

# The Best of Parkinson Post

A quarterly magazine for Canadians living with Parkinson's

## Pitch in for Parkinson's

Cherie and Gregg Zaun  
raise funds and awareness

### "Best of" issue

- Living and working with Parkinson's
- 10 ways to take control
- A quick guide to drug therapy

**PLUS**  
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Ease the Burden; Find a Cure

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#### ON OUR COVER:

**Gregg Zaun, catcher for the Toronto Blue Jays, supports the Pitch In for Parkinson's campaign in honour of his mother Cherie Zaun, who was diagnosed with Parkinson's in 2003.**

## The pleasures and perils of publishing

I would like to say a big "thank you" to all of you who took the time to respond to our recent *Parkinson Post* Editorial Survey. Your comments were very helpful.

We have already taken some of your feedback into account in this special issue, which presents some of the "best" articles featured in *Parkinson Post* over the past few years, as chosen by readers.

In addition to being helpful, your comments were very encouraging. You told us that, overall, we were doing a good job in providing interesting and informative editorial content. You indicated that you appreciated both the practical educational articles and the inspirational real-life personal experiences and stories that we regularly feature.

These results confirmed our belief that *Parkinson Post* is a valuable tool and that you enjoy reading it as much as we enjoy publishing it. Unfortunately, however, publishing and distributing a quality magazine in today's world is a very expensive proposition. Without the benefit of revenue from regular advertising support that commercial profit-oriented magazines are able to call upon, publishing *Parkinson Post* remains an ongoing financial challenge—one that we must face with limited resources.

To help us meet this challenge and still deliver a top quality magazine, we will be adjusting our publication schedule. Starting immediately, *Parkinson Post* will be published three times a year, with Spring, Summer, and Fall/Winter issues. Current subscribers will receive the appropriate number of issues remaining in their subscription, while new subscriptions will reflect this revised publishing schedule.

This revised schedule will allow us to continue to provide the type of articles and information you have told us you want and will help us to improve the overall quality of this important magazine. You will receive *Parkinson Post* regularly and on time. Its content will continue to reflect your needs and wants and, perhaps more importantly, to share your inspiring stories.

A handwritten signature in cursive script, appearing to read 'Joyce Gordon'.

Joyce Gordon,  
President and CEO,  
Parkinson Society Canada

#### P.S. A word to our corporate friends

To members of Canada's corporate community, I suggest that *Parkinson Post* represents an excellent opportunity to show your support and help improve the quality of lives of Canadians with Parkinson's disease and their caregivers. Why not consider sponsorship or advertising in this well-regarded magazine? We would love to hear from you. Please call us at 1-800-565-3000.



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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.*



*Issues of interest to people with Parkinson's*

## Help spread the Parkinson's message

By Yvon Trepanier, Chair, National Advocacy Committee

**A**s we continue to build relationships and momentum with government representatives and staff, it has become increasingly evident that we need more voices at the local level to make the most effective impact on government decision-makers. Elected representatives are directly accountable to the people who live in their riding and, therefore, will listen carefully to what constituents have to say.

### **A national network**

With this in mind, Parkinson Society Canada is working with our Regional Partners to build a national network of advocates, volunteers willing to communicate with their elected representatives about issues related to Parkinson's disease. This network will link individuals in every federal riding across Canada and will serve as an effective grass-roots, constituent-based conduit of information to each of the 308 Members of Parliament and their staff.

The reality is that many organizations are working to be heard and to position their issues as the most pressing and deserving of support. To stand out from the pack, the Parkinson's community must find ways to unify the message and communicate

effectively to draw attention.

Imagine what might be possible if every Member of Parliament (MP) understood the complexity of issues facing Canadians with Parkinson's and their families. What kind of decisions would they make knowing the full economic and social impact of Parkinson's to Canada as a nation? What kind of investments would they make into research for a cure and improved treatment? Imagine the policy decisions that might be made if they knew what we know. Imagine what this could mean for the Parkinson's community in Canada and around the world.

### **Local support**

All of this is possible, but first we must educate our decision-makers about our experiences and our challenges. We must present a compelling case and tell them exactly how they can help. To do this, we need local support through a fully functioning national network of advocates.

Our primary objective is to identify in each federal riding at least one person willing to be the local Parkinson's advocate. For this role, Parkinson Society Canada is seeking individuals willing to establish a rapport and communicate with their MP on

an ongoing basis by phone, written communication or in-person meetings. We expect that volunteer advocates would communicate with their MP up to six times per year as part of the nationally co-ordinated advocacy program. In each instance, volunteers would be provided the material and messages required to communicate effectively and answer any questions that may arise. Additional support will be available as required.

If you're interested in being a volunteer advocate, please e-mail [advocacy@parkinson.ca](mailto:advocacy@parkinson.ca) with your contact information, your province and riding, and we will be in touch.

### **Everyone involved**

The Canadian Parkinson's community is rich with talented and passionate people wanting to make a difference. And we need everyone involved: from people with Parkinson's and caregivers to friends and family members; from medical professionals and researchers to therapists and support workers. By working together, we can elevate the profile of Parkinson's disease exponentially and begin to effect truly meaningful change for all—but we must act now!



# Pitching in for Parkinson's:

*Cherie and Gregg Zaun throw their support  
behind the fight for a cure*

By Ian Corks

**C**herie Zaun looked right at home on the pitcher's mound at Toronto's Rogers Centre, and the throw to her son, Blue Jay catcher Gregg Zaun, was straight and strong.

At first glance, not many in the crowd would have associated the fit, attractive woman who threw out the ceremonial first pitch at PSC's 17th annual Pitch In For Parkinson's event with PD, but Cherie was diagnosed with young-onset Parkinson's over three years ago.

"It feels like just yesterday when the doctor told me I had PD," Cherie recalls. "My first worry was what it would mean to my family. Then, of course, I was concerned about how it would affect my second great passion: golf."

## Facing the diagnosis

Golf was actually more than just a "passion" for Cherie. In her 20s, she became the women's golf coach at the University of Southern California and played on the Ladies Professional Golfer's Association (LPGA) as a minor league pro. She put the game on hold for nearly two decades while she and her husband raised their three children. Then in the late '90s, Cherie joined the Futures Golf Tour, competing in more than 36 tournaments over three years.

*Diagnosed with PD in 2003, golfer Cherie Zaun is active in raising awareness and funds with the help of her son, Toronto Blue Jay's catcher Gregg Zaun.*

"Gradually, I began to feel something was wrong," Cherie remembers. "My right arm often seemed frozen at my side, my right foot dragged and I tired easily. It felt like I had only half a body. My golf game suffered, and I struggled just to sign my name. I hoped I had a pinched nerve, but I thought it could be something worse.

"It was my son Gregg, then playing for the Houston Astros, who set me up for a battery of tests with the team doctors. In 2003, I was diagnosed with PD."

Cherie and her family were taken aback. But it wasn't long before her natural competitiveness took over. "At first, I felt helpless," she says. "Then I read everything I could to learn how to live my life in spite of the disease. Armed with information, I set out to fight the battle against Parkinson's."

### Putting her life back on course

Today, Cherie is as active as she ever was—both as an athlete and an advocate for people with Parkinson's. "I am able to teach and play competitive golf again," she states. "I talk about my PD with doctors and other people with Parkinson's. Everyday, I learn more about this disease and its impact on the body and spirit. My disease is still in its early stages, so I don't have any tremors. I'm taking medications. I'm exercising; I find yoga and golf especially helpful. And I welcome the support of my family and friends.

*Gregg Zaun, Honourary Co-Chair of this year's Pitch In For Parkinson's, welcomes the 2005 Morton Shulman Award winner, Dr. Gordon Hardacre.*

"Attitude is everything," Cherie adds. "You can sit in a recliner and let it take you, or get on with it. Living with Parkinson's is not all that different from playing a great round of golf. It takes practice and determination."

Cherie's spirit and, of course, her relationship to one of the Blue Jays' most popular players, made

her a natural choice to throw out the first pitch at this year's Pitch In For Parkinson's on June 28. Gregg has been involved in raising funds for Parkinson's research since his mother was diagnosed, even starting a foundation in Houston

when he played for the Astros, prior to becoming a Blue Jay. He is a big part of Pitch In For Parkinson's, arranging for his mother to be there and signing autographs for many of the fans who supported the event.

### A great night at the ball park

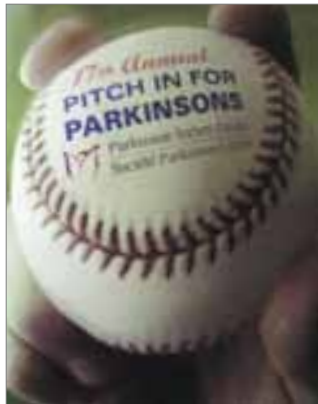
This marks the 17th year in which PSC and the Toronto Blue Jays

have teamed up to raise both funds and awareness of PD. This year's Honourary Chairs were Gregg Zaun and Ryan Paton of the Score Television Network. Also on board as sponsors and supporters were the Rogers Centre, Munich RE Group, KPMG, Mizuno and Levy Restaurants.

The event was a success both for the Blue Jays, who chalked up a 6-1 win over the Washington Nationals, and for PSC.

"It was a lot of fun with good media coverage. We raised over \$21,000 to help address the four pillars of our mission statement," says PSC President and CEO, Joyce Gordon. "I am really proud of the success of Pitch In For Parkinson's and of CNOR (Central Northern Ontario Region) staff and volunteers who organized such a first-class event."

Meanwhile, Cherie Zaun keeps on going. Two weeks after the Toronto event, she attended a Young-Onset Parkinson's Network conference in Washington, DC. Now she's off to a Duramed Futures Tour event in Connecticut, where, she laughs, "I plan to teach some of those young pups how to play golf!"





# Taking control: 10 steps to help you cope

By Carol Jamieson

**Y**ou've just received a diagnosis of Parkinson's disease. You leave your doctor's office upset and confused, and you wonder what comes next.

The first step should be to start thinking about a basic plan to get help, support and information to make informed decisions about your future. Here are 10 steps to consider.

## 1. Get information from reputable sources.

All of the information out there can be overwhelming. What can you believe?

To learn what resources are available in your community, start with Parkinson Society Canada. Contact one of our Regional Partners (see page 22) or call our national toll-free Information and Referral Service at 1-800-565-3000.

## 2. Start talking about it.

When you're ready, discuss your diagnosis and share information with your family and, as time passes, with good friends. Recognize that you may feel a variety of emotions: anger, denial, frustration, fear and sadness.



Proceed at your own pace (don't feel pressured), but make sure you stay connected with those close to you. Support each other, and don't be hesitant to ask for help.

## 3. Create a resource file.

Use a binder, folder or file box. Keep it in a convenient location (e.g., near the phone) and fill it with pertinent information such as dates, locations and phone numbers for

medical appointments; and questions for your doctors. Include articles about Parkinson's disease, research findings and other reference materials you come across and want to discuss with your health care team. Include a list of your medications (prescription and over-the-counter) by

using PSC's "I have Parkinson's Medication Card" in case your health care providers, including your pharmacist, requests a copy.

## 4. Get the most from your doctor.

Make full use of your time at medical appointments. Don't feel rushed, and don't leave until all of your questions have been answered. (This is where your resource file comes in handy.) If you don't understand certain terms, ask for an explanation in "plain English."

Never be afraid to question the treatment you're receiving, if new medications that you've heard about could help you, whether you should consider alternative therapies, or pursue a "second opinion." Find how to access your doctors' nurses or assistants between visits to answer your questions or ease your fears.





## 5. Look for help and support.

Find out what's available in your community for people with Parkinson's and their caregivers.

Consider joining a support group. These groups can offer useful information about local services and "Parkinson's-friendly" health professionals. You'll get practical advice on how to cope and education about the illness and treatment. More importantly, a support group offers a safe place to talk with others who understand. Some groups provide specific help for a particular aspect of Parkinson's (e.g., newly-diagnosed individuals, young onset Parkinson's, caregivers, older adults or those with communication or other problems). If a support group to meet your specific needs doesn't exist, think about starting one.

## 6. Plan for the future.

Now you can develop plans for the future. Avoid putting off important decisions, especially legal and estate planning. Talk to your family about your concerns.

Visit the Parkinson Society Canada website at [www.parkinson.ca](http://www.parkinson.ca) and click on "Parkinson Post." You'll find a comprehensive guide called "Preparing for the years ahead: A guide to long-term planning" (Spring 2003). If you're working, you'll find practical advice in the article "Living and working with Parkinson's: Determining the best strategy for you," summarized in this issue on page 10.

## 7. Maintain an active social life.

Don't isolate yourself from family and friends. Keep in touch by phone, visits or e-mail. You may

feel depressed and anxious at times, so ask your doctor about available treatment to alleviate the symptoms.

Continue doing the things you enjoy, and look for new hobbies or an interesting class at your local high school, community college or church.

Think about volunteering: SuperWalk for Parkinson's, for instance, is a fun way to raise funds and connect with caring people in your community.

## 8. Learn how to pace yourself.

Tiredness is a problem for many people with Parkinson's. It can be caused by the condition itself, sleep disturbances or medication side effects.

Plan activities carefully, and give yourself time to complete them. Alternate light and heavy tasks—both physical and mental. Learn your limits and balance effort with rest periods. Try boosting energy levels with an exercise program. Learn to be satisfied with what you have accomplished. Don't compare it with what you could do before.

If fatigue becomes a serious concern, talk to your doctor.

## 9. Eat well.

Eating a well-balanced, healthy diet can benefit anyone, but for people with Parkinson's it takes on added emphasis. Your diet should include a variety of foods from all four food groups: grain products, vegetables and fruit, milk products, and meats and alternatives. *Canada's Food Guide to Healthy Eating* is an excellent source of information.

(Editor's note: Visit [www.hc-sc.gc.ca/fn-an/food-guide-aliment/index\\_e.html](http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index_e.html) and click on the

*Canada's Food Guide* icon.)

Recognize that Parkinson's may present some eating-related challenges as it progresses, and some dietary modification may be needed. Talk to your doctor, or consider asking for a referral to a registered dietitian.



## 10. Stay active and exercise regularly.

A good exercise plan can help your body cope better with Parkinson's disease. Regular exercise can help maintain flexibility and good posture, keep muscles strong and joints supple, and improve circulation to the heart and lungs. It can also help you to deal with day-to-day stress and give you a sense of achievement and control over your condition.

Exercise could be as easy as finding a simple activity that you enjoy, such as walking, gardening, housekeeping or swimming, and making it part of your daily routine. You might find exercise classes beneficial, which provide fitness and social benefits. Your regional Parkinson Society may be able to direct you to a local exercise group.

*Editor's note: Adapted from Taking control, Parkinson Post, Volume 4, Issue 3, Fall 2004.*

# Living and working with Parkinson's:

## Determining the best strategy for you



By Ian Corks

**T**he diagnosis of Parkinson's disease (PD) is likely to trigger a flood of questions: Why me? What will happen? How will I tell my family? And, of course, What about my job?

Work is a vital part of most of our lives. It offers a sense of accomplishment and identity, not to mention the obvious financial and family support implications. It is normal to ask, "How will PD affect my ability to work and pay the bills?"

The truth is that Parkinson's can affect your job in many ways, depending on the severity of your symptoms, the progress

of the condition, the demands of the work you do and even the culture of the company you work for.

While there may be no hard and fast rules, there are some basics you need to know.

"A good place to start is to understand the balance between your rights and the rights of your employer," notes Sandra Dudley of the Toronto office of Eckler Partners, Ltd., a leading actuarial and group benefits consultant. "The employer has an obligation to make a reasonable effort to accommodate occupationally-related physical conditions.

This is covered by workers' compensation regulations and supported by human rights legislation.

"Typical accommodations can include modifications to the workplace and alteration of job descriptions—things that make it possible for you to do your job, or a similar one. However, there are limits to what an employer is obligated to do. Accommodations must be reasonable—meaning affordable and realistic. Also these obligations end when the employee is no longer able to fulfill his or her job contract." In other words, once you are incapable of doing what you have been hired to do, the company no longer has to employ you.

The only options at that point are disability pension, early retirement or similar alternatives. That's the situation in black and white. In the real world, however, you will often find yourself dealing with an infinite number of shades of gray. And, of course, there is a vital human side to every story (see *Tales from the workplace* throughout this article).

### Six steps to follow

While just about anyone involved in this area will tell you there are

## Tales from the workplace

A stay-at-home-mom for 12 years, Calgary's **Cindy Exton** was in the middle of a planned return to the workforce when she was diagnosed at age 42.

"After some thought, I decided that Parkinson's shouldn't interfere with my plans," says Exton. "I applied for a home-based position for a major science and technology company and was offered the job.



Cindy Exton

"I decided to come clean and lay my cards on the table," she states. "Parkinson's was part of my life now, and was not affecting my abilities to do the job. I didn't want to hide it."

Exton's supervisor was sympathetic and admitted she didn't know much about the condition. Then followed a series of discussions with the company, physicians and the Parkinson's Society of Southern Alberta. Eventually the company's doctor came back and said, "If Cindy feels she can do the job, I see no reason why she can't."

## Tales from the workplace



**Ron James** was one of the first to take advantage of a new flexibility on behalf of some companies and insurers (in his case, Manitoba Blue Cross). James is a program host for Golden West Broadcasting, a three-station radio network. "I was 55 when I was diagnosed," he explains. "My first concern was my ability to speak. I felt it only fair to tell my boss right away.

"It was the company that suggested meeting with Blue Cross," James continues. "What was eventually proposed was a kind of sharing arrangement. I would work 50 per cent of the time, and be paid accordingly. The rest of the time, I would be on disability."

no one-size-fits-all solutions, here are six basic steps that may help.

### 1. Learn about Parkinson's:

"Get as much information and as clear an understanding of your condition as you can," advises Derek Thompson, a senior partner at Managed Disability Resources, a disability management consulting firm. "Talk to your doctors,

talk to Parkinson Society Canada, join support groups. Try and get a good understanding of how your condition may affect your ability to perform the specific tasks of your job, now and in the future."

### 2. Take stock of your finances:

Get a clear picture of your financial situation. Make sure you understand all the benefits available to you. Get advice from your financial planner, insurance broker, etc.

**3. Be realistic about work:** "You must realistically evaluate your working future," says Thompson. "You have to ask yourself some tough questions, such as Can I do the job safely? Will it pose a risk to others? Will it worsen my symptoms? Will the very act of trying to work actually have a negative effect on my quality of life?

"Some medical conditions, like early stage Parkinson's, are easy to mask," Thomson continues. "It is tempting to try and carry on. But in my experience, it's not advisable. For example, if your work is deteriorating due to your symptoms, but your employer is not aware of your condition, you might end up losing your job because of poor performance."

"You also have to be realistic in what you can expect from your employer," reminds Sandra Dudley. "There are legal obligations, but

there are also the realities of the business world. A smaller company may just not be able to make the adjustments."

### 4. Check if your employer offers an employee assistance program (EAP):

An EAP can provide a confidential sounding board or an objective mediator who can sit down with the two parties to work out solutions. They can also offer specific workplace wellness programs such as a stress

## Tales from the workplace

**Dr. Aubrey Matthews**, a family physician in Regina, had to accept early retirement at age 62, less than three years after his diagnosis. The deterioration of his motor skills made it difficult for him to practice. "I was upset, but I had to face up to medical-legal issues, plus the fact that I couldn't really practice medicine," Dr. Matthews recalls. "You have to do the right thing for yourself, and sometimes others—in my case, my patients."

reduction strategy. A situation like yours—having an employee with a chronic disease—may even prompt your company to approach an EAP provider for the first time.

**5. Decide what you want to do:** It's advisable to have an idea of what you want to do before approaching your employer. However, as Sandra

## Tales from the workplace

**Jim Bennett**, Senior VP for the Canadian Federation of Independent Business (CFIB), decided to tell the president and director of HR immediately when he was diagnosed at age 52. "I had been there for 22 years and felt comfortable talking about it," he explains. "We did a bit of assignment shuffling and someone else took over the more stressful aspects of the job. That reduction in stress is important to someone with Parkinson's."





Harold and Joy Wainwright

## *Tales from the workplace*

Insurance agent **Joy Wainwright** told her employer the day after she was diagnosed. "I had been experiencing tremors at work, so people knew something was up," recounts Wainwright, who worked for a medium-size insurance brokerage in Port Moody, BC. "We talked about it and decided there was no need to change anything. With my medications, I was able to keep going at full speed for another four years. Then I cut back to four days a week. As time went by, it became increasingly difficult.

"My boss pretty much left it up to me to call the shots, but he did expect a certain level of production," she continues. "Things did become a bit contentious. At the end I finally made the decision to apply for disability when my medications began to drop off suddenly and I had to rely on co-workers to step in.

"There is a balancing act to be kept in mind," Wainwright says. "Your worth as an employee is directly connected to your ability to perform. As much as your employer may like you as a person, he or she has to consider the bottom line. Be professional in keeping your employer aware of your limitations, and remember you are not doing anyone a favour by pretending."

Dudley explains, this isn't always simple. "Even with a fistful of information, a person may be unable to reach a decision," she says. "You can be overwhelmed or lose your confidence and be unable to evaluate your options." Dudley is a firm believer in finding an advocate or advisor. "Someone who can help you objectively evaluate your risks and gains and

help you make the right decision would be ideal," she notes.

**6. Treat your employer professionally:** Most experts agree the sooner you tell your employer, the better it will be in the long run. The HR department is the logical place to start, if your company has one. If not, talk to the person responsible for this area, your

immediate supervisor, or even the president. Again, it is important to let your employer know that PD affects people differently, and there are no hard and fast rules. Encourage and help key individuals in your company to learn more about the condition.

Once the decision is made and your condition disclosed, you and your employer can discuss alternatives. Disability pension is one option. Other options may include part-time or reduced hours. If you plan to continue to work but feel your symptoms will affect your stamina, ask your company to investigate all options, including "sharing" work and disability. "Insurers are increasingly considering plans that allow part-time work while receiving reduced benefits (as in the case of broadcaster Ron James [see *Tales from the workplace* on page 11])," notes Derek Thompson. "Be aware that not all insurers or companies are open to this, but it may be worth asking about."

*Editor's note: Adapted from Living and working with Parkinson's, Parkinson Post, Volume 2, Issue 3, Fall 2002.*

## *Tales from the workplace*

It took **John Levangie** almost five years to come to terms with his Parkinson's, at least as far as his job was concerned. Levangie had worked for the Nova Scotia government for more than 20 years, reaching the position of Assistant Deputy Minister, Finance. He was only 42 when diagnosed. For a number of reasons, he decided to keep his condition a secret from the people at work. At first his symptoms were mild and he managed to get by—but at a cost.

"Keeping that secret was one of the most foolish things I have ever done," Levangie now concludes. "I felt terribly guilty all the time. And there was no one to share the burden with." However, Levangie couldn't keep his secret indefinitely. His symptoms got worse, often exacerbated by the stress of trying to cover up. "I realized I was pushing myself to the verge of doing serious harm by carrying on," he adds.

Eventually he applied for disability. "I felt that a huge burden had been lifted," Levangie states. "I would advise any one in this situation not to do what I did. Don't try to hide it."



John Levangie with grandchildren Bailey and Kaitlyn.

# World Parkinson Congress brings experts together

**T**he world's Parkinson's community gathered in Washington, DC, recently in a unique event aimed at creating an international dialogue.

The World Parkinson Congress (WPC) was the first truly international gathering of researchers, health professionals, people living with Parkinson's, and caregivers. Held from February 22–26, the WPC's purpose, as found in their mission statement, was "to build a sustained worldwide effort to better understand, combat and ultimately conquer Parkinson's disease."

A not-for-profit organization, WPC is dedicated to providing an international forum for the best scientific discoveries, medical practices and caregiver initiatives. It encourages involvement from all stakeholders, including people with Parkinson's and societies and voluntary associations representing people living with Parkinson's and their families.

The event featured more than 100 presentations, seminars and workshops on a variety of topics, ranging from the latest research to advice and tips for people with Parkinson's and their caregivers. Canadians were well represented, both as presenters and attendees. Parkinson Society Canada staff and volunteers were among the many who attended to learn about the latest coping and

patient education strategies.

Among the Canadian contingent on the WPC faculty were: Dr. Donald Calne, Susan Calne, Dr. Anthony Lang, Dr. Andres Lozano, Patrick McGeer, Remil Quirion, Dr. Jon Stoessel, and Karol Traviss—a clear indicator of the leading role Canada continues to play in Parkinson's research and education.

One of the key themes featured at WPC was the potential of genetics and epidemiology in finding ways to prevent and eventually cure Parkinson's. The meeting also included presentations on innovative therapies that show promise in controlling symptoms, restoring function and even altering the progression of the disease.

The next World Parkinson Congress has already been scheduled for Paris, France, in 2009.

*Editor's note: We will be following up on some of the more interesting presentations at the World Parkinson Congress in future issues of Parkinson Post.*

## Notes from Washington Cindy Exton reports on the World Parkinson Congress

So many people, gathered in one place—all here to share, discuss, present, and learn about Parkinson's. Professionals from far-away countries like Israel, England, Australia, and some of our finest from Canada are here.

The mood is positive all week. Listening at various workshops and seminars, I was truly thankful for all these people who are devoting their life's work to finding the cure to this disease. What's nice is that they all seemed genuinely interested in speaking to us, helping us to understand, to cope, to deal with PD.

All the people out there living with Parkinson's really need to know that they are not alone, and that there are a lot of dedicated professionals on our side. As we strive to make each day count, we need to know that each of these days brings a cure closer.

*Cindy Exton is on the Board of Directors of The Parkinson's Society of Southern Alberta.*



*PSC staff and volunteers were well represented at the World Parkinson Congress, and they brought a wealth of new information home.*

# Medication matters: *A quick guide to drug therapy*

By Chee Chiu, BSc Pharm

**R**esearch has shown that people with Parkinson's disease (PD) do not produce enough dopamine, a chemical that acts as a "messenger" in the brain and helps to control movement. Since their introduction in the early 1970s, dopamine-based drugs have been the mainstay of PD treatment.

Over the past few years, the development of new drugs and formulations have continued to improve treatment. However, PD drug therapy can be complex, often requiring multiple medications to improve mobility, to treat other symptoms, and even to counter adverse reactions caused by a person's main medication. As a result, people receiving drug treatment for PD need to be aware of a number of medication-related concerns.

### Drug therapy

Here's a brief overview of the common medications used to treat PD, and how to get the most out of your drug therapy.

**Levodopa:** This is the most commonly used medication in PD and remains the most effective treatment. The body converts levodopa into dopamine in the brain, helping to control some of the main mobility-related symptoms. Levodopa is always administered with carbidopa or benserazide. It has a relatively

short duration of action in the brain, so people often need frequent dosing to maintain optimal therapeutic benefit. Since 1989, a controlled-release formulation of levodopa/carbidopa (Sinemet-CR) has been available in Canada.

Initially, most individuals respond favourably to levodopa therapy. However, with disease progression and chronic levodopa therapy, most people will eventually experience fluctuation in drug response. When this occurs, levodopa is usually supplemented with other antiparkinsonian drugs.

*Things to watch for:* There are no significant interactions between levodopa and other antiparkinsonian agents. However, foods with high protein content can interfere with the release of levodopa in the brain. Because of this, it is recommended that levodopa medications be taken between 30 minutes to an hour prior to meals, or between one to two hours after a meal. Iron supplements can decrease levodopa absorption from the intestine and should thus be taken at a different time from the medication.

**Dopamine agonists:** These medications (bromocriptine, pergolide, ropinirole, pramipexole) mimic the effects of dopamine and act directly on dopamine receptors in the brain. These agents may be used to treat patients with early PD or combined with levodopa



in more advanced stages. Most dopamine agonists have a longer duration of response than standard formulations of levodopa. Studies suggest that these agents may be less likely than levodopa therapy alone to provoke involuntary movement. However, they are more likely to cause postural hypotension and hallucination.

*Things to watch for:* Dopamine agonists rarely provide symptom relief at the lowest dose levels. People often require several weeks, or even months, of gradual increases in their doses before benefits can be observed. People taking ropinirole need to be aware that some commonly used drugs (e.g., ciprofloxacin and ranitidine) or high doses of estrogens might increase the amount of ropinirole in the blood by decreasing its breakdown in the liver.

**COMT inhibitors (entacapone):** This medication restricts elements of the metabolism (or processing within the body) of levodopa, thus enhancing its availability in the brain. Entacapone should always be taken with levodopa, as it is not effective when used



alone. As an adjunct to levodopa, it provides reduced off-times, increased on-times, and enhanced motor function.

*Things to watch for:* Diarrhea has been reported as a side effect of entacapone.

**Amantadine:** This agent may have a modest effect on the motor symptoms of PD. It can help lessen levodopa-induced motor fluctuation (loss of smooth, regular symptom control).

*Things to watch for:* Side effects include ankle edema, red skin blotches on the legs, hallucination and mental confusion.

**Selegiline:** This drug may provide mild symptomatic benefit in some patients.

*Things to watch for:* Selegiline is usually taken once or twice daily. It is best taken in the morning and no later than noon, to avoid night-time sleep disruption. Common adverse effects include hallucination and mental confusion. Selegiline should never be given with meperidin (Demerol). Using selegiline while taking antidepressants should also be avoided.

**Anticholinergic agents:** These agents (e.g., trihexyphenidyl, benztropine) may help in treating tremor, but patients, especially the elderly, may experience cognitive changes.

*Things to watch for:* Many over-the-counter preparations (allergy product, cold and cough products, sleeping aids) have anticholinergic side effects, thus impairing certain nerve impulses. They are best avoided in older individuals.

## Managing drug-related problems

**Contraindications:** A number of drugs are contraindicated in PD. This means that they can have a negative effect, such as interfering with other drugs or making certain symptoms worse. As such, they should not be taken if you have PD.

For example, some medications used to treat other conditions block dopamine in the brain and, as a result, can induce or worsen the primary features of PD. These medications should be avoided. They include the following:

- some drugs indicated for gastrointestinal symptoms (e.g., etoclopramide and prochlorperazine)
- some drugs used to treat hypertension (e.g., reserpine and alpha-methyldopa)
- flunarizine, used for the prophylaxis of migraine

## Hallucinations and psychosis:

Unfortunately, many antiparkinsonian drugs can cause hallucinations or psychosis. Treatment involves discontinuing the drugs in the following order: first anticholinergics, then selegiline, amantadine and dopamine agonists, followed by lowering the dosage of levodopa.

Clozapine and quetiapine are the only antipsychotics not contraindicated in PD. Clozapine has been proven to control psychosis

effectively without worsening PD symptoms. Quetiapine appears to be less potent than clozapine in relieving psychosis.

**GI dysfunction:** Delayed emptying of stomach contents, common in people with PD, can result in constipation, abdominal discomfort, bloating, nausea and vomiting. Impaired stomach emptying can also reduce the effectiveness of levodopa by delaying its progress to the intestine.

The medication domperidone is often used to manage delayed emptying of stomach contents and the resulting nausea and vomiting. Domperidone should be taken 15 to 20 minutes before eating. If you are taking the drug, space any other gastrointestinal medications (such as ranitidine or any antacids) by two hours to maintain the stomach's acidic environment that domperidone requires for absorption.

*Chee Chiu, BSc Pharm, is the co-ordinator of the Living Well with Parkinson's program in Toronto, Ontario.*

*Editor's note: This article contains general information only. It should not be considered as advice on any particular situation or to replace the advice of a doctor and pharmacist.*

## Keeping track of your tablets

Some people with Parkinson's have to take medications more than eight times a day. The precise timing of when the medication is taken is as important as what is taken. Your personal dosing schedule should be designed based on your daily activity and drug response. Your pharmacist can design a schedule that will allow you to manage your medications.

It is important that you buy all medications at the same drug store and tell all doctors (specialists and family physicians) about all medications being taken, including over-the-counter products. Above all, if you have any questions or concerns regarding medications, consult the doctor and pharmacist immediately.



# Easing the burden: Supporting psychosocial research into Parkinson's

By Fran Squire

**W**hen you hear the word "research," what image immediately springs to mind? Most likely, it's a picture of white-coated scientists peering through microscopes in a specialized laboratory.

While this image is perfectly valid, it primarily represents *biomedical* research, just one of the two main areas of research that hold the key to improving life for people with Parkinson's disease. There is another vital area of research—*psychosocial*—that also has an important role to play in serving the Canadian Parkinson's community.

The mission of Parkinson Society Canada (PSC) states, "Our purpose is to ease the burden and find a cure." Biomedical research, focused on *finding a cure*, has been funded through the PSC's National Research Program. Since 1981, over \$12 million in grants have been awarded; \$3.35 million over the past three years alone. PSC remains fully committed to supporting this crucial research.

### Understanding the issues

But what about research devoted to *easing the burden*? This is an area with great potential but has, so far, not been in the mainstream of research funding. PSC is currently expanding its research program to include a new psychosocial strand of research that will increase our understanding of the quality of life issues faced by people living with Parkinson's and their caregivers.

The Canadian Institutes of Health Research (CIHR) have identified four pillars of medical research: (1) biomedical, (2) clinical, (3) health services and systems, and (4) population studies. PSC has modeled its research-funding program on the CIHR to support a broad range of research streams.

Under the first two pillars, researchers specializing in Parkinson's are investigating a wide spectrum of topics, including the death of brain cells in Parkinson's, environmental/gene interactions, cell biology and function, protein

aggregation and genetic studies, functional neuroimaging and cognitive deficits, among many other topics.

On the other hand, psychosocial research is located within the third and fourth pillars of research and deals with the social and psychological aspects of Parkinson's. The purpose of this research is to gain knowledge and understanding about how to maintain and improve the quality of life for people living with Parkinson's.

Researchers may investigate caregiving approaches, examine economic impacts on families, or explore the role of support groups and exercise programs. The emphasis is on gaining insight into the experience of the person with Parkinson's and those in caregiver or health provider roles.

### What is happening at PSC

PSC's Research Policy Committee formed a psychosocial workgroup in July 2005 which is now positioned to introduce a three-part psychosocial program. Because it is important that the actual needs of people living with Parkinson's are identified, the workgroup will first use the results of a national needs assessment study to determine issues that could be investigated through a psychosocial research agenda.

Secondly, based on the needs assessment, a new research award category has been created to provide





grants to doctoral students who wish to pursue their studies within these identified areas of Parkinson's research. A priority announcement in partnership with CIHR was made public this summer, with a call for applications in the fall of 2006. The objectives of the CIHR/PSC partnership are to increase interest in Parkinson's disease and to encourage young researchers to work in the area of psychosocial Parkinson's research.

The third component of the new program will be future Team Planning and Development grants to facilitate multidisciplinary teams in planning innovative research projects in the targeted psychosocial fields.

The researchers conducting the national needs assessment have so-far identified several emerging

themes. These include the following:

- Projects focused on improving education and awareness to reduce the stigmatization associated with PD.
- Research directed toward filling the gap in understanding and treating non-motor symptoms of PD.
- Projects that focus on methods of improving support and access to services for all individuals living with PD.
- Projects that focus on methods for improving appropriate services for people living with PD from ethnic communities, incorporating accommodation of language and cultural barriers.
- Research that investigates the social, physical and psychological impact of PD on the quality of life of seniors living alone.

- Research that identifies best practice by focusing on the diagnosis and early treatment experiences.
- Research in the area of concurrency of psychiatric disorders, including depression and drug/alcohol abuse among people living with PD.

Psychosocial research will provide a way to gather information about the quality of life of people living with Parkinson's. This information goes beyond the physical aspects of the disease to examine the context of the lives of individuals who live with Parkinson's. The data gathered can be translated into improved support and service delivery for those living with Parkinson's.

*Fran Squire is Chair of the Psychosocial Research Committee at PSC.*

# Teaming up to fight Parkinson's

By Carol Jamieson



**B**eing diagnosed with Parkinson's can be confusing and frightening. For a time, you feel alone, angry and isolated. And then you hear about Parkinson Society Canada's National Information and Referral Centre. Alan Riccardi, Chair, National Board of Directors, Parkinson Society Canada (PSC), says, "When it first opened in 2001, most of our inquiries were by phone. Today people can also access information via our website, e-mail or from our regional partners. We strive to be the ultimate information destination for anyone looking for credible, up-to-date information on Parkinson's resources across Canada."

PSC has received incredible financial support from Manulife

Financial—a contribution of \$150,000 over two years. "Manulife believes in the importance of supporting charitable organizations, such as Parkinson Society Canada, to work toward a healthier future for Canadians," says Judy Blasutti, Manager, Community Affairs for Manulife's Canadian Division. "We hope someday there will be no need for PSC's National Information and Referral Centre because Parkinson's disease will become a thing of the past. Until then, Manulife is pleased to help."

According to Joyce Gordon, PSC's President and CEO, the Centre sends out more than 20,000 pieces of information each year. Inquiries range from how to access local community

services (for example, exercise classes and support groups) to educational brochures and medical articles on Parkinson's. "We've noticed recently," says Gordon, "that we are getting more calls from parents whose adult children have just been diagnosed with Parkinson's. The other day we heard from an elderly lady with Parkinson's who is moving into an assisted living centre and wants several Parkinson information packages for staff at her new residence so they can better understand the disease. Often, all someone wants is a sympathetic ear. We're here to help everyone whose life is affected by Parkinson's."

To access the Centre, visit [www.parkinson.ca](http://www.parkinson.ca) or e-mail [general.info@parkinson.ca](mailto:general.info@parkinson.ca).

## National Research Program Awards, 2006–2008

Granting period July 1, 2006, to June 30, 2008

Research is one of the four pillars of PSC's mission and is key to improving the lives of people with Parkinson's and to finding a cure. Since 1981, PSC has invested more than \$13 million in Canadian Parkinson's disease research, supporting over 200 top researchers.

This support continues in 2006 with the commit-

ment of \$1,280,521 to fund 11 research grants and eight fellowships over the next two years. This is in addition to the \$374,760 already committed to ongoing projects from the 2005–2007 cycle. In total, PSC will be supporting 36 Canadian grants and fellowships in 2006.

Researcher	Name of project	Institution	Amount year 1	Amount year 2	Total award
<b>Pilot Project Grants (one year grant)</b>					
<b>Friedman Pilot Project Grant</b>					
Brian E. Staveley	Preliminary analysis of PINK1 (PARK6) and LRRK2 (PARK8) in Drosophila models of Parkinson's disease	Memorial University of Newfoundland	\$45,000	n/a	\$45,000
Mandar Jog	Network level changes in the basal ganglia in a rodent model of dyskinesia	London Health Sciences Centre	\$45,000	n/a	\$45,000
William D. Hutchison, Jonathan O Dostrovsky, Mojdan Hodaie and Andres M. Lozano	Pathological oscillations in basal ganglia and synaptic plasticity	Toronto Western Hospital	\$40,924	n/a	\$40,924
Philippe Seguela and Edward Fon	ASIC-mediated Excitocytosis in Parkinson's disease	McGill University	\$45,000	n/a	\$45,000
Francesca Cicchetti and Frederic Calon	Effects of dietary omega-3 polyunsaturated fatty acid on pesticide-induced neurotoxicity	Laval University Medical Center (CHUL)	\$45,000	n/a	\$45,000
David Park	The role of the base excision repair gene APE/Ref-1 in dopamine neuron loss in an animal model of PD	University of Ottawa, Ottawa Health Research Institute	\$45,000	n/a	\$45,000
Michel Panisset, Brigitte Stemmer, Alain Dagher	Neurobiology of gambling in patients with Parkinson's disease	Hotel-Dieu du CHUM	\$45,000	n/a	\$45,000
Harold A. Robertson	Neuroprotective strategies in Parkinson's disease: The role of microglia	Dalhousie University	\$44,597	n/a	\$44,597
<b>New Investigator Grant</b>					
Julie Messier	Sensorimotor integration and adaptation-learning in Parkinson's disease.	University of Montreal	\$45,000	\$45,000	\$90,000
Julie Desbarats	A proteasomal mechanism for Fas-mediated neuroprotection in Parkinson's disease	McGill University	\$45,000	\$45,000	\$90,000
Quincy J. Almeida	A research-based evaluation of exercise rehabilitation for symptomatic and functional improvement in PD	Wilfrid Laurier University, Movement Disorders Research Centre	\$45,000	\$45,000	\$90,000
Fellow	Field of training	Institution	Amount year 1	Amount year 2	Total award
<b>Basic Research Fellowships</b>					
Vladimir Rymar	Pitx3 determines vulnerability of subsets of dopaminergic neurons affected in Parkinson's disease	McGill University, Montreal Neurological Institute	\$50,000	\$50,000	\$100,000
<b>The Anthony Hooydonk Basic Research Fellowship</b>					
Frank Jangsup Lee	DJ-1 response to oxidative stress regulates intracellular dopamine levels: Implications toward Parkinson's disease	Centre for Addiction and Mental Health (Toronto)	\$50,000	\$50,000	\$100,000
Karim Mukhida	Neural transplantation	Dalhousie University	\$52,500	\$52,500	\$105,000

chart continues on next page

Researcher	Name of project	Institution	Amount year 1	Amount year 2	Total award
Elissa M. Strome	The effects of chronic L-DOPA on the blood-brain barrier in an animal model of Parkinson's disease	Lund University, Lund, Sweden	\$40,000	\$40,000	\$80,000
Dianbo Qu	Role of the antioxidant enzyme PRDX2 in dopaminergic loss in an animal model of Parkinson's disease	University of Ottawa, Ottawa Health Research Institute	\$50,000	\$50,000	\$100,000
Anna-Maria Szczesniak	Neurotransplantation/neuroprotection	Dalhousie University	\$40,000	\$40,000	\$80,000
<b>Clinical Movement Disorders Fellowship (one year fellowship)</b>					
Thomas Steeves	Clinical Movement Disorders Training	Toronto Western Hospital, Movement Disorders Centre	\$45,000	n/a	\$45,000
<b>Boehringer Ingelheim CMD Fellowship</b>					
Andrew Edward Borys	Clinical Movement Disorders Training	University of Manitoba, St. Boniface Medical Clinic	\$45,000	n/a	\$45,000
<b>Total funds awarded</b>			<b>\$863,021</b>	<b>\$417,500</b>	<b>\$1,280,521</b>

## National Clinical Program Awards, 2006–2008

Granting period June 1, 2006, to May 31, 2008

Funded centre	Location	Lead contact	Grant amount
<b>Clinical Assistance Grants</b>			
McGill University Health Centre	Montreal, QC	Dr. Anne-Louise Lafontaine	\$29,000
<b>RBC Foundation Clinical Assistance Grant</b>			
Unite des troubles du mouvement Andre Barbeau, Centre Hospitalier de l'Université de Montreal	Montreal, QC	Drs. Michel Panisset and Sylvain Chouinard	\$38,000
Movement Disorders Program, Foothills Hospital	Calgary, AB	Dr. Oksana Suchowersky	\$38,000
Jewish General Hospital Movement Disorders Clinic	Montreal, QC	Dr. Calvin Melmed	\$29,000
<b>K Bearg Clinical Assistance Grant</b>			
Parkinson's Disease and Movement Disorder Clinic, Ottawa Civic Hospital	Ottawa, ON	Dr. David Grimes	\$38,000
Movement Disorder Program, University of Manitoba	Winnipeg, MB	Dr. Doug Hobson	\$38,000
Movement Disorders Clinic, Glenrose Rehabilitation Hospital	Edmonton, AB	Dr. Wayne Martin	\$30,000
Movement Disorders Clinic, Kingston General Hospital	Kingston, ON	Dr. Giovanna Pari	\$38,000
<b>L Harper Clinical Assistance Grant</b>			
Eastern Health, Health Sciences Centre	St. John's, NL	Dr. Alan Goodridge	\$29,000
<b>K Bearg Clinical Assistance Grant Centre for Movement Disorders</b>			
Markham Stouffville Hospital	Markham, ON	Dr. Mark Guttman	\$38,000
Movement Disorders Clinic, London Health Sciences Centre	London, ON	Dr. Mandar Jog	\$38,000
Pacific Parkinson's Research Centre, University of British Columbia	Vancouver, BC	Dr. Jon Stoessl	\$38,000
<b>Community Outreach Grants</b>			
<b>CIBC Community Outreach Grant</b>			
The Maritime Parkinson Clinic, Halifax	Halifax, NS	Dr. George Turnbull	\$38,000
<b>RBC Foundation Community Outreach Grant</b>			
CNOR Thunder Bay Clinic	Thunder Bay, ON	Dr. Mandar Jog	\$10,000
<b>E. Conner Community Outreach Grant</b>			
VON St. John	St. John, NB	Ms. Mary Narrowmore	\$38,000
<b>E. Conner Community Outreach Grant</b>			
Société Parkinson du Quebec	Montreal, QC	M. Jean-Marie Bergeron and Mme Ginette Mayrand	\$38,000
<b>The Brian Hennick Community Outreach Grant</b>			
Baycrest Centre for Geriatric Care	Toronto, ON	Ms. Angela Chan	\$15,000
Parkinson Society Ottawa	Ottawa, ON	Ms. Ruth Vant	\$19,000
<b>TD Bank Financial Group Community Outreach Grant</b>			
Toronto Western Hospital Movement Disorders Centre	Toronto, ON	Dr. Janice Miyasaki	\$31,000
<b>Total funds awarded</b>			<b>\$610,000</b>



The Burns family (from left to right): Jennifer, Adam (standing), Sharon, Cliff, Jeannine and Catlin.

## “Parkinson’s disease doesn’t define me”

By Cliff Burns, Edmonton, Alberta

*Cliff Burns joined the Edmonton Police Service in 1980. Cliff’s mother was told she had Parkinson’s at 44, and at roughly the same age, Cliff received a similar diagnosis.*

**A**s a police dispatcher, it is extremely important to be able to multi-task. As my symptoms progressed I found myself getting lost. I also found it more difficult to speak loudly and clearly. Stress caused these symptoms to become more severe. By the winter of 2000/2001, I was suffering from insomnia, depression and severe weight loss. I was no longer able to function well at work. I needed to get out, and my supervisor and

physician agreed. I went on medical pension in July 2001.

With the help of my wife, Jeannine, my family and medical specialists, I have recovered somewhat over the last three years. Parkinson’s has mostly affected my right side, with my right shoulder vibrating my whole body in crowd situations. I fight muscle rigidity and slowness in the morning. The symptom that bothers me most is “cognition-freezing,” which affects my speech and the speed at which I think.

Parkinson’s has given me a new career as a “home dad.” I’m able to be there for my kids. I have spent many hours keeping their old clunker cars in good shape.

I have learned that Parkinson’s is a one-day, sometimes one-minute-at-a-time battle. In spite of the troubles of the moment, Parkinson’s disease doesn’t define me. I’m me and I only have Parkinson’s disease.

*Update: Today, Cliff is still very much a “home dad.” “I’m slowing down and have less stamina now,” he says. “But that goes with the territory. I still manage to do what I have to, when I have to do it!”*

*Editor’s note: For Cliff’s complete story, see Parkinson Post, Volume 4, Issue 3, Fall 2004.*

## There is life after Parkinson’s!

By Betty Geddes,  
Irishtown, New Brunswick

*Betty Geddes was diagnosed with Parkinson’s in 1992 at age 48. She worked as long as she could, but eventually had to give up her career as a licensed practical nurse.*

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

My support group is 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, yet it does have resources to help educate us about our disease.

For my husband Merton and me, 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 with-

out feeling resentful or angry; he has learned to offer aid and has become aware of when I need help.

Life has turned out differently than we planned. We worked hard all our lives raising 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 have each other.

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. Along the way, we have learned not to worry and to do our best to make the most of today.

*Update: Betty admits that things have "changed a bit" over the last few years. While she can no longer drive, she still keeps up with the housework. Betty also regularly attends support group meetings and is actively involved with the local Parkinson's Society.*

*Editor's note: For Betty's complete story, see Parkinson Post, Volume 3, Issue 4, Winter 2003.*



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

## Talk about it!

By Lindsay Parkhurst,  
Midland, Ontario

*Lindsay's mother, Margot, was diagnosed with Parkinson's when Lindsay was in kindergarten. She has some terrific advice for young people facing the challenges of a parent with Parkinson's disease.*

**K**ee a sense of humour: We laugh a lot about mom having PD. Like when she tries to tease dad by handing him a hot cup of coffee with her shaky hand. Because mom can laugh at herself, it makes it easier for all of us to cope.

**Live your life:** I stay involved with community activities like music and dance classes. Along the way, my parents have been right beside me encouraging me.

**Plan ahead:** Mom has had PD for 11 years, and it's progressing slowly, which allows us to make changes gradually. We're planning ahead by renovating our home and making it wheelchair accessible.

**Get involved:** For the past three



*Being open and honest about Parkinson's have helped Margot, John and Lindsay.*

years, I've been the youth representative for PSC. My job is to communicate with other teens who live with someone with PD. Lots of teens are embarrassed and don't want their friends or teachers to know they have a parent with PD. I'm helping them see that it's easier for everyone if they talk openly.

*Update: Lindsay is now in her third year at the University of Virginia. Margot underwent deep brain stimulation surgery earlier this year after her symptoms worsened.*

*"Now, we can do things we've never been able to do before," says Lindsay. "We can play golf as a family and ride bikes together."*

*Editor's note: For Lindsay's complete story, see Parkinson Post, Volume 3, Issue 2, Summer 2003.*

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www.parkinson.ca

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### **PSC Southwestern Ontario Region**

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Toll Free Ontario:  
(888) 851-7376  
Fax: (519) 652-9267  
www3.sympatico.ca/pf.swo

### **Parkinson Society Ottawa**

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

### **Parkinson Society Quebec**

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

### **PSC Maritime Region**

5991 Spring Garden Road, Suite 830  
Halifax, NS B3H 1Y6  
Ph: (902) 422-3656  
Toll Free (NS, NB & PEI):  
(800) 663-2468  
Fax: (902) 422-3797  
www.parkinsonsocietymaritimes.ca

### **Parkinson Society Newfoundland and Labrador**

The Viking Building  
136 Crosbie Road, Suite 305  
St. John's, NL A1B 3K3  
Ph: (709) 754-4428  
Toll Free (NFLD/Labrador):  
(800) 567-7020 Fax: (709) 754-5868



Parkinson Society Canada  
Société Parkinson Canada

## Nominate a volunteer for a PSC Award

Each year, PSC recognizes a few select volunteers by awarding three distinguished awards:

### **David Simmonds Parkinson's Leadership Award**

- recognizes achievements of the former Chair of PSC (from 1999–2001) who, through exceptional vision, leadership and commitment, has strengthened the voice of people living with Parkinson's
- acknowledges the perseverance and negotiation skills required to make a significant contribution to Canadian society

### **Dr. Morton Shulman Award**

- memorializes Dr. Shulman who used unorthodox, often controversial methods and innovative approaches to solving problems and easing the burden of those living with Parkinson's
- acknowledges how one person can make a difference

with creativity, tenacity and energy

### **Mimi Feutl Award**

- honours the former Director of Patient Services for 22 years with the Parkinson Foundation of Canada (now PSC) for compassion, energy and unwavering commitment to make life better for people with Parkinson's and their families
- acknowledges the ability to respond to requests for information and support while ensuring and respecting the client's dignity and individuality

Nominations are being accepted until Friday, September 15, 2006. For nomination forms, visit [www.parkinson.ca](http://www.parkinson.ca).

# SuperWalk for Parkinson's: A growing success



**T**he annual SuperWalk for Parkinson's has become Parkinson Society Canada's largest fundraising event, and it continues to grow each year. Seven Ontarians founded this event in 1990 as they walked to raise funds for Parkinson's research. From these humble beginnings, SuperWalk has grown to remarkable heights and continues to raise increasing awareness and funds for Parkinson Society Canada (PSC).

Each year a fundraising goal is set, and each year the revenue raised from SuperWalk exceeds that goal. In 2000, Canadians walked in 37 different communities and raised \$600,000. In 2001, SuperWalk locations increased to 57 walk sites and the event raised gross revenues of \$942,787. By 2002, SuperWalk locations increased to 65 sites and participants raised \$1,262,429. By 2005, Canadians walked in 78 communities and raised over \$1,750,000! Since 2000, SuperWalk for Parkinson's has grossed almost \$8,000,000!

### Earn great prizes

SuperWalk for Parkinson's has



something for everyone: great incentives and prizes for all walkers, a Canada-wide team challenge, on-line registration in every region, and special incentives for walkers who raise over \$1,000! The walk's website at [www.superwalk.com](http://www.superwalk.com) always has updated information on these prizes, incentives and programs.

Along with the support of determined walkers and volunteers over the years, Parkinson Society Canada has been fortunate to have many corporate sponsors who consistently give to SuperWalk. All of our sponsors, many of whom return year after year, want to make a difference in

the fight against Parkinson's. Through their cash and prize donations, they make our event exciting and our impressive success a reality!

### Help us find a cure

Our purpose is to raise funds to help ease the burden and find a cure for those affected by Parkinson's disease. Funds raised from this walk are used for research and support services. We need you to help us grow. Please call your regional office or visit [www.superwalk.com](http://www.superwalk.com) and join us as we walk to find a cure for Parkinson's.

*See you at the walk!*



Collect pledges and walk with your family and friends. There are so many ways to be involved...

**Be a SuperSTARWalker**

Raise over \$1,000 and in addition to your shirt receive a hat and pin for each year you reach this level. Plus, there are special prizes and incentives just for these walkers!

**Be part of a team**

Bring your friends and family and share the fun by walking as a team

**Be a volunteer**

Call the regional office closest to you and volunteer to work on a SuperWalk committee.

**Great prizes! Great fun! Easy to be involved with on-line registration!**

For every \$100 raised each walker gets a chance to win some great national prizes so come out and join the fun! On-line registration opens May 1st, 2006 for all walkers across the country.

**For details about a walk near you and to register on-line visit [www.superwalk.com](http://www.superwalk.com)**

# Join us. Be part of SuperWalk for Parkinson's this September!



 Parkinson Society Canada  
Société Parkinson Canada