWalk raised over $13,000 (a 35% increase over last year) with 44 walkers (a 30% increase over last year).
- Edmonton SuperWalk raised over $73,000 with 415 participants (a 45% increase in participation).
- Received a Wild Rose Grant in September to develop and maintain a volunteer program.
- Third annual Speech Educational Program underway until December with full capacity enrolment.
- Planning in full swing for the First Annual Golf Tournament on June 17.

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

- Held another very successful Parkinson's Tulip Golf Tournament in July and realized a 50% increase in profits over 2002.
- Successful SuperWalks were held in Medicine Hat, Red Deer, Calgary and Lethbridge.
- Started a new support group in High River for those with moderate Parkinson's and their care partners.
- An eight-week pilot project looking at the benefits of Brain Gym (a series of simple exercises and activities, which involve whole brain learning) for those with mild to moderate Parkinson's began in October.

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

- Please note new address, phone and fax number.
- Second SuperWalk raised $50,640 in Saskatoon including goods and services, and $3,100 in Moose Jaw plus goods and services. We were delighted to have Roger Ali, National Director, Resource Development, PSC join us.
- Parkinson's Awareness Week on September 21–27. Guest speaker Dr. Jon Stoessl, University of British Columbia, Vancouver, spoke in Regina and Saskatoon.
- Tulip bulbs sold across the province.
- PW Golf Classic for Parkinson's Research at Avonlea on August 27 was a success, raising about $50,000.

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

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

- ▶ Annual Golf Tournament raised over $38,000.
- ▶ SuperWalk Winnipeg raised over $35,000.
- ▶ Morden, Manitoba's first SuperWalk raised over $12,500.

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

- ▶ Piloting a seminar series for people with Parkinson's who have been newly diagnosed.
- ▶ Planning two educational conferences in 2004: April 3 in Thunder Bay and May 1 in Toronto.
- ▶ Held 18 SuperWalks raising $469,455 (a 21% increase over last year).
- ▶ Sold 42,000 tulip bulbs raising over $12,000.

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

- ▶ Over 1,400 walkers joined our seven SuperWalks, raising $245,974 (a 44% increase over last year). Thanks to our dedicated staff and 300 volunteers!
- ▶ A SuperWalk wrap-up meeting was held to celebrate the many successes and consider new ways of increasing participation for 2004.
- ▶ Sold 50,000 tulip bulbs.
- ▶ Presentations were recently given to schools, long-term care facilities, the Supported Integration Program for Community Living and a CCAC-sponsored workshop to health-care professionals.

Parkinson Society Ottawa

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

- ▶ Our 25th anniversary celebrations continue with a '25 Weeks for 25 Years' program.
- ▶ Over 300 walkers raised $66,000 at our eighth annual SuperWalk.
- ▶ Started two new support groups: a group for the francophone community around Ottawa, and a Parkinson-plus group for people living with PSP and other Parkinson-plus conditions.
- ▶ Dr. Kathleen Norman, an Assistant Professor of Rehabilitation Therapy at Queen's University, presented on 'Movement and Exercise in Parkinson's Disease.'
- ▶ Following a flood in our old premises at the Civic Campus of The Ottawa Hospital, we moved into a nearby temporary space. This new space is so ideal that it will become permanent.

Parkinson Society 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

- ▶ Raised $27,000 at the Annual Parkinson Open.
- ▶ Contributed $100,000 to the national Parkinson's research program.
- ▶ Opened a new regional office for Montreal and surrounding areas.
- ▶ Raised $93,000 for the SuperWalk, as of October. We are expecting a total of over $100,000. The Eastern townships chapter organized their first SuperWalk this year and raised $10,000.
- ▶ Reached a record number of visits to www.infoparkinson.org. We are looking forward to the English version being on-line as soon as the end of December.

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

- ▶ Our third annual Golfing for Parkinson's tournament was held in August with over 80 golfers raising almost $10,000. Mark August 20, 2004 on your calendars for next year!
- ▶ Held 14 SuperWalks and raised over $62,000. The Valley in Nova Scotia hosted their first SuperWalk and raised an incredible $7,000! The Greater Moncton Chapter raised $10,000 (an increase of $2,000 over last year).
- ▶ The Plant Hope for Parkinson's Campaign sold more than 47,000 tulip bulbs!

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

- ▶ Central Newfoundland, Conception Bay North and St. John's support groups each held summer picnics.
- ▶ Almost 20,000 tulip bulbs were sold by volunteers in the region.
- ▶ Stephenville and Conception Bay North became new SuperWalk sites in 2003, joining St. John's and Central Newfoundland in raising $20,818.
- ▶ Information sessions were scheduled for Corner Brook, Grand Falls and Clarenville in October.
- ▶ Consultation has begun with the region's support groups to assist in the development of a regional strategic plan.

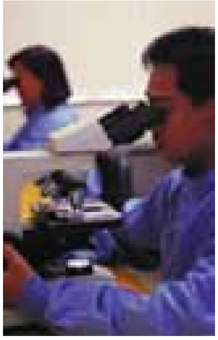
Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

Bill C-13 passed in House of Commons

In late October, the House of Commons passed Bill C-13, the *Assisted Human Reproduction Act*, which many in the Parkinson community have been following closely over the past few years. Among other things, the Bill would allow a government-appointed agency to apply safeguards and approve using embryos left over from fertility clinics for stem-cell research. Embryonic stem cells are considered by many scientists to be a very promising area of research, one that could lead to potential revolutionary therapies for Parkinson's and for countless other conditions.



The Bill requires Senate approval before it becomes law. There will likely be opportunities for people with Parkinson's to make their support of the Bill known to Senate members. Watch the What's New section of Parkinson Society Canada's website at www.parkinson.ca.

* * *

PSC plays integral role on *In Synchrony* project

Parkinson Society Canada recently partnered on a project called *In Synchrony* with five other health charities which provide service to people with degenerative or progressive disabilities.

The project's purpose was to conduct research on the specific issues of progressive disabilities given that, too often, government supports and services are provided through programs that assume disabilities to be of a chronic or non-fluctuating nature.

Data was collected from a literature review, a pre-survey with key informants and nine focus groups with people or family members who live with progressive or dynamic disabilities in locations across Canada.

The research confirmed what many people with Parkinson's already experience, including:

- There are currently many gaps in disability supports.
- There is limited co-ordination of services between provincial/territorial ministries.
- There is little recognition of the economic impact of living with a progressive disability.

In Synchrony partners:

- ALS Society of Canada
- Alzheimer Society of Canada
- Huntington Society of Canada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada.

The project led to the creation of a common definition of progressive disability and a tool called the 'progressive disability lens' to guide policy development and improve program design of services for persons with progressive disabilities.

Parkinson Society Canada and other partners will continue to work with government officials, policy makers, program designers, disability support service providers and other organizations to disseminate the *In Synchrony* report and to advocate for acknowledgement of the issues and adoption of the recommendations. To read the Executive Summary of the report, visit www.parkinson.ca and see 'What's New.'

Ease the Burden; Find a Cure

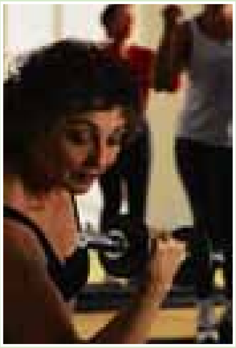
Health Tips

Stay active in cold weather

Being active is one of the most important things you can do to maintain your physical and mental well-being. Exercise will not alter the progression of Parkinson's but it is *essential* for maintaining your quality of life. Studies clearly show that people with Parkinson's who exercise fare better in the long run than people with Parkinson's who do not exercise.

People with Parkinson's need to exercise to prevent the negative effects of inactivity. Moving, stretching and exercising as much as you can will also help prevent secondary effects that may develop, such as: poor posture, losing flexibility, a tendency to stoop forward, decreasing endurance and poor balance.

As the cold weather sets in, some people find it more difficult to stay active. Here are some activities that work well indoors:



- using a treadmill, stationery bike or rowing machine
- walking in a shopping mall
- swimming laps at your local indoor pool
- dancing to your favourite music
- joining a Parkinson's exercise class (call the PSC regional partner nearest you – see pages five and six for contact information)
- signing up for a yoga, tai chi or pilates class
- using the stairs instead of the elevator if you are able
- exercising while watching television. For example, try leg exercises or lifting small weights to exercise your arms.

Begin with activities you can perform comfortably and listen to your body! Gradually add minutes of activity to your program. Minutes count and your goal is to build up your activity level to a total of 30 to 60 minutes a day.

Call 1-800-565-3000, ext. 225 if you'd like a free copy of *Exercises for People with Parkinson's*, which gives illustrated examples of posture, flexibility and strengthening exercises that you can do at home.

Someone to lean on:

Support groups show you're not alone

By Ian Corks

Lois Harper remembers her reaction when her doctor suggested that she join a Parkinson's support group.

"I said 'no'," she recalls. "I just couldn't bring myself to do it."

It was 1991 and the teacher and librarian from Markham, Ontario, was still dealing with her recent diagnosis. "I didn't tell him why," she adds. "But I didn't want to be among other people with Parkinson's and see what it was doing to them. I thought it would be discouraging and depressing."

Sister Thelma-Anne McLeod started an English-speaking support group in St. Lambert, Quebec, shortly after her diagnosis.

Top photo: Group members, who meet monthly, share education and advice.

When Lois was finally persuaded to join a few months later, she discovered exactly the opposite. She found the group – about eight people with Parkinson's and their caregivers who met in members' homes – gave her encouragement, hope and an empowering sense of community.

"That first meeting turned things around for me," Lois recalls. "People were so supportive and there was this positive energy. Everybody in the group got up and told their stories. Nobody refused. The courage of some of these people was inspiring. It was wonderful to share my fears and questions with people I knew were in the same boat. People who could truly understand what I was going through."

Today, Lois is still involved with the Markham-Stouffville Parkinson's Support Group. Now over 65 strong, the group meets monthly and offers a variety of educational, social and support services.

Lois Harper is just one of the thousands of Canadians with Parkinson's and their caregivers who have reaped the potential – and proven – benefits of membership in a support group.

Sharing anxieties, hopes and dreams

"A support group can provide someone with help in understanding and normalizing their condition," explains Dr. Marvin Westwood, Professor of Counseling and Psychology at the University of British Columbia. "Understanding allows someone to come to terms with their illness, and normalization occurs through talking about anxieties, hopes and dreams with others in similar situations."

Dr. Westwood is an expert in group theory, process and development and has helped in the start-up and development of a variety of condition-specific support groups. He views support groups as a valuable 'treatment tool' in Parkinson's and similar conditions.

"When someone is confronted by a condition like Parkinson's, a common first reaction is to go into a kind of isolation, removing yourself emotionally and even physically from friends and family," he explains. "This can often lead to depression and anxiety, which, in turn, can aggravate some of the symptoms of the disease. Support groups can be one of the most effective ways of coping with these tendencies.

"They also offer an invaluable chance for emotional expression and catharsis. People in support groups often express feelings that they are unable to share with their families or health professionals.

"In addition, there is scientific evidence showing that when we help others, we feel better," Dr. Westwood adds. "Support groups allow people to share good ideas or help solve other people's problems. These are great ways of boosting self esteem."

To top it off, support groups may even contribute to a longer life, points out Dr. Westwood, citing studies showing that cancer patients who belonged to support groups had longer life spans than those who didn't.

Individual benefits

As important as support group theory may be, however, the ultimate success of any group is determined by what it provides to its individual members. For Lois Harper, for instance, the group gave her "positive energy" as well as providing a source of the information and education that her curious mind craved.

Education was also the main reason Dale Malischewski of Wadena, Saskatchewan, joined. Diagnosed with Parkinson's 14 years ago at age 46, Dale only joined his local group this spring to help keep up with the latest information. However, he soon found the group provided him with much more.

"I found that the group did wonders for my mental health," Dale notes. "There's a great social aspect. Being with the group lifts my spirits when I'm down and I have been quite low sometimes. I really look forward to the monthly meetings."

Joanne Kuchard, a member of the Foyer Dorval Support Group since its inception in 1998, has 'grown' along with her group and relishes the community it provides.

"With the group, I don't have to hide anything … I can be myself," Joanne explains. "Family and friends I confided in about having Parkinson's just can't seem to fully relate or understand. I could sense their embarrassment, so we avoid the subject. Questions like 'how are you?', sound more like 'how long do you have to live?'; and when they say 'you don't tremble very much', they seem more relieved than I am.

"In the group we can be honest and open with each other. Together we learn more about our condition. We have become an extended family."

David Cheyne of Calgary remembers the immediate "sense of belonging" he felt on attending his first support group meeting. The former RCMP and Calgary city police officer was introduced to his group by the Parkinson's Society of Southern Alberta. "The monthly group meetings are facilitated by staff who lead discussions and introduce the occasional speakers who address topics relating to research, medications or anything else related to Parkinson's," David states. "My wife Donna and I both derive many benefits from attending these

What support groups offer

Support groups can offer many things to many different people. They are often the easiest way to find out about local services and 'Parkinson's-friendly' health professionals in your area, and to meet people who really understand what you're going through.

Groups offer practical information on how to cope, education on the illness and treatment, friendship and camaraderie, and a safe place to unburden yourself about things you may not be able to share anywhere else.

Some support groups are aimed at a particular group or aspect of Parkinson's. For example, support groups exist for newly diagnosed individuals, young onset Parkinson's, caregivers and older adults; other groups are structured to support people with communication or other problems.

Meeting style and schedules vary from group to group and could consist of anything from an informal gathering to a chaired discussion. Many groups regularly bring in expert speakers to provide advice or updates.

Above all, support groups offer an opportunity to share your experiences and understanding with others. No one can understand Parkinson's like someone who's been through it. Your experiences can make a difference in someone else's life.

Parkinson's support groups exist in most regions of Canada. Parkinson Society Canada (PSC) and its regional partners can help direct you to existing support groups in your area. They can also help you start one if no relevant group exists. See pages five and six for a list of Regional Partners, or visit the PSC website at **www.parkinson.ca**.

Watch the Spring 2004 issue of *Parkinson Post* for tips on starting a support group.

Ten reasons why I joined a support group

1. It was the only place where I could say how I felt and knew people would understand.
2. I learned where to go for help in coping.
3. I realized it was possible to laugh at some of the impossible, crazy things that happened during the day.
4. I could be angry about how I was dealt a low blow by fate and others would say it's OK to feel that way.
5. I could find help on how to handle difficult situations from others who had dealt with similar ones.
6. I became aware of how much it helped to know that I was not the only one in the world going through this nightmare.
7. I found I could cope because of the support, caring and understanding of others in my support group.
8. I never had to apologize for, or explain, my symptoms.
9. I made new friends during a time that I seemed to be losing old ones.
10. I found my experiences helped others, too.

Adapted from InterAction.

Above: Sister Thelma-Anne's (second from left) leadership and personal touch have helped provide fellow members with the support they need.

meetings. We have acquired a deeper understanding of the complexities of the disorder and learnt a myriad of coping strategies. One of the main reasons that I continue to attend is to help others with Parkinson's who may be struggling as I once did."

Group goals and expectations

The one thing that all these people have in common is that they are all getting something of real value from their group. That's what is important, according to Dr. Marvin Westwood. "The group has to provide a positive experience for you or else membership will be counter-productive," he states. When considering joining a group he recommends asking some questions. "Look at the goals of the group and ask if they match your own goals," he suggests. "Are you OK with what the group expects of you in terms of disclosure, sharing feelings, etc.? Can the group deliver what you expect? Is the process suitable – will you be able to make the meetings? And, perhaps most importantly, will you feel comfortable in the group?"

Comfort is vital, echoes Lois Harper. "If a support group isn't to your liking, don't be discouraged," she advises. "Try another one until you find one you are comfortable with." Joanne Kuchard agrees, pointing out that her group was started by a woman who didn't like the one she was in.

In fact, starting their own support group is something many people with Parkinson's do. Often this is because they can't find a group in the area that meets their needs. In the case of Sister Thelma-Anne McLeod of the Sisterhood of St. John the Divine in St. Lambert, Quebec, it was a question of language.

"When I was diagnosed with Parkinson's two years ago, I needed some support to help me communicate about Parkinson's to my own household," Sister Thelma-Anne recounts. Parkinson Society Quebec in Montreal told me that the only support group on the South Shore was a francophone one. I told them to let me know if anyone started an English-language group. Then I thought about it and decided to start one myself."

The Sisterhood, an Anglican community formed in Toronto in 1884, offered space in the St. Lambert household and Sister Thelma-Anne made up a flyer which she distributed through local libraries, community centres and other venues. They even ran an ad in a local paper.

"In spring 2002, we held our first meeting with about 15 attendees – about half caregivers and half people with Parkinson's," she states. "Since then we have continued to meet once a month. We started just getting together and chatting, then we added speakers and other educational components. It has met a great need in this area. I have enjoyed being part of the group, both learning from it and contributing with my own expertise. I will be moving to Toronto in the new year, so now we are working on developing new leadership in the group."

Sister Thelma-Anne is confident her group will do just fine and is expecting to join a new support group in Toronto. Like Lois, Dale, Joanne and David, she is a firm believer in support groups.

"I would recommend to anyone living with Parkinson's to link up with his or her local support group immediately," David Cheyne sums up. "You may think that a group is not for you but you may just be pleasantly surprised. You will find many fine people who can help you to face what you are dealing with and who will be willing to share ideas on how you can better cope with your situation."

Ask the Experts

Q ***I've heard that people with Parkinson's have more eye problems than usual. Is this true? What can be done about it?***

A Visual complaints are common in patients with Parkinson's disease (PD).

With increasing age there is an increased incidence of age-related eye problems. These include cataracts, glaucoma, age-related macular degeneration (ARMD) and dry eyes.

The person with Parkinson's is likely to experience additional problems related directly to the disease (e.g., dopamine deficiency) or as a complication from the medications used in treatment.

To understand how Parkinson's affects vision, think of the eye as a camera. In order to see clearly we need a clear window, we need to be able to keep the image in focus and we need a good quality photographic film.

1. The window

- Needs an adequate tear film to keep the surface clean and regular blinking to keep the window clear.
- In PD
    - ○ Dry eyes may be aggravated by medications. The tear film may be oily (seborrhoea).
    - ○ The eyelid muscles can be affected, blinking may be infrequent and a staring tendency occurs, so the eyes dry out and get irritated. Rarely, there may be involuntary closure of the eyes (blepharospasm).

What can be done?

- Supplementary tear drops.
- Treat any underlying sebborrheic dermatitis (staphylococcal infection) with lid hygiene, antibiotic drops or ointment.
- Botox injections into the surrounding muscles for blepharospasm.

2. Focus

- In PD
    - ○ There may be difficulty with fast eye movements, as well as in following – pursuit eye movements (i.e. tracking as in reading). There is in particular more difficulty on looking up and in converging on a near object. This may lead to double vision and confusion with tired eyes.
    - ○ The ability to focus may be affected by medications (e.g., Artane and Cogentin) leading to blurred vision.

What can be done?

- Eye exercises and prisms in glasses.

3. Film/Perception:

- The photographic film in the eye is called the retina.
- Dopamine is found in the retina and in the visual cortex. In PD contrast sensitivity can be affected, so patients lose vision in low lighting conditions. Also the person with PD is more prone to visual hallucinations, which may be aggravated by medications.

What can be done?

- Increased lighting in the house. Assure good contrast in transition areas.
- Avoid confusing flooring.
- Curtail driving at dusk.
- Visual hallucinations may indicate a need to change medications.

If you are experiencing any of these problems, be sure to visit your eye care professional.

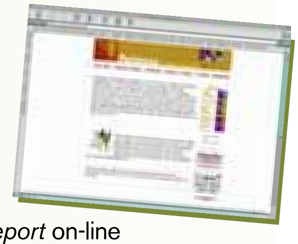
Margaret W. Kilshaw, FRCSC
General Ophthalmologist
(with special interest in strabismus)
Victoria, BC

WEBSITE HIGHLIGHTS

Visit Us On-line: www.parkinson.ca

We are always adding new content to our site. Check out the latest additions:

- *Taking Charge: A Guide to Living with Parkinson's* is one of our most popular resources and the revised edition in French is now available on-line. **(See Parkinson's Disease/Resource Materials)**
- Parkinson Society Canada recently partnered on a project called In Synchrony: Looking at Disability Supports from a Progressive Disability Perspective. Be sure to read the Executive Summary in English or French. **(See What's New/December).**
- If you haven't requested a print copy (see page 23), you can review Parkinson Society Canada's *Annual Report* on-line in an easy-to-read format in English or French. **(See The Society/Annual Report)**
- Events are always in the works at regional partners across Canada. For details, check our website. **(See The Society/Regional Partners and select the region nearest you).**
- We've added some new resources to our 'For Medical Professionals' section. You can view *What You Need to Know About Parkinson's: Information for Health Care Staff at Long Term Care Facilities* or link to The Movement Disorder Virtual University. **(See Parkinson's Disease/For Medical Professionals).**



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

Research Report

A look at current Parkinson's research arou

Research Editor: Dr. John Wherrett

The number and quality of the ongoing studies on Parkinson's disease (PD) are an indication of the global effort to understand this condition and improve care.

Cell transplantation in advanced Parkinson's

The second controlled study of fetal cell transplantation in human patients with advanced disease has provided some valuable information.

The study, led by the Canadian-trained C.W. Olanow of Mt. Sinai Hospital in New York, determined that the 23 subjects that received grafts as a group failed to derive continuing benefit after a year and were at a 50% risk for developing persisting dyskinesias that, in a small proportion, were disabling.

While initially reported as a 'disappointment', it is important to remember that this was a carefully planned and executed scientific study and was designed to ensure that valuable information would be obtained whether or not the result was 'positive' in therapeutic terms. For example, it was confirmed that the transplanted fetal cells would survive and make connections.

There was evidence that the recipients of grafts mounted an immune reaction to the grafts and that the results were better if this reaction was suppressed.

In addition, the evidence strongly suggests that by optimizing the numbers and targeting of transplanted cells the development of dyskinesias may be prevented.

Reference: *Annals of Neurology*, Vol. 54

Neurogenesis possible in nigrostriatal system

Until this last decade it has been assumed that, on reaching adulthood, the human brain comprised a fixed cellular apparatus of connecting nerve cells that would serve until death. If any of these cells were injured, they could not be replaced, and it was expected that there would be a continuing fallout of cells from this apparatus throughout the life span.

One of the major discoveries of the last decade in mammalian biology is that new brain cells do appear during adulthood to participate in the cellular apparatus underlying brain function in a process termed 'neurogenesis.' An important question is whether the nigrostriatal system, which is affected by loss of its cells in Parkinson's disease, is a site for neurogenesis. Using the techniques that have confirmed neurogenesis in other parts of the brain, researchers at the famous Karolinska Institute in Sweden have demonstrated that new nigrostriatal neurones appeared in the adult mouse and formed the appropriate connections.

Their work suggests that formation and death of the nigrostriatal neurones (turnover) continues in the normal adult. It has always been assumed that the nigrostriatal system failed in Parkinson's disease because cells died and were not replaced. It now seems equally likely that the system could fail because the generation of new nigrostriatal neurones does not keep pace with normal 'wear and tear' loss. Other investigators will now be able to confirm and extend these findings and explore the controls on neurogenesis so that it might be therapeutically manipulated to the benefit of people with Parkinson's.

Reference: *Proceedings of the National Academy of Science*, Vol. 100

Hallucinations and Parkinson's

About one-third of people with Parkinson's will experience vivid visual hallucinations. Even though these false, dream-like visions are usually recognized as such, they may create anxiety and disrupt the daily activities of both patient and caregivers.

Two new studies provide insight into these hallucinations. Diederich, et al., formally questioned 88 patients about hallucinations ("seeing something before your eyes that does not exist"). Forty-six of the subjects had experienced hallucinations and 78% of these had used at least one coping strategy. The most commonly used coping strategies were cognitive techniques, such as turning the lights on, consciously telling themselves that the hallucinations were not real or reassuring themselves that the hallucination would resolve shortly. Almost as common was the use of interactive techniques, i.e. relying on family or caregivers for reassurance, particularly about the non-reality of the hallucinations. The least common techniques used were visual, such as focusing more closely on the hallucination, focusing on another object or looking away. Those who did not use coping strategies reported

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

the hallucinations to be more bothersome and depressing.

These findings suggest that further trials to assess and optimize coping strategies should be undertaken, in particular to compare them to treatment by medication. The role of the hallucinations as a risk for depression also deserves further study.

The second study by Japanese researchers examined sleep mechanisms in people with Parkinson's who experience visual hallucinations. In the last decade, it has been found that it is common for people with Parkinson's to exhibit vigorous, sometimes injurious sleep behaviours associated with vivid, action-filled and, at times, violent dreams that occur in a stage of deep sleep called rapid eye movement (REM). Sometimes the dreams persist into wakefulness.

Nocturnal sleep in a group of daytime hallucinators was compared with that in a group of non-hallucinators. Those with hallucinations spent a greater proportion of sleeping time in the REM stage. Individuals with hallucinations also had a greater tendency to rapidly lapse into REM sleep than the non-hallucinators, although they did not fall asleep more rapidly.

The authors concluded that daytime visual hallucinations are related to a disordered sleep mechanism. A small dose of the drug clonazepam was found to reduce the hallucinations in a majority of the subjects and to also reduce the proportion of nocturnal REM sleep. A carefully controlled trial will be required to determine the effectiveness of clonazepam for control of visual hallucinations.

Reference: *Movement Disorders*, Vol. 18

Focus on…

Dr. Alain Dagher

Montreal Neurological Institute

Alain Dagher was an undergraduate studying electrical engineering when he first went to the Montreal Neurological Institute (MNI) to do some research. That research helped spark his interest in brain imaging.

Since then Dr. Dagher has switched careers, earning his medical degree at the University of Toronto and doing a neurological residency at Cornell University in New York and McGill University in his home town of Montreal.

Now he is back at the MNI, where he divides his time between seeing patients at the Movement Disorders Clinic and conducting promising research into Parkinson's disease.

"I am involved in a number of inter-related research projects, pertaining primarily to the role of the brain chemical dopamine in Parkinson's," Dr. Dagher states. "Dopamine is directly linked to Parkinson's. We are trying to understand why dopamine deficiency causes the symptoms of Parkinson's, as well as exactly what the 'normal' function of dopamine is. You would think that the two would be closely related and that dopamine's natural role would have something to do with movement. That doesn't necessarily seem to be the case. The normal role of dopamine seems to be to 'reward' the brain in some way. It may even play a role in why people become addicted to substances such as alcohol."

Part of Dr. Dagher's research is funded by PSC and involves studying dopamine release using positron emission tomography (PET) and transcranial magnetic stimulation (TMS). "Using these advanced measurement technologies we can study how and why dopamine is released in the brains of people with Parkinson's compared to non-Parkinson's subjects," he explains. "This could provide valuable information on the function of dopamine. It could also give us insights into the efficacy of various treatments – from levodopa, to deep brain stimulation, to neuro transplants – that are aimed at slowing the loss or restoring natural levels of dopamine in the hope of controlling the symptoms of Parkinson's disease."

Research shows possibility of additional points of therapeutic intervention

In the past 20 years, two discoveries have profoundly influenced our understanding of the degeneration of nigrostriatal neurons (the cause of the motor symptoms of Parkinson's disease).

The first is the discovery that Parkinson's disease could be induced by the toxic drug analogue MPTP, and the second is the discovery of rare genetic causes of Parkinson's disease. These discoveries have provided the rationale for new treatments to arrest the degeneration process and have accelerated research efforts.

MPTP has been widely used to develop models of nigrostriatal degeneration. Genetic forms of the disease and their affected genes continue to be mapped out. As the normal roles of these genes and the effects of the mutations have become clearer, evidence for a toxic effect of mis-folded cell proteins to account for neurodegeneration has been accumulating.

Gene mutations that cause Parkinson's disease have now been confirmed for four proteins – a-synuclein, Parkin, UCH-L1 and DJ-1. The mutation in a-synuclein appears to cause a mis-folding of this protein to render it toxic and the other protein mutations appear to affect the normal processing of a-synuclein such that it becomes toxic. It is no surprise that the mechanisms through which a crucial system in the brain subtly and gradually deteriorates would be complex. However, as research continues, the possibility of an increasing number of potential points for therapeutic intervention to halt the progress of Parkinson's becomes increasingly apparent.

Reference: *Annals of Neurology*,Vol. 54

Calgary

Cindy Exton, a top pledge earner in Calgary, Alberta, enjoys the day with her children.

SuperWalk for Parkinson's

Walkers in Sherbrooke, Quebec, raise an incredible $10,000 in their first year.

$1.46

SuperWalk for Parkinson's a huge

SuperWalk for Parkinson's, the single most-important national awareness and fundraising event for Parkinson Society Canada (PSC), took place during September in 74 communities across Canada. Once again a new record was set as we raised $1,460,000 – a 15% increase over 2002! Thank you.

SuperWalk for Parkinson's 2003 had many highlights including: nine new walks, on-line registration available at **www.superwalk.com**, walkers proudly wearing SuperSTARWalker hats (as they personally raised over $1,000 to support their local walk) and 352 teams participating representing a 140% increase in team participation.

PSC gratefully acknowledges the support of those who contributed to this success: Honorary Chair Vicki Gabereau, and PSC's many sponsors: National Bank of Canada, GlaxoSmithKline, The Running Room, Novartis,

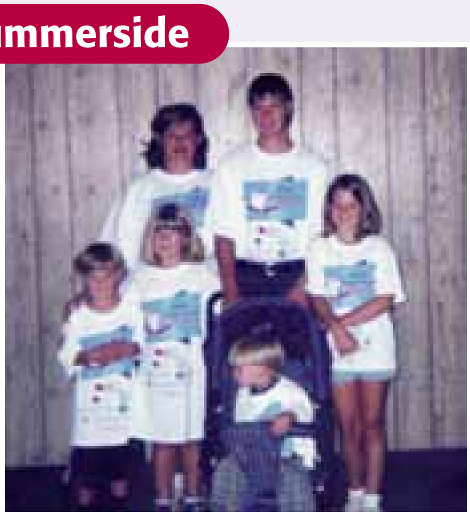
Winnipeg

Our SuperWalk Honorary Chair Vicki Gabereau having a little fun at the Winnipeg, Manitoba, walk.

Alliston

Heather Mochan celebrates her 10th birthday at the first walk to be held in Alliston, Ontario.

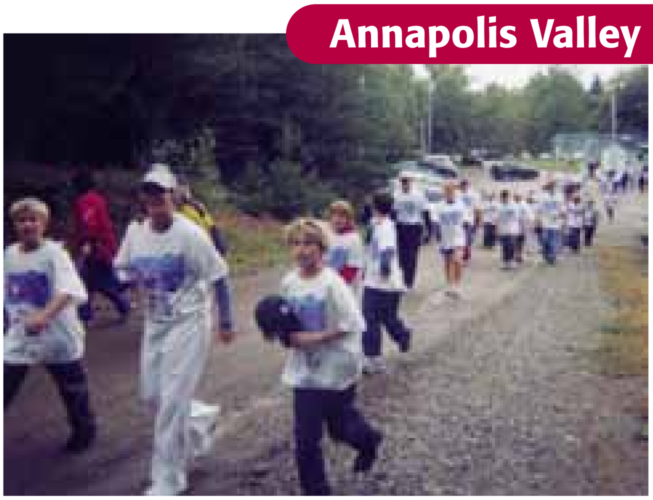
Summerside



Rob and Barb Gillis and their children enjoy the day in Summerside, Prince Edward Island.

Sherbrooke

Annapolis Valley



Walkers enjoy their first walk in Annapolis Valley, Nova Scotia.

million!

success from coast-to-coast

Eldertreks, Air Canada, Draxis, Hayhoe Mills, Allison Canada, Astra Zeneca, Bristol-Myers Squibb, Central Park Lodges, We Care and Rio Can.

To top off the excitement of our SuperWalk year and our impressive results, the National Grand Prize draw took place in November. The winner of the Costa Rica Rainforest Adventure, courtesy of Eldertreks, is Dr. Mark Guttman; the winner of two Air Canada tickets is Ellen Shilton and the winner of the Famous Players Big Card is Marj Robinson. The Bearg Family Team was declared the National Team Challenge winner with a total of over $33,000!

Planning in your area for SuperWalk for Parkinson's 2004 has already begun. Get involved today! Plan to be a SuperSTARWalker, get a team of friends together or call your local office and volunteer your time. Visit www.superwalk.com for details.

Kingston

Walkers in Kingston, Ontario, raise almost $10,000 – over double last year's results!

Edmonton

SuperSTARWalkers showing off their hats in Edmonton, Alberta. Edmonton had 17 walkers earn this special title and there were close to 200 proudly wearing their hats across Canada!

Calgary

The Super Fly Team from Calgary, Alberta, was one of over 350 teams participating across Canada.

Getting to know your pharmacist

Jennifer Patry

Chee Chiu

Chances are that at some point in the treatment of Parkinson's disease, you or a family member will be prescribed some type of medication. At this point, you will come into contact with that vital member of the health care team – the pharmacist. But exactly what can you expect from this professional?

Pharmacists Jennifer Patry of Strathcona Prescription Centre in Edmonton, Alberta, and Chee Chiu of North York General Hospital in North York, Ontario, provide answers to some key questions.

Q *What role does the pharmacist play in helping someone with Parkinson's disease?*

A Medication is not effective therapy unless it is used properly. For all patients, including people with Parkinson's, the role of your pharmacist is to ensure that you receive the most benefit from your medications. Pharmacists optimize your drug therapy in order to improve your health and ultimately your quality of life.

Q *What specific information can pharmacists provide to people with Parkinson's?*

A Pharmacists study pharmacology, physiology, pathology and anatomy among other things. Pharmacists can provide important details on:

- **Drug information:** Your pharmacist can provide details on all your prescription medications. This information can include what the medication is for and how it works, what the expected benefit(s) are, what the possible side effects are and what to do about them. Pharmacists are required by their licensing colleges to keep up-to-date on the latest products and drug information.
- **Medication assessment/review:** The average person with Parkinson's has three prescription drugs, and having four to seven different prescription drugs to take is very common. Some also take over-the-counter (OTC) medications for colds, constipation and other conditions, as well as vitamins and herbal supplements. Because of this extensive medication use, the risk of drug interactions and adverse drug reactions is increased. It is important that you buy all your medications at the same drug store so your pharmacist can identify any combination drug interactions or side effects if they occur. Your pharmacist may give you advice to resolve the problem or make suggestions to your doctor.
- **Counseling on medication management:** Some people with Parkinson's have to take medications more than eight times in the day. The timing of when medication is taken is as important as what medication is taken. Considering your daily activities and your drug responses, your pharmacist can work with your doctor to formulate a medication schedule to help you manage your daily doses easily and effectively.
- **Monitoring:** Most anti-Parkinson's drugs need to start at a very small dose, perhaps half a tablet once a day, and then increase slowly over time. Because each person's response and tolerance are different, your pharmacist can monitor you for drug efficacy and side effects and help you to follow the regimen correctly.

Q *Where exactly does the pharmacist fit in the health care and treatment 'team'?*

A Pharmacists are often one of the first health care team members that people turn to for health-related information. This is largely due to the fact that you don't require an appointment to talk to a pharmacist, and pharmacies and pharmacists are often easily accessible within most communities.

Pharmacists are in daily contact with physicians, so they can help you deal with any problems by contacting your doctor directly and discussing the situation and potential solutions. Pharmacists often work side-by-side in a treatment team with physiotherapists, occupational therapists, nurses, social workers and dietitians as well.

Pharmacists can also play a role with home care nurses and support staff to solve any medication or related problems that they discover.

Q *There are a lot of specific medication-related problems that someone with Parkinson's may encounter. How can the pharmacist help a person deal with the following important issues...*

Compliance?

A Many people with Parkinson's have trouble remembering when to take medications, especially when they are on multiple medications. Pharmacists can offer devices to help with this challenge. For example, pharmacies stock weekly pill boxes (dosettes) that patients can fill themselves or that can be pre-filled by the pharmacist. There are even some pill boxes with alarms that beep when medications are to be taken. And, of course, the pharmacist can suggest tips to help you remember when to take your medications.

Side effects and adverse reactions?

With today's Parkinson's treatments there are some side effects that can occur, such as nausea, dyskinesia, hallucinations and mental confusion – but it is still important to continue taking your medications. Your pharmacist can help you to minimize and/or deal with these and other side effects. The pharmacist can provide a personal consultation to answer any questions you or your caregivers may have.

Often people wonder if what they are experiencing is a side effect of their medication or a separate medical problem. Pharmacists have the knowledge to determine what is likely the cause of specific symptoms and can provide suggestions on how to manage these symptoms. For example, patients taking levodopa may have trouble sleeping (nightmares, etc), and may not realize this can be a side effect of this particular drug. A pharmacist could help reassure the patient and make suggestions on what can be done to help – such as working with your doctor to adjust the dosage.

The same is true when dealing with adverse reactions – a pharmacist can help determine whether it is an allergic reaction or just a side effect of the medications.

Managing multiple medications?

It can be very challenging when someone is faced with treating multiple medical conditions, such as Parkinson's, heart problems, diabetes, arthritis, etc. This is especially difficult when there are a variety of medications required. It is difficult to remember what medications are to treat which condition, when each drug should be taken, etc. Again, the pharmacist can be a great source of information and assistance. Weekly dosettes or alarm reminders can help. Pharmacists can also provide private consultations to review all of your medications and identify any duplication or unnecessary OTC medications.

Q *What advice would you offer someone with Parkinson's or their family in dealing with their pharmacist?*

A The best thing I can suggest is to get to know your pharmacist. Don't be afraid to talk to them about your condition or medications. Remember, there is no such thing as a stupid question. The pharmacist's job is to answer any questions you have and make sure you get the most from the medications you are taking. If you are part of a Parkinson's support group, consider inviting a pharmacist to come to one of your meetings, present information and answer questions – many groups have found that helpful.

DON'T MISS AN ISSUE!

Coming in the Spring 2004 issue of *Parkinson Post*

Highlights from the first-ever Dr. Calne Lecture

Don't miss our recap of the first Dr. Donald Calne Lecture, given by Dr. Yoshikuni Mizuno from Tokyo, Japan, in November 2003. Dr. Mizuno's lecture was a highlight of Parkinson Society Canada's Annual General Meeting in Montreal. We'll share what he explained about the latest in research and treatments.

Inspiring personal stories

Read profiles of Parkinson Society Canada's annual award winners. Four inspiring Canadians were awarded for their efforts in leadership, patient services and advocacy in the Parkinson's cause.

Caring with (and for) Parkinson's

A caregiver from rural Manitoba describes what it is like to care for her husband with Parkinson's. What is most amazing about her story: this wife and caregiver also has Parkinson's!

Tips on starting a support group

If you liked our article in this issue on support groups and are tempted to start one in your area, don't miss our follow-up piece which will give you tips on starting your very own support group.

Parkinson Society Canada
Société Parkinson Canada

Life after Parkinson's: Making the most of today

By Betty Geddes, Irishtown, New Brunswick

In 1989 at the age of 45 I first noticed my symptoms, which no one was able to alleviate or diagnose. Three long years passed before they finally put a name to my condition: I was diagnosed with Parkinson's disease in 1992 by Dr. Curran, a neurologist in Newfoundland. Dr. Curran started me on medication the very day I saw him. The struggle, however, was far from over.

By the time I was diagnosed, my symptoms had already progressed considerably. My right arm hung down by my side and did not swing when I walked. When I would go up or down stairs my right toe would catch and I would stumble. I could no longer brush my teeth in the normal way. I would have to hold the toothbrush in both hands and shake my head back and forth and from side to side. I only slept in naps because of the relentless pain and burning sensation in my arm and leg. Fatigue and dizziness were also concerns: I would arrive at work exhausted each day.

I learned quickly that, along with the symptoms, I had to deal with the medication side effects. I couldn't work for three months. The dizziness and nausea became far worse and lasted for more than a year. I lived on dry crackers, ginger ale and popsicles. Whenever we went to town my family would take a plastic container and a handful of paper towels along because they knew I would need them before we returned home.

J.J. the Hobo and Betty at the 2003 SuperWalk finish line. "J.J. never misses a SuperWalk and his dedication is inspiring to all persons with Parkinson's," says Betty.

In this together

I didn't give up my career as a licensed practical nurse without a struggle. My husband Merton would iron my uniform, help me dress and drive me to work. When we came home at night we usually prepared supper together (Unless, of course, I was so tired that I crawled on the couch without even taking my coat off). Or, I would start the laundry and he would see that it was dried, folded and put away. We were in this together. Thank goodness for Merton!

I would be ready for bed by 8:30 pm. Merton would tease me saying I should be embarrassed to be going to bed before dark. Thank goodness for a sense of humour! It came in handy many times. Like the day Merton's sister, Verlie, tried to teach him how to put my makeup on. We scratched that idea before he poked out one of my eyes. I guess there are some things men just shouldn't do!

I had to change my way of dressing and style of clothes. I now needed pull-on pants, over blouses and sweaters. One evening when we went to a party I spent what seemed like forever in the washroom. I had to wait until Merton came looking for me because I couldn't get my blouse tucked into my slacks!

In 1995 I finally had to admit that working was too much. I had been a licensed practical nurse for 33 years. Even my medication wasn't enough to keep me going. I had loved my job and my co-workers but even with their help I had to stop.

Above: Betty with the "greatest support group anyone can have" – her family. Standing with Betty (from left to right) are her two sons Matthew and Joel and husband Merton.

Life is better

There is life after Parkinson's. These days, life is better. I don't have to use a shower chair. I can even have a bath if I choose. Many of the medication side effects have stopped. I can drive again. Staying home alone is no longer a problem.

I have learned to pace myself and prioritize my day's activities. Mornings are best for me so I do the important things then. I have learned to listen to my body: When I am tired I rest which helps me enormously. This is something many Parkinson's people have not learned to do.

Exercise is an important part of my life. It will help me stay strong and keep me out of a wheelchair. Exercise also helps keep your body in the best possible condition if you ever need surgery. It also gives you energy and reduces your chance of getting pneumonia, a secondary complication of Parkinson's disease.

To get started, I visited Janet Millar at the Physio Clinic in Halifax. She developed a personal exercise program for me and made it fun! She even set it to music that I enjoy. Those of us with Parkinson's are fortunate to have the expertise of Dr. G. Turnbull and Janet Millar available so close to Moncton.

The support of friends

My support group is also important to me. It was the beginning of many great friendships. The group provides people I can lean on and who share a common understanding of Parkinson's-related problems.

A support group doesn't have all the answers but it does have resources to help educate us about our disease. You can surf the net for hours to educate yourself but it is the people who give their time and energy to help others that make the biggest difference.

For Merton and I, Parkinson's disease is very hard on our marriage. We have had to learn a new way of living and communicating with one another. I have learned to ask Merton for help without feeling resentful or angry; he has learned to offer aid and has become more aware of when I need help.

There are days when it must seem to him, that no matter what he does, it just isn't right! He must deal with my irritability and crankiness regularly. How frustrating it must be for him when he tries to help and I lash out in anger – not at something he has done but because of my inability to do the task alone.

A change of plans

Life has turned out differently than we planned. We worked hard all our lives raising our children. We looked forward to our retirement and the occasional trip. Because of my condition, many of our dreams have been shelved but we still love each other. We find lots to laugh about. Most importantly, we are best friends and are determined to stay that way!

At the end of the day my faith in God is most important. He has allowed my life to take this journey for a reason and I pray that I am making the most of His plan for me. He has blessed me with a positive and determined outlook and I trust Him to help me to use this trait to help others.

I am thankful for my husband and two wonderful sons – Matthew and Joel – who love and support me. I am grateful that I can still garden and enjoy the outdoors. I am appreciative of the most amazing people we have met who show what courage and determination is all about.

Would I have chosen Parkinson's disease? No. However, I have not spent one minute of regret. It has been 14 years since Merton and I began this journey. We are not the same people and we have a few scars. Along the way, we have learned to not worry about the future and do our best to make the most of today.

NO RESPECTER OF AGE:

Practical advice for coping with young onset Parkinson's

Parkinson's disease is no respecter of age. As many as five to 10 per cent of people diagnosed with this condition are under the age of 50.

For people facing the challenges of young onset Parkinson's, life suddenly looks totally different. Yet they must learn to face these challenges and, with help from family, friends and the right attitude, take control of their lives.

In addition to the very real physical symptoms, a person with young onset Parkinson's is forced to deal with a variety of unique psychological, social and lifestyle implications.

The diagnosis brings denial, anger and bitterness just as it does in older people but it also triggers a sense of having been cheated out of many of the best years of life. One of the results of this feeling can be an overwhelming sense of denial. In many cases, people ignore or minimize the effect that their illness has on them and those close to them. Facing up to the diagnosis is one of the first and most important steps someone with Parkinson's can take.

"Attitude is vital," notes Janice Stober, a clinical social worker with the Centre for Movement Disorders in Markham, Ontario. "The young people who cope most successfully are those who take the view that 'sure I have Parkinson's but my life is about much more than that.' In some cases, they find some positives in the situation, like the chance to work at home, spend more time with their family, etc. Others start to look at everything from a Parkinson's perspective and let the condition dominate their lives with negative results."

Myles Boyko
Aurora, Ontario

Now 38, Myles was diagnosed with Parkinson's in 1999. He is married with two daughters, age four and seven. A graphic designer by trade, Myles is no longer working due to his condition. He credits his personal faith in helping him deal with his condition.

Myles Boyko

"My first emotion when my diagnosis was confirmed was relief that my symptoms weren't due to a brain tumor. Once I knew it was Parkinson's, I went into a kind of denial. I guess I never really got over that feeling but I have come to accept my condition.

My mother felt a bit guilty, because there was a history of Parkinson's in her family and she thought that contributed to me getting it. She said she 'would take it from me if she could.'

The role reversal was also tough – my wife became the main breadwinner and I help around the house. The kids are young. They know Daddy 'shakes' but take it in stride.

It's easy to give in to self-pity and become introverted. But I fight that. Sure you don't want to be different and it's hard when people stare. But you have to have self-confidence and tell yourself you haven't done anything wrong. You're not different, so why worry?"

Family life: The stress of dealing with a chronic disease can take its toll on family relationships. Added to this is the frequent accompaniment of depression, anxiety and other conditions (e.g., sexual dysfunction). It is vital for couples to keep an open dialogue about the physical and emotional challenges of living with the condition.

"The significant other also has to deal with Parkinson's, and while the person with the condition has the support of the doctor and others, they are left to face it alone," Janice Stober points out. "They also need help and support."

Communicating with children also presents unique challenges. Open, honest communication is essential, with the feelings and fears of all – regardless of age – being tabled and discussed.

Financial: The person with young onset Parkinson's will likely still be in the workforce with the intention of working for years to come. While many continue to do so, others are forced by their condition to reduce their hours or stop working. This has an obvious and sometimes frightening impact on financial security.

The need to financially provide for a young family is a major concern. The potential cost of medical care for the future also requires planning to optimize available resources. Professional financial planners can help deal with these important issues. *Editor's note: See* Living and Working with Parkinson's *(*Parkinson Post, *Fall 2002) and* Long Term Planning *(Spring 2003).*

Relationships: For single people, the changes brought on by Parkinson's can also have a negative effect on relationships with the opposite sex. It can be hard to feel attractive and sexually desirable when your body is out of control. This issue needs to be dealt with and a new sense of

Marg Meikle
Vancouver, British Columbia

A former journalist and broadcaster for the CBC, Marge was diagnosed with Parkinson's in her early 40s. Today, she writes children's books and is involved with an on-line business. She is also the founder of Porridge for Parkinson's, which will have raised $100,000 for Parkinson's research by year-end (See ***www.porridgeforparkinsons.com****).*

"My advice is watch what you read. It can be very depressing if you get the wrong type of information. I also found support groups didn't work for me.

I struggled with my medications and diet, and worked hard with my pharmacist, doctor and other professionals to come up with a plan – medications, diet, exercise, etc. – that worked for me. I do much better when I exercise regularly.

Right now my Parkinson's is an 'annoyance' but it has been crippling at times and I realize it may be again. I just take it 'one dose at a time' and I make sure I have the best tools to deal with it.

Let's face it, the disease sucks but you can do things to make it better. You really have to make things work for you and you need a sense of humour."

Marg with her son Mac MacDonald

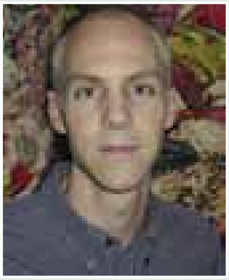
Jeff Burns
Sackville, New Brunswick

Jeff is a visual artist and an art professor at Mount Allison University. He was diagnosed with Parkinson's in 2002 at age 37. Jeff lives with his wife and 14-year-old daughter. He continues to teach and exhibit his art.

"Parkinson's has changed my life. There isn't a day that goes by when I don't reflect on it. But it doesn't change everything and I am determined to continue to live my life. I am still working with the help of some practical adjustments, like using voice recognition software to cut down on my typing.

We acted very practically when I was diagnosed. I sort of skipped the denial phase and got straight into learning as much as I could. We also took a look at our financial situation. That is very important for anyone with young onset Parkinson's. It's one of the first things you need to do. I was lucky enough to have tenure at the university, so my job was secure. But even then, we had to change some of our plans. When looking for a house we had to consider not only the future financial situation but access to medical care, where my wife would work, etc.

Exercise helps me a lot. I stay as active as possible. I also get a lot from the on-line community. I recommend **www.youngparkinsons.com** and there's a good new chat group for Canadians with Parkinson's at **http://groups.msn.com/CanadiansWithParkinsons/CWP/home.htm**."



Jeff Burns

Grant Kozak

Red Deer, Alberta

When diagnosed with Parkinson's at age 42, Grant admits to being 'stunned.' A branch manager for IKON Office Systems, he was then faced with the prospect of leaving the job he loved. Married with two girls (12 and 14) Grant has found ways to make the most of his life and plans to write a book about his experiences.

"Financial concerns were immediate and we spent time planning for our future. When the time came in 1999, I hated leaving work. But then I realized there was more to life than work. I devoted my time and energy into volunteer work, raising funds for Parkinson's and cancer and the local school playground. It gave me an outlet for my energy and talents.

Another tough thing was realizing that there are things you won't be able to do with your kids down the road. That helped me decide to make the best of everyday right now. I have also come to realize that you can still find ways to do things. For example, I have always played goal in hockey as long as I remember. The thought of giving it up was awful – so I didn't. I play in an old-timers league now but it still gets me on the ice.

Above all, I stay positive and keep my sense of humour. I stay in the best physical shape I can in case they find a cure and I will continue to work towards that goal. I think a cure is just around the corner. And even if it doesn't come in my lifetime, it will be there for someone else like me."

Bonnie Clay-Riley

Nanaimo, British Columbia

Bonnie with her sailing buddy, Captain Curt.

When she was diagnosed at age 49, Bonnie told her doctor that she didn't think she was the "kind of person to get a disease like Parkinson's." Today, Bonnie is Assistant Manager of the BC Ferry Terminal in Nanaimo, in touch with other active people with Parkinson's.

"I didn't take the diagnosis easily. I asked for a second opinion and when it was confirmed went through a period of crying in my beer. Telling my boss at the terminal I worked in at the time in Northern BC was the toughest thing I had to do. I think she thought I would be out of there in a couple of years in a wheelchair.

I guess I wish I had known how my condition would progress. I would have worried a lot less.

I had the usual denial, followed by depression. At first I refused an anti-depressant, then gave in. It has worked for me. Once I accepted my condition, I became proactive and got involved. I think it's very important to do this. I helped get a website going for single people with Parkinson's but it was a lot of work, so I backed off that.

I still enjoy work and now travel whenever I can. I've even sailed around the San Juan Islands for a week with six singles, four of whom had Parkinson's. I stay active and don't dwell on my condition. I'd like to revive the idea of a support or chat group for single people with Parkinson's. And I'm always looking out for that single, active guy with young onset Parkinson's. That would be great!"

self-worth developed. Support groups and professional counseling can help in this area.

So how does a person deal with the challenges of young onset Parkinson's? There is no definitive answer. However, there are a few basic strategies that experts agree can help in most cases:

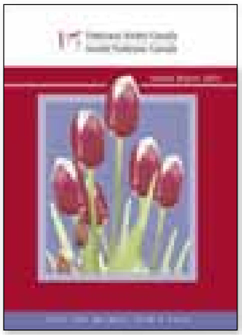
- Accept the diagnosis and get on with the job of living life.
- Take 'control' of the disease. Learn about the options available.
- Join a young onset patient support group (if there is one in the area) and learn from others how to cope. Janice Stober suggests joining a support group with other members of the same age and, most importantly, at the same stage of life – who may have kids of a similar age, work issues or other common challenges.
- Always remember that partners and families are living with young onset Parkinson's as well. Respect what family members are going through and try to help them.
- Keep a positive attitude.
- Exercise and eat right. One way to fight back is to maximize physical strength and overall health in a realistic and achievable way.

The best way to cope is to develop a personal strategy, as each of the five individuals profiled in this article have done. What they have in common is that they have all found ways to make the most out of life with young onset

Do you have good ideas to share?

Sharing good ideas can be encouraging. Do you have suggestions or personal advice to share with people with young onset Parkinson's? Please e-mail us your comments to **editor@parkinson.ca**. We'll publish a selection of the suggestions we receive in a future issue.

Resources



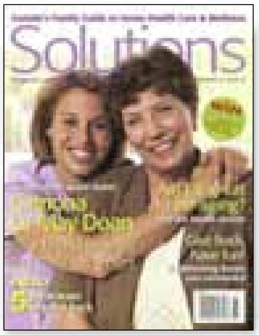
Annual Report 2003

Parkinson Society Canada

If you are interested in what's happening in the Parkinson cause across Canada, be sure to request this report.

Just released in November, it reviews the progress of the past fiscal year at the national level and includes highlights of accomplishments of PSC regional partner organizations across Canada. Extended coverage of the national research program is new this year and features four PSC-funded researchers/teams and their exciting work. Also see the detailed financial accountability section. Updates on education, advocacy and support are included. Read about five inspiring people with Parkinson's from all across Canada and learn how they cope.

To order a free bilingual copy, call 1-800-565-3000, ext. 225, or view it on-line at www.parkinson.ca.



Solutions magazine

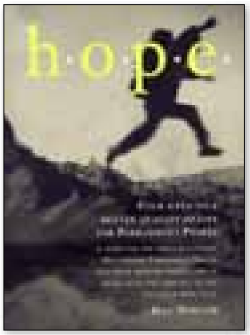
Reviewed by Suzanne Tobin

If you are a caregiver to a parent with Parkinson's, you'll find *Solutions* magazine helpful. It is written for adults balancing work and family, particularly those caring for a family member. Today's active baby boomers are moving into the future 'sandwiched' between the needs of their children and their aging parents, and looking for info and support.

Canada's Family Guide to Home Health Care and Wellness, Solutions® is a respected resource. Each quarterly issue has 48-pages of tips, tools and information about your health as well as valuable advice on home health care and caring for a loved one.

An annual subscription costs $15.86 for six issues. Copies are also available at local newsstands, or visit www.solutions-online.ca. For a complimentary issue, call 1-800-798-6282 ext. 336 and mention this review.

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.



h.o.p.e.
Four keys to a better quality of life for Parkinson's people

By Hal Newsom
Reviewed by Daniel Thibault

h.o.p.e. is an acronym the author uses to summarize his personal advice for dealing with various aspects of life when faced with Parkinson's. Clear and precise, the information offered is upbeat, positive and conveys the message that hope is realistic and most of all, necessary.

Using personal stories and suggestions, author Hal Newsom illustrates the four components of hope that he relies on to live a better quality of life: help, optimism, a compassionate physician and exercise.

This book is a quick, yet empowering read for the newly diagnosed and for others who want to see how believing in a favourable outcome puts you on target for a better quality of life.

This book is available for $14 U.S., including shipping. To order call 1-877-980-7500 or e-mail nwpr@nwpf.org.

www.caregiver.com

Reviewed by Jill Pritchard

Are you looking for practical advice and positive reinforcement for your very demanding role as a caregiver? You may want to check out the American www.caregiver.com site.

You can sign up for a free weekly electronic newsletter. Each issue carries an insightful message from editor Gary Barg along with feature stories covering topics as diverse as nipping depression in the bud, the caregiver's role in rehabilitation and the unique issues faced by male caregivers.

There are always 'caretips' to provide handy practical advice and 'carenotes' for sharing the successes and frustrations common to all in the caregiving role.

Check out www.caregiver.com or call 1-800-829-2734 for subscription details for the electronic version (free). A print magazine, *Today's Caregiver*, is available by subscription for $26 U.S. for six issues.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To become a part of The Parkinson Legacy, or for more information about making a Planned Gift, please contact any of the following offices:

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
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Toll Free Ontario:
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Parkinson Society Ottawa
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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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