Spring 2003 ▪ Volume 3 ▪ Issue 1
$4.50

ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Long term planning:

Wayne Buchanan and others share why you need to act *now*

PSC salutes outstanding volunteers

Ali brings his message to Canada

PLUS:
The latest news in Parkinson's research

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

Sales Product Agreement No. 40624078. Photo D. Bonner, Canadian Press

Controlled-Release
SINEMET® CR

If you would like more information about Parkinson's and its management, you can discuss treatment options with your physician or call Bristol-Myers Squibb for medical information at **1-800-267-1088** extension 4302 or 2078.

SINEMET® CR

levodopa/carbidopa controlled-release

Bristol-Myers Squibb
Pharmaceutical Group

Letter from Parkinson Society Canada

Leaving a legacy

It's not often that we get to write about a million-dollar legacy. This extra-ordinary story is about two brothers and their life-long journey from humble family beginnings in Sicily to Hamilton, Ontario. Over many years Frank and Angelo Agro worked in and operated the growing family fruit business. They went into the 'cow' business, developing an empire that included an artificial insemination center visited by breeders from around the world. Eventually, they owned five farms. Along the way, their personal wealth grew exponentially. They both drove old and run-down vehicles, and while they were alive, they spent very little money.

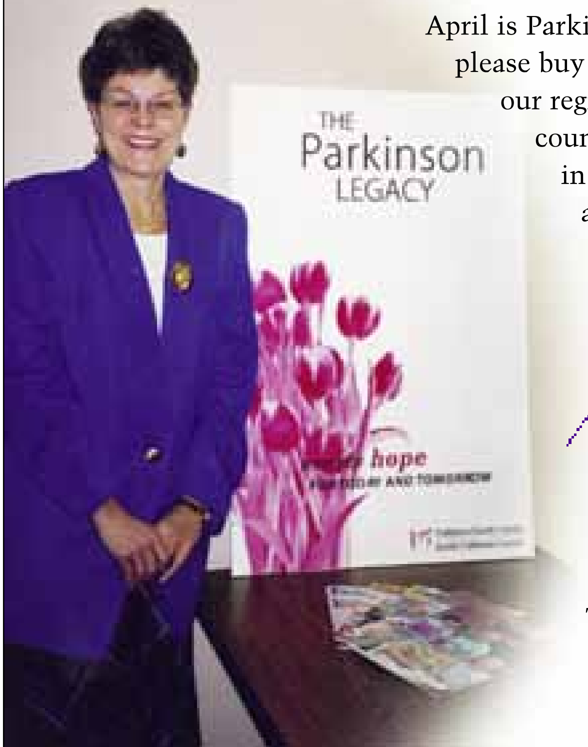
The brothers never married. They outlived four siblings. Angelo developed Parkinson's disease, and then had a stroke. He died in 1996. Frank passed away in June 2000. Before they died, Frank and Angelo created their six million dollar-plus legacy. Six organizations (five health-related and one university) were named as beneficiaries. They wanted to give back to the city that had given them so much. They wanted to ensure that several health charities had significant funds to address those conditions/illnesses that plagued their family.

Parkinson Society Canada is one of the six beneficiaries. We are humbled by this gesture, and so very grateful to Frank and Angelo Agro, who had the foresight to know what this kind of legacy would mean.

We are grateful, too, to the lawyers, volunteers, family and staff who worked on this estate over several years. This legacy is a sterling example of goodwill and teamwork from all perspectives.

As we inaugurate "The Parkinson Legacy, a Gift of Hope for Today and Tomorrow" program at Parkinson Society Canada, it is very timely to take a moment to acknowledge the generosity of two brothers who, through their legacy, will make an enormous difference in the lives of Canadians with Parkinson's.

April is Parkinson's Awareness Month – please buy fresh cut tulips on sale through our regional partners across the country and watch for our Hope in Bloom display cards on sale at National Bank branches, Garden Centre Co-ops and other retailers across Canada.



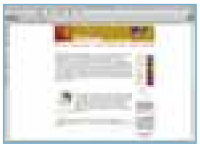
Mary Jardine

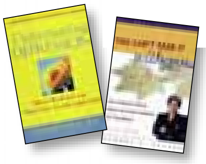
Mary Jardine,
National Executive Director,
Parkinson Society Canada
Toronto, ON

Contents

FEATURES

COLUMNS





ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

Parkinson Post Vol. 3, Issue 1, Spring 2003

Parkinson Society Canada
4211 Yonge Street, Suite 316,
Toronto, ON M2P 2A9

Editor:
Suzanne Tobin

Publisher:
BCS Communications Ltd.

How to contact *Parkinson Post*:

Parkinson Post
4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
Phone: (416) 227-9700
Toll Free: (800) 565-3000
Fax: (416) 227-9600
E-mail: editor@parkinson.ca
subscriptions@parkinson.ca
Website: www.parkinson.ca

Parkinson Post (ISSN #1489-1964) is the official publication of Parkinson Society Canada, and is published quarterly by BCS Communications Ltd., 101 Thorncliffe Park Drive, Toronto, ON M4H 1M2. Tel: (416) 421-7944 Fax: (416) 421-0966. All rights reserved. Contents may not be reproduced without permission of Parkinson Society Canada. Printed in Canada. All material related to Parkinson's disease contained in this magazine is solely for the information of the reader. It should not be used for treatment purposes. Specific articles reflect the opinion of the writer and are not necessarily the opinion of Parkinson Society Canada or the publisher. Canadian Publication Mail Sales Product Agreement No. 40624078. © 2003

Advertising Policy
The acceptance of advertising in *Parkinson Post* is not an indication that Parkinson Society Canada or any of its divisions endorses any of the products or services listed. For people living with Parkinson's, it is recommended they consult their health professionals before using any therapy or medications. Parkinson Society Canada accepts no responsibility for any claims made in any advertisement in *Parkinson Post*.

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.parkinsonbc.ca

- Sent $83,000 to PSC and $12,500 to UBC for research.
- *Newly Diagnosed* video with Mandarin voiceover now available.
- PSBC hosted a Chinese speaking regional conference in Vancouver on January 18 with keynote speakers Dr. Tsui, Neurologist, and Dr. K.C. Li, Psychiatrist.
- Hosted an education meeting January 25 in Vancouver with keynote speaker Susan Calne, CM, RN, Coordinator, Pacific Parkinson's Research Centre.

Victoria Epilepsy and Parkinson's Centre Society

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

- Fall education event by a local geriatric physician on 'Practical Management of Parkinson's' was very well attended.
- Evening series for newly diagnosed and family members resulted in participants opting to join an ongoing group program.
- Topics for upcoming education events with expert presenters include 'Getting the Most from Your Medications', 'The Power of Exercise for Parkinson's', 'Managing Speech and Swallowing Changes', 'Stress and Anxiety Management', 'Eyesight, Aging and Parkinson's'.
- Several fundraising events are planned for the next few months.

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

- Successfully completed our second 'Education in Action: Speech, Swallowing and Communication' program in conjunction with the University of Alberta in Fall/Winter 2002.
- Started preparations for our eighth Annual 'Hot Wing Eating Challenge for Parkinson's' to be held in March.
- Planned activities for PSA's 30th Anniversary in 2003 include an open house in March and quilt raffle.

The Parkinson's Society of Southern Alberta

480D 36th Avenue SE
Calgary, AB T2G 1W4
Ph: (403) 243-9901
Toll Free (Alberta): (800) 561-1911
Fax: (403) 243-8283
E-mail: pssa@canuck.com
www.parkinsons-society.org

- February 23, 2003: Traditional Chinese New Year dinner hosted by Calgary Taoist Tai Chi Society. Proceeds to benefit PSSA.
- February 4 and 5: PSSA showcased their 'Tulips of Distinction' Planned Giving Program at Leave-a-Legacy Calgary's two-day Wills Workshop.
- Speech improvement workshops scheduled for March, April and May 2003.
- April: AGM, Cut-A-Thon for Parkinson's, participation in MDC's Brain Awareness Day (April 12), and various activities for Parkinson's month.

Saskatchewan Parkinson's Disease Foundation

Box 102, 103 Hospital Drive
Saskatoon, SK S7N 0W8
Ph: (306) 966-8160
Fax: (306) 966-8030

- Tenth Annual Regina Curling Classic for Parkinson's Research. Popular auction Friday, April 4 at the Victoria Club and the curling at the Callie Club, Saturday, April 5.
- Parkinson's Clinic in Regina held two days each month. Phone 1-306-966-8009 for appointment.
- Saskatchewan has seven Parkinson's support groups. Each has books and videos in their library.

Parkinson Society Manitoba

825 Sherbrook Street, Suite 204
Winnipeg, MB R3A 1M5
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 786-0860

- First formal by-laws for the region have been completed and adopted by the Board.
- Ian Yamron Memorial Golf Classic doubled last year's revenues, raising over $30,000.
- Planning a corporate launch event for SuperWalk 2003 for February and our annual April Awareness event to introduce families with Parkinson's to the Society's services.

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

- Launched a new regional newsletter to keep members informed of regional events and Parkinson's information.
- Developed first regional brochure describing our services for medical professionals and people with Parkinson's. Plan to distribute 10,000 copies province-wide.

PSC Central & Northern Ontario Region

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

- April awareness plans include: 'Tea for Two, or More' with sponsorship from Mother Parkers, and fresh-cut tulips for sale across Toronto.
- Golfers will tee off at Granite Ridge in Milton on June 11, and baseball fans are invited to join the Blue Jays in the annual Pitch-In for Parkinson's on June 26.
- Long-term care initiatives are moving along with a strong volunteer committee and in-services taking place with health professionals and students in community agencies, colleges and private facilities.
- Plans are underway to develop a Toronto District, with the help of a cross-section of key stakeholders in the city.

PSC Southwestern Ontario Region

4500 Blakie Road, Unit #117
London, ON N6L 1G5
Ph: (519) 652-9437
Toll Free Ontario: (888) 851-7376
Fax: (519) 652-9267
www3.sympatico.ca/pf.swo

- Support groups sold 45,000 Tulip Bulbs, creating excellent awareness.
- Recognized sponsors and volunteers who made 2002 campaigns so successful through major writing campaigns, Christmas open houses, and the Winter newsletter.
- Now re-convening Parkinson April Awareness Planning Committees with a special focus on a new Cut-A-Thon in Windsor.
- Working with volunteers to develop key community partnerships to enhance every aspect of our mission.

Parkinson Society Ottawa

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

- Holiday party, including a talent show featuring children through to seniors, provided wonderful entertainment.
- Assisted with the start-up of a new support group in Pembroke.
- Dr. Tilak Mendis gave a presentation on various research developments with the most potential.
- Family education nights are popular. We invite newly diagnosed people with Parkinson's and their families to hear presentations by health care professionals, about Parkinson's and coping mechanisms.
- Plans are underway to celebrate our 25th anniversary in 2003.

Parkinson Society Québec

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

- Created a young onset support group.
- Saw a seven percent increase in fruit cake sales, generating profits of over $61,000.
- Received a contribution of $5,000 (U.S.) from Medtronics for the InfoParkinson website.
- Launched the French Info-Parkinson electronic newsletter. Sent to those who subscribed on our website.

PSC Maritime Region

5991 Spring Garden Road,
Suite 290
Halifax, NS B3H 1Y6
Ph: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468
Fax: (902) 422-3797
www.parkinsonsocietymaritimes.ca

- Hosted the Moncton Forum on November 8 with guest speakers Dr. Reg Hutchings, PEI Neurologist; Mary Jardine, National Executive Director; Jill Pritchard, National Information and Referral Coordinator; and Dr. George Turnbull and Janet Millar from the Maritime Parkinson Clinic.
- Board of Directors held its semi-annual meeting in Moncton.
- Chapters and support groups across the region hosted holiday events such as parties, craft sales and dinners.
- Two new support groups have been established in Bedford/ Sackville and New Minas.

Parkinson Society Newfoundland and Labrador

31 Peet Street, Suite 219
St. John's, NL A1B 3W8
Ph: (709) 754-4428
Toll Free (NFLD/Labrador):
(800) 567-7020
Fax: (709) 754-5868

- Awarded Queen's Jubilee medals to Frances Nichols, Grand Falls-Windsor; and Denise Murphy, St. John's in December.
- Porridge for Parkinson's (and pancakes) event scheduled for February 22, at the College of the North Atlantic in St. John's.
- Provincial Parkinson conference scheduled for May 2, 3 and 4 at the Holiday Inn in St. John's.
- April Awareness: Central Dairies will be highlighting us on the side panel of their two litre milk containers.

The Advocate

Issues of interest to people with Parkinson's

Training decision makers about Parkinson's

Parkinson Society Canada recently had an opportunity to inform a key group of decision makers about the daily challenges of living with Parkinson's.

When an application for disability pension is refused, individuals can appeal the decision. If they appeal it, they must go before a three person government tribunal that includes a lawyer, a health care professional and a layperson. There are 300 tribunal members nationwide. PSC was invited to one of the training workshops for tribunal members.

Beth Holloway, a national board member with Parkinson's from Newfoundland, joined Maryann Istiloglu and Jill Pritchard from PSC's national office to explain what panel members need to understand about Parkinson's to knowledgeably review claims.

Parkinson's cruise

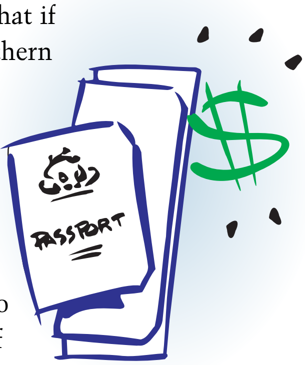
A unique vacation is available for people with Parkinson's, their caregivers and friends aboard the 2003 Parkinson Glacier Bay Alaska Cruise. The National Parkinson Foundation organizes an annual seven night cruise. Participants vacation with experts in medical management, research and caregiver outreach for the Parkinson community to learn the latest in coping strategies. Departing Vancouver on September 10, 2003. Prices range from U.S.$1380 to U.S.$1860 per person. Call Travel Syndicate/American Express at 1-800-248-0388 for a complete information package.

Make your voice heard!

As anyone who follows the news has noticed, many changes to our health care system are being discussed at various levels. If you have an opinion on the *Final Report of the Romanow Commission on the Future of Heath Care* or any of the other recent announcements, we'd like to hear from you! Please send your ideas and concerns to maryann.istiloglu@parkinson.ca. We need your input!

Income tax tip

Don't forget that if you are a northern resident and you have significant medical and related travel expenses, you may be able to claim some of them on your 2002 income tax return. Talk to your accountant or visit the CCRA website for more information: www.ccra-adrc.gc.ca/newsroom/factsheets/2003/jan/travel-e.html or www.ccra.gc.ca



CPP-D under review

The House of Commons Sub-Committee on the Status of Persons with Disabilities is undertaking a study on the Canada Pension Plan Disability program. They are reviewing the program's policies and operations in light of some of the issues and challenges that Canadians have identified. Parkinson Society Canada has prepared a submission in response to their call for input, to reflect the concerns of people with Parkinson's.

Ease the Burden; Find a Cure

Health Tips

Managing low blood pressure

Orthostatic hypotension is a fall in systolic blood pressure within three minutes of standing and may be symptomatic (dizziness, fainting) or asymptomatic (without symptoms).

PD patients with a combination of postural hypotension and impairment of postural reflexes are candidates for falls. Prevention strategies include: increasing intake of fluids and salt; remaining seated after a meal, a hot bath or shower for about 20 minutes; and always sitting down after any exercise, even walking around the house.

If you have very low blood pressure, it may go up too much when you lie down. We recommend that, when lying down, your head be 30 degrees higher than your feet. This can be done with lots of pillows, or by raising the head of your bed.

To learn more, call **1-800-565-3000, ext. 245** or e-mail **info@parkinson.ca**

DBS and diathermy therapy alert!

The U.S. Food and Drug Administration (FDA) has issued an alert concerning reports of deaths of patients with implanted deep brain stimulators who received diathermy therapy.

Diathermy treatment uses shortwave, microwave or therapeutic ultrasound to deliver 'deep heat' to body structures. It is used by physiotherapists, chiropractors, nurses, dentists and others to promote wound healing or to relieve swelling, pain and stiffness in muscles or joints.

This treatment can be hazardous to deep brain stimulator patients, as it may cause implanted electrodes to heat up excessively, damaging brain tissue.

If you have undergone deep brain stimulation surgery, and are concerned about your risk, please discuss with your doctor.

The entire FDA alert can be read by visiting **www.fda.gov/cdrh/safety/121902.html**

Preparing for the years ahead: A guide to long term planning

By Ian Corks

Planning for the future is something that many of us go out of our way to avoid. We come up with all sorts of excuses: "I'll get around to it, soon... I don't need to worry about it now... There's plenty of time for that."

The truth is, as financial and legal experts will tell you, there may not be plenty of time and you do need to worry about it NOW. And that's in the best of circumstances. Throw Parkinson's into the mix and the need for planning ahead becomes even more urgent.

In many ways, it also becomes that much more difficult. "I was diagnosed with Parkinson's 11 years ago," explains David Simmonds, an Ottawa-based estates and trust lawyer. "It was a tough enough time dealing with the diagnosis and worrying about the present. The future was hard to think about."

Winnipeg's Wayne Buchanan recalls the "shock" of the diagnosis (at age 33), and how he and his wife had to force themselves to sit down and do some serious planning.

As difficult as accepting the diagnosis is, coming to terms with what the future might hold can be even tougher. For many, it's hard to imagine a future where work will become more difficult and even impossible – or where medical and care costs could become a financial drain. The sooner plans are put in place, the better.

"Having a long term plan in place makes things that much easier," notes David. "It takes some of the pressure off, gives you peace of mind and you have one thing less to worry about."

Wayne Buchanan

Where to start

Where you start planning depends very much on the situation at time of diagnosis. Some families may already have simple or complex plans in place, while others will be starting 'from scratch'. In either case, the process is similar and revolves around establishing or revising your plans with the realities of Parkinson's disease in mind.

There are essentially three interrelated and equally important facets of future planning: financial, legal and estate planning. Before tackling these, however, you have to take a step backward and decide what you want. This single question can be the most difficult aspect of the planning process. The answers you come up with will determine how you proceed.

"Everyone will have their own priorities," explains David Simmonds. "You have to determine what is important to you and your family... enjoying life now, retiring early, preparing for future care, providing support for your spouse, making provisions for your family, etc."

As any financial planner will tell you, before you map out your route, you need to know your destination. Starting to think and talk about the future can be difficult. Is there someone you can trust who can help you assess priorities? Consider family and loved ones, trusted friends, your doctor, priest, rabbi or other spiritual advisor or even a professional counsellor.

Financial planning

Ian Xenias, CFP, a senior consultant with Investors Group in Toronto has counselled several clients with Parkinson's disease. He recommends getting an expert to do a complete financial review including a risk analysis. Key considerations include sources of assets, income and expenses, both present and future

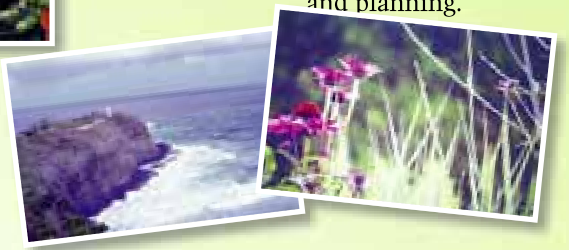
Each scenario will be different and the financial review should cover all variables. What assets do you have? How long will you be able to work? What benefits do you qualify for (CPP, private)? Is your spouse working? For how long? Do you have insurance? Will you have to change housing (sell, modify, move)? Do you have dependent children? The list goes on.

Norman Coridor and Kathy Ford of Burnaby, BC were faced with Norm's diagnosis of Parkinson's at age 55. They decided to pay for a complete professional financial review. This looked at the couple's income sources, existing investments and, most importantly, what they wanted out of life.

One of the key things was determining Norm's ability to earn money. The progression of Parkinson's combined with the effects of a previous motor vehicle accident made it difficult for him to continue in his job as truck driver instructor. On the advice of his doctor, Norm applied for Canada Pension Plan (CPP) disability.

Disability payments can be a major source of income for people with Parkinson's. Unfortunately, it is not something that can be taken for granted, as James Ludwar points out. James is a lawyer with Bayda Ludwar in Calgary, AB specializing in disability claims. "Just because you are able to keep working when you are diagnosed, or even for many years after, doesn't mean you will always be able to," he advises. "At some point you may have to file for CPP or private insurance disability. It's not automatic. It will be necessary to prove that you cannot work. That's where documentation comes in."

James advises keeping detailed records from the point of diagnosis. "Keep your doctor in the loop and write down what he or she says all along the way," he suggests. "Always talk in terms of 'functional' as opposed to 'general' disability – in other words your ability to do your job," he suggests. This information will help when you file your claim, especially if you are refused at first and have to appeal or seek legal action.



Norm Coridor and Kathy Ford's priority is to spend serious "together-time" while Norm's health is still good. He is working on turning his nature photography hobby into a part-time business, selling original prints like these.

Next, with the help of their financial planner, Norm and Kathy made some adjustments to their RRSPs and investments that secured them a reasonable financial future. They also adjusted their personal priorities. Funds for travelling were put into the creation of a special garden – a place Kathy had long dreamed of and where Norman could pursue his hobby (and new part-time business) of photography. In addition, they had some money put aside for redecorating their home. This has now become more of a renovation project that includes customizing the house with an eye to the future. "We are widening doorways to make room for a wheelchair, replacing area rugs and doing other things to make it easier for Norm as his disease progresses," Kathy says.

In making their financial plan, Norm and Kathy sought advice from many key people. "We tried to anticipate the impact of any financial and lifestyle decisions we made," explains Norm. "We talked to our neurologist, our sister-in-law (a retired nurse) and Parkinson Society British Columbia. They all answered key questions that helped us plan."

Wayne Buchanan and his family also chose quality of life as the foundation for their financial review and planning.

"My wife and I already had some things in place, like life insurance and a modest RRSP," recounts Wayne, who was working as manager at Safeway when he was diagnosed. "My wife was at home raising our three sons, 12, eight and five at the time."

"We started planning in earnest as soon as the shock wore off. We did some research and then went out and found a financial advisor."

With the help of their advisor Wayne and his wife took a hard look at the present and future, "We set short and long term goals and adjusted our finances accordingly," he recalls. "We changed our priorities. We started working towards me retiring at 50. We paid off our mortgage. We never moved into the dream home we had hoped to

Bill and Elaine:

Getting advice from the experts

Bill is a 47-year-old press operator. Elaine is 45 and works as a customer service representative. They have one daughter, who is now married.

Bill and Elaine own their own home with about eight years of mortgage payments remaining. They have modest RRSPs and small savings. Neither one has any type of personal insurance. They have standard wills, naming each other and their daughter as prime beneficiaries.

Bill was diagnosed with Parkinson's disease three years ago. He is still capable of working, but is aware that his condition may require him to leave work before retirement age.

Q: ***What long term planning should they do?***

A: Bill and Elaine should visit their lawyer to ensure their wills are up-to-date and include provisions for care for Bill in the event that Elaine dies first. Bill should appoint a power of attorney for property and for personal care.

A complete risk management analysis should be prepared by a qualified financial planner to protect sources of income in case one spouse dies prematurely.

Elaine might consider life insurance. This would serve two purposes:

1) financial protection for her husband if he were to survive her (i.e. so Bill could afford paid care), and
2) estate preservation/estate tax savings if she outlives Bill.

Elaine should also consider long term care insurance for herself. If she did need long term care in the future, her current asset position would deteriorate quickly without this coverage.

As Bill's disease progresses and his ability to work becomes compromised, he should consider early retirement by applying for CPP disability. He should start keeping thorough records of his disease progression.

It is unlikely that Bill will qualify for any new insurance coverage due to his condition. However, if Bill has group insurance at work, he should investigate his options. If he has to leave work due to illness, he might be able to convert his coverage to the same carrier without proof of 'insurability'.

A complete financial plan should be completed by an expert, taking into account what Bill and Elaine's personal and lifestyle priorities are.

At this point in their lives, with their daughter married and what should be relatively low mortgage and bill payments, their savings and wealth creation capacity should be healthy. They should consider maximizing this capacity as soon as possible, considering the uncertainty of Bill's condition. This can be done via mutual funds, RRSPs or other investments. Another option would be to prioritize paying off their house. This would provide them with some useful equity in the future.

The financial plan should contain a few models addressing the 'what if' situation surrounding Bill's Parkinson's. Cost of care should be factored into these models. The plan will need to ensure that the current assets and future income potential is properly utilized to allow Bill and Elaine to meet their lifestyle requirements in sickness and in health – and not ignoring the possibility that they could both live for a long time.

Compiled from advice submitted by: Ian Xenias, CFP, Senior Consultant, Investors Group, Toronto; and Sandra Foster, RFP, founder of Headspring Consulting Inc., Toronto.

and suspended our vacations for a while. Instead we started investing in mutual funds to secure us in the future."

The result? Wayne was able to retire on disability at age 47 and finally take that long-delayed vacation. Today, with a new recreational vehicle, Wayne and his wife plan to enjoy their 50s and 60s, knowing that they have some funds set aside for the years beyond.

Both families relied on the expertise of professional financial planners to help them come to grips with their situations. Apart from the knowledge and experience these professionals offer, they can also view things more objectively, removed from the emotional aspects that can confuse the issue.

"Many people naturally go into immediate savings mode when something threatening happens," notes Sandra Foster, RFP, a financial planner and founder of Headspring Consulting in Toronto. "That may not necessarily be the best thing.

"You need someone to explain all the options. That will let you be proactive rather than reactive."

A primary consideration in any financial planning is the possibility of significant future care costs. The realities of Parkinson's dictate that some type of professional in-home care or an eventual move to a long-term care facility are very real possibilities. Government funding in this area is limited and many of the costs of this care are borne by the family itself.

Costs of care can be influenced by many factors, such as: your overall health (taking into account Parkinson's and other conditions), the health of the primary caregiver (usually a spouse or partner), the availability of family support (family members living near by, etc.), your personal wishes and so much more.

Again, a financial professional can be a valuable resource in investigating possible costs and developing scenarios to accommodate them.

Financial planners can be found in a variety of places, from investment companies and banks (who obviously tend to build plans around their own products) to independent financial advisors and accountants. The best thing to do is ask friends and family members for referrals. Don't be afraid to 'interview' two or three planners before making your choice. Ask the advisor if they have some type of certification (e.g. Chartered Accountant, Registered Financial Planner or Certified Financial Planner), have handled cases like yours before or are particularly knowledgeable in planning for people with medical conditions.

If you are considering an accountant, the Canadian Institute of Chartered Accountants (CICA) maintains a registry of CAs who have taken special training through their Prime Plus/ElderCare program. For more information, contact the CICA at **416-977-3222** or on-line at **www.cica.ca.**

Legal planning

This basically involves ensuring that your rights and properties (and those of your family) are protected for any eventuality that might occur, whether due to your Parkinson's or not.

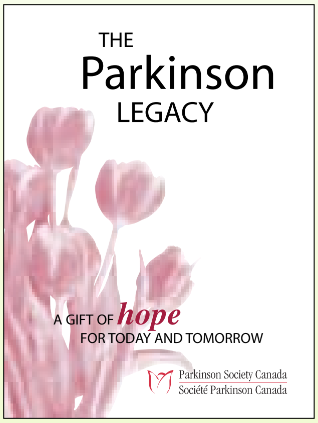
For many people, that simply involves making a will – a document that clearly and legally states how your estate will be distributed upon your death and outlines certain personal wishes you may have (e.g. cremation vs. burial).

A will is something everyone should have. Even people who do have existing wills are advised to review them in the event of a life-changing event like Parkinson's. The so-called 'mirror' will – where each spouse leaves the bulk of his or her estate to the other – may need to be revisited to reflect changing realities, such as looming health care costs.

Having a suitable will is only a starting point, however. There are two other legal documents that should be considered. For the sake of this article we will refer to them as **powers of attorney** and **living wills**, although they do go by different names across the country.

Parkinson Legacy:
An estate planning option

When preparing your will, consider a planned gift to Parkinson Society Canada or one of our regional partners. Call **1-800-565-3000** for an information kit on the new Parkinson Legacy program, or visit **www.parkinson.ca** and go to the Donating section.



A **power of attorney** allows someone else to make crucial decisions for you in the event that you are unable to due to mental incapacity. It allows a trusted individual whom you have chosen to pay your bills, access your bank accounts, conduct business in your name – whatever specific tasks you determine. This is generally known as a power of attorney for property.

Through a power of attorney, you can also nominate a person to make personal health care decisions for you if you are mentally unable to. This is called a power of attorney for personal care.

Who you choose to act as power of attorney is up to you. Many people select a spouse, family member or friend, while others appoint a third party, such as a lawyer. Basically, you are looking for a person who has the skills and knowledge to manage your personal and financial affairs in an effective and sensitive manner. It is also possible to have more than one person act as your power of attorney. A widow, for example, might appoint two or more of her adult children.

A **living will**, or advanced care directive, is a similar document, but it is more focused on how you wish to be treated if incapacitated by illness, injury or old age.

Living wills or other health care directives ensure that your wishes are communicated to family and medical personnel in on-going medical care and end-of-life circumstances. If properly witnessed or notarized, these documents can also serve as powers of attorney in some cases.

They allow a person to make choices, while they are still capable of doing so, about how they will be treated if they become incapable of making decisions. It can cover basic issues like where you will live and who will care for you, and complex medical issues, such as informed consent.

Under Canadian law, physicians and other health professionals require 'informed consent' before initiating (or suspending) specific medical treatments (except in emergency situations). If you are incapable, someone has to make the choice for you, and it is obviously better if they make the choice you would want. (*Editor's note:* The Ontario Seniors' Secretariat produces a reference called *A Guide to Advance Care Planning*. Call **1-888-910-1999** or visit **www.gov.on.ca/citizenship/seniors/english/advancecare.htm**.

"Enduring continuing powers of attorney or living wills may be the most important legal instruments a person ever executes," notes lawyer Ann Soden, who chairs the Canadian Bar Association's new Elderlaw Section.

If you don't have these documents and something happens that results in your inability to make decisions or handle your own affairs, you cannot assume your family can take over. In fact, that power could initially go to the provincial Public Trustee office. Even a husband or wife could technically have to apply to the court for permission to act on your behalf.

While the specific rules vary, the hallmarks of these agreements are that you (and the representative you appoint) must have the requisite mental capacity to execute the document. It must be signed before two witnesses, each of whom must sign in your and each others' presence. Technically, the involvement of a lawyer is not mandatory, but it is wise to use legal counsel to ensure the document is properly prepared. A lawyer specialising in Wills and Estates or who is familiar with Elderlaw is preferable.

The key in any such document is to ensure that your wishes are fully understood. "You need to layout exactly what you want to happen, when you want it happen and under what circumstances," Ann explains. "Detail everything you feel is important. For example, talk to your physician and plot the decision course you want followed in terms of medical treatment options."

She also suggests that if there is any potential for conflict, you should consider appointing different representatives for your personal affairs and your property or financial affairs. The person monitoring your financial assets should report regularly to the person responsible for your health or personal affairs.

The earlier these documents are prepared the better. Once the mental competency of an individual comes into the slightest question, he or she will likely be regarded as incapable of appointing a power of attorney.

Estate planning

Estate planning begins with a will and other legal documents, but also involves tax planning, family law, asset allocation and much more.

As Sandra Foster, author of *You Can't Take it With You: The Common-Sense Guide to Estate Planning for Canadians* explains, "Estate planning is about providing for others – your family, your business partners, charities – and it deals with the final chapter of your life."

Experts advise against the natural tendency to put off estate planning till you are 'older'. Yet it's something many people do. Sometimes it takes an event, like the diagnosis of Parkinson's, to get us going. However, you are never too young to plan your estate.

Estate planning is extremely personal, and depends on what the estate consists of and who the beneficiaries will be. If you have dependent children, for example, they will figure prominently in your planning. Some people like to factor a legacy contribution into their wills.

Sandra Foster has developed a useful Estate Planning Checklist to help people get started. It is available on her website – **www.whosmindingyourmoney.com** – under the Estate Planning Workbook heading. "Estate planning is part of your overall financial planning," she says. "Depending on your situation, it can be fairly straightforward or very complicated. But once it is in place you may experience a sense that everything is in order."

The time and effort invested in developing a solid future plan will pay dividends in many ways.

"Now all we do is review our plans bi-annually and make adjustments as needed," Wayne Buchanan says. "The peace of mind we've gained by having a plan in place has been priceless."

Norm Coridor and Kathy Ford agree. "If there's such a thing as feeling at ease in a Parkinson's household, we are close to it," Kathy concludes. "We feel so much better now that the planning is done. It's our best defence against the unknown of the future and allows us to concentrate on our lives together."

Editor's note: The following *Parkinson Post* articles may also be helpful in planning. *Living and Working with Parkinson's* (Fall 2002) and *Money Matters* Part 1 – 4 (Winter 2001 and Spring, Summer and Fall 2002).

Building a solid plan

Some of the common issues a good estate plan will address include:

- Putting aside funds, investments and resources to meet your needs during life
- Making investments (e.g. life insurance) that will pay dividends to your beneficiary
- Documenting who will receive what after your death
- Appointing an executor to administer your estate
- Ensuring your family will be able to manage financially after your death
- Choosing who will look after your children if relevant
- Protecting the interests of your family
- Selling or ensuring your business will survive
- Minimizing tax burden on your estate
- Facilitating the fast, smooth payment to your beneficiaries
- Planning charitable contributions from your estate.

The Commemorative Medal for the Golden Jubilee of Her Majesty Queen Elizabeth II.

Queen's Golden Jubilee Medal presented to Parkinson's contributors

Fifty receive medal for their contribution to the fight against Parkinson's disease

By Kathryn Webber

"Absolutely stunned!" Holly Metcalfe chuckled as she described her feelings upon hearing she was a winner of the prestigious Queen's Golden Jubilee Medal.

"I never expected to receive such an honour. It means a great deal," says Metcalfe, original founder of The Parkinson's Society of Southern Alberta in 1979 and a Parkinson's activist.

It was a sentiment expressed by many of the fifty Medal winners, an extraordinary list of deserving individuals nominated by Parkinson Society Canada for their contributions to the nearly 100,000 Canadians living with Parkinson's disease.

A total of 46,000 Canadians were presented with the Queen's Jubilee Medal at ceremonies organized by the Department of Heritage Canada to commemorate the fiftieth anniversary of Her Majesty's reign as Queen of Canada.

Above: Isabel Ward (left) from Ingersoll, ON, receives her Medal from Lt. Governor Lois Hole in Calgary, Alberta.

Parkinson Society Canada, invited by the federal government to submit a list of people who they felt were most deserving of the award, proudly nominated fifty people.

For Neil Menzies, a past president of the B.C. Parkinson's Disease Association and former Vice Chairman of Parkinson Society Canada, receiving the medal was truly an honour. "To be nominated by those within the Parkinson community means so much to me." For Menzies, the Medal signifies more than just recognition of hard work. "Volunteer-ism is a wonderful investment, where you are guaranteed to get back far more than you put in," he says.

The Society had a difficult task in selecting only fifty nominees. Many more people across Canada help contribute to the fight against Parkinson's on a daily basis. However, nominating Dr. George Turnbull, Chair of PSC Maritime Region, was obvious. Dr. Turnbull was pivotal in establishing a unique clinic in the Maritimes that specializes in exercise-based therapy for people with Parkinson's.

To Turnbull, however, news of the award was both surprising and humbling. "I was humbled in that I could not have chosen two better people to receive the award with me in Moncton: Merton Geddes and Sheldon Cameron. They are people I admire hugely because they live with Parkinson's 24 hours a day, seven days a week."

For more information on the Medal winners, visit Parkinson Society Canada's website at **www.parkinson.ca/volunteer/jubilee.html**.

Parkinson Society Canada proudly congratulates the following recipients of the Commemorative Medal for the Queen's Golden Jubilee. These outstanding individuals are just a few of the many making a difference in the lives of people living with Parkinson's:

Mrs. Judy Axelson
Mrs. Lorrie Bett
Mr. Gordon Bragg
Mr. Wayne Buchanan
Mr. Roger Buxton
Dr. Sheldon R. Cameron
Dr. Sylvain Chouinard
Mr. F. Keith Critchley
Mrs. Jan Duff
Mrs. Pat Fleming
Mrs. Thelma Flemming
Mr. Roland Fortin
Mr. Merton Geddes
Mrs. Judy Glustien
Mrs. Cathy Graham
Mrs. Peggy Gray
Dr. David A. Grimes
M. Marcel Groulx
Mme. Monique Paradis Groulx
Mr. Bill Harshaw
Mrs. Judy Hazlett
Mrs. Waltraud Jensen
Mrs. Sandie Jones
Mme. Sylvie Lemay
Mr. Norman J. Levac
Mrs. Mary Martin
Mrs. Lynda McKenzie
Mr. Robert McNutt
Mrs. Holly Metcalfe
Ms. Denise Murphy
Mr. Neil Menzies
Mr. Klaas Moes
Mrs. Frances M. Nichols
Mr. Geoff Norquay
Mr. Arthur Palmer
M. Claude Rivard
Dr. David Russell
Mme. Micheline Savoie
Mr. John W. Scott
Mr. Gordon Sharwood
Mr. Frank Shortreed
Dr. A. Jon Stoessl
M. Louis Tremblay
Dr. George Turnbull
Mrs. Margaret Turner
Mme. Harriet R. Wagner
Mrs. Isabel Ward
Mr. Les Whiting
Mrs. May Wong
M. Alcide Yelle

A look at current Parkinson's research arou

Measuring quality of life

A Canadian team has completed the first ever study examining the impact of Parkinson's on 24-hour Parkinson's caregivers. The team used a validated and published Parkinson Specific Quality of Life rating scale.

A multi-centre team under the direction of Susan M. Calne of the Pacific Parkinson's Research Centre at the University of British Columbia asked 135 caregivers to complete the Parkinson's Impact Scale (PIMS) on four seperate occasions in either English or French. This tool measures how caregiving affects everyday life. (The PIMS is available on the PSC website at **www.parkinson.ca/pd/prof.html**). Caregivers were defined as "the primary person living at home full time with an individual with Parkinson's."

Caregivers rated sexuality, travel and leisure (in order) as their top three concerns. The PIMS scores also revealed the correlation between the well being of the individual with Parkinson's and that of the caregiver.

Reference: *Advances in Neurology*

Editor's note: Congratulations to the nurses who participated in this useful study, all of whom are closely associated with Parkinson Society Canada.

Newest test differentiates between types of Parkinson's

A new clinical test called brain parenchyma sonography (BPS) has been shown to be useful in discriminating between more common, or idiopathic, forms of Parkinson's disease and atypical syndromes.

BPS is a new form of ultrasound that shows the tissue echogenicity of the brain through the skull. By studying the images, clinicians can detect differences in the basal ganglia and other subtle changes in the brain in individuals with Parkinson's. This can help them determine if the person has idiopathic Parkinson's or some other, less common, Parkinson syndrome, such as multiple-system atrophy. Earlier detection of the specific type of disease will allow appropriate treatment options to be considered at an early stage.

Though more studies are needed, preliminary results indicated that the advantages of BPS – specifically its potentially wide availability, low cost, and noninvasiveness – might make it a standard investigative tool in Parkinson's disease.

Reference: *Journal of Neurology*

Mystery gene may provide clues

A European research team has found initial indications that the gene DJ-1 may be linked to the development of Parkinson's disease.

The team, led by Drs. Bonifati and Heutnik at the Eramus Medical Center in Holland, studied unrelated Dutch and Italian families affected by a rare form of Parkinson's know as PARK7. They discovered a common link in that both families had mutations in a gene for the protein DJ-1. While the exact function of DJ-1 is unknown, its mutation (and resulting deactivation) is believed to have a significant effect on neurons and may play a role in neurodegeneration.

These findings indicate that DJ-1 may be a third gene linked to Parkinson's, along with the previously identified Parkin and alpha-synuclein.

References: *Sciencexpress*, Reuters Health

Montreal scientist awarded Fox Foundation grant

Dr. Edward Fon of McGill University and the Montreal Neurological Institute has received a U.S. $296,656 grant from the Michael J. Fox Foundation. The grant was awarded to allow Dr. Fon to continue his study of molecular events leading to the death of dopamine neurons in Parkinson's disease. Dr. Fon's initial work in this area was funded by Parkinson Society Canada.

Reference: Canadian Press

Clinical Movement Disorders Fellowship awarded

Parkinson Society Canada is pleased to announce the award of its 2003/2004 Boehringer Ingelheim Clinical Movement Disorders Fellowship to Dr. Sajeel Chowdhary. Dr. Chowdhary will be training under the supervision of Dr. Michel Panisset at the McGill Centre for Studies in Aging in Montreal commencing July 1, 2003.

Dr. Chowdhary joins the scant 50 or so Parkinson's disease specialists practicing in Canada. "Nearly 100,000 Canadians suffer from Parkinson's disease, yet only 45% of these patients see a specialist

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

nd the world

annually, so appointments such as Dr. Chowdhary's are critical if we are going to provide patients with the specialized care and treatment they require," says Mary Jardine, National Executive Director of Parkinson Society Canada.

This is the second time that this fellowship has been awarded (see profile of Dr. Scott Kraft on this page). The fellowship is a clinical training program for the subspecialty of Movement Disorders. This post-residency training is to provide expertise in the diagnosis and management of Parkinson's and may include other movement disorders. Research may be a component of the program but the largest component is clinical training (at least 80%).

The fellowship is funded through a generous donation from Boehringer Ingelheim. The selection of the fellows and administration of the fellowship program is the responsibility of Parkinson Society Canada.

Focus on…

Dr. Scott Kraft

Parkinson Society Canada Boehringer Ingelheim Clinical Movement Disorders Fellowship 2002–2004

Dr. Scott Kraft has travelled many miles on his on-going medical journey. A native of Saskatoon and graduate of the University of Saskatchewan College of Medicine, Dr. Kraft journeyed to St. John's, Newfoundland to complete his neurology residency, before returning to the west.

Now, with the help of Parkinson Society Canada's fellowship and funding from Boehringer Ingelheim, Dr. Kraft is continuing his clinical training at the Movement Disorders Clinic at the University of Calgary Foothills Medical Centre.

"The main component of the fellowship is clinical training. I spend at least 80 per cent of my time doing work in the clinic," he notes. "Most of the patients seen in the Movement Disorders Clinic have Parkinson's Disease. I spend a large amount of time with our movement disorders surgical program, which includes deep brain stimulation for Parkinson's Disease. I am involved in the assessment of patients for their suitability for the procedure, as well as the programming of the stimulators and adjustment of medications while this is being done."

"Through my involvement in the surgery program I am looking at the benefits and side effects in the patients who receive stimulators," Dr. Kraft adds. "This will hopefully lead to a better understanding of how these procedures work as well as assist us in selecting which patients are the best candidates to have the surgery done."

Working under the direction of Dr. Oksana Suchowersky, Dr. Kraft also finds some time for research.

"While research is not the focus of my fellowship, there is some time available to pursue this aspect of medicine. I am a co-investigator in some of the drug studies that our clinic is involved in. I have completed the coursework and am currently finishing my thesis for my Masters of Science in clinical epidemiology."

Dr. Kraft is confident that the future will be brighter for people with Parkinson's disease. "I am certain that significant advances in management of Parkinson's, and quite possibly a cure, will occur during my career," he states.

Note: Parkinson Society Canada acknowledges Boehringer Ingelheim for its support of this fellowship which allows a neurologist to gain specialized training in movement disorders.

WEBSITE HIGHLIGHTS

Visit Us Online: www.parkinson.ca

Some of the new content on our website includes:

- Parkinson Society Canada is frequently asked to represent the opinions of people with Parkinson's on various topics. If you want your voice to be heard, be sure to regularly check the What's New section of our website where we post health care news and any current requests for input to a specific hotline or website. **(See What's New)**
- Learn more about the 50 winners of the Queen's Golden Jubilee Medal (listed on page 13) and their personal contributions to the Parkinson's community **(See Volunteering/Queen's Golden Jubilee Medal)**
- If you are a young person with a parent who has Parkinson's, consider connecting with others your age through e-mail. We have some suggestions about how to get connected from a Canadian teenager with experience. We also highlight two booklets that explain Parkinson's for younger children. **(See Parkinson's Disease/For Kids)**
- If you've missed previous issues of *Parkinson Post*, you can read a selection of diverse stories online. We select one story from each issue and post it online. **(See The Society/*Parkinson Post*)**

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

What do an Alberta nurse, an Ontario resident living with Parkinson's and a former British Columbia Senator have in common? The question was answered at the annual meeting of Parkinson Society Canada (PSC) in November, where volunteers from diverse backgrounds were recognized for their outstanding achievements on behalf of people with Parkinson's.

Compassion and commitment:
A salute to three outstanding volunteers!

It takes a special kind of person to receive the *Mimi Feutl Award*. Created to honour PSC's former Director of Patient Services for more than 20 years, it salutes volunteers who demonstrate compassion, energy and unwavering commitment to people with Parkinson's and their families.

Gina Rohs: A pioneer in personal care

Gina Rohs shares her experiences during the PSC annual meeting.

A pioneer in Canada, **Gina Rohs** was the first nurse in Alberta and the second in Western Canada to work in a Movement Disorders Clinic. In 1990, she became the first designated Parkinson's Clinical Assistance nurse (funded by PSC) at Foothills Hospital in Calgary, AB.

At first, Gina divided her time between working with patients and participating in clinical research studies. As things got busier at the clinic, Gina knew direct patient care was what she enjoyed most. "I was very excited about working one-on-one with people with Parkinson's. I learned to walk a little way in their shoes and listened carefully to what they were saying."

Gina says her job was being an ambassador for patients and their families, spending time with them before they saw the specialist and answering questions afterwards. She knew people were often intimidated talking to physicians so she made sure they left the clinic with written information – and her phone number. "The most important thing is to ensure people have everything they need to make decisions about their treatment and care." She unravelled the complexities of Living Wills, Powers of Attorney and wrote instruction manuals for people with movement disorders. She was an architect of the Parkinson's Impact Scale – a tool for measuring quality of life specifically for people with Parkinson's.

Gina served on the Board of The Parkinson's Society of Southern Alberta, spoke regularly to support groups and became involved in fund raising events. Gina recently retired and says she is "busy being a grandmother, hiking, growing roses and making wedding cakes and wine." Her legacy is expressed by someone she helped, "She has warmth, an instinctive understanding of people and you just know she cares!"

Judy Hazlett: Education and awareness advocate

Judy Hazlett's guidance and support have helped many fellow Canadians from coast to coast.

Judy Hazlett of Unionville, ON has lived with Parkinson's for more than half her life, for over 25 years. Diagnosed in her late 20s, her philosophy is simple: "Those of us who live with Parkinson's ease our own burden when we share with one another. It is our responsibility to live fully with Parkinson's and not become it."

An associate says Judy guides, supports and nurtures – allowing people to recognize their own inner strengths. Judy is always there when help is needed. When the longstanding chair of her local support group died, she took the reins and kept the group together. She provided inspiration by taking charge of her own destiny, being the first person in the world to have sham brain surgery in 1995 and having a real transplant in 1997. She and her husband, Roger, have shared their experience of living with Parkinson's and of the transplant frequently at conferences and support groups.

After Judy was thrown out of a mall at Christmas time a few years ago because her dyskinesia (involuntary, uncontrollable movement) appeared threatening to shoppers, she and Roger developed the "Police Awareness Project." They talk to police services and police students about recognizing Parkinson's and what assistance people living with Parkinson's may need. A video version of their presentation has been distributed across Canada. A colleague says, "Judy exemplifies the principle of encouraging those with Parkinson's to work on their own behalf." Currently she wants to do a comedy review about living with Parkinson's. She also wants to encourage others to be physically active (she skates, does yoga, and loves to dance). She and Roger are also working on an awareness presentation for students preparing to work in long term care facilities. Judy feels, "With every opportunity we make to create awareness, we contribute to a more compassionate world where we may learn to accept, even celebrate, differences and imperfection of all kinds in ourselves and each other."

Hon. John Nichol, C.C.: Dedicated Research Fundraiser

The Hon. John Nichol played a key role in founding the Pacific Parkinson's Research Institute.

How do you measure a volunteer's impact on people's lives? What kind of person has the perseverance and vision to effect change? The *David Simmonds Parkinson's Leadership Award* – named for the Chairman of Parkinson Society Canada (PSC) from 1999 to 2001 – was created to honour an outstanding leadership volunteer who has made a significant difference in the lives of people with Parkinson's.

The recipient was **The Hon. John Nichol** of Vancouver, BC who has worn many hats during his illustrious career – World War II veteran, Senator, President of the Liberal Federation of Canada, businessman, newspaper columnist, husband, father and extraordinary volunteer. David Simmonds says John was selected as the award's first recipient because "he used his influence in a focused way to bring about tangible results" in the fight against Parkinson's.

John's involvement started more than ten years ago when he accompanied his wife, Elizabeth (a person with Parkinson's) to the clinic at UBC in Vancouver. At that time, funding for biomedical research in Canada was being cut back so John, with help from many people who had a personal connection with Parkinson's, established a group which raised millions for Parkinson's research. John is a Founding Chairman of the Pacific Parkinson's Research Institute, one of the top-ranked centres in the world for studies of Parkinson's and other movement disorders.

According to Dr. Donald Calne, Past Chair of PSC's Scientific Advisory Board, "It is no exaggeration to say the research enterprise here would almost certainly have closed but for the local fund raising efforts of John Nichol and his friends." John was instrumental in encouraging the Institute to host the 1998 International Congress on Parkinson's disease – the largest ever held (2,300 scientists attended): it generated media awareness about Parkinson's around the world. Simmonds says that John "will unabashedly tell the government what needs to be done" in the area of Parkinson funding. His contribution to the Parkinson community is best captured in the citation announcing John's elevation to the Companion of the Order of Canada: "His devotion to his community and his lifelong experience has contributed to his reputation as a most exceptional Canadian."

A Champion battles on

Muhammad Ali in Toronto

By Ian Corks

Left to right: Bill Harshaw, Muhammad Ali, Judy Hazlett and Mary Jardine.

It's not often you see 25,000 people rise to their feet and cheer wildly (with another 500,000 watching on TV) for a man with Parkinson's disease. But that's exactly what happened at Toronto's Skydome on October 20th of last year.

Sure, the man in question was Muhammad Ali, arguably the 20th century's greatest boxer and most famous athlete: not exactly your typical person with Parkinson's. Yet, the people in the crowd and watching across the country were there to honour Ali not only for what he once was, but also for what he is today – a symbol of strength and inspiration, and a man who has not let Parkinson's disease beat him.

The three-time heavyweight champ was in Toronto to participate in a tribute held at half time of the Canadian Football League (CFL) game between the hometown Argonauts and the visiting Ottawa Renegades. The event, entitled *Muhammad Ali: For the Greatest Good*, was also a fundraiser for Parkinson Society Canada (PSC) and the Parkinson's Research program at the University of Toronto.

While the undisputed star of the show, Ali was far from the only celebrity at the event. The list of people there to honour him included other great boxers, ranging from former opponents George Chuvalo and Larry Holmes to Evander Holyfield and current World Champion Lennox Lewis. Also on hand were Maple Leaf hockey captain Mats Sundin, Elvis Stojko, NFL and CFL great Warren Moon and 2000 Olympic gold medallist Daniel Igali. Each admitted to being inspired, in their own way, by Ali's accomplishments over the years.

For Canadian rock singer Tom Cochrane, it was Ali's public struggle against Parkinson's that was the greatest inspiration. Cochrane performed his new song *Just Like Ali* – inspired by a remark made by Cochrane's father, who also has Parkinson's. "My Dad told me he was going to fight his condition – just like Ali," Tom explained. (*Editor's note:* Sadly, Tom's father, Tuck, has since passed away.)

Muhammad Ali: Career highlights

Born: 1942

Amateur record: 100–5

Olympic Gold Medal: 1960

Professional record: 56–5

Knockouts: 37

World Heavyweight Champion: Three times

Retired from boxing: 1981

A moving experience

But it wasn't only celebrities who drew strength from the presence of the 60-year-old Ali, who was diagnosed with Parkinson's in 1984.

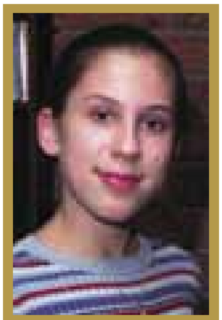
Judy Hazlett, who has had Parkinson's for 25 years, was one of those fortunate enough to meet Ali after the half-time show. "Of course I knew about the boxer Ali, with all his strength, speed and coordination, but my most vivid memory is of him lighting the torch at the 1996 Olympic Games in Atlanta with his hand shaking," Judy recalled. "It moved me so much. And now to meet him as he is today, knowing what he has to endure and putting the energy he has to good use, was wonderful. When I shook his hand and he looked into my eyes I felt that he understood what I have to deal with every day. Parkinson's leaves you with no choice but to accept it. But he has done more than that. He seems comfortable with it and it doesn't stop him."

Former Canadian heavyweight champ George Chuvalo, who went the distance with Ali in Toronto in 1966, echoed the sentiment. "Ask me if I feel sorry for Ali and I say, no, I do not," he stated. "I look at Muhammad and I see a man at peace with himself in so many ways. To me he is a happy person."

Indeed, the 60-year-old Ali did seem happy to be in Toronto helping PSC and Parkinson's research. Despite moving slowly and obviously carrying the weight of his condition, he climbed unaided to the stage, acknowledging the fans and well wishers. He exhibited his famous wit, joking with the celebrities ("Don't worry, I didn't hurt him," he quipped after a mock sparring session with Lennox Lewis) and teasing reporters ("That's a good question, you're not as dumb as you look," he told one).

Bill Harshaw, who has had Parkinson's for 22 years, was impressed by the stamina and determination Ali showed throughout the event. So was Judy Hazlett. "I know how difficult it was for him to do all the things he did that day," she noted. "But he kept on without complaining. You felt that he really wanted to help."

And help he did. The event raised approximately $50,000 – with $30,000 going to PSC and $20,000 to the Centre for Research into Neurodegenerative Diseases at the University of Toronto. Funds came from ticket sales, through phone-in pledges from across Canada and from 'Bucket Brigades' that collected donations from the Skydome crowd. One such donation came from 12-year-old Julia Sugden of Aurora, Ontario. Julia, whose father has Parkinson's, asked her friends for donations instead of gifts at her birthday party. She knew a little about Ali from her uncle, who was a boxer, and her family came down, enjoyed the event and donated $200 to the cause.

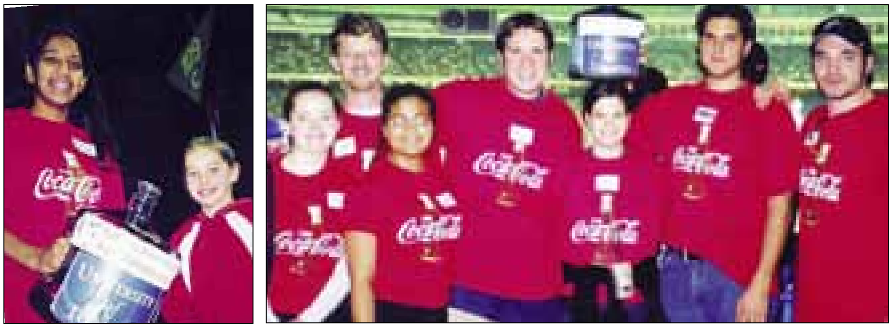


Twelve-year-old Julia Sugden raised $200 in birthday money for Parkinson's research.

Don't give up

The event did more than raise funds, however. It also raised awareness and delivered the message of Parkinson's to a huge national audience. And it provided special moments of inspiration for those individuals with Parkinson's and their families who got to listen to one of the most famous men in the world talk openly about his condition.

"I have Parkinson's," Ali said without hesitation. "I'm fighting Parkinson's now, and that's my daily fight. We're looking for a cure, and hoping to find one." And he offered some straightforward advice for people with the condition. "Take your medicine on time," the champ advised. "And don't give up hope."



University of Toronto 'Bucket Brigade' volunteers walked through the Skydome stands collecting money from sports fans to support Parkinson's research.

DON'T MISS AN ISSUE!

Coming in the Summer 2003 issue of *Parkinson Post*

A teenager's perspective:
Read the story of one teenager and how she copes with Parkinson's in her family. She has found a way to balance being part of a supportive family while living her own busy life and volunteering in the Parkinson community. See the valuable tips for kids that she has compiled.

Travelling with disabilities:
If you are disabled, your travel options may seem very limited. We'll let you know about special privileges, on-line and print resources, and various suggestions to make travel by air, train and ferry simpler and more accessible.

How speech language therapy can help:
If you need help managing the speech and swallowing challenges of living with Parkinson's, you'll want to read about what speech language therapy can do for you. We'll cover how to find a speech language pathologist and some of the innovative programs available across Canada.

SuperWalk for Parkinson's

SuperWalk 2003:
Plans are underway for the best SuperWalk yet. Read about the prize winners from 2002, get more details about what is happening across Canada, and learn how you can get involved to make a difference in your community.

Parkinson Society Canada
Société Parkinson Canada

First Person

Farming with Parkinson's

By Lawrence Massey, Castleton, ON

"You have Parkinson's," said the neurologist. I had barely lowered myself into his chair. It was February 1998. I was only 55-years-old.

How was I to deal with this thing that has no known cause, is incurable and progressively degenerative?

And I had a farm to operate.

My great, great grandfather, William Massey, purchased the farm in 1869, and it has been in the Massey family ever since. To me farming has been more than a job. It has been a way of life, a family tradition and a labour of love. That Parkinson's might threaten all of this struck me as nothing less than tragic.

Clutching at straws, I asked the neurologist right away if the problem could be a pinched nerve.

"No," he said. "It's Parkinson's."

I was crushed. I asked him how he could be so sure. He said he could tell by the way I walked into his office, by my eyes, and by the way my left arm hung at my side. There also was the tell-tale tremor. I didn't know whether to laugh or cry as he demonstrated the shuffling type of gait that Parkinsonians acquire in time.

Early signs

My despair was somewhat tempered because I had already begun to fear Parkinson's. I first noticed that something was amiss about two years prior to being diagnosed. I felt a tingling in the fingers of my left hand. Just a pinched nerve, I thought. Then a tremor appeared in my left arm and I began having trouble putting on a coat.

Lawrence's parents, Don and Velma.

But a year after my initial diagnosis I still could not bear to believe my doctor. I wanted a second opinion and I arranged to see a neurologist at Kingston General Hospital. The diagnosis was the same. I was devastated but not surprised. And I finally had to accept the fact that I had Parkinson's disease and would have to deal with it in the days ahead.

An education in Parkinson's

From day one I was determined to find out all I could about Parkinson's. I devoured books, searched the Internet, subscribed to the *Parkinson Post*, and went to group support meetings. My wife and I attended a recent regional conference. What I found was that Parkinson's afflicts farmers disproportionately, already something of a dying breed. Most Canadians are two generations removed from direct contact with a farm. Farmers now make up only about one per cent of Canada's population and the average age of farmers has been steadily increasing.

Modern crop production involves the use of 'chemical' fertilizers and pesticides. During my 27 years of farming I have handled numerous pesticides, either through direct application in a sprayer or through purchase of pretreated seed. I have always handled these chemicals with care.

Research in the U.S. suggests, however, that chronic exposure to pesticides could contribute to the incidence of Parkinson's disease. Moreover, the disease is more prevalent in rural areas and among those who, like my family, drink well water. In other words, living as my family has done for

Left to right: Adam, Angie, Joanne's mother, family dog, Nick, Joanne and Lawrence.

generations may have put me at risk.

But both my grandfather and his nephew had Parkinson's disease, and neither of them was exposed to pesticides. Was I predisposed to Parkinson's? Scientists think that genetics probably contributes to the disease. Further work is needed to identify defective or mutant genes. Dr. David Grimes of the Ottawa Hospital is hoping to find a genetic link in a large French Canadian family in which 13 members have Parkinson's disease. Was my condition caused by environmental, or genetic factors? I'll never know.

Coping on the farm

What I know is that farming and Parkinson's are not a good combination. There are too many jobs on the farm that require brute strength, excellent reflexes and fine motor skills. I have had difficulty this past year handling bags of seed and fertilizer. Routine tasks such as greasing machinery, doing minor repairs, tying up bags of grain, etc, have become major jobs which seem to take an eternity to accomplish. When I change the oil on the farm truck, I must look like a contortionist as I squirm under the truck to get my good hand on the filter.

The simple act of threading a nut on a bolt is not so simple anymore. The smaller the bolt, the more difficult is the task. At least I didn't choose watchmaking as a career!

Climbing in and out of the tractor cab is a chore now that I am so stiff. Because of an existing arthritic condition in my feet, now aggravated by Parkinson's, walking, particularly on uneven ground, can be a painful experience. The progressive loss of muscle control has made it difficult for me to eat, wash, and dress, let alone perform normal farming activities.

I have had to make some major changes in my farming practices. I no longer have livestock on the farm. The farm now produces only cash crops. Custom operators are hired to come in to plant and harvest the crops. The symptoms of fatigue, slow movement and decreased motor ability are not conducive to the operation of complex machinery for long periods of time.

Lessons learned along the way

Parkinson's is not life threatening but it changes your life and robs you of your dignity. In the first year or two I wanted to hide. I thought of myself as looking, walking and feeling like a freak, with one arm shaking and one foot dragging. Even Michael J. Fox, former T.V. and movie star, turned author and crusader for Parkinson's research, admitted that he kept his condition hidden for years. When I was diagnosed, I told only family and close friends at first.

But now I know I have nothing to be ashamed of. And my early despair has given way to new resolve and even hope.

Medication, even with its plethora of side effects, has helped me to cope with Parkinson's disease. I am more fortunate than my grandfather. The drugs that are available today were not there for him 40 to 50 years ago.

Although I have been forced to make compromises in my everyday life, I am still outside every day, working on the same land my family has for years.

I am grateful for the loving support of Joanne, my wife and caregiver. Support from other family members, friends, doctors and therapists has helped me to battle against an illness that has changed life on the farm.

Lawrence Massey operates a fifth generation family farm in Ontario's Northumberland county. He and his wife Joanne have two grown children.

Do you have a story to tell? ***Parkinson Post*** welcomes your submissions about what it is like to live with Parkinson's. Please e-mail your 1000–1100 word story to **editor@parkinson.ca**. Don't forget to include your phone number!

Ask the Experts

Q As my dad's Parkinson's progresses, we've noticed our family relationships have changed. How do we, as a family, begin to address having Parkinson's?

A Parkinson's can be described as an 'unwelcome' guest in the family: It changes things for everyone. Routines, personal space, expectations and relationships can all be casualties. Unfortunately, until we find a cure, it is here to stay. It demands adjustments be made.

Communication is vital. Being open about your love, hopes, frustrations, fears and dreams, can allow your family to explore the choices that are right for you. These choices involve how roles may change in the family – both now and over time. You can't change how someone will react but you can allow space for your feelings, make choices about how you want to deal with them, and tell your family member how their actions affect you. Each family member is affected in a different way and it takes strength to ensure everyone is heard and respected.

Part of being a family is caring for each other. When Parkinson's comes to stay, the ways people care will change with time but each family member is a partner in the relationship. The compromising that may need to happen is reciprocal. This is important to maintaining respect and self-worth for each family member.

Sometimes families find the 'unwelcome guest' takes up a large amount of time. It changes the pacing and schedule of the day. People become more isolated, lose hobbies and socialize less. Again, it is important for people to continue to grow and learn, and to have time as individuals. This will make the family stronger as time progresses.

A large part of the effect Parkinson's will have on your family is determined by the meaning each person gives to it. Different experiences can have many different meanings. A traffic jam can mean a waste of time to one person and a chance to look at the sunrise to another. Often people find that adjusting to having Parkinson's in the family is an opportunity to evaluate what is important and find personal ways to express that. Grief and joy are a natural part of the process.

In the end, your family is not alone in living with Parkinson's. Seek help if you need it. There are 100,000 people in Canada and their families who are able to relate. A network of health professionals are there to help. Sometimes it is wise to talk to a family counsellor or psychologist to help negotiate the transition and tailor solutions for your family's needs. Finding someone who your family can relate well to is key. Unfortunately, the guest is here. How much of the house it takes over is up to you.

Kirsten Maier
Support Services Coordinator,
Parkinson Society British Columbia

Q What can I do to ensure that my driving is as safe as possible?

A Consider taking a course in defensive driving from a reputable driving school. Contact the Canadian Automobile Association or Young Drivers of Canada for more information. The best courses are the ones that combine theory and practical training on the road. They'll cover things like positioning yourself in traffic to avoid accidents, checking spacing between cars, anticipating what other drivers will do, assessing the risk at different intersections and situations on the road, and being prepared to respond quickly. You can also:

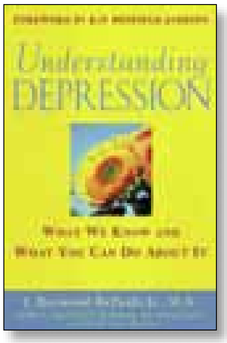
- Have your eyes checked regularly.
- Stay physically active.
- Read medication labels.
- Avoid driving in rush hour, at night, in bad weather or on highways.
- Ask someone whose judgment you trust to ride with you.

It is essential that all road users be physically and mentally competent. Since Parkinson's is progressive, it will eventually no longer be safe for you to drive. You may be sent for a driving assessment with an Occupational Therapist and a driver rehabilitation specialist. The results could lead to the suspension of your driver's licence for medical reasons. This is always a difficult decision to accept but it is in the interest of you and other road users.

Remo Minichiello, CDRS
Certified Driver Rehab Specialist
Manager, Driver Rehab Services,
Bloorview MacMillan Centre

Shirley Rolin, BSc, (OT)
Reg. (Ont), CDRS
Occupational Therapist, Certified
Driver Rehabilitation Specialist Clinical
Co-ordinator, Driver Rehab Services,
Bloorview MacMillan Centre

Resources



Understanding Depression: What We Know and What You Can Do About It

By J. Raymond DePaulo Jr., M.D., Johns Hopkins School of Medicine and Leslie Alan Horvitz

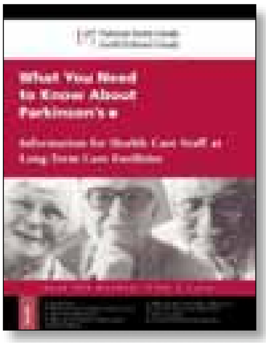
Reviewed by Susan Calne

As many as 50% of people with Parkinson's become depressed. For some it's a major part of their illness. Access to good psychiatric care is limited due to a shortage of psychiatrists. This leaves people looking for advice.

Understanding depression is a book by an academic physician who knows his subject very well and who has written a book that neither condescends to nor reaches above the head of the average reader.

If you are depressed, or are living with someone who you think or know is depressed, please read this book.

Available for $36.95 at most bookstores or by calling John Wiley and Sons at 1-800-567-4797.



What You Need to Know About Parkinson's: Information for Health Care Staff at Long Term Care Facilities

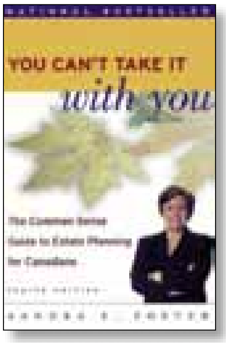
Parkinson Society Canada

This eight page booklet will help staff at long term care facilities better understand and meet the special needs of residents with Parkinson's.

It describes Parkinson's and the importance of medication scheduling; explains Parkinson mobility problems and how to help; and offers tips to help ensure socialization, communication, safe eating and family involvement. Quotes from people with Parkinson's illustrate what it feels like for a resident with Parkinson's.

Details about how Parkinson Society Canada and its regional partners can help staff are also listed.

If you have a friend or family member with Parkinson's in long term care, request a copy and share it with the staff. Call 1-800-565-3000, ext. 225 for a free printed copy.



You Can't Take It With You: The Common-Sense Guide to Estate Planning for Canadians

By Sandra E. Foster

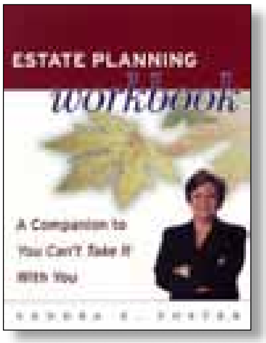
Reviewed by Suzanne Tobin

If you own a house, RRSPs, or even some savings, then you have an estate and need to consider what will happen to it when you are gone.

Estate planning and death are difficult subjects for many Canadians to discuss so many people just ignore it. This book explains why it is so important to plan ahead and covers all aspects, including: wills, powers of attorney, minimizing taxes, implications of family law and – key for people with Parkinson's – documents concerning health care.

Sandra Foster's writing style makes this subject easy to understand. The lists, tips, examples and glossary are all informative. This book will help you to ask your advisors informed questions and organize your financial affairs.

Pick up a copy for $26.95 at your local bookstore.



Estate Planning Workbook: A Companion to You Can't Take it With You

By Sandra E. Foster

Reviewed by Suzanne Tobin

Once you've read *You Can't Take It With You*, consider using the checklists, worksheets and sample documents in this *Workbook* to help you record and organize all your documents, plans and wishes.

The book helps you prepare for meetings with your lawyer, accountant, or other professionals. Once complete, Sandra Foster recommends updating the info once a year. A completed *Workbook* will make it easier for your executor and representatives to locate all your personal and financial documents, carry out your instructions and make decisions on your behalf.

Available for $18.95 at your nearest book seller.

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.

At Draxis, we're committed to the support system. Both inside and out.

Each person has a complex support system made up of bones, muscles and nerves. When Parkinson's disease (PD) affects this support system, medication can help by managing symptoms like stiffness and tremor.

Draxis Pharmaceutica was founded to provide PD medication. Today, we are proud to be one of Canada's leading pharmaceutical marketers of medication for all stages of PD, and we remain dedicated to helping patients make the most of each day.

That's why we are committed to another type of support system as well. Draxis supports Parkinson Society Canada in its activities, such as this magazine. We hope through this support you'll find useful information, motivation and inspiration.

Because even a support system needs a support system sometimes.

DRAXIS PHARMACEUTICA
A Division of Draxis Health Inc./Une Division de Santé Draxis Inc.

Marketers of
PERMAX® and **ELDEPRYL**®
(pergolide mesylate) (selegiline hydrochloride)