Fall 2005 ▪ Volume 5 ▪ Issue 3
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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Leaving a legacy: A smart financial option

Fighting back: Yvon Trepanier's life with young-onset Parkinson's

PLUS A look at international research

Beating the blues: Let's talk about depression

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

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www.parkinson.ca

Parkinson Society Canada
Société Parkinson Canada

What affects 1 in 300 Canadians?

Parkinson's Disease

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

Symptoms may include:

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

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

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

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

Ease the Burden; Find a Cure

Letter from Parkinson Society Canada

The spirit of Parkinson's

My first meeting as a director with Parkinson Society Canada (then known as the Parkinson Foundation of Canada) was in Halifax, Nova Scotia, in October 2000. When I initially accepted the position, I had no idea what it entailed, but, because it was only a one-year term, I thought I could "wing it." Five years and a few wing it's later, I am officially retiring from the Board.

I'm leaving some very good friends that I met through my involvement. People from every walk of life: teachers, nurses, lawyers, business men and women, homemakers, even a milkman. These are ordinary Canadians who volunteer in the hope they can somehow make a difference. I am also in awe of my fellow Board members, who epitomize the true spirit of the National Board. The commitment and dedication of all members is amazing and inspiring.

To most people who read this letter, the National Board is faceless and its work often appears abstract and unrelated to the everyday concerns of the ordinary Canadian. In reality, this is not the case. The directors are truly in touch with the everyday world, because they live it. They are fathers, mothers, grandparents, aunts and uncles. Some have Parkinson's disease; some do not. Yet they all put themselves on the frontlines of criticism and opposition.

As a Board, we have not yet made the transition from the new, up-and-coming description of five years ago to the highly successful, productive organization that we envisioned. We could not predict the obstacles we would face, but in meeting these obstacles, we did not admit defeat.

Instead, we took each obstacle, focused on the positives, identified our weaknesses, and turned them into strengths. As a result, we became more productive. We worked hard to improve disability tax laws. We lobbied for stem cell research. We nudged friends and businesses for donations to meet our PD research commitment. And we improved relations with the regional offices in order to improve services for all Canadians. Now, Board governance is more manageable. Our financial operation is more transparent. Our strategic plan is constantly monitored. And our education materials, which are of excellent quality, are readily available.

I am proud of my involvement with this Board and prouder still of the people I have met. While I will miss each person, I am confident in PSC's future because it is in the hands of people who care—people who certainly do not have to wing it.

Beth Holloway

Beth Holloway,
National Board of Directors and
Chair of the Board Governance Committee
Newfoundland and Labrador

Parkinson Society Canada
Société Parkinson Canada

ON OUR COVER:
Yvon Trepanier was only 47 when he was diagnosed with young-onset Parkinson's disease. At first shocked, he soon turned to Parkinson Society Canada for support. Now, he's quite active in the Parkinson's cause, primarily as President of the Board of the Victoria Epilepsy and Parkinson's Centre.

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ParkinsonPost
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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

- Held the sixth annual Parkinson Society British Columbia/Ballet BC "Play-a-Round" Golf Tournament, which raised $66,000.
- The 10th annual SuperWalk took place in eight communities in BC and raised $145,000.
- North Vancouver residents organized a concert in honour of a North Shore drama educator recently diagnosed with Parkinson's. The event raised $10,200.
- Health care in-services were offered throughout the province in partnership with Susan Calne, co-ordinator at the Pacific Parkinson's Research Centre.
- Eight well-attended conference and education meetings were held around BC including a three-day facilitators' conference in October.

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

- Fall programs have been launched with revisions to the seated exercise service.
- A three-week early stage Parkinson's group received specialized education and the opportunity to network.
- September marked the start of numerous educational events with a geriatric psychiatrist presenting on "Managing psychological challenges with PD."
- Board and staff met for two productive planning sessions, resulting in new approaches to external communications and fundraising.
- A new Parkinson's mind-body program is being planned. The program involves a team of two yoga instructors and two physicians living with PD.

The Parkinson's Society of Alberta
Edmonton General, Room 3Y18
11111 Jasper Avenue
Edmonton, AB T5K 0L4
Ph: (780) 482-8993
Toll Free: (888) 873-9801
Fax: (780) 482-8969
www.parkinsonalberta.ca

- Guest speaker Susan Calne, co-ordinator at the Pacific Parkinson's Research Centre, spoke at the 27th Annie Wyley Memorial Lecture.
- Educational meeting held with Dr. Wayne Martin, director, Edmonton Movement Disorder Clinic, on "Identifying complications associated with medical treatment in Parkinson's disease."
- Fifth annual speech education and action program.
- Two successful SuperWalks for Parkinson's in Grande Prairie and Edmonton raised more than $133,000. The Honourable Norman L. Kwong, Lieutenant Governor of Alberta, and The Honourable Anne McLellan, Deputy Prime Minister of Canada, attended the Edmonton walk.
- Erin O'Ray joined our staff as the Volunteer Coordinator and Program Assistant.

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

- Annual Tulip Golf Tournament for Parkinson's raised over $40,000.
- Dr. Zbigniew Wszolek, Mayo Clinic, provided an excellent presentation on "The genetics of Parkinson's" for close to 100 attendees.
- Held six very successful SuperWalks for Parkinson's in Red Deer, Medicine Hat, Lethbridge, Cochrane, High River, and Calgary.
- Support groups, exercise classes, counselling sessions, a series of information sessions for newly-diagnosed, Brainwaves, physical therapy advice, and a newly started Tai Chi program were all offered throughout the fall.

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

- Thirteenth annual PW Golf Classic for Parkinson's Research raised approx $60,000.
- SuperWalk for Parkinson's was once again a resounding success.
- Movement disorder clinics held in Saskatoon and Regina.

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

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Parkinson Society Canada
Société Parkinson Canada

Fax: (204) 786-2327

- Seventh annual golf classic raises $68,000. Title sponsors Lawton Partners Financial Planning Services signs on for three-year sponsor commitment. Eighth annual golf classic to be held on May 29, 2006.
- Support group guidelines were adopted and presented across the region to 14 groups. New exercise groups, care partners and early onset groups take self-help to a new level and chose advocacy to champion for the region.
- Nichola Lastella, Executive Director, achieved her designation as a Certified Association Executive through the Canadian Society of Association Executive (CSAE). Nichola has also been awarded the Starwood scholarship to attend the CSAE conference in Charlottetown, PEI.
- SuperWalk for Parkinson's held in five cities: Winnipeg, Brandon, Morden, Nelson House, and Gimli. Awareness bracelets were made available before the walk at various retail outlets.

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

- Six chapters/support groups identified that over the course of 2004–2005, volunteers offered 6,250 hours of service.
- Partnerships continue to increase visibility of all organizations involved, including Extendicare, Tai Chi Society, Bayshore, Baycrest, North York General Hospital, and Metro Homes for the Aged.
- Creation of information sessions for newly diagnosed individuals and Progressive Supranuclear Palsy.

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

- Continued to collaborate with volunteer health care professionals to develop a learning tool for PEP for community caregivers, an educational program for health care professionals caring for people with advanced Parkinson's.
- Launched extensive media campaign in support of local SuperWalk and to encourage volunteerism for Parkinson's.
- Prepared for seven SuperWalks and fall tulip bulb campaign

Parkinson Society Ottawa

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

- Marissa Leblanc, a dietician, provided an informative talk on "Nutrition and Parkinson's."
- SuperWalk 2005 brought a record number of walkers, as approximately 400 people helped to raise over $63,000.
- A third-party event that highlighted the paintings of well-known local artist Ben Babelowsky raised both awareness for Parkinson's and money for Parkinson's research.
- Parkinson Society Ottawa, as part of a national charity partnership, enjoyed a second year as a recipient charity of the HOPE Volleyball Summer Fest. This event attracts over 25,000 people to Ottawa each year.
- The Parkinson Society Ottawa office moved to a bigger, brighter location situated at the edge of Ottawa's downtown core. On-site programs including physiotherapy, Tai Chi, speech therapy, support groups and the lending resource library now have much more space.

Société Parkinson du Québec

1253 McGill College, Suite 402
Montreal, QC H3B 2Y5
Ph: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.infoparkinson.org

- Eight SuperWalks for Parkinson's took place last September.
- Dr. Abbas F. Sadikot presented on the various surgical treatments available to persons with PD.

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

- HOPE Volleyball was held once again in mid-August as part of a three-year partnership.
- SuperWalk 2005 raised over $80,000—a 23% increase over 2004.
- First-ever corporate SuperWalk raised $17,200, well above the goal of $10,000.
- 2005 East Coast Parkinson Conference held on October 23–25 in Halifax, NS.
- Community Initiative Grants awarded to Pictou, Fredericton, Saint John and Bridgewater for 2005–2006

Parkinson Society Newfoundland and Labrador

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

- Region received government funding to hire a summer student for July and August.
- A Needs Assessment Survey for People with Parkinson's and Care Partners was mailed to all members in September.
- United Way provided a grant for volunteer training.
- The region held three major SuperWalks and four family

Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

Working together to deliver results

The Advocacy Committee met for a two-day think-tank in September to develop a clearer understanding of the issues facing Canadians with Parkinson's disease. To this end, we received a tremendous amount of input and perspective from people with Parkinson's, caregivers, nurses, physicians, professional staff and others.

Valued insight


The 11-member Advocacy Committee is working to develop a big picture understanding of Parkinson's disease in Canada.

As we all anticipated, the scope of work to be done on behalf of Canadians with Parkinson's is enormous: from elevating the public's understanding of the disease, to pushing for more research dollars, to lobbying for specific policy change across a spectrum of issues. The Advocacy Committee must therefore clearly define its mandate and areas of focus, and the valued insight provided by so many within the Parkinson's community will be very helpful in achieving these goals. In September, the committee also heard presentations and discussed key topics that have significant impact on Canadians with Parkinson's including

- Canada Pension Plan disability benefits and the Income Tax Act
- mandate and funding interests of federal health institutions
- funding of Parkinson's health delivery services
- federal health care policy relevant to Parkinson's disease

Effecting change

Our goal is to present a big picture understanding of Parkinson's disease in Canada along with the critical information and data that we presently lack, so we can effect change. We've heard from many stakeholders over the past few months and their message is clear: we must secure more funding for research to ease the burden and find a cure, address the gaps within the medical community including understanding of Parkinson's and access to care, increase availability and ease of negotiating supports and services, and plan for the future.

Recently, Health Minister Ujjal Dosanjh wrote an article for *The Toronto Star* where he spoke of Canadians holding their governments' feet to the fire on health care issues. Canadians with Parkinson's have the right to expect results, and by working together, staying focused, and holding the feet of government (at all levels) to the fire, we will make progress.

Ease the Burden; Find a Cure

Health Tip

Managing side effects of Parkinson's drugs

By Chee Chiu, BSc Pharm

People who take antiparkinsonian medications often have complex dosing regimens and have to deal with interactions with other drugs. (Editor's note: For an overview of Parkinson's drugs see "Medication matters," *Parkinson Post*, Summer 2005.) In addition, they need to be aware of the potential effects of their medications on other aspects of their health. Two key areas of concern are the gastrointestinal (GI) tract and hallucinations/psychosis.

GI dysfunction: Delayed emptying of stomach contents, common in people with Parkinson's disease (PD), can result in constipation, abdominal discomfort, bloating, nausea and even 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, nausea and vomiting. Domperidone should be taken 15 to 30 minutes before eating. If you are taking this drug, space any other gastrointestinal medications, such as ranitidine or any antacid, by two hours to maintain the stomach's acidic environment that domperidone requires for absorption.

Drug-induced hallucinations and psychosis: Unfortunately, any antiparkinsonian drug can cause hallucinations or psychosis. Treatment involves discontinuing the offending drugs in the following order, beginning with anticholinergics, selegiline, amantadine and dopamine agonists, followed by lowering the levodopa dosage.

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.

If you have any questions about these or other potential effects of your Parkinson's medications, talk to your physician or pharmacist.

Coming to terms with young-onset Parkinson's disease

By Ian Corks

A diagnosis of Parkinson's disease (PD) is tough to face at any age, but having to come to terms with the impact of this condition in your 40s, 30s, or even younger can be especially difficult. Yet every year, thousands of people are diagnosed with young-onset Parkinson's disease (YOPD).

For these individuals, the disease brings not only the realities of the physical symptoms but also a future suddenly jeopardized by uncertainties and filled with questions such as "What can I expect?", "Will I be able to continue working?", "What kind of medical bills can I expect?", and "Will I still be able to function as a nurturing parent and spouse?"

Maintaining function

Although the neuropathology and most clinical symptoms are the same at whatever age PD develops, the medical implications of YOPD can be very different.

"People with YOPD need to be treated longer," notes Dr. Mandar Jog, Director of the Movement Disorders Program at the University of Western Ontario in London, Ontario. "All the phenomena associated with PD and its treatment, including the side effects of medications, will be around for more years—sometimes many more. We have to consider this. For example, we may need to choose medications that may be a bit less potent but have fewer long-term side effects."

Another key concern is the maintenance of function. "Because of their young age, many people with YOPD have more financial and family responsibilities," Dr. Jog notes. "They are important contributors to the family's financial stability and are active in raising young children. Quite simply, they have to be able to keep working as long as possible. Treatment strategies have to be aimed at long-term

control of symptoms and maximizing function to allow daily activities. Naturally, this is important in all cases of PD, but it carries that extra bit of weight in YOPD."

It is important to find a physician who has an understanding of the unique requirements of the person with YOPD and who can develop the right treatment approach.

Special needs

In addition, there are a number of important psychological and social implications to consider.

The family: The person with YOPD, and family members, will likely experience a roller coaster of emotions as they come to terms with their situation. Children need to be reassured and have their questions answered directly and honestly. Emotional support should also be provided. Educational materials and other resources are available from the local branches of PSC. Professional counselling may be needed.

Sexuality: The physical and emotional symptoms of YOPD can have a significant impact on sexual activity. Sexual partners may also experience depression and fatigue as they struggle with the caregiving role. Issues involving sexuality can be complex, but help is available through professional counselling or sex therapy.

Employment: Perhaps the most commonly asked question by the newly diagnosed individual with YOPD is "How long will I be able to work?"

Fortunately, levodopa, along with other new Parkinson's therapies, has greatly improved treatment and allowed people with YOPD to function longer. While the body may not be acting "normally," there likely will be many work years ahead. In later years, decisions regarding when to stop working and apply for medical disability may have to be made. Employment-related decisions should be made in consultation with the family, physician, employer and financial advisor.

Financial planning: Facing a future with the increased financial demands of a growing family and the possible decrease in financial resources can be stressful. Help

Dr. David Grimes

Causes & cures?

"We are now leaning towards a genetic cause of YOPD as opposed to an environmental one," says Dr. David Grimes, Director of the University of Ottawa's Parkinson's Disease and Movement Disorders Clinic, and one of Canada's leading researchers. "It appears that the younger the person is when they get PD, the more likely they are to have a genetic mutation. In juvenile Parkinsonism, for example, about 70 per cent of cases are linked to a mutation in the Parkin gene.

"As recently as eight years ago, if you asked if genetics played a role in YOPD, a few people may have said 'maybe,' but most would have said you were crazy," he continues. "Then the first gene linked to PD was discovered. Now we are aware of at least eight."

As Dr. Grimes explains, pinning down that genetic link, if it exists, is the first step towards a cure. "Once we know why you have YOPD, we can move forward," he says. "Once you understand the genes and the mechanism by which they influence the development of PD, then you can look at possible ways of interrupting that mechanism."

may be needed in planning for the financial long term. Financial planners, attorneys, and investment counsellors can all be useful resources.

Depression: Depression accounts for the majority of psychiatric referrals in people with Parkinson's, and YOPD is no exception. It is important to be aware of the dangers and symptoms of depression and seek professional help if needed.

(*Editor's note:* See the article "Beating the blues: Don't let depresioon control your life" on page 11).

Get involved

Young-onset Parkinson's disease can be quite a challenge, but with the right treatment, a positive attitude and support, a full, productive and satisfying life is more than possible. One key to coping with YOPD is to play a part in the treatment.

"Be involved," advises Dr. Jog. "Don't get carried away, however. There's a big difference between being proactive and thinking you can do it yourself. There are many issues involved in YOPD beyond movement difficulties. Learn about the condition and communicate honestly and often with your physician and other health professionals. Working together is the best way to develop a plan that works for you."

Fighting back: Yvon Trepanier refuses to give in to YOPD

Yvon Trepanier was only 47 when he was diagnosed with young-onset Parkinson's disease (YOPD).

The Vancouver schoolteacher had been in otherwise perfect health when he first experienced the symptoms that led him to see his doctor. "They tested me for a lot of things," Yvon recalls. "Only when they had ruled out other conditions did they conclude that I had Parkinson's."

His reaction? "Quite frankly, I was freaked out," Yvon says. "I felt like I had grown old in minutes." Yvon's feelings are typical of someone facing a diagnosis of YOPD. Along with the fear of what might lie ahead are the added burdens of the loss of youth and the questions "Why me" and "Why so young?"

A remarkable journey

Yvon faced these issues and more on a remarkable journey that took him from the depths of despair to where he is today–an empowered individual with a positive outlook and a commitment to do whatever he can to fight the condition, both as an individual and an advocate.

"The first year was very difficult," he relates. "I was really down and feeling sorry for myself. I admit that I even thought about suicide. My personal relationship was also in crisis. I didn't want to be a 'burden' so I offered my partner a chance to opt out of our relationship."

Getting on with life

Fortunately for Yvon, things got better. Or to be more accurate, he made them better. "The grieving was important and I advise people in a similar situation to let it take its course," he notes. "But I got through it and realized that things could be worse. So I set out to make the best of my new life."

He credits his honesty with the people in his life with playing a major role in his acceptance of his condition. Unlike many others, Yvon was open about his decision from the beginning. "I was upfront and told my family, friends and colleagues," he says. "I needed support and they provided it. I also think telling them relieved some of the stress. And you don't need more stress, believe me. It just makes things worse."

Yvon decided to learn as much about Parkinson's as he could. So he turned to Parkinson Society Canada and other resources for information–something he highly recommends. While the information he received helped tremendously, Yvon found that there didn't seem to be much devoted to YOPD. This was one of the reasons he decided to get involved. "Young-onset Parkinson's is different," he explains. "Our problems and needs are unique. As someone with YOPD, I felt that we needed more of a voice in the Parkinson community."

Yvon (right) attends a PSC Advisory Committee meeting in Toronto, along with PSC President and CEO Joyce Gordon.

Supporting others

Now retired and living in Victoria, Yvon is President of the Board of the Victoria Epilepsy and Parkinson's Centre (VEPC) and also Chair of the PSC's Advocacy Committee and a member of their Implementation Team. His life is settled and he looks forward to the future. "I still have my bad days, but I have learned not to give in to them," he says. "I have become a great believer in exercise and am fitter than I have ever been. My partner and I have started to talk about a family again, and I am very involved with the VEPC and PSC. I do my best to support others like me, both in Victoria and across Canada.

"People with YOPD still have a lot of energy to give to the fight," Yvon adds. "I encourage them to use that energy. Don't be afraid to speak up and say what you need, both for the present and the future. We want a cure. We want to break the cycle and end the misery that Parkinson's disease can cause."

Beating the blues:

Don't let depression control your life

By Ian Corks

You've just found out you have Parkinson's disease. Surely, it's only natural to feel "down," isn't it?

The answer, of course, is yes. Once you've dealt with the shock, fear, grief and other emotions that accompany a life-altering event like the diagnosis of Parkinson's disease (PD), it's normal to experience feelings of often overwhelming sadness.

For some, these feelings will pass, or at least they will learn to come to terms with them. For many other individuals with Parkinson's, however, these feelings may be more difficult to deal with and may actually be the symptoms of a different disease: clinical depression. And like any other disease, it should be treated.

Depression is a serious medical condition that affects thoughts, feelings and the ability to function in everyday life. It can even make the symptoms of other medical conditions appear worse.

Depression can occur at any age and in anyone. Studies estimate that each year, almost 10 per cent of North American adults, or about 20 million people, experience some form of depression. Although available therapies alleviate symptoms in over 80 per cent of those treated, less than half of people with depression get the help they need.

Greater risk

Unfortunately, while depression can strike anyone, people with PD may be at greater risk.

The true prevalence of depression among people with Parkinson's disease is difficult to determine, primarily because there are no standardized assessment tools designed to evaluate depressive symptoms in PD. However, it is undoubtedly common, with most experts estimating that as many as half of the people with Parkinson's suffer from depression at some time.

In fact, scientists have long debated whether depression is the result of a person realizing they have Parkinson's, or whether it has an underlying connection to PD itself. New evidence seems to point to a definite connection between the two conditions.

"The same neurotransmitters that are implicated in the development of PD, such as dopamine and seratonin, are also known to play a role in depression," notes Dr. Diana Koszycki, Research Director, Stress and Anxiety Clinical Research at the Royal Ottawa Hospital and an Associate Professor of Psychiatry, University of Ottawa.

In addition, recent studies at Columbia University have linked a gene known to cause the movement disorder known as dystonia with a type of early onset depression, leading researchers to investigate the possible link between movement and mood in conditions such as PD.

"There's a huge amount of suffering out there due to the depression that comes so frequently as part of Parkinson's disease."

“Whatever the reason, the reality is that many people with Parkinson’s will suffer from clinical depression,” Dr. Koszycki continues. “The combination of the two can have a tremendous impact. A recent study of people with Parkinson’s in six countries showed that the concurrent presence of depression was a major contributor to a lower quality of life.”

Experts estimate that of the individuals with PD who become depressed, about 50 per cent have “serious” depression that can have a significant impact on their lives. The remainder suffer from milder forms of depression, which can still be distressing to themselves and their families.

Warning signs of depression

- persistent sad, anxious or “empty” mood
- feelings of hopelessness, pessimism
- feelings of guilt, worthlessness, helplessness
- loss of interest or pleasure in hobbies and activities that were once enjoyed
- decreased energy, fatigue
- difficulty concentrating, remembering, and making decisions
- insomnia, early-morning awakening, or oversleeping
- appetite, weight loss, overeating or weight gain
- restlessness, irritability
- persistent physical symptoms that do not respond to treatment, such as headaches, digestive disorders, and chronic pain
- thoughts of death or suicide

If you or a loved one is experiencing up to five of these symptoms for more than two weeks, this may represent a serious depressive episode. If so, talk to a doctor as soon as possible.

Source: National Institute of Mental Health

"There’s a huge amount of suffering out there due to the depression that comes so frequently as part of Parkinson’s disease,” says Dr. Irene Richard, Associate Professor of Neurology and Psychiatry at the University of Rochester Medical Center in Rochester, New York. “The depression is part of the illness, not simply a reaction to the disease.”

Dr. Richard agrees that depression can be devastating. “Quite simply, it’s the number-one factor responsible for poor quality of life among PD patients,” she states.

Facing up to depression

Dr. Richard also believes that many people with Parkinson’s and depression fail to do anything about it. “Many patients assume it’s normal to feel this way,” she notes. “They might say, ‘If you had Parkinson’s, you’d feel this way too.’ That's not necessarily true. Depression is one aspect of the condition that may be very treatable.

“We’ve found that if a physician brings up the topic, people will be honest and will discuss their depression, but most times they won’t bring it up themselves,” Dr. Richard continues. “We need to educate people—both patients and physicians—to talk about depression.”

Before you can talk about depression, however, you have to recognize that you may have a problem. “We all experience the ‘blues’ from time to time, especially when something distressing happens,” Dr. Koszycki comments. “In most cases these feelings are transient and will pass in a day or two. Most of us think we will get over it, and we do. True clinical depression is something else. It lasts much longer and affects many aspects of your daily life. It’s not something that you can simply ‘snap out of.’ You need to be aware of the warning signs of clinical depression [*Editor’s note:* See Warning signs of depression]. And equally important, you have to be motivated to do something about them.”

According to Dr. Koszycki, if the symptoms of depression are present for a period of two weeks, you should talk to your physician or a qualified health professional. She also believes partners and informal caregivers have a vital role to play. "Sometimes, someone close to you will see the signs even if you don't," she advises. "They may see you withdraw, or bear the brunt of your irritability or silence. Spouses or other family members often are the ones who initiate the treatment process."

Seeking help

The good news is that, in most cases, depression can be treated. Effective treatment can reduce suffering and help improve your quality of life.

Common treatments for depression include antidepressant medications, psychotherapy, or a combination of the two. "In general, the newer generation of antidepressants are quite effective," explains Dr. Koszycki. "However, in PD some of these can be problematic, reacting with Parkinson's medications. In addition, there are no real studies showing how effective some medications are in treating depression in people with Parkinson's. As a result, we need to be careful which products we use and how we use them. But if chosen properly, medications can help.

"Therapy can be very effective in treating mild to moderate depression," she continues. "Cognitive behaviour therapy and interpersonal psychotherapy are two methods that I find particularly helpful for people with Parkinson's. I've found that many people respond quite well. It helps them come to terms with their condition, adapt, and still maintain a good quality of life."

Dr. Koszycki adds that psychotherapy is also a good alternative for people who simply don't want to take more medications. In fact, many experts will recommend a combination of medications and therapy.

Regardless of the treatment, the sooner you start it, the sooner you will begin to feel better. As with other medical illnesses, the longer you have the depression before you seek treatment, the more difficult it can be to treat.

Most people who are treated for depression find that their mood and functionality improves and it is easier to "get on with life." As Dr. Irene Richard says, "If you treat the depression, you'll still have the other symptoms of Parkinson's, but you may feel much better overall."

Depression can add to the burden of Parkinson's disease. By facing up to depression and seeking professional help, you can lessen that burden.

DON'T MISS AN ISSUE!

Coming in the Winter 2005 issue of *Parkinson Post*

We are the Faces of Parkinson's
Parkinson Society Canada (PSC) is launching an awareness campaign featuring the faces and stories of Canadians' living with the disease. Working with our regional partners across the country, our goal is to raise PSC's profile by highlighting local heroes. Read about our national campaign and about your fellow Canadians who live with Parkinson's disease.

SuperWalk 2005
SuperWalk 2005 was the most successful yet! Read about the walks held across the country; find out where Tom Cochrane, SuperWalk's 2005 Honourary Chairman, took part in his first walk; and share in the success of this year's SuperWalk.

Nutrition and Parkinson's
Learn why nutrition matters when it comes to Parkinson's disease, how it can optimize your health, how protein interacts with levodopa and other medications, and much more.

World's experts share Parkinson's knowledge:

A report from the 16th International Congress

By Lorelei Derwent, RN, O. Suchowersky, MD, and Carol Pantella, RN.

The 16th International Congress on Parkinson's Disease and Related Disorders held from June 5 to 9, 2005, in Berlin, Germany, highlighted the latest research and advances in the management of Parkinson's disease (PD).

The Congress, organized by the World Federation of Neurology, Research Group on Parkinsonism and Related Disorders, was chaired by Canada's own Dr. Donald Calne. More than 3,000 participants from 73 countries took part, including many Canadian doctors and scientists.

The theme of the Congress was "Present and Future Perspectives of Parkinson's Syndrome." Highlights included educational seminars, lectures, symposia, video sessions and over 600 poster presentations. A useful new feature to this year's event was guided poster tours and "Hot Topic" sessions highlighting the work of young up-and-coming scientists.

Gaining a better understanding

Researchers are gaining a better understanding of the pathogenesis, or causes, of PD leading them to believe that it is more complex and may, in fact, be a syndrome or multi-system disorder, rather than a single neurological disease.

Presentations at the Congress clearly showed that PD is more than a loss of dopamine neurons in the substantia nigra; additional areas of the brain and other systems are involved.

Motor symptoms of PD result from the loss of dopaminergic neurons in the substantia nigra. However, PD is also characterized by many non-motor symptoms, some of which may be presenting symptoms before the onset of motor symptoms. Some of these symptoms include olfactory dysfunction, anxiety, depression, sleep disorders, constipation, and erectile and bladder dysfunction.

Presently, there are good treatments and therapies available to treat motor symptoms. But neuronal degeneration continues and there are limited therapies to treat non-motor symptoms. A major goal of PD research is to develop strategies looking at "neuroprotection" —ways to slow or prevent disease progression. The development of neuroprotective strategies depends on the ability to identify the causes and pathogenesis of PD.

Researchers may look at going back to basic science, re-examining the disease and developing new models more relevant to humans.

Seeking new medications

Future pharmacologic strategies will involve studying the impact on disease progression, addressing non-motor symptoms, neuroprotection and dopa-related motor complications, such as dyskinesias. Researchers are working on better methods of treatment delivery; for example, a patch, continuous dopamine infusion by pump into the small bowel, and administration of once-daily medication.

Research is also being conducted on non-dopa strategies, such as acetylcholine inhibitors, other neurotransmitters and biotherapies, such as Spheramine—a potential new cell therapy. Spheramine, an investigational cell therapy, consists of cultured levodopa-producing retinal pigment cells (obtained from donor eyes) that are adhered to gelatin micro carriers. The cells are then implanted surgically in the striatum. A trial is currently being conducted to assess

Top photo at right
Oksana Suchowersky is ready to share her knowledge of her research "Bilateral Qualitative Impairments of Skilled Reach in de novo Parkinson's disease patients," a collaborative project with three other researchers.

Second photo from top
Dr. Donald Calne chats with Oksana Suchowersky about Canadian research and its important role in international Parkinson's research.

Third photo from top
Conferences attendees from around the world learn about Spheramine, an investigational new treatment for Parkinson's patients.

Bottom photo
The authors celebrate a day of learning by sampling some local fare.

this promising new therapy.

Stem cell and genetic research is ongoing, although as yet there are no practical applications in the clinical setting.

Advances in surgery

Surgical treatment continues to play an important role in PD management. Noted French neurologist Dr. Alim Benebid, who pioneered stimulation of the subthalamic nucleus (STN) in PD, discussed his 12-year experience in 250 bilateral STN cases. Overall, good benefits from surgery is still seen a dozen years later. Benefits include a reduction in medication doses and dyskinesias and an improvement in motor function.

Although a cure has not yet been found, it was encouraging to see so many people researching the etiology and pathogenesis of PD—going beyond symptomatic treatment and hopefully modifying the progression of the condition.

***Lorelei Derwent**, **RN**, **Dr. O. Suchowersky**, **MD**, and **Carol Pantella**, **RN**, attended the 16th International Congress on Parkinson's Disease and Related Disorders in Berlin on behalf of Parkinson Society Canada.*

For the love of Leo and Walter

The inspiration behind two young SuperSTARWalkers

Alyse Geiger and Melanie Ozdoba of Edmonton, Alberta, are two of the youngest SuperSTARWalkers. Alyse, 13-years-old, handed in pledges in 2004 for $8,746. This year, she again raised more than $8,000. Melanie, 13-years-old, has already completed six SuperWalks, starting when she was in grade two. Last year, her total reached $4,250. This year, she raised $5,700.

What motivates these kids? Youthful exuberance, determination, and love for two special men in their lives, their grandfathers Leo and Walter. The girls describe it best themselves.

My name is Alyse Geiger and I'm 13 years old. My grandpa Leo Geiger, who is a very special love of mine, has Parkinson's disease.

Grandpa Leo is the most loving, kind, sensitive man I know. He has very courageously lived with Parkinson's disease for 20-plus years. It was only about three years ago that I realized just how much this disease has affected his life. As each of his grandchildren were born, Grandpa Leo would build either a doll bunk bed for his granddaughters or a deacon's bench toy box for his grandsons. Parkinson's has robbed him of his wonderful gift of working with wood. His hands shake too much now, and he is not able to use saws safely anymore.

Making a difference

At the age of 11, I decided that I wanted to make a difference in the lives of my Grandpa Leo and other people who suffer from Parkinson's disease, so my family and I brainstormed about how we could raise money for SuperWalk for Parkinson's. We decided that we would not only ask friends and family for pledges but also host garage sales, with all the proceeds being donated to the Parkinson's Society of Alberta. The first year, my goal was $1,000, and I actually raised $1,400. The second year, I set my goal at $7,000 and raised $8,746. This year, I have set my goal at $10,000, and I am working very hard to achieve this.

Phase one of my fundraising consists of contacting all my previous year's sponsors as well as any new people who I think might be willing to sponsor me. One moment that really touched my heart happened recently. After I rang a doorbell at one neighbourhood home, a lady I did not know answered. I explained my fundraising efforts for Parkinson's. She gave me a big hug and a $5 cheque. The cheque was not very easy to read, and she said, "I'm sorry I cannot contribute more, but I live on one income. I have Parkinson's disease, so the writing is not very easy to read. Good luck dear, and thank you so much for helping [those] who live with Parkinson's." My heart was singing as I walked away from her house, and I felt so blessed that I could help people living with Parkinson's know that they are not forgotten and that many people care about them in their struggle with their illness.

Phase two consists of hosting garage sales, and phase three consists of asking everyone I come in contact with to sponsor me. From my experience, young people are very powerful when it comes to fundraising to help find a cure for diseases. I am very fortunate to have the moral and financial support of my school, neighbourhood, family, friends and many other people who live with Parkinson's.

Attending an important event

At SuperWalk, Grandpa Leo is not

Alyse and Leo.

able to walk with us, but he is always there to meet us when we cross the finish line. My cousin Marissa and I usually walk together, and Grandpa always greets us with tears in his eyes. As you can see, SuperWalk for Parkinson's is an extremely important event, not only to help raise funds for Parkinson's research but also to show people who suffer from Parkinson's disease how much they are loved by having their families and friends come out and walk in support of them.

Helping in the quest for a cure

When I first started fundraising, I was curious as to what it was all about. I have come to know that the person who benefits the most from my fundraising efforts is me. Every time I become tired of collecting items for garage sales, or cleaning, pricing and selling them, I hear my Grandpa's quiet voice telling me how proud he is of me, and I have the energy to carry on with the next sale, phone call, or pledge. I know in my heart that all my efforts will make a difference in finding a cure and in helping people like my Grandpa live a more normal life.

Aly Steiger

My name is Melanie Ozdoba and I'm 13 years old. I have been a volunteer for the Parkinson's Society of Alberta for seven years—more than half my life. Why did I participate in seven SuperWalks, fundraise all year round, sell tulips in April, distribute SuperWalk packages to many businesses year after year, and play Santa's elf at the Parkinson's Christmas party? The answer is easy: I do it for my grandfather Walter Meyer, whom we call Bestefar (that's grandfather in Norwegian).

My Bestefar, who has Parkinson's, is the most loving, kind, and funny person I know. He always sees the positive in every situation, always has a smile on his face, and is proud of his family.

Deciding to participate

My love for Bestefar motivated me to walk in my first SuperWalk when I was in grade two. I wanted to do something to make him feel good and to make a difference. My Bestefar came to my first SuperWalk and was at the finish line to cheer me on. I felt I had made a difference not only for my Bestefar but also for others who struggle with Parkinson's. I am so glad I participate.

My Bestefar is now in a continuing care facility. It is really hard to see him struggle through his days, but he never complains and is always so excited to see us. I love it when he tells me he is so proud of me that his buttons are popping off. His love and his pride keeps me going.

Raising funds

Part of my fundraising involves collecting, sorting, and taking in bottles and cans for refunds. It takes a long time to collect enough bottles and cans to reach a goal of $5,000. (I do get some sponsors too.) At times, it is difficult, but my family and friends help.

My volunteering is important because I help raise money for research, help people become aware of the struggles of those who suffer with Parkinson's, and help the environment. Participating makes me feel great about myself. It is hard to describe how I feel about knowing I'm doing something to help my Bestefar and others.

Melanie.

Helping people with Parkinson's

My wish for the Parkinson's Society is that they are able to help individuals that suffer with Parkinson's and provide the support people need. I really want all the people suffering with Parkinson's to know they are not forgotten and that they are important.

I will always be a volunteer, as it has become a part of who I am. I really hope that my volunteering inspires other kids to lend a hand. I know that together we can help make the world a wonderful place for everyone. I can see my Bestefar smiling now!

Melanie Ozdoba

Parkinson's research around the world

Research Editor: Dr. John Wherrett

Parkinson's disease and cancer

The recent discoveries relating to the genetics of Parkinson's disease (PD) suggest a very interesting relationship to cancer.

Studies associating Parkinson's with other diseases and environmental exposures over the past 20 years have consistently found that people with PD have a reduced risk of dying of cancer, particularly those forms of cancer not attributed to smoking.

At least five of the genes in which mutations can result in PD produce proteins that are required for regulation of protein shape and disposal in the cell. When this regulation breaks down, types of protein that are toxic to healthy cells may collect. With the greater understanding of the biochemical workings of cells and tissues achieved in the last few decades, we now appreciate the remarkable efficiencies in which biochemical processes commonly serve more than one function. This appears to be true of these particular genes and the protein-regulating system.

Indeed for some of these genes, research has already shown that they play a role in regulating the abnormal cell proliferation associated with cancer. For example, the Parkin gene (the gene shown to have mutations most commonly causing PD) was already known to be abnormal in other ways in different kinds of cancer. From the information now available, it is reasonable to theorize that specific mutations in one of these genes might predispose a person to cancer while protecting him from PD, while a different mutation might predispose a person to PD and protect him from cancer.

Experiments are now possible to determine if specific forms of PD are protected from, or predisposed to, cancer, and if this can be demonstrated in animal models. This could lead to the investigation of broader questions; for example, why and how the mutations lead either to Parkinson's or cancer and if other cancer genes play a role in the development of PD.

Reference: *Trends in Neuroscience*, July 2005.

A life-style prescription for Parkinson's disease?

People with Parkinson's and their families frequently ask about the role of diet and mental and physical activity in preventing and delaying the progress of Parkinson's disease (PD). Talk about healthy diets and the importance of staying mentally and physically active are all very well, but what is needed is practical information on what specific measures may be helpful.

Research into the specific benefits of diet and activity in PD has been accelerating. For many decades, it has been suspected that dietary restriction in humans, such as fasting, skipping meals and reducing intake of calories, is associated with increased freedom from degenerative disorders, such as PD and heart disease. These observations have prompted animal studies that have begun to show, in convincing fashion, how caloric restriction, mental stimulation and exercise not only prolong life but protect against Parkinson's, Alzheimer, and Huntington's disease as well as heart disease and stroke.

In the last five years in particular, it has been possible to use animal models of PD (produced by insertions of human disease-causing genes into test animals) to understand what happens in the brain subjected to caloric restriction, mental stimulation and physical exercise. Not surprisingly, these interventions have multiple effects; for example, they stimulate production of proteins that protect against stress in the nerve cell in the form of excessive oxidation, energy failure and distorted calcium balance—stresses that are common in all of these diseases. The interventions also promote synthesis of growth factors that favour formation and maintenance of nerve cells (such as adult stem cells) and formation of new nerve connections.

This work is a great example of how discoveries in one aspect of Parkinson's research—for example, the identification of genes in families with Parkinson's—stimulates work in other fields that could ultimately lead to very practical "non-medical" means for reducing the burden of the disease. It may also be possible,

EDITOR'S NOTE: Please remember that clinical studies, research findings and other information featured in *Research Report* are often of a preliminary or investigative nature. Results may not be applicable to all cases and actual treatments resulting from findings can take time to be developed. The information contained here is for interest only and should not be construed as advice or recommendations.

through an understanding of the changes caused in the brain, to devise medical means to protect and preserve brain function in those who are unable to exercise or tolerate a restricting diet.

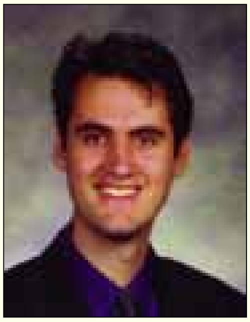
Reference: *NeuroRx: The Journal of the American Society for Experimental NeuroTherapeutics*, January 2004.

New avenues for treatment being explored

Recent genetic and cellular discoveries could eventually lead to therapies that actually limit the neuronal degeneration responsible for the progression of Parkinson's disease according to leading Canadian researchers.

Writing in *Scientific American*, Dr. Andrew M. Lozano and Dr. Suneil Kalia of Toronto Western Hospital explain that advances in the understanding of the role of proteins and genetics have lead to a number of promising lines of investigation. These include the use of so-called chaperone cells to limit neurodegeneration, the use of neurotrophic factors, and the use of gene therapy to "shut-down" areas of the brain that become overactive when dopamine production declines.

Reference: *Scientific American*, July 2005



Focus on …

Dr. Frederic Calon

Laval University
Quebec City, Quebec

Dr. Frederic Calon's goal is to break down barriers–or at least, one barrier in particular. Dr. Calon and his team at Laval University are trying to find a way to overcome the so-called blood-brain barrier that prevents a promising anti-Parkinson drug from reaching the areas where it may be effective. The blood-brain barrier is a microscopic physical barrier that stops substances in the blood vessels from crossing into the central nervous system.

"There are several potentially therapeutic drugs that are simply not available to people suffering from conditions like Parkinson's because they do not cross the blood-brain barrier," Dr. Calon explains. "One such drug candidate is glial-derived neurotrophic factor, or GDNF. This has been shown to be effective in slowing down or reversing the neurodegeneration of dopamine cells, a root cause of Parkinson's disease. Right now, because GDNF doesn't cross the blood-brain barrier, the only way to administer it is through expensive and invasive stereotaxic injection, which involves drilling a hole in the patient's skull. It's not practical for widespread usage."

Dr. Calon's work is focused on finding a way of delivering GDNF intravenously. "We need a vector, a molecule that will carry the drug past the blood-brain barrier," he explains.

The research is complex and takes up most of his time. The rest is spent in teaching and other academic duties at Laval University, the institution where Dr. Calon got his start.

He received his pharmacy training at the university, complementing his degree in biochemistry. He also first became interested in Parkinson's here, doing research with the respected team of Dr. Paul Bedard and Dr. Therese DiPaolo. After some time at UCLA in California, he returned to Laval University where, among other accomplishments, he was awarded the Canadian Institutes of Health Research New Investigator Award.

"My experience with monoclonal antibodies at UCLA has proved very valuable in our current research," Dr. Calon notes. "But it is still painstaking work. However, indications are that our strategy is working and we are making progress.

"If we are successful, it might mean that GDNF, and other large molecule drugs, could be used successfully to treat Parkinson's disease."

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca

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

- PSC announces the first competition of our July 2006 to June 2008 research cycle. Applications are being accepted for the Clinical Research Fellowship and the Boehringer Ingelheim Clinical Movement Disorders Fellowship. **For more information including research guidelines and applications forms, visit www.parkinson.ca/research/grants.html.**
- Increase your knowledge of Parkinson's disease. **Click on Parkinson's and then click a topic under the "What you need to know about Parkinson's" on the right hand side of the new page.**
- Connect to different Parkinson's organizations worldwide and other health-related websites. **Click on Parkinson's and then click on Links on the right hand side of the page.**
- Get all your regional news, including the latest update about SuperWalk. **Click on the map of Canada to view regional information.**
- The third annual Donald Calne Lecture and 2005 Annual General Meeting will be held in Winnipeg, Manitoba, from November 4–6, 2005. This year's recipient, Dr. Zbigniew Wszolek, from the Mayo Clinic in Jacksonville, Florida, will present the lecture. **Click on Research and then Donald Calne Lectureship on the right hand side.**

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

How the Hooydonk family made a difference

With roots in Holland, patriarch Tony Hooydonk settled in London, Ontario, to begin the successful Grandpa's Garden Landscaping. But life has many challenges, and Tony developed Parkinson's disease.

To honour this warm, gentle man, the Hooydonk family decided to make a planned gift to Parkinson Society Canada's research program, and they named PSC as a beneficiary of a RRIF. With the careful planning of their professional advisor, several goals were considered. First, the family wanted to control their assets during their lifetime. Second, they wanted to make a significant gift to help find a cure for Parkinson's. Finally, they wanted to ensure that taxes on their estate are minimized.

The Hooydonk's wishes are now being fulfilled. Together, they enjoy a feeling of great satisfaction in arranging "the gift of a lifetime" to the PSC—a legacy that will help the search for a cure.

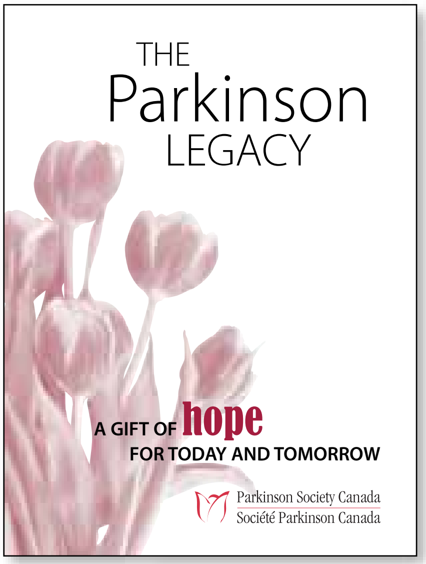
Editor's note: For information on the Parkinson Legacy, please visit www.parkinson.ca/donating/theparkinsonlegacy.html or call Roger D. Ali at 1-800-565-3000.

A win-win financial planning option

By Rachel L. Blumenfeld, BA, MA, LLB, Miller Thomson LLP

An individual's tax bill on death is often much higher than during lifetime, because, on death, a person is deemed to have disposed of all capital property. Any capital gains that have accrued become taxable, unless the property is left to a spouse or to a disabled or dependent child or grandchild. In addition, the value of any RRSPs or RRIFs owned by the deceased as of the date of death are included, even though they are paid out directly to a named beneficiary.

However, when a registered charity (e.g., Parkinson Society Canada) is designated as the beneficiary of a RRIF or RRSP, the estate of the deceased individual can use the tax credit for the donation in the terminal tax return. If the amount of the donation exceeds 100 per cent of the deceased's net income, the remaining amount can be carried back to the previous tax year.


THE Parkinson LEGACY

A GIFT OF hope FOR TODAY AND TOMORROW

Parkinson Society Canada
Société Parkinson Canada

Let's look at the advantages. Joe and Mary owned a house and a cottage. Joe had a RRIF, and the couple together held about $50,000 worth of GICs and bonds. Mary passed away in 2002, and Joe died two years later.

At Joe's death, there was $200,000 left in his RRIF. The cottage was valued at $550,000—$400,000 more than he and Mary had paid for it 20 years earlier. The house was worth $750,000.

Because the cottage was not his principal residence, Joe's estate would be liable to pay the capital gains tax on the increase in value. The amount of $200,000 (50 per cent of the capital gain) was included in Joe's income in his terminal tax return, along with the full amount of the RRIF ($200,000). The tax on these assets was over $100,000.

Joe's two children were afraid they would have to sell the cottage to pay the taxes. However, after Mary's death, Joe changed the beneficiary on his RRIF from Mary to Parkinson Society Canada (PSC). The resulting tax credit the estate received offset about half of the tax payable. The funds in the GICs and bonds were sufficient to pay the tax liability. The children were able to keep the cottage and PSC received a significant donation to help in the fight against Parkinson's disease.

My voice is making a difference: Speaking out on Parkinson's

By Gerry Kelleher, Milton, ON.

I was diagnosed with young-onset Parkinson's disease three years ago, but I can trace it back six years. By the time I was diagnosed, I had tremors, I had lost the use of my left arm and my sense of smell and taste, my voice was affected, and my writing was so small that people could not read it.

Fighting Parkinson's

The medication I was prescribed gave me back my life. One day while at a restaurant with my wife, I noticed I was regaining the use of my left arm. My wife and I leaped from our seats and we hugged each other. I decided that I was going to fight Parkinson's and win. I decided I was going to use this disease to my advantage. I was going to raise money for research and help the politicians understand this disease. I soon contacted Parkinson Society Canada (PSC) for assistance. I shared my goals and told them of my determination to see this through. Their support was immediate.

My fight for the cure started two years ago when I secured a meeting with a Health Canada official. The meeting was a great success. The woman said that Health Canada wanted to be a part of finding the cure for Parkinson's, and she asked us to send her more information on research. I quickly realized the need for a voice for increased funding for Parkinson's. The voice would need to be non-confrontational. It would unite people to forge a path and to stay on that path to the discovery of a cure.

An improvement in his symptoms inspired Gerry Kelleher to lend his voice to Parkinson's advocacy.

Photo: Mike Heffernan, Binary Rhyme

Last spring, I returned to Ottawa and met with a senior official with Health Canada. He was very understanding and encouraged me to work with PSC and come back with more information and a formal proposal. I have since done that and now anxiously await Health Canada's response.

Seizing every opportunity

Grabbing every opportunity I could, I went to a roundtable on Health Care Reform, where I met a former Ontario minister and a doctor. Much to my dismay, neither knew much about Parkinson's. It became clear that if we are to raise funds to find a cure for this disease, we must educate politicians, medical professionals, and the public about Parkinson's. I am now on two PSC advocacy committees: one at the national level and one in Ontario. My voice is making a difference.

I refuse to let this disease keep me from living my life. I adjust my day to rest briefly and recharge. Having Parkinson's has given me a golden opportunity for self examination. I say to people "Thank God I have Parkinson's." After I see the blank looks on their faces, I say I am so lucky for there are far worse diseases than mine.

By thinking positive, I will achieve my goals: to help the Government of Canada understand the need for increased funding; to have funding directed to the research that holds the most promise; to educate the medical profession about Parkinson's; and to educate the public on young-onset Parkinson's.

Being heard

No matter what I have been through, I have risen above it. By focusing on your goals and learning from your mistakes and achievements, you too can drive forward with confidence and pride. Remember, your voice can make a difference. Let us help each other educate Canadians on Parkinson's.

Ask the Expert

Q ***I have Parkinson's and my husband and I would like to have a child. Will my Parkinson's medications affect my baby?***

A Because so many drugs are used to treat Parkinson's, a pregnancy in a woman with the disorder raises difficult questions about what effects her medications may have upon her child. The whole question of pregnancy should be discussed in detail by both prospective parents and with the physician, preferably before the woman becomes pregnant. The discussion should include the stage of her disease, the exact diagnosis, and the prognosis (anticipated progression of the disease). Although the progression of Parkinson's in younger people varies widely, overall it tends to be slower than when the disease begins at an older age.

Fewer than 50 pregnancies have been reported in Parkinson's patients. Despite this limited base of knowledge, some helpful guidelines and findings are available.

Animal studies have shown that levodopa can cause fetal abnormalities including low birth weight and liver, heart and bone problems but only when given in very high doses (500 mg/kg). All dopamine agonists in high doses have been shown to lower pregnancy rates in animals. Among them, pergolide, bromocriptine and pramipexole seem safe, but high doses of ropinirole may cause reduced survival rates in lab animals. Selegiline is associated with an increase of miscarriages and still births.

Human experience shows that Parkinson's may worsen, improve or be unchanged during pregnancy, but there have been cases where the symptoms did not improve after delivery. If the mother is already on antiparkinson medication, stopping it may not be a good option. Levodopa use during human pregnancy has not been associated with any major maternal problems, but one case of osteomalacia (bone softening) in an infant has been reported. Bromocriptine has been widely used to facilitate pregnancy in women with prolactin disorders who did not have Parkinson's—prolactin is a hormone involved in breastfeeding, among other things, and its production is affected by dopamine—and was used in at least one woman who did have the disease, and all was well.

There is similar but more limited experience with pergolide in women without Parkinson's. There is one report of a woman using pramipexole during her pregnancy, but her Parkinson's symptoms deteriorated. Major birth defects have been reported in humans following the use of amantadine, and there are no reports on selegiline but neither of these two drugs should be used by a woman who is pregnant.

It's quite feasible for a woman to breastfeed while on antiparkinson therapy. Dopamine agonists interfere with lactation, so they probably should not be used, but amantadine shows up in breast milk in very low amounts but no infant problems have been reported. We don't know whether selegiline is excreted in milk. Levodopa does appear in breast milk, but the dose the infant receives is small and no problems have been reported.

Our experience with Parkinson's in human pregnancy is limited. However, by combining our knowledge of animals and humans, we can come up with the following general guidelines:

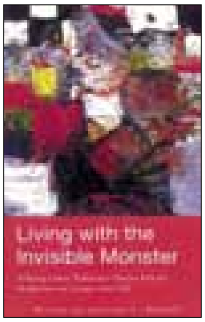
- Parkinson's may worsen during pregnancy.
- You should not suddenly stop taking any drug.
- During pregnancy, levodopa is probably safe, but experience with animals suggests caution.
- Dopamine agonists seem safe, judging from extensive use among women without Parkinson's.
- For breast feeding, levodopa is safe for the infant but dopamine agonists may reduce lactation.

With a positive family approach, your children will grow up well equipped to handle other crises in life. As one Parkinson's mother reports, you will be rewarded with comments like "Mom doesn't smile as much as before [because of reduced facial expression], but she always smiles in her heart."

Dr. David Grimes
Parkinson's Disease and Movement Disorder Clinic, Ottawa, ON

Editor's note: Adapted from Dr. Grimes' book, *Parkinson's: Stepping Forward*, Copyright (c) 2004. Reprinted with permission of Key Porter Books.

Resources



Living With the Invisible Monster

By Kathleen E. Webster

Reviewed by Bonnie Bereskin

The invisible monster, Parkinson's disease, presents particular challenges to the person with young-onset. Author Kathleen Webster first noticed her symptoms at age 33. In her book, she vividly describes dealing with the symptoms of Parkinson's while trying to be a loving mother, wife and teacher.

Family, work, and financial strain are often part of the lives of young people with Parkinson's. At times, the challenge is overwhelming. Webster describes the supports that allow her to manage.

The book would have been better if it did not have as much detail about the author's personal life; however, Webster's courage, perseverance and willingness to accept solace from family, support groups, and medical professionals are among the book's great strengths.

Visit your local bookstore to order a copy.

Parkinson's Disease and Me

By Patricia Lightner

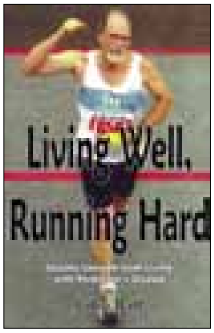
Reviewed by Ron Penwarden

Parkinson's Disease and Me is the story of one person's brave struggle with Parkinson's. Lightner is obviously hopeful and optimistic that a cure is "just around the corner." In fact, she is a vocal advocate of stem cell research and the pursuit of a cure.

However, the dated material, occasionally repetitive, offers nothing new to the informed reader. There is a lot of information about Parkinson's disease that could easily be obtained from other manuals. And she has nothing new to say about research. The different bills that she discusses are irrelevant as far as Canada is concerned.

If tightened up and brought up-to-date, this could be a good book, but, as it stands now, it is not relevant for the Canadian reader.

Available at a bookstore near you.



Living Well, Running Hard

By John Ball

Reviewed by Peter Oliphant

John Ball is a survivor of early-onset Parkinson's disease. Approaching age 40 in the early 1980s, he experienced the frustration of trying to find a doctor who understood the cause of his physical decline that began a suspected 15 years earlier.

Ball had been a runner most of his adult life, and, in spite of his Parkinson's diagnosis, he ran his first marathon in 1996. He continued running in annual fund-raising marathons until 2003. Throughout *Living Well, Running Hard*, it is clear that Ball believes that exercise can slow and even temporarily reverse the advance of PD.

Ball writes well. Runners may love the book. Others may find themselves skimming the lengthy descriptions of his athletic experiences; however, no one can fail to admire his courage, conviction and spirit.

Living Well, Running Hard is available through your local bookstore.

www.bambooweb.com

Reviewed by Peggy Yates

The Bamboo website is an on-line encyclopedia, which, among other topics, offers information about Parkinson's disease and its causes, treatments, and related disorders. The "view live article" icon will take you to another area of the site where you will find links to external sources of information such as articles, books, and so on.

Also posted on this encyclopedia-based website are other related topics of interest to persons living with Parkinson's such as depression, dizziness, speech impairment, swallowing difficulties, and more.

To learn more, visit www.bambooweb.com/articles/p/a/Parkinsons_Disease.html.

Please remember that while Parkinson Society Canada provides information about the availability of new resources in this section, this does not necessarily imply recommendation or endorsement of the contents.

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Toll Free: (800) 565-3000, ext. 3385
www.parkinson.ca/donating/theparkinsonlegacy.html

Parkinson Society British Columbia
Ph: (604) 662-3240
Toll Free (BC only):
(800) 668-3330

Victoria Epilepsy and Parkinson's Centre Society
Ph: (250) 475-6677

The Parkinson's Society of Alberta
Ph: (780) 482-8993
Toll Free: (888) 873-9801

The Parkinson's Society of Southern Alberta
Ph: (403) 243-9901
Toll Free (Alberta):
(800) 561-1911

Saskatchewan Parkinson's Disease Foundation
Ph: (306) 966-1348

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

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