Fall/Winter 2006 · Volume 6 · Issue 3
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ParkinsonPost

A magazine for Canadians living with Parkinson's

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Steps in the right direction

Don and Marg Turner's 130 km walk

Creativity and Parkinson's

International project taps the artistic spirit

SuperWalk 2006

sets new records

PLUS

Timely tips for winter fitness

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Ease the Burden; Find a Cure

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www.parkinson.ca/donating/theparkinsonlegacy.html

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Ph: (604) 662-3240
Toll Free (BC only):
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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) 966-1348

Parkinson Society Manitoba
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Toll Free: (866) 999-5558

Parkinson Society Canada Central & Northern Ontario Region
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Parkinson Society Ottawa
Ph: (613) 722-9238

Parkinson Society Quebec
Ph: (514) 861-4422

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

Parkinson Society Newfoundland & Labrador
Ph: (709) 754-4428
Toll Free (NL):
(888) 567-7020

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www.parkinson.ca

Ease the Burden; Find a Cure

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ON OUR COVER:
Don, 74, and Marg Turner, 70, enter the city of Hamilton, Ontario, after a 130-kilometre trek that began in Oshawa, Ontario. They walked to increase awareness for SuperWalk and to raise money for research.

Giving throughout the year helps everyone

The holiday season is a time for giving. It's the time to make those last minute charitable contributions that ease our tax burden and benefit so many others.

I'm sure that for readers of this magazine, supporting Parkinson Society Canada (PSC) and our efforts to conquer PD is high on the list of worthy causes. And for that, I thank you.

While those year-end donations are always welcome, I would like to suggest some other ways of giving throughout the year. These could help eliminate some of the stress of rushing to meet the donation deadline and still provide you with valuable tax credits.

Here are a few year-round "giving" ideas:

- Make a donation in honour of someone special. This solves the problem of what to get for the "hard-to-buy-for" person. This doesn't have to be restricted to the holiday season. You can celebrate birthdays, anniversaries and other special occasions. In each case we send a card acknowledging the gift. Just make sure to leave us enough turn-around time.
- Make monthly donations. Of course, this doesn't preclude "topping up" at year-end with a special gift to ensure you receive the tax credit you are looking for.
- Make a donation in lieu of having wedding favours. We provide you with a letter and cards for the tables letting your guests know that a donation has been made in their honour. It's a way of showing your guests that you care.
- Make a bequest. Leave a gift to PSC in your will. We can provide your lawyer with examples of the appropriate language to make sure your wishes are carried out.

These are just some of the ways you can help to fulfill our goal of easing the burden and finding a cure. For more information on these and other options call us at 1-800-565-3000 or visit the PSC website at **www.parkinson.ca**.

Alan Riccardi
Chair, Board of Directors
Parkinson Society Canada
Toronto, ON

P.S. Be sure to read "Where the money goes," an interview with Joyce Gordon, President and CEO of PSC, on page 12 of this issue.

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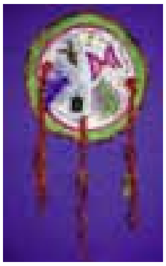

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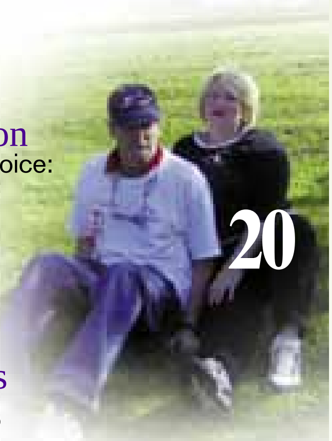

ParkinsonPost
A magazine for Canadians living with Parkinson's

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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

- June 30 marked the establishment of The James A. Moore Chair in Parkinson's Research. Initiated by Mrs. Donna-Mae Moore in honour of her late husband, James Moore, the partners of the $4 million endowment are Mrs. Moore, University of British Columbia (UBC), Vancouver Foundation, Pacific Parkinson's Research Institute and Parkinson Society British Columbia (PSBC). The new Chair in Parkinson's Research will be an anchor for recruiting the world's best researchers and supporting innovative state-of-the-art investigation. Dr. Jon Stoessl, Director of the Pacific Parkinson's Research Centre at UBC, is leading the search to find the best candidate.
- We are proud to announce that Global TV reporter Linda Aylesworth is now the Honourary Chair of PSBC. Her role will include recording public service announcements and appearing at fundraising events. Linda is a long-time supporter of PSBC, and her participation will assist us greatly in raising awareness of Parkinson's disease.

Victoria Epilepsy and Parkinson Centre

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

- A new Parkinson's relaxation program was launched in October. Its goals will be to help PD clients develop stress-management techniques and to support positive self-talk.
- The Parkinson's chair exercise program is very popular, with over 20 participants attending twice weekly.
- Several spouses of people with Parkinson's have volunteered to develop a caregiver support group. Following several meetings, the volunteers are now making outreach phone calls to expand this service.

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

- Bill Cogan started in his position as CEO in June 2006.
- Trevor Gent became President of the Board at the April 2006 AGM.
- A casino fundraiser was held at the end of August and raised approximately $85,000.
- New staff were hired: Kelly Parkatti as Communications/Volunteer Coordinator, Ray Williams as Operations Manager, Sive O'Neil as Administrative Assistant and Paula York as Process Planner.
- The Regional Health Authority for the Edmonton Region, Capital Health, conducted a consultation in August with PSA members on improving current rehabilitation programs in light of the opening of their new Community Rehabilitation Interdisciplinary Service clinic.
- A new monthly spousal and caregiver support group for the Edmonton area was started in September.
- Two successful SuperWalk for Parkinson's were held in Edmonton and Grande Prairie, raising over $115,000 and $24,500 respectively.
- Recruitment is underway for the addition of a Client Services/ Education Manager to better serve the needs of members and the community.

The Parkinson's Society of Southern Alberta

102-5636 Burbank Crescent SE
Calgary, AB T2H 1Z6
Ph: (403) 243-9901
Toll Free (Alberta): (800) 561-1911
Fax: (403) 243-8283
www.parkinsons-society.org

- The fifteenth Annual Tulip Tournament for Parkinson's was held on July 13 and raised over $40,000.
- A spiritual retreat for people with Parkinson's and their caregivers was held on Saturday August 12 in Cochrane, Alberta. The event was well attended.
- PSSA's 25th Anniversary luncheon and celebration was held on September 7. Dr. Oksana Suchowersky was the keynote speaker.
- Southern Alberta held SuperWalk for Parkinson's walks in Calgary, Cochrane, Red Deer, Medicine Hat and Lethbridge.
- PSSA is offering a pilot program in Reiki treatments for people with Parkinson's this fall.
- PSSA held a two-day fundraising casino on October 10 and 11.

Saskatchewan Parkinson's Disease Foundation

103 Hospital Drive, Box 102
Saskatoon, SK S7N 0W8
Ph: (306) 966-1348
Fax: (306) 966-8030
E-mail: spdf@sasktel.net

- Parkinson SuperWalk Saskatoon went very well. We had great weather with gross revenue over $65,000.
- There is a new pamphlet put out by our region called "Parkinson's disease: Information for patients and their families."
- Movement disorder clinics are held in Saskatoon and in Regina two days per month.

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

- The Annual Regional Conference 2007 will be held on Saturday April 21, 2007. The event will include regional awards, a volunteer

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Parkinson Society Canada
Société Parkinson Canada

recognition luncheon, speakers, interactive sessions and a chance to re-connect with old friends and make new friends.

- The Early Onset Speaker Series, geared to those diagnosed before the age of 60, consists of three information sessions held in the fall, winter and spring. Topics include family dynamics, CPP and other benefits, navigating relationships, and work-related issues.
- The Parkinson's resource library supported by the Thomas Sill Foundation contains over 100 publications (books, videos, audio) on a wide variety of Parkinson's-related topics, personal journeys and alternative therapies. The library is open Monday to Friday, from 8:30 to 4:30. There is a $5 user fee for non-members.
- Newly diagnosed information sessions run twice annually in the spring and fall. The sessions are geared to those who have been diagnosed in the last three years. Topics include speaker sessions on medications, an overview of the disease, and what you can expect on your journey.

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 a record $636,000 this year, with over $222,000 coming from Toronto.
- A newly confirmed advisory committee has been created for Toronto and CNOR.
- A collaborative project between ALS Ontario and PSC-CNOR has resulted in a staff member being deployed to work in the Northern Ontario region.
- The new Niagara Region Chapter held its inaugural meeting. This brings the total number of chapters and support groups to 37 across CNOR region.

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

- We are actively seeking funds for Community Development Programs in Waterloo Regional Municipality, Grey and Bruce Counties, and Essex County.
- Freedom 55, a division of London Life, has pledged $45,000 over three years to The Community Development Program (CDP) for Waterloo Regional Municipality.
- We are piloting PEP for Community Caregivers in Brantford, Strathroy, St. Thomas and Tillsonburg. Feedback from staff in private agencies and long-term-care facilities indicates that it has already made a positive difference.

Parkinson Society Ottawa

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

- The Parkinson community welcomed Dr. Michael Schlossmacher to the University of Ottawa. He will be named Canada Research Chair for Parkinson's disease.
- A coordinated effort with local representatives from Alzheimer, ALS, MS and Parkinson's resulted in a presentation entitled "Memory Matters."
- Parkinson Society Ottawa participated for its third and final year in the annual HOPE Volleyball Tournament. Over 25,000 people gathered at Ottawa's Mooney's Bay to play beach volleyball and listen to great music.
- Tracy Tremble organized a third-party fundraiser called "Pounding the pavement for Parkinson's" in which Team Parkinson ran the national Capital Marathon.
- Parkinson Society Ottawa worked with Parkinson Society Canada to host the 2006 Annual Meeting.

Parkinson Society Quebec

550 Sherbrooke Street West
Office 1470, Tower West
Montreal, QC H3A 1B9
Ph: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.infoparkinson.org

- The Parkinson Society Quebec Annual General Meeting took place in September. The Board will now consist of nine representatives from various areas in Quebec, five representatives from the business community or individuals with an influential background, and two representatives from the medical field.
- This year's SuperWalk attracted thousands of participants and raised $196,000. Kudos to all the participants and the many enthusiastic volunteers that donated their time to this great cause.

Parkinson Society 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.parkinsonmaritimes.ca

- Maritimes SuperWalk posted record results raising more than $112,000, a 33 per cent increase over 2005.
- The Maritime Regional Conference will be held in Charlottetown on October 20 and 21 with Dr. David Grimes as keynote speaker.
- Substantial media coverage was garnered as the Maritimes received a PSC research award.
- The Maritimes Regional Newsletter has been renamed *Parkinson's Today* and will be published three times a year.

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 (NL):
(800) 567-7020 Fax: (709) 754-5868

- Advocacy: We succeeded in having the St. John's exercise class re-instated through organizational and government contacts.
- Fundraising: SuperWalk was held in eight sites in the region, and 23,000 tulip bulbs were sold.
- Awareness: Excellent media coverage for SuperWalk through community and regional media.
- Staff: A part-time accounting/administrative assistant has been hired.

Parkinson Society Canada
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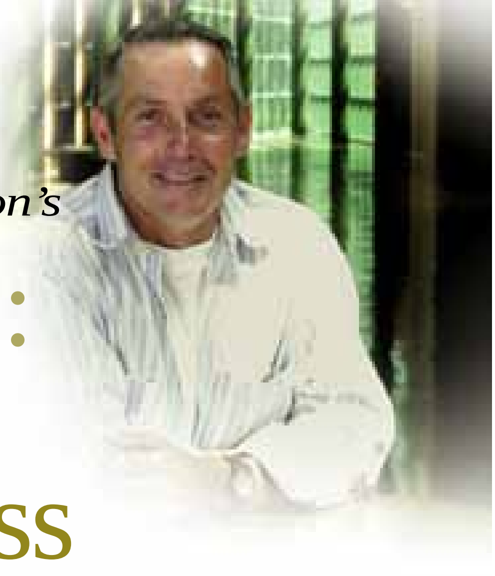
Issues of interest to people with Parkinson's



Starting to engage: Practical pointers for advocacy success

By Yvon Trepanier, Chair, National Advocacy Committee

At the recent regional conference hosted by Parkinson Society Ottawa, government-relations expert Ryan Clarke was very helpful in clarifying advocacy—the concept and process—and providing practical next steps for members of the Canadian Parkinson's community.

What is advocacy?

According to Clarke, advocacy is the telling of one's story for the purpose of compelling someone to do something (or not to do something). It is a process driven by reason and logic, not emotion, and it may be about something important to one individual or to a group.

Many of us don't immediately see ourselves as "advocates," but if we think back to negotiating with our child's teacher, going through job interviews, or getting a second opinion from a health care professional, the fact is that we have all advocated for what we wanted or needed at some point in our lives.

How do we prepare to advocate?

It's important that we don't create confusion in the minds of our audience, so taking the time to develop three key elements is essential:

1. A key message. What we are saying in 25 words or less.
2. Tools such as brochures, fact sheets, website, press releases, etc.
3. Make one "ask": what is the one thing that we really need?

> *We have all advocated for what we wanted or needed at some point in our lives.*

How do we advocate effectively?

Effecting change takes time, so consistency and determination are critical, especially when it looks like we're not making progress. Clarke suggests that the proven path to success is a three-step process: educate, demonstrate, and advocate.

Educate: First and foremost, we must know our facts and issues so that we can educate people. Communicating consistent information that can be supported is essential to building credibility with our audience. Our audience must understand that we know what we're talking about and that we can back it up.

Demonstrate: The next step is learning to tell our personal stories in a way that reinforces the issue(s) we have raised. This may be uncomfortable, particularly for people living with Parkinson's who prefer to focus on being productive and optimistic rather than the many challenges presented by the disease.

However, we must move through any discomfort or embarrassment as sharing our stories is the most compelling and memorable way to communicate. Our personal stories will stay with people long after the meeting is over.

Advocate: This is when we ask our audience to do what we want. Clarke tells us that this action should be tangible—write a letter, make a statement, give a donation, change a policy—something that we can see they actually did as a result of our advocacy effort. Again, this may be challenging for those of us not used to asking for what we want, but if we don't ask for something tangible, how will we measure our progress?

To learn more about how you can participate in Parkinson Society Canada's advocacy efforts, please e-mail us at **advocacy@parkinson.ca** or call 1-800-565-3000.

Steps in the right direction: Couple's 130km trek boosts awareness of SuperWalk

Photos: Victoria Roberts

Marg and Don Turner walked to raise awareness for SuperWalk and to celebrate their 50th wedding anniversary.

It was 12 noon, to the second, when Marg and Don Turner walked up to City Hall in Hamilton, Ontario, to the strains of a bagpipe played by their son-in-law Michael Cuffe and to welcoming cheers from Hamilton Mayor Larry Di Ianni and members of the Hamilton Support Group and Durham region chapter of Parkinson Society Canada (PSC). Their arrival was right on schedule, and marked the end of a trek that started an incredible 130km away in Oshawa.

For Don, 74, and Marg, 70, the reason for their long trek was a simple one: to raise awareness for Parkinson's SuperWalk and for the condition that Marg has lived with for the past 12 years. "We both believe that SuperWalk is extremely important," explains Don. "It is PSC's single largest fundraiser. And if we are going to make progress towards beating this disease, we need research and that means money. So we really need to raise as much as possible. We felt that if we did this walk before SuperWalk, it would help to increase awareness and get people involved."

"We walked for the people who can't walk anymore," adds Margaret.

The Turners achieved their goal, garnering excellent media coverage for their effort—and SuperWalk—in local media, including a segment on Toronto's CITY TV.

Celebrating two anniversaries

This was the second year that the Turners have walked to draw attention to SuperWalk. "We originally decided to walk last year to celebrate the 40th anniversary of the Canadian Parkinson organization," says Don. "We covered about 103 kilometres. This year we wanted to do something to mark our 50th wedding anniversary, so we set the bar a little higher."

This year, their walk was completed over 11 days, ending on August 31. The couple averaged 10 to 15km a day of walking, each time picking up where they left off. Marg recalls being a little bit intimidated by the 130km route. "I was a bit apprehensive when we started," she says. "Don estimated that it was about 234,000 steps in total, and that's a lot. But once we passed the halfway mark, I knew we could do it. But, I admit I did let out a sigh of relief when it was over!

"I was walking at a slower pace at the end," she adds. "But overall, things went very well. And, of course, we were lucky to have the support of family and friends, including people from the PSC chapters in Durham Region, North

York, Mississauga, Burlington and Hamilton, as well as the National and Regional offices; many of whom joined us along the way."

The Oshawa to Hamilton walk combined two of the great passions in Don's and Marg's lives: raising funds to find a cure, and hiking.

They have long been active and enthusiastic supporters of PSC, participating in the last 11 SuperWalks and regularly volunteering for a variety of tasks, including staffing information booths and speaking to groups on the challenges of PD. Don and Margaret also founded the North York support group back in 1997, and only recently turned over the facilitator role to others. Parkinson's is obviously a cause that they both believe in.

Staying mobile

Their belief in the value of physical fitness is equally strong. Long-time hikers and canoeists, the Turners have not let Margaret's Parkinson's dampen their enthusiasm for the outdoors. "We simply love hiking," Don notes, listing off a few of their recent hiking holidays. "We have trekked through Slovania, New Zealand, the United Kingdom, Austria and Hawaii—all since Marg was diagnosed," he says. "Just last year, we hiked on the island of Madeira."

After 130km and 11 days, the Turners marched triumphantly up Main Street in Hamilton to applause from the mayor and many supporters.

The fact that Marg can still participate in such physically demanding endeavours is no coincidence. Since she was diagnosed with PD in 1994, Marg has fought back against the limitations of the disease. "The first thing I did was go straight to the local Parkinson office to get as much information as I could," she remembers. "I decided to try whatever strategies I could to counteract the symptoms of PD. For example, I even consciously project my voice to overcome the soft voice syndrome that some people with Parkinson's have. My handwriting is the only thing I can't seem to do anything about.

"One of the first things I learned was the importance of physical activity," she continues. "I knew that if I stayed as fit and mobile as possible, I would still be able to do things."

Marg concedes that as the disease has progressed getting up each morning can be "a challenge." But she still begins each day with her kinesiology Brain Gym program, an eight minute routine of simple exercises designed to help the brain work with the body. "These exercises improve my balance and mobility and just make the day go smoother," she notes.

And she takes every chance she can to push herself physically, even walking up a couple of flights of stairs whenever possible instead of riding the elevator.

"I feel empowered by knowing that I can somehow influence my condition through activity," Marg explains. "I know that if I didn't stay active, I wouldn't be active—if that makes sense."

If still being able to walk 130km—at age 70, with a 12-year history of PD—is any indication, it makes perfect sense.

The welcoming committee in Hamilton included family, friends and members of the Hamilton Support Group and Durham Region Chapter of PSC.

We keep growing!

SuperWalk for Parkinson's


Toronto, ON

Happy faces of families and friends highlighted the success of SuperWalk for Parkinson's 2006. In September, Parkinson Society Canada's single most important national awareness and fundraising event took place in 82 Canadian communities and raised $1.97 million, an 11% increase over last year.

During the walks, an ocean of red and blue hats worn by the record number of SuperSTARWalkers (each raising more than $1,000) bobbed above the crowd. This year, we not only recognized more SuperSTARWalkers but also had more teams enter our National Team Challenge. As well, our on-line donations soared past all previous records.

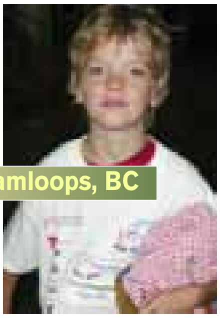
Once again, walkers earned one chance to win some fabulous prizes for every $100 they raised. At a special event on November 4, names were drawn from thousands of ballots. Congratulations to our lucky winners:

- Marie-Paule Sigmen from Shawinigan, QC, is the winner of a 10-day Costa Rica Rainforest Adventure, courtesy of ElderTreks.
- Ginette Vincent from Montreal, QC, is the winner of two hospitality class airline tickets to any scheduled international Air Canada destination, courtesy of Air Canada.
- M.A. Blake from Sarnia, ON, is the winner of a Cineplex Entertainment VIP Card, valid for one year of unlimited movie admissions for two, courtesy of Cineplex Entertainment.
- Each member of the Garth's Gang team from Saskatoon, SK, won a leather bag, courtesy of Roots.
- Herb Durand, a SuperSTARWalker from Ottawa, ON, won an Aquos LCD Television, courtesy of SHARP.
- Steve Cohen, a SuperSTARWalker from Toronto, ON, won a $500 gift certificate from Roots.
- Also announced that evening, Melanie Ozdoba, a student from Edmonton, AB, raised $7,825 to win a $500 gift certificate from Roots.

Since all money raised from this event will help fund Parkinson Society Canada's national research program and provide local support services for people living with Parkinson's, the success of this annual event is extremely important. Thank you to everyone who participated as a volunteer, walker or sponsor. You made this event great!

Be part of our success in 2007. Lead a team of friends and family in the National Team Challenge, raise $1,000 or more and become a SuperSTARWalker, or volunteer with your local region. On-line registration opens May 1, 2007, so visit **www.superwalk.com** early. See you at SuperWalk!

Victoria, BC



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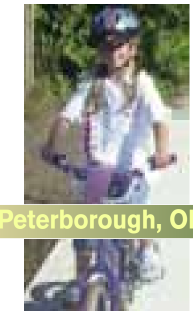

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Ottawa, ON

Montreal, QC

Charlottetown, PE

St. John's, NL

Thank you to our national sponsors

Parkinson Society Canada gratefully acknowledges the support of many sponsors who contributed to the success of this year's SuperWalk: GlaxoSmithKline, Kohl & Frisch Limited, Naturegg, Solstice, Teva Neuroscience, Air Canada, ElderTreks, Mind Fit, Novartis, Astra Zeneca, CB Richard Ellis Limited, Deep Cold, The Brian Hennick Memorial Fund, Pure Metal Galvanizing, RioCan, and Running Room Sports Inc.

Where the money goes:

Why fundraising is so important

Fundraising is one of the primary tasks of Parkinson Society Canada (PSC) and its regional partners. Initiatives such as SuperWalk, April Awareness, tulip bulb sales, calendar sales and numerous other activities across Canada are focused on raising money. But where does that money go? And why is fundraising so important? Parkinson Post *asked Joyce Gordon, President and CEO of PSC, to provide some insight into how PSC spends the funds it raises.*

Joyce Gordon, President and CEO of Parkinson Society Canada.

Q How much money does PSC raise, and where does it go?

Joyce: In the past three years alone, PSC has funded $3.35 million in research into Parkinson's disease (PD) and support for clinical programs. In the current year, we are investing $1.89 million in the same areas.

Q What types of programs does PSC support?

Joyce: PSC supports four key types of programs:

Scientific research: Our research grants support Canadian investigators who are trying to find the cause of PD, new treatment methods, and ultimately, a cure. We are working with some of the best researchers in Canada, people who are internationally prominent and respected and who are contributing an enormous amount of knowledge to the field of Parkinson's and neurodegenerative science. We are the only national organization whose sole research focus is Parkinson's disease.

Education: We work to educate, inform and raise awareness among the general public, educational institutions, health care professionals, caregivers and people with Parkinson's. This includes developing and distributing a variety of accurate, critically needed literature on all facets of Parkinson's, from information pamphlets and newsletters to this magazine. We also have undertaken initiatives such as the development and distribution of the *Information & Resource Kit for Family Physicians* and most recently a bilingual webcast on "The Non-Motor Symptoms of Parkinson's."

Advocacy: We act as an advocate for people living with Parkinson's, representing their interests to municipal, provincial and federal governments and other organizations that have an impact on our community. We empower people with Parkinson's to speak out about the issues that affect them and their families.

Support services: We help our regional partners in their delivery of support services, training, and workshops for people with Parkinson's, caregivers and health professionals across the country. We provide funding to recognized outstanding centres that are providing unique and crucial programs that serve our community.

Q How does PSC determine what research gets funded?

Joyce: The Research Program is modeled on the Canadian Institutes of Health Research's four pillars of research. The adjudication process takes place in December for applications related to our autumn competition (Clinical Research Fellowship and Clinical Movement Disorders Fellowship) and April for applications related to our spring competition (Pilot Program, New Investigator award and Basic Research Fellowship).

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Unleashing the power of creativity:

Exhibit explores art and Parkinson's

By Ian Corks

They came in all forms and from all over. Paintings, poems, sculptures, embroidery, dances and more from Canada, the U.S., China, Chile and all four corners of the world. By the time it was ready to open, the display had over 200 works of art from 189 people from 13 countries—all created by people with Parkinson's disease (PD).

This inspiring collection was part of the *Creativity in Parkinson's* display featured at the World Parkinson Congress held last February in Washington, DC.

Canada was well represented, with creative works on display from a dozen artists with Parkinson's from across the country, some of which are featured on these pages.

Reaching the researchers

An initiative of the New York-based Parkinson Disease Foundation (PDF), *Creativity in Parkinson's* was a truly international effort,

continued on next page

Stained glass

The Cardinal

“Stained glass is hard for people with Parkinson's. It involves small motor skills and precision work. Some days I have to go really slow to draw a straight line let alone cut one. The results however make all the effort worth while.”

Diane Wickstead, Bradford, ON

Photography

Poppy

“Photography has always been my passion, and it helps take my mind off my Parkinson's. [Taking pictures] provides me with an escape.”

Shay N. Redmond, London, ON

continued from previous page

and one with multiple goals.

"We wanted to promote the power of creativity on the human spirit and encourage people to share their talents and wisdom," notes Sharon Stone, PDF's Director, Research and External Programs, who played a major role in this ambitious endeavour. "But we also wanted to inspire and encourage researchers to seriously investigate the role of creativity and even do some evidence-based research."

That is what led to the display at the World Congress, where many of the world's foremost Parkinson's experts and researchers talked about the creative process.

The art chosen for display was selected by a 15-member committee comprised of members of international Parkinson's organizations and people with Parkinson's. In addition, a journal was produced featuring the art and a few brief lines from the artist on how their creativity affects their condition—and vice versa.

But that was just the beginning

Measuring the power of creativity

Do art and creative expression have the power to affect Parkinson's? The definitive answer is yet to come, but many experts believe that answer is "yes."

One such expert is renowned neurologist Dr. Oliver Sacks. "The therapeutic power of art is temporary—it can liberate the patient only while the creative act is occurring," claims Dr. Sacks. "But knowing that they can be liberated in this way ... is profoundly encouraging and therapeutic for patients with Parkinson's.

"I suspect … that the ability to turn to creative activity may, perhaps, slow the advance of the disease," he adds. "And even if it does not, it can activate the patient, allowing him to fight ... it for years on end."

His belief in the power of art prompted Dr. Sacks to accept the role of Honorary Chair of the Creativity and Parkinson's Committee at the World Parkinson Congress.

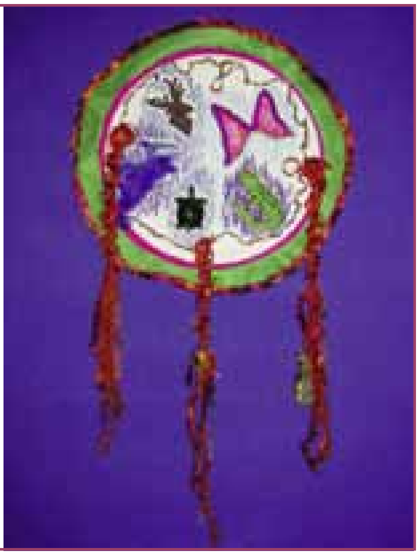
"Can we learn about the actual mechanisms of disease from this extraordinary power of art and creativity in overcoming Parkinsonism? I cannot help thinking it is a subject ripe for exploration."

Fabric with mixed media

A Healing Journey

"The past six years has led me
through exploration and contemplation.
This art piece is the first public
offering and expression of
my journey with PD.
A medicine shield seemed
an appropriate format for a
healing journey and is symbolic
of my contemplations."

Rosemary Craig, Toronto, ON



Poetry

Phone Call

You just called
distress in your voice
"How are you?" I ask, already suspecting the truth
of course you lie "I'm OK. How is your morning?"
I know you are not OK and you do not hold back for long
almost quizzical you say
"I had the weirdest night. I woke at 4 a.m. very 'on'."
meaning your body was out of control
contortions, distortions of limbs
I hear the despair, the fear
you are tired and I wonder how much more you will take
before you reveal emotions long stored deep
the anger, the hatred, the jealously
to those who visit and sympathize
and wash your dishes
and say, "My, you look great today."
when you feel like your legs have been ripped
from your hips
and reattached with a staple gun
the line goes dead
a convulsive hand disconnects us
this time I dial
knowing you are unable to navigate the numbers
but needing to conclude our conversation

I say something irrelevant almost cheerful

I close my eyes wishing my lips could whisper
blessings from the angels
you believe watch over us.

"Writing helps me cope and relieves me
of the fear that I am adding stress to my family
if I tell them my inner problems dealing with
Parkinson's disease."

Beth Holloway, St. John's, NL

for the *Creativity in Parkinson's* project. "We now have all the art submitted up on our website," Sharon explains. "Anyone can visit and scroll through the gallery. They will encounter some amazing work. They will see images or be able to listen to music, view videos, and much more. You will also get the full commentary from the artist—not just the distilled version that appeared in the journal."

Calling all artists

Parkinson Society Canada (PSC) is planning to showcase Canadian creativity on its newly redesigned website (coming soon). The new website will provide an opportunity for Canadians with Parkinson's to share their talent and their creativity.

Poetry

Life

Once upon a time life was predictable, linear.
I drew the days around me
like bedcovers on a chilly night
Reality left outdoors,
Nothing disturbed the ordered sanctity
of my curled-up world.
Between covers of well worn books
my imagination soared on wings unseen
to a Camelot reborn,
Little rocked the towering ramparts
of my castled days.
Adventures carefully navigated.
Life's stages passed.
A fairy-tale existence with no fairy tale,
Knights without shining armour.
Castles with no fiery dragons.
A heroine in waiting.
Until one day the dream awoke
to find the story being written.
Complete with battles and heroes dying,
Bedcovers flung aside, ramparts bridged,
a heroine unrehearsed
left standing centre stage.
Curtain final, applause silent,
With dream's desires in full retreat,
I crawl back to my bed-linen world,
and begin to write.

> "Imagination. Ideas. Problem solving. These are the key elements to not only working successfully in the arts but also to living life positively with Parkinson's. We might not want to reveal our inner frustrations, but we can 'act them out' in poetry, prose, painting, music, etc."
>
> Sheena Roberts, Mount Pearl, NL

Where the money goes
continued from page 12

The adjudication processes for both competitions are directed by our Scientific Advisory Board (SAB). The SAB is made up of 12 skilled scientific researchers from a variety of specialties. The peer-reviewed process incorporates the CIHR scoring system to rank eligible applications. Successful applicants are funded in order of scoring priority based on available funds.

Q How important is this funding?

Joyce: PSC makes a difference in the lives of Canadians with Parkinson's and their families. Through our National Clinical Program, we ensure that specifically tailored services are available to over 20,000 people on a regular basis. We support our regional partners' efforts in maintaining and developing more than 200 chapters and support groups across Canada.

We invest more than $1 million in research every year and have provided funds to some of the most prominent Canadian researchers working in this field. Our National Information and Referral Service fields thousands of requests for information and provides referrals to our regional partners and local resources.

Without this funding, these services would not be available. Each year we fund research projects that would otherwise not receive the funding they need to exist, yet alone yield results. In addition, the data gathered through these projects enable researchers to apply for more substantial grants from larger organizations such as the federal government (through the Canadian Institutes of Health Research). This, in turn, leads to greater knowledge about PD and advances in treatment—something the researchers simply would not be able to achieve unless we provided them with the funds to gather the preliminary information that indicated they are on the right track.

Q How important are financial gifts from donors?

Joyce: Because we are not supported by government, financial gifts from donors are critical. We rely completely on the generosity of corporations and individuals for all our funding.

Correction
Parkinson Post, summer 2006

On page 14 in "Medication matters: A quick guide to drug therapy," it was stated that "foods with high protein content can interfere with the release of levodopa in the brain." The sentence should have read "Foods with high protein content can interfere with the absorption of levodopa in the gastrointestine."

Self-management: Taking an active role in controlling your Parkinson's

By Melissa Tafler, MSW, RSW

Social worker Melissa Tafler (right) talks with Lottie Greenspan, a participant in Baycrest's Parkinson's Self-Management program.

Each Monday and Wednesday a group of people with Parkinson's disease (PD) and their partners walk into the Day Treatment Centre at Toronto's Baycrest Centre with a little lift in their step. They are looking forward to spending a morning with others who really understand what they are going through.

These individuals are a part of the Parkinson's Self Management Program, a 12-week, multi-disciplinary approach to helping individuals and their families manage the challenges of living with Parkinson's. The program has been running at Baycrest for the past five years and has helped over 200 people.

Baycrest physiotherapist Tanya Aggett (left) provides therapy to program participant Anna Wilson.

"Personally, I got myself into a rut where I didn't want to go anywhere or do anything," recalls program graduate Shirley Cohan. "This got me out of my shell. My doctor couldn't get over how I had put myself together. He really noticed a change."

A professionally led group

The program consists of three modules: a regular exercise program targeting flexibility, muscle strength and endurance; a group discussion and education session; and individual therapy that includes physiotherapy, occupational therapy, nutrition, social work, speech therapy, medicine, nursing and recreation. There is also a professionally led support group for care partners.

When participants first enter the program, the most common challenges they identify are walking, tremor and speech, but participants have also asked for guidance with time management, home safety, staying socially connected, planning for the future, and even getting back to forgotten hobbies.

Participant-determined goals

With a diverse team of therapists, the program offers help with a wide range of issues typically not addressed in the neurologist's office. Over the 12 weeks, participants are taught strategies for managing and minimizing the effects of PD. The therapy sessions focus on so-called participant-determined goals, which allow each person to work on achieving things that are meaningful and important to each of them in his or her own life.

Baycrest's program was designed around the philosophy and principles of self-management, a concept that teaches people to see themselves as active partners with their health care professionals. The concept works well with people who have a chronic condition because it helps them focus on getting the tools they need to get the most out of their lives. It encourages people with PD to take an active role in their treatment and to learn how to problem-solve so that they can meet challenges head on.

Many people often believe that medication is the only thing one can do to treat Parkinson's. However, Parkinson's is a multi-systemic condition and needs a multi-faceted treatment approach. Learning individual strategies is an empowering process because it restores a sense of control. Research shows that when people feel a sense of control over life's challenges, they cope much better.

A celebration of success

The Parkinson's Self-Management Program emphasizes breaking problems down into smaller parts so that people with Parkinson's feel less overwhelmed, setting personal goals that are attainable, and celebrating the successes no matter how small they are.

Social support is a crucial and integral piece of the program's success. For many clients, it is the first time they have had an opportunity to speak about their Parkinson's in such an honest way.

The program creates a safe and supportive environment so that group members can use the time to talk about their issues and challenges—and "say it like it is." Peer support is crucial in this setting. When people see firsthand that others share the same experiences they often feel a huge sense of relief knowing they are not alone.

Group discussions allow attendees to share their views on any topic relevant to living well with Parkinson's.

"I learned not to be ashamed of the sickness and to speak my mind," says Shirley Cohan. "At one time I never wanted to listen to others' problems because I felt I had enough of my own. Now, I see others are in this situation and I'm not alone, and if I can help them by speaking my mind, I will."

The group discussions, facilitated by a therapist, are often quite lively as participants trade and share strategies on overcoming some of the obstacles in their daily lives. For partners, the caregiver support

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The science behind self-management

By Rebecca Gruber, BPT, MSc

Despite tremendous advances in recent years, medical management alone cannot address all the needs of people with Parkinson's disease (PD). For many, help can be found in self-management programs (SMPs).

Self-management has been defined by U.S. experts and professors Kate Long and Virginia Gonzalez as "learning and practising the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic illness. SMPs for chronic illnesses have proven effective in encouraging people to make informed choices, to adopt new perspectives and skills that can be applied to new problems, to practise new health behaviours, and to maintain or regain emotional stability."

These programs do not replace medical care; rather, they aim to empower people living with PD and other chronic illnesses to become active members of their overall care team.

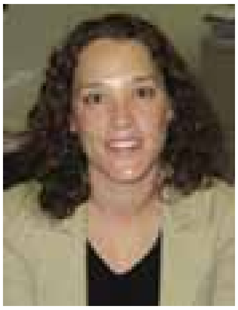
Self-management skills are learned and practised in a group setting, with facilitation by trained health professionals or volunteers with the condition. Participants in SMPs learn that living well with a chronic illness such as PD involves adapting behaviours to meet new challenges.

Goal setting and active problem-solving are essential components of this process. Knowledge alone is not sufficient for behaviour change or improved health; active problem-solving increases a person's confidence that he or she can manage issues and challenges as they arise, and can contribute to improved health.

Results of evaluations of the Early Management Programs show that not only do participants show improvement in their self-confidence to manage PD and report more engagement in healthy activities (such as relaxation and exercise) but also their physical abilities improve compared with status prior to participation. These findings tell us that the programs are of benefit to participants. They also provide us with important information about how people newly diagnosed with PD differ from people their age without PD, and how exercise and other healthy behaviours help to limit these differences. Evaluation of programs for people with later-stage PD, now in progress, will enhance our knowledge of benefits to these participants.

To paraphrase Dr. George Turnbull of the Maritime Parkinson Clinic, the person with PD needs to be in the best physical and emotional shape possible, so that when new and better treatments (and an eventual cure) for PD are available, he or she will be able to make the most of them. Self-management programs can help the person with PD to achieve this aim.

Rebecca Gruber, BPT, MSc, is a Co-Director of Physiotherapy and Self-Management Services at the Centre for Movement Disorders in Markham, ON. She can be contacted at 905-472-7082, ext. 26, or via e-mail at rgruber@movementdisorders.org.



Focus on...

Dr. Elissa Strome,

PSC Fellowship, Lund University, Lund, Sweden

By Ian Corks

"Unravelling the mystery that is Parkinson's is an international endeavour," notes Canadian researcher Dr. Elissa Strome. "Excellent research is being conducted at centres around the world."

One such centre is Lund University in southern Sweden, where Dr. Strome will be spending the next two years looking at better ways to treat and prevent dyskinesia, one of the main complications of levodopa treatment. "There is a significant PD research program in Lund," she says. "They have been pioneers over the years, both in increasing our understanding of the basic cellular mechanisms of PD, and in developing therapeutic interventions."

With the help of a fellowship from Parkinson Society Canada (PSC), Dr. Strome will be joining a team led by Dr. Angela Cenci, an expert in dyskinesia. The team will be trying to understand exactly what happens when levodopa crosses the blood-brain barrier (BBB) and is transported into the brain (see sidebar). On a more complex level, the group will be using animal models of levodopa-induced dyskinesia to study the functional status of the BBB, as well as the anatomy and physical properties of new blood vessels in the brain that appear to develop after long-term levodopa treatment.

"Levodopa is still the most effective treatment for PD," she explains. "However, after five or six years it begins to lose effectiveness and is associated with the development of dyskinesia. If we can understand why, it could be the first step to stopping or reversing the development of dyskinesia."

The chance to join the team at Lund University represents a terrific opportunity for Dr. Strome and will ultimately benefit Canadian Parkinson's research.

"It is definitely an investment on behalf of PSC," Dr. Strome states. "I intend to come home after the two-year fellowship and join a Canadian research team. The international collaborations and the experience I gain in Sweden will positively affect the rest of my research career."

The blood-brain barrier: How does it work?

The blood-brain barrier (BBB) is a microscopic membrane of highly specialized cells that protects the brain from the many potentially harmful substances in the blood stream, while allowing essential nutrients through. Medications that need to reach the brain to be effective must be able to penetrate the BBB in therapeutic levels. In addition, the breakdown or dysfunction of the BBB is suspected as being a factor in many central nervous system disorders. As such, an understanding of how and why the BBB functions is important to researchers working on Parkinson's and similar conditions.

Source: National Institute of Health

Self-management
continued from page 17

group allows them to focus on their needs and on how Parkinson's in their spouse or relative has had an impact on their own lives.

People with Parkinson's are usually educated and well informed about the condition. What is missing for many is the emotional outlet, the chance to talk about the frustrations, the depression, and all the other challenges that, from the outside looking in, are not visible to family and friends. When participants graduate from the program, they feel more confident and hopeful about the journey ahead of them.

The real difficulty for program "graduates" is saying goodbye to other group members who were total strangers such a short time ago.

Editor's note: The Parkinson's Self-Management Program runs at Baycrest Centre, 3560 Bathurst Street, in Toronto, ON. For more information, call 416-785-2500 ext. 2683.

Melissa Tafler, MSW, RSW, is a Social Worker at Baycrest Centre in Toronto, ON.

Take time to get it right:

PSC urges Ontario government to slow down

By Shannon MacDonald

By all accounts, spending on prescription drugs in Canada is growing at an unsustainable rate. According to the Canadian Institute for Health Information, in 2005 $20.6 billion was spent on pharmaceutical drugs to fill almost 500 million prescriptions—that's over 15 prescriptions per Canadian in that year alone.

Most people agree that Ontario's proposed *Transparent Drug System for Patients Act* (Bill 102) is an important step in tackling the issues around escalating drug costs. With our aging population and the rising cost of treatment, health care delivery demands new thinking.

In the government's words, this plan would deliver the following:

- improved access to drug treatments at reasonable costs,
- no changes for Ontario Drug Plan or Trillium Drug recipients,
- faster funding decisions for new drugs and clear communication about these decisions, and
- an opportunity for consumers to be involved through a committee.

Additionally, the government suggests this Bill, which passed final reading in June, will mean substantial savings for employers through increased generic drug substitution.

It sounds good, but it's the absence of detail, along with an incredibly short timeline, that has members of the health care community sounding alarm bells. "This is a good start," says Joyce Gordon, CEO of Parkinson Society Canada (PSC), "but we just don't know the full impact of this Bill. Without careful consultation and consideration of these impacts, we risk creating a situation where people are not receiving optimal care."

These concerns are shared by numerous individuals and organizations who have called on the government to slow down and work through the many unanswered questions before implementing this legislation.

From PSC's perspective, the primary issues for Ontarians with Parkinson's focus on three main areas:

1. Drug interchangeability. The legislation proposes that drugs will be interchangeable with similar drugs—those that *"contain different active ingredients that are considered to be therapeutically equivalent, without authorization from a person authorized to prescribe drugs."*

What this means is that a pharmacist could substitute a generic drug that was similar to the brand drug prescribed by one's doctor. For people with Parkinson's, this could be highly problematic. Parkinson's is a complex and highly individualized chronic condition. If a person is doing well on a particular drug intervention prescribed by their physician, the notion that their well-being may be compromised by replacing their medication with a "similar" drug is unacceptable.

2. Drug savings not the whole picture. Drug treatment is a key part of keeping people with Parkinson's well. The healthier they are, the less need they have for other health care services and supports, including hospitalization and long-term care facilities. If changes are made regarding the availability or substitution of drugs in the name of savings, the government must consider the potential impact to other parts of the health care system.

3. Transparency and accountability. The proposed legislation calls for the appointment of an executive director with broad-sweeping authority. Although this person would work with the input of a citizens' council and a pharmacy council, there is fair concern about the degree of power within one role. The government suggests that this legislation promises a new era of transparency and accountability; however, this executive director role, as described in the Bill, seems to conflict with this notion.

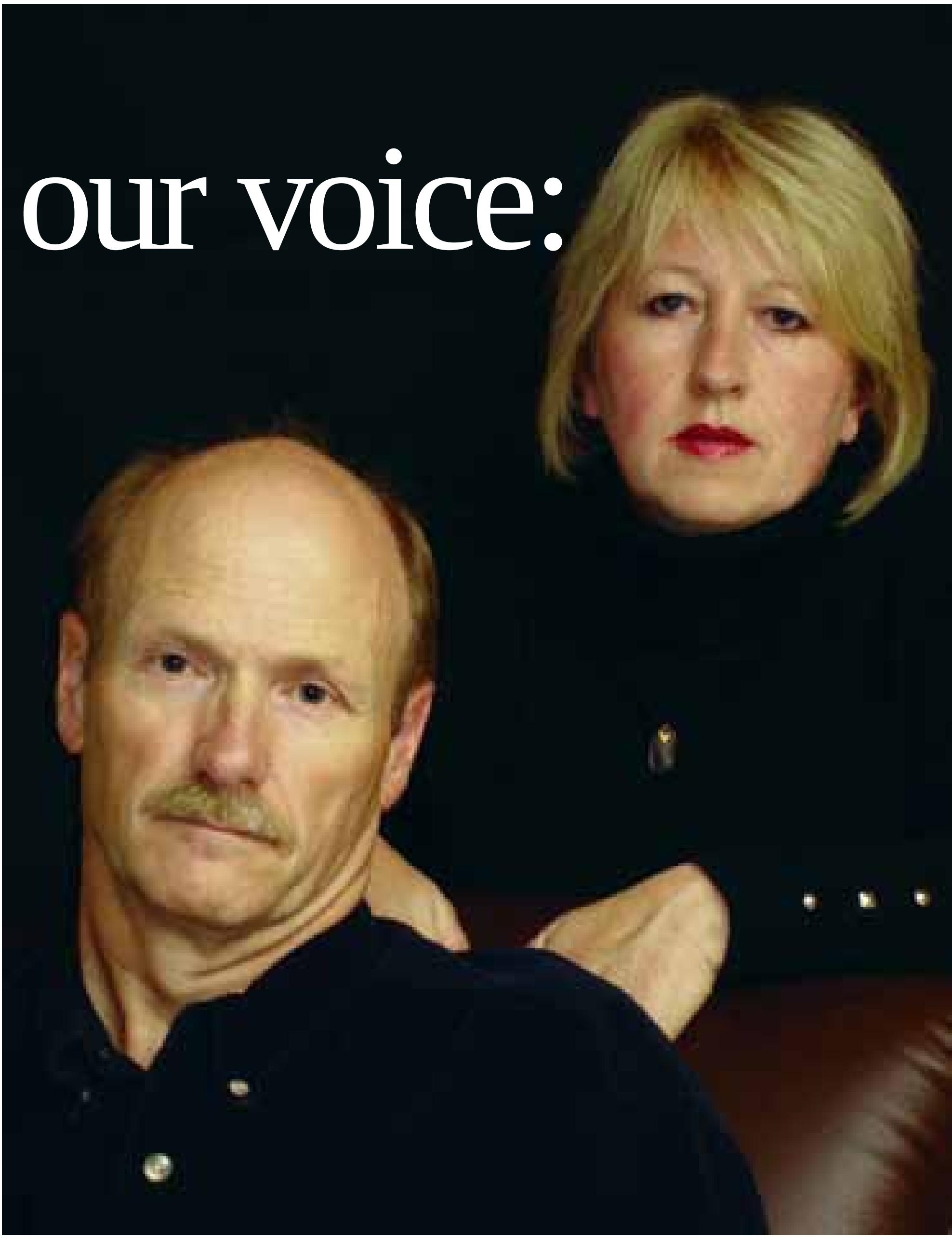
Overall, PSC applauds the Ontario government for addressing this critical issue. Every Canadian province and territory faces the same question of how to afford the rising costs of pharmaceutical drugs in the future. Knowing that the Ontario experience may stand to benefit all Canadians, PSC joins other stakeholders in encouraging decision-makers to take the time for appropriate consultation.

Editor's note: To review the Transparent Drug System for Patients Act, *visit www.health.gov.on.ca.*

Finding our voice:

Adjusting to young-onset Parkinson's

By Bev and Barry Roberts, Paradise, NL



Photos: Terry Anthony

For Barry and Bev Roberts, Parkinson's has changed every aspect of their lives.

We were 39 and in the prime of our lives. Barry was building a career that he loved, and our two boys were growing up quickly. If you believe the saying that "life really begins at 40," then we were almost there. But something was wrong with Barry. We didn't know exactly what it was, but something was definitely wrong. He was so tired.

The doctor thought it was simply too much stress from work and suggested that Barry take a drink at the end of the day to relax—but that didn't help. Then came the tremor in his hand, and we knew it was more serious. The specialist first considered a brain tumor but ruled that out with an MRI (brain scan). He eventually diagnosed Barry with young-onset Parkinson's. We had no idea what that meant but it didn't matter. We were just relieved that it wasn't a brain tumor.

Early retirement

Barry continued to work after his diagnosis, but things gradually became too overwhelming for him to continue. At age 45 he retired from a job that he loved. In some ways his early retirement came as a relief, yet it was also very hard for him to give up his career when he was doing so well. At the same time, I knew I needed to get a job. We were uncertain about how the disability insurance would work out, and I was scared. I learned quickly that life does not stop for Parkinson's; our youngest son was heading to college and we had financial responsibilities.

That was six years ago. Since then, we've been on a journey filled with emotions: everything from fear and frustration to gratitude. As the spouse and caregiver, I live Parkinson's with Barry, although we experience the disease in very different ways. There's no question, Parkinson's has changed every aspect of our lives, yet for a long time I lived in denial. I didn't want to see what was happening, so I shut down. It's only been the past couple of years that I've come to a place of acceptance, which has allowed me to open up and deal with things more effectively.

A tough reality

Our initial understanding of Parkinson’s led us to believe that with medication, Barry and I would go on with our lives as planned. We didn’t know much about the disease so we weren’t worried. Besides, the general sentiment was that Parkinson’s wasn’t so bad. The reality of our experience has been quite different.

Parkinson’s is tough. Barry is one of the youngest people diagnosed in Newfoundland. I believe that the full impact of the disease has a lot to do with the stage of life you’re at. At 51, Barry’s Parkinson’s has progressed quickly, resulting in his loss of independence and a constant physical battle between the extremes of severe dystonia (muscle spasm) and dyskinesia (involuntary movement). Neither of us had any idea that the disease could be so debilitating or that it would take away so much so soon. Again, that’s part of the acceptance.

A determined spirit

At this point, Parkinson’s controls everything in our lives, but feeling sorry for ourselves just isn’t an option. Sure, some days are more frustrating than others, but we have to get through them. Like everyone else, we have aging parents who need our support and care, and we have children and grandchildren we love to spend time with, yet we also have Parkinson’s. Of course, it sounds much simpler than it really is; I have days when fear takes over and I don’t know how I’ll get through. I then feel guilty because Barry has so much more to deal with than I do. Sometimes I get angry—never with Barry but with the disease—and then I tell myself that people depend on me, so I have to keep going!

Every so often, I allow myself a sad moment, usually at the end of the day when I am alone. During these times, I wish that Barry could be with me to sit and talk. But that’s impossible: the exhausting physical demands of Parkinson’s force Barry to bed very early in the evening. Sometimes, I think that our busy life is a blessing, because it doesn’t afford much time for this kind of contemplation.

Many positive emotions

Barry and I do experience many positive emotions as well. Joy comes in the form of our eight-year-old grandson who brings laughter and energy into our lives. He’s a bright spark for Barry and a wonderfully willing companion for me. He’s always up for a nature walk or any kind of outing.

Support comes from close family and neighbours who have come to understand the challenges we face on a daily basis. They recognize, from time-to-time, that both partners need a change, and they help out. Through the local Parkinson’s Society, I have also met a woman who has become a kindred spirit. Having a husband who battles Parkinson’s, she knows exactly what I’m experiencing. We have become each other’s lifelines and a place of support where we can laugh, cry or just talk something through.

I also have hope. Of course, what we all want more than anything is a cure, but while we wait, I hope that we find a way to make daily living easier for people with Parkinson’s. Finding a treatment that would manage the disease so people could live without the huge swings in mobility and mood, and the range of side effects that are sometimes worse that the symptoms themselves, would make such a difference.

A wide community

We have met so many nice people who try to cope quietly without making too much fuss. We try to stay optimistic and not bring other people down with our challenges. While Parkinson’s is generally not considered fatal, young-onset Parkinson’s can kill the spirit. If we hope to develop better treatments and eventually find a cure, private people like us need to find our voice and help the wider community understand the reality of Parkinson’s. Together, we can fight Parkinson’s.

Barry and Bev relax after another successful SuperWalk event.

Available now: The 2007 Parkinson Society Calendar

The 2007 Parkinson Society Calendar is now available for purchase. The calendar features paintings of Canada's key legislative buildings, graciously donated by Kingston, Ontario, artist Shirley Hulley. It is the culmination of years of inspiration and effort by Felicity McKendry of the Kingston Chapter of Parkinson Society Canada.

In addition to the beautiful images, the calendar is full of useful information and interesting facts related to Parkinson's disease.

Funds raised from the sale of the calendar will go to ease the burden and find a cure for Parkinson's.

The 2007 Parkinson Society calendars cost $5 each. For ordering information, call PSC Central and Northern Ontario Region at 1-800-565-3000 or 416-227-1200 (in Toronto).

A limited number of calendars has been printed, so order now to avoid disappointment.

The cover of the 2007 Parkinson Society Calendar features the Peace Tower in Ottawa and the City Hall in Kingston, Ontario, Canada's first designated capital. Both are fronted by colourful displays of the Parkinson tulip, the official international symbol of Parkinson's disease.

Photo: Rob Mooy, *Kingston This Week*

Artist Shirley Hulley donated 15 original paintings—representing over two years of work—to the 2007 Parkinson Society Calendar.

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca

Our website has a new look and is being updated regularly! Please watch for more changes in the months ahead.

- **Click on the What's New section** and learn about non-motor symptoms by watching Dr. Mandar Jog's Webcast.
- Read your region's latest newsletter by **clicking on the map of Canada**.
- **Visit the What's New section** to read through *Parkinson's Report*, featuring Parkinson's stories from across Canada.
- Watch for our new bilingual website coming soon. It will be easier to read and a breeze to navigate.

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

Ask the Expert

Q Now that winter is here, how can I maintain my mobility and independence?

A Keeping active is not only a good idea but also essential for those of us coping with Parkinson's, especially if we wish to maintain our mobility and independence. Let's explore a few ways to do this during winter.

Some folks find that joining an exercise facility, such as a gym or fitness facility, or signing up for classes in yoga, Tai Chi or general fitness works for them. If an organized program is not for you, why not set up a program at home? If you live in an apartment building or other residential facility with long hallways, you can easily set up your own walking program. Pace yourself by using either minutes of walking or number of lengths of the hallway and gradually increase the distance or time. Keep track with a chart.

You can also set up a similar program with a treadmill or stationary bike. Put a big map on the wall and use pins to mark the number of kilometres you walk or bike each day. When you walk, insert short periods (perhaps 10 or 20 steps) during which you concentrate fully on taking long steps. Then relax and keep walking. After a short time, concentrate on the long steps again. Try wearing a pedometer on your belt to track how much you walk in a day.

If you use a wheelchair, you can set up a similar program. Move aside the footrests and use your feet to "walk" up and down the halls. Pull yourself forward to the end of the hall and then push backwards the other way. Then put the footrests down and use your arms to push the chair. Keep a chart of your distances.

One of my favourite leg strengthening exercises is to simply stand up from sitting—but the exercise must done very specifically. Sit in a firm chair such as a kitchen chair. Lean forward and slowly stand while counting to four. Don't stop! Now slowly sit while counting to four. Without stopping, repeat this at least five times in a row. Work up to 10 times in a row. Try not to hang on to anything as you do this and do not use momentum to help you up. Stay controlled.

For strengthening, try keeping a six-foot piece of Theraband (available at most medical supply places) beside a favourite chair. Whenever you sit down, take a few minutes to perform some resistance exercises for arms and legs. If you are a TV addict, do the exercises every time a commercial comes on. You can adjust the difficulty by lengthening or shortening the hold on the Theraband. Ask a local physiotherapist or fitness expert to help you design the exercise program.

You can also try a therapeutic ball (available at most department stores) to improve your balance. Be sure that it suits your height. When seated on the ball, your hips and knees should rest at approximately 90 degrees. Start safely by placing the ball in a corner and sit on it facing out. This way, you will have the walls on either side of you to hang on to if you lose your balance. Begin by sitting on the ball and bouncing a little bit. As you feel more safe, move the ball out from the walls. Try lifting one foot off the floor. Progress to moving your arms around while lifting one foot. For more options, ask a local expert.

Going up and down stairs is another wonderful exercise. I have a friend (age 80) who lives on the fifth floor of his building. He intentionally takes the garbage, one bag at a time, down to the basement and walks back up the stairs. When he returns from any outside activity, he takes the stairs. This is his way to exercise daily.

There are many ways to keep active, so it's easy to find activities that you enjoy. The most important requirement of any program is consistency. You will need to *do something every day*. Pace yourself so that the activity becomes enjoyable.

If you have questions about how much activity you should do, always check with your physician first. Then start small and increase slowly.

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Thank you to all who participated as a volunteer or walker during SuperWalk for Parkinson's 2006 – we succeed because of you!

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