Spring 2006 • Volume 6 • Issue 1
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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

The Faces of Parkinson's

Courageous and determined: Pat Fleming takes on Parkinson's

On the genetic trail: Dr. Wszolek's search for LRRK2

SuperWalk 2006: Join our quest

PLUS

Meet our Volunteer Award Winners

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

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

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

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

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

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

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

For details about a walk near you and to register on-line visit www.superwalk.com

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

SuperWalk
for Parkinson's

Parkinson Society Canada
Société Parkinson Canada

Letter from Parkinson Society Canada

Parkinson Society Canada
Société Parkinson Canada

ON OUR COVER:
Pat Fleming from Toronto, Ontario, was diagnosed with Parkinson's disease 19 years ago. Today, thanks to her courage and determination, Pat is enjoying life to the fullest. Read her inspiring story on page 8.

Moving forward with purpose, energy and promise

What an exciting time to become Chair of Parkinson Society Canada!

I have been committed to the "cause" since 2000, when I was inspired by a close friend with Parkinson's to become involved with the Ottawa chapter. I was subsequently invited to join the national board in 2003.

Now, as Chair of PSC I see my primary roles as ensuring that our efforts are coordinated and that we all work together effectively. By helping to build a cohesive and focused team, we will be able to best meet the many challenges that lie ahead, both external and internal.

We are constantly amazed at how PSC challenges itself—always searching for the best and most innovative ways to meet the needs of approximately 100,000 Canadians living with Parkinson's.

Change is vital to the success of any organization. It provides opportunities for open dialogue and problem solving. It improves communication and provides the chance to reconfirm commitments.

Our team of dedicated, enthusiastic volunteers and staff are planning together for the future—to ***move forward*** as a united organization with a common mission and values.

- Our **goal** is to respond quickly to requests for support, create partnerships to strengthen our national voice and advocate for crucial resources.
- Our **mandate** is to continue funding the best in Parkinson research with the ongoing support of generous individual donors and the business community.
- Our **desire** is to inspire and energize a group of caring volunteers from every corner of this country in a shared quest to make a *real* difference in the fight against Parkinson's.
- Our **collective objective** is to be compassionate and respectful of the people we serve.
- Our **hope** is no matter where you live in Canada, you are able to find an effective Parkinson community with a sympathetic ear, factual information and access to a variety of essential services.

Our **vision** will always be to guide the decisions we make by asking one simple question, "How will this benefit or serve people living with Parkinson's, their families and care partners?"

We will keep you informed on our progress and look forward to your input.

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

Contents

FEATURES

COLUMNS

ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

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Parkinson Society Canada
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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

- Hired a part-time information and programs co-ordinator, Robbin Jeffereys.
- Carmen Dyck, director of support services, visited 12 support groups.
- Participated in two major health fairs in the lower mainland.
- Held a successful major fundraising gala event on April 27, 2006.

Victoria Epilepsy and Parkinson Centre

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

- A new Parkinson's Mind Body program has been launched that incorporates special needs yoga with attention to positive thinking and stress release.
- A clinical nurse specialist presented a very helpful educational session on "Dealing with constipation and other digestive problems."
- Specialists delivered excellent presentations on "Living well with Parkinson's: A physician's perspective," "Getting the most from your medications," and "Managing speech and swallowing changes."
- Collaborated on an interactive website to help clients track health symptoms in regards to Parkinson's. Site launched in the spring.
- Golf tournament plans are well underway with an anticipated $50,000 net revenue from the event.
- A Parkinson's Festival and SuperWalk for Parkinson's will be held in September.

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

- Three posters/abstracts based on a survey of persons with Parkinson's and their caregivers were presented at the World Parkinson's disease Congress.
- New support groups started in Vegreville and Slave Lake.
- The Edmonton speech support group was revived and will meet twice a month.
- Over 2,100 potted tulips bloomed across northern Alberta for Parkinson's awareness month.
- Annual general meeting was held and "28th Annie Wyley Memorial Lecture" was presented by Dr. Richard Camicioli on "Thinking changes in Parkinson's disease," attended by over 100 people on April 22, 2006.

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

- An evening of free massage therapy for people with Parkinson's was offered by the local College of Massage Therapy.
- A new series of the Brain Waves program is being offered in northwest Calgary.
- Yang-style Tai Chi programs are well attended in two locations in Calgary.
- Exercise programs and support groups are doing very well with the addition of three new groups.

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

- Held Million Dollar Dream Dinner on March 30. The event, which was organized by the Curling Classic and PW Golf Classic Committees, represents a 13-year goal to raise one million dollars for Parkinson research in Saskatchewan.
- Annual Curling Classic for Parkinson's Research held on March 31 and April 1.
- SuperWalk 2006 in Saskatoon is planned for September 10.

Parkinson Society Manitoba

171 Donald Street, Suite 302
Winnipeg, MB R3C 1M4
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 786-2327

- Welcomed Laura Asher, BComm (Hons), new events and development co-ordinator.
- New slate of officers for advisory Board of Directors: Marc Pittet, Chair; Tom Hodgson, Vice-Chair; Colleen Johnston, Secretary; Shaun Hobson, Acting Treasurer; Bob Ashuk, National Representative; Adrienne Toews; Don Dietrich; Wayne Buchanan; Louis Maric; JoAnne Minkus; and Terry Snell, Past Chair.
- Speech therapy and Brain Gym programs for people with Parkinson's have been successful, based on satisfaction surveys received.
- Lisa Gilmour, BA (Advanced), administrative assistant, has been named to the National Advocacy Committee.

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

- Education session was held in Barrie in February with movement disorder specialist Dr. Rana.
- Spring 2006 *Livewire* publication was distributed to 7,100 individuals.

continued on page 6

Parkinson Society Canada
Société Parkinson Canada

- April Awareness events included tulip sales and tulip card fundraisers.
- Additional education sessions held in April, including the First Annual Agro Series Educational Session featuring Dr. Mandar Jog.

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

- Submitted $172,496 to PSC National to support research and services. Congratulations to our volunteers, walkers and supporters for making this support possible!
- Introduced an exciting new format for the 2006 spring issue of *The Parkinson Update*, reflecting the energy and enthusiasm of volunteers and partners and encouraging even more community involvement.
- London held its third annual Spell the End of Parkinson's Scrabble Tournament, raising $8,267. More tournaments are anticipated this spring.
- Michelle Monger and Darrin Beaupre, two students from Fanshawe College, worked to make April Awareness 2006 the best ever.

Parkinson Society Ottawa

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

- "Why is this my medication?" presentation, given by pharmacists Judy Glustien and Mary Joy, attracted a full house of participants.
- The second annual Yuk Yuk's Comedy Night for Parkinson's was held in mid-January. Over 550 people attended and, along with sponsors and donors, helped to raise over $21,000.
- Selected donors, SuperSTAR Walkers and Board members were invited to join in our annual donor appreciation in February. Each guest was treated to either cut or potted tulips.
- Three new support groups were added, bringing the total to 18. One group, "Thursday Night Live," is unique: they meet the first Thursday of each month to discuss current issues and recent resource materials.

Société Parkinson du Québec

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

- New executive director is Jean-Marie Bergeron. The Quebec Board will decrease the number of board members from 22 to nine, the regional representatives from 18 to two, and increase the number of influential people to five. The two positions reserved for medical professionals were not touched by this reform.
- Currently searching for a permanent spokesperson who will lend his or her name and image to mass mailings, membership renewals, and other media activities. We are currently accepting proposals.
- This year, SPQ decided to emphasize World Parkinson Day by renting Complexe Desjardins' La Grande-Place. Roughly 10 stands were set up, that of PartenairesSanté, SPQ, SPQ Montreal Region, neurologists, nurses, massage therapists and stands for sponsors related to our cause.
- Fanie Noiseux has joined our team as our new associate director, replacing Diane Van Erum. Mrs. Noiseux is a major financing campaign specialist.
- Our lease at 1253 McGill College has ended. We have relocated to 550 Sherbrooke Street West.

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

- New interactive website has been launched, featuring "Ask an Expert," an interactive database of questions and answers about topics related to Parkinson's. Visit www.parkinsonmaritimes.ca.
- Awareness month lecture series with Sandie Jones of Central and Northern Ontario Region held in Saint John, Summerside, Sydney and New Glasgow.
- Bridgewater chapter hosted an Awareness Month workshop on April 11, World Parkinson Day.
- Annual "Wing It For Parkinson's" was held in Moncton and Saint John on April 24.
- Fourth annual "Porridge for Parkinson's" was held on April 22. CBC morning host Terry Seguin and Canadian Idol runner-up Casey Leblanc were celebrity hosts.
- A resource guide has been published listing all materials held in the Region's Banyan Tree Foundation Resource Centre.
- Eight sessions from the fall conference are now available on video and DVD.

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

- Successfully applied to the United Way to fund a speech therapy program in St. John's metropolitan area. Special thanks to Mary Chibuk and The Parkinson's Society of Alberta for sharing details of their speech education program.
- Recruited two new Board members with past board experience, and continued training for current members.
- A new April awareness and fundraiser event, "Piggies for Parkinson's," and a successful flea market and ticket sales were held.
- Excellent media coverage for Joyce Humphries, winner of first regional Anne Rutherford Memorial Award, and Maxine Thistle, winner of the national David Simmonds award.

Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

Asking the government to act now!

By Joyce Gordon

The Honourable Jack Layton, leader of the NDP, discusses Parkinson's disease with Yvon Trepanier, Advocacy Committee Chair, PSC; and Joyce Gordon, President and CEO, PSC.

Thanks to the diligent work of the Advocacy Committee, advocacy efforts continue to gain momentum at the national level. By building upon the grassroots work done during the federal election campaign, PSC staff and volunteers successfully secured meetings with key Members of Parliament and decision-makers in April. We were first pleased to meet with

- Jo Kennelley, Senior Policy Advisor to the Minister of Health
- Nadir Patel, Senior Policy Advisor, Privy Council Office
- Rahim Jaffer (Edmonton-Strathcona), National Conservative Caucus Chair
- Gary Lunn (Saanich-Gulf Islands), Minister of National Resources
- Ken Dryden (York Centre), Liberal Health Critic
- Penny Priddy (Surrey North), NDP Health Critic
- Denise Savoie (Victoria), NDP

These meetings provided an opportunity to make personal connections, to educate MP's about Parkinson's disease, and to ask for help in achieving our three key objectives:

1. That the Government immediately double the effort to find better treatment and a cure by committing to either match or surpass Parkinson Society Canada's annual research funding of $1 million.
2. That the Government help Parkinson Society Canada uncover and gather the data needed to understand the full impact of Parkinson's, so we can deliver the best care and support today while planning for the future.
3. That the Government make universal access to home care supports and services a priority issue nationally.

Our message to government officials and decision-makers is that we need their help and that with each passing day, the urgency increases. Very simply, we must **act now!**

Over the coming months, Parkinson Society Canada will continue to communicate with key decision-makers to build our network of friends. We must generate a groundswell of support. To do so, every Member of Parliament and the Senate needs to hear from someone from the Parkinson's community. We welcome volunteers who are willing to write a letter, make a phone call or meet with their representative.

For more information about how you can help, please contact Shannon MacDonald, Project Manager for Advocacy and Government Relations, at **(416) 512-8642** or **advocacy@parkinson.ca**.

Ease the Burden; Find a Cure

Health Tip

Common questions answered by the Canadian Pharmacists Association:

Q Should I keep a record of the medications that I am taking?

It's a good idea to keep a written record of all medications you are taking, including nonprescription and herbal products. Bring it with you whenever you visit your doctor or pharmacist, and carry a copy with you at all times, in case of emergency. Your pharmacist will also keep a record of the medicines you take and how you have reacted to them. Remember to tell the pharmacist of all nonprescription or herbal products you take, since he or she will only know for sure about the prescription medications you have filled at the pharmacy.

Q How do I store my medicines safely?

You should keep your medicines in the container that they came in. The bathroom cabinet is not a good place because it gets warm and damp. Always keep medicine out of a child's reach, and refrigerate medication only if it says to on the label.

Q How do I get rid of my medications safely?

You should take all outdated or unused medicines you have cleaned out to your pharmacy for safe disposal, including prescription and nonprescription. If you don't know if a medicine is good, ask your pharmacist. Medicine should not be flushed down the toilet: it's not friendly to the environment. Don't throw it in the garbage because children or animals may be able to get at it.

Source: www.pharmacists.ca

Courageous and determined:

Pat Fleming challenges Parkinson's and herself

By Ian Corks

"You have Parkinson's disease." With those four words, Pat Fleming's world was changed forever. It was 1987, and the words of the neurologist took a few seconds to sink in. "I felt as if I had just been handed a life sentence, with no appeal process!" Pat recalls. "My view of the future was extremely bleak. In fact, I had a vision of living another five or six good years, followed by spending the rest of my life sitting in a wheelchair shaking."

It's now been almost 20 years since that fateful moment in the doctor's office. And Pat has long since shattered that gloomy vision. Though not without their trials and tribulations, the years since her diagnosis have been productive and fulfilling. Pat has more than met the challenges of Parkinson's with a courage and determination that has earned her selection as one of PSC's Faces of Parkinson's.

A good life

The world that changed for Pat that day was a good one. Born and raised in Toronto, Pat's formative years were happy ones. She married Ross Fleming, a busy local physician, and devoted the next few years to her family, raising four children. When the kids were old enough, Pat returned to university, studying education, gerontology and counselling. This led to an 18-year-plus career with the Family Services Association, where she ran a program offering information and support to older adults and their families in Toronto. It was a job Pat enjoyed, and one that would help prepare her for the challenges that lay ahead.

"I had always felt so lucky," Pat smiles ruefully. "Everything I could dream of I had either achieved or had been given to me. Life was great! I often wondered if the future would bring something to even things up a bit. And indeed it did!"

The diagnosis of PD marked the beginning of a new chapter in the lives of the Fleming family. "The next few months were the most difficult of my life," Pat recalls. "My first hurdle was to deal with the shock of the diagnosis. My next step was to get more information about this devastating disease. I became more depressed with each piece of new knowledge I acquired. I remained in the doldrums for a long time."

Coming to terms

But rather than meekly give in to her situation, Pat decided to fight back. "One day I had a sudden powerful insight into what I was doing. I was letting my preoccupation with my health and the bleak future I faced waste the very real potential of the present. Gradually, I began to come to terms with my situation and tried to work out some sort of daily routine. I decided to do as much as I can for as long as I can, taking one step at a time, challenging myself, but being open to change and adapting as needed."

This positive attitude has become one of the foundations of Pat's life, and she continues to challenge herself, both physically and mentally. "I remember attending a presentation by Dr. George Turnbull," she notes. "He strongly recommended regular exercise for people with PD. He said exercise was only slightly less important than taking pills. He also emphasized the importance of keeping active mentally, socially, and physically. It was a call to action for me.

"I have always believed in fitness and I love the outdoors, but over the years I have had to adapt. When swimming no longer became safe because I could not stay afloat, I obtained a good quality life jacket and now swim passably well. When downhill skiing was no longer safe for me, I switched to cross-country skiing. In time, I had to stop this too, because of poor balance and numerous falls; so I took up snowshoeing.

"These days, I try to hike for an hour or two several times a week, either with my husband, a family member or a friend. I love nature trails. Sometimes I walk safely, and other times I need to hold someone's arm for support. I find the weekly exercise and Tai Chi programs offered by the PSC Central and Northern Ontario Region very helpful. I attend them regularly."

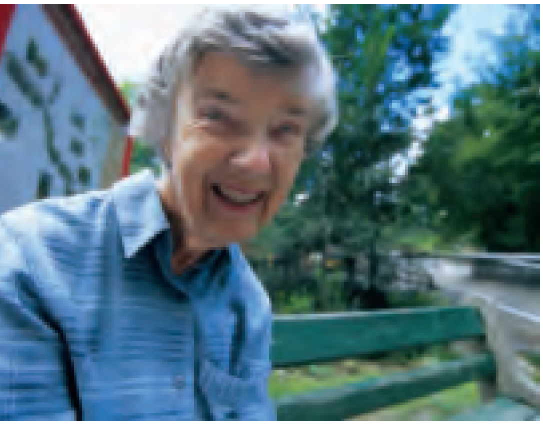
Staying alert mentally is also important. Pat kept working for another 10 years after her diagnosis. "Ironically, many of our clients were also coping with Parkinson's," she notes. "I certainly had no problem empathizing with them!"

Keeping busy

When she finally retired at the age of 65, Pat still felt the need to stay busy. "What was I to do with all the extra hours I had just been granted?' Pat recalls asking herself. "I wanted to find a truly meaningful volunteer job. I happened to notice a newspaper item saying that the then Parkinson Foundation of Canada was planning to set up a Peer Support program. It would provide practical counselling and support on a one-to-one basis, especially to people who were newly diagnosed. That is exactly what I would have appreciated when I was in those bleak early months. With my professional and personal experience, I knew I could really be helpful. Everything just fell into place after that."

Pat spent the next few years working two days per week as a volunteer co-ordinator of the Peer Support Program, recruiting, training and supervising volunteers.

"It helped me to handle my own condition better because I learned so much from the people I worked with," Pat recalls. "I learned from volunteers in the Peer Support program and clients themselves. Some were in pretty bad shape but still able to share their practical coping skills and wonderful sense of humour."



Another key to Pat's ability to deal with her condition has been the unwavering support of her husband. "Ross has been wonderful," she smiles. "He has reached a level of patience and understanding neither one of us would have believed possible. More importantly, he has always gently challenged me to do just a little more than I felt I could."

These days, Pat has cut back on her activities a bit, but she still keeps herself busy. She continues to be involved in the cause that is dearest to her heart: helping people with Parkinson's and their families and loved ones. She still contributes her expertise and experience to PSC, serving on two committees. Pat also regularly speaks to pharmacy students at the University of Toronto, providing valuable insights into PD medications from a patient's perspective that the next generation of pharmacists find extremely useful. And, of course, she has been selected as one of the Faces of Parkinson's.

"I was a bit reluctant at first," she notes. "I'm not the type of person who likes to stand up and say look at me." However, it was Pat's memory of her initial fears that helped convince her. "I knew that image of an old person sitting in a wheelchair drooling and shaking uncontrollably all the time is one that too many people associate with PD," she recounts. "I think the Faces of Parkinson's campaign can help give people a more realistic view of what Parkinson's is, how people are affected and, most importantly, what they are not!

"As one of the Faces of Parkinson's, I hope that I can tell—and show—people that you can't stereotype someone just because they have Parkinson's disease. We are still members of the human race and more than capable of making a contribution. People with Parkinson's disease can still do so much—often much more than we think we can. I hope this campaign will help everyone, from men and women with Parkinson's to the general public, understand that."

Of course, Pat still has "those days," as she calls them. Days when her movement is almost totally restricted or everything seems overwhelming. And she still experiences times of doubt. For example, she admits being worried that her periods of dyskinesia (or the "wigglies," as the family call them) would scare her grandchildren—a fear that has proven ungrounded, as her 10 grandchildren have responded with unconditional love, support and understanding.

"Life is certainly far from perfect," Pat relates. "I still have my ups and downs. I still have PD and try to live one day at a time. However, with God's help, I am determined that my relationship with my illness will always be one of accommodation, not surrender!"

Meet the Faces of Parkinson's

The Faces of Parkinson's is PSC's exciting three-year campaign aimed at increasing public awareness and understanding of Parkinson's disease (PD) by presenting real images and stories of Canadians with PD.

Using advertisements, public service announcements, press releases, bookmarks and other initiatives, the campaign will showcase the realities of the disease and profile the courage, challenges and successes of a number of people with PD. A few exceptional individuals were selected to be the Faces of Parkinson's (from many possibilities) following a nationwide search. They come from across the country and represent a full range of ages and backgrounds. One thing they all have in common is that they are not letting PD stand in their way.

The Faces of Parkinson's campaign was launched at the end of 2005 and is already well underway. (Editor's note: For more background on the campaign, see the Winter 2005 issue of *Parkinson Post*.)

Honouring people who *make a difference*

Mimi Feutl Award 2005: *Sandie Jones*

Sandie Jones has been described as a "hard working and dedicated servant" to people with Parkinson's disease and "a pillar of strength to the Society."

As Director of Client Services and Education for PSC Central and Northern Ontario, Sandie is involved in developing educational programs and staff and volunteer training, as well as speaking on PD and its effects throughout central and northern Ontario, and even across the country. In spite of her busy schedule, however, Sandie always finds time for individual consultation.

Sandie has used her nursing knowledge and experience to teach other nurses and caregivers about PD. As one award nominator notes, "Many thousands will benefit from better-informed nursing and personal care staff who have attended in-service workshops that Sandie has presented on the special requirements of PD." Since joining PSC in 1996, Sandie has touched and helped to improve the lives of countless people with Parkinson's and their families.

Morton Shulman Award 2005: *Dr. Gordon Hardacre*

Dr. Gordon Hardacre has worked tirelessly to improve the lives of people with Parkinson's, not just within his region but also across Canada.

For over 30 years, Dr. Hardacre has served his Toronto community as a family physician, researcher, teacher and advocate. He is currently Director of Undergraduate Family Medicine Education, University Health Network and Assistant Professor of Family & Community Medicine, University of Toronto.

Dr. Hardacre was diagnosed with Parkinson's in 1996. In the face of his own challenging symptoms, he has not only continued to serve his patients, but has worked to increase the level of understanding of PD among his fellow family physicians. He was instrumental in developing the Medical Education and Support Program for GPs, and he continues to advocate on behalf of PSC.

David Simmonds Award 2005: *Maxine Thistle*

Maxine Thistle has had a tremendous impact on the lives of people with Parkinson's in Newfoundland and Labrador.

Since joining the Executive of the St. John's Support Group in 1995, Maxine has been a tireless advocate for a regional board that truly served the needs of the people in the province. In 2002, she became Chair of the newly formed Parkinson Society Newfoundland & Labrador (PSNL) Regional Advisory Board. Armed with her commitment and a true understanding of the challenges of the region, Maxine has been the "driving force" behind the board and its ever-expanding programs and activities.

In the words of one of her nominators, Maxine has "infused the PSNL Regional Advisory Board with a wealth of knowledge, an infectious dedication to the cause, and a sense of joy and humour that is an inspiration to all."

Following a genetic trail:

Dr. Zbigniew Wszolek's search for the elusive cause of Parkinson's disease

By Ian Corks

The Donald Calne Lecture series was launched in 2002 by Parkinson Society Canada (PSC). Each year, PSC invites a leading international expert on Parkinson's disease to address attendees at the PSC's Annual General Meeting. The 2005 Donald Calne Lecture was delivered by Dr. Zbigniew Wszolek of the Mayo Clinic in Jacksonville, Florida.

A specialist in the neurogenetics and neurophysiology of Parkinson's disease (PD), Dr. Zbigniew Wszolek is world-renowned for his groundbreaking work on genetics and PD.

Dr. Wszolek has a long-standing connection to Canada, frequently working with Dr. Calne and his colleagues at the University of British Columbia. His Canadian research played a major part in the discovery of the gene LRRK2. This has been hailed as a significant finding that could lead to a better understanding of cell death in Parkinson's and, eventually, curative treatments. Dr. Wszolek detailed his role in the discovery of LRRK2 and its potential implications during his fascinating talk.

Understanding genetic PD

While genetic—or familial—forms represent a small minority of all cases of PD, the study of genetically determined PD is a vital component of understanding the disease as a whole. Genetic PD closely resembles the more common—or sporadic—form of the disease in virtually every respect, except that it is usually inherited or passed on from a family member.

The very nature of familial PD allows it to be studied in successive generations, providing researchers with a natural "laboratory." Over the past 10 years, new techniques and research tools have allowed scientists to achieve unparalleled successes in tracking and understanding genetic PD. Researchers hope that data gained on why and how cell death occurs in genetic PD would also apply to sporadic forms and, therefore, strategies for modifying the process and preventing cell death would potentially work for anyone with the disease.

The first gene identified as a factor in PD was discovered in 1997 by a group from the National Institutes of Health (NIH). The NIH team had been studying a large family from southern Italy with a history of autosomal (passed down from the parents) PD. Since then, researchers have identified a number of genes that play a role in the disease's development. Among these is the parkin gene, discovered by noted Japanese researcher Professor Yoshikuni Mizuno (the inaugural Donald Calne lecturer). Until recently, the parkin gene was the gene most commonly identified in cases of familial PD.

The road to LRRK2

During this period of discovery, Dr. Wszolek was very active in research on the genetics of PD. In 1992, he had started on a line of investigation that would eventually lead to an important breakthrough: the discovery of the novel gene LRRK2. It started with a single patient seen by Dr. Wszolek: a 57-year-old woman with moderately severe PD. Of particular interest to Dr. Wszolek, the woman reported that her mother and several other family members had also been diagnosed with Parkinson's. Eventually, she and several family members agreed to participate in a genealogical study. This family was named the Western Nebraska family and about 200 members were identified.

Cases of PD within this family had an average onset age of 64 and were associated with the classic symptoms of sporadic PD. However, a series of four autopsies showed some interesting "abnormalities." In each of the four autopsies, the state of the Lewy bodies (abnormal concentrations of protein that can accumulate in nerve cells in the brains of people with PD) was different. This caused Dr. Wszolek and his team to ponder why, in four members of the same family all presenting with the typical features of PD, were autopsy results different enough to almost be indicative of different diseases? Though a mystery at the time, the data from these studies would provide a key part of the LRRK2 puzzle.

Meanwhile, in Japan

At the same time, Japanese researchers were studying another case of familial PD in a family, known as the Sagamihara family. Members of the Sagamihara family with PD had a mean onset of 54 years and members also exhibited the typical symptoms of the disease. The researchers found important clues to the gene involved—but could not quite pin it down. Dr. Wszolek likened the situation to "finding out the province where a person lived, but not quite identifying the city or the street."

Back in North America, Dr. Wszolek was involved with yet another family with a history of PD. This was a German-Canadian family who he studied in co-operation with Dr. Calne and Dr. Jon Stoessel of the University of British Columbia. The clinical presentation was different, with some family members showing signs not only of PD but of Alzheimer disease-like dementia as well the amyotrophy associated with Lou Gehrig's disease. Autopsies on two family members revealed some abnormal features, specifically the absence of Lewy bodies.

Putting the puzzle together

The data from these three families allowed Dr. Wszolek and others to, as he puts it, "piece the whole story together," leading to the 2004 discovery of the novel gene *Lecucine-Rich Repeat Kinase 2*, or LRRK2. This gene appeared to be the only plausible genetic explanation for Parkinson's in the families studied.

Now LRRK2 is known to be one of the most common genes affected in familial PD. Dr. Wszolek estimates that if you have a family history of PD, the chances of you having a mutation in the LRRK2 gene are approximately 13 per cent if you are Caucasian, and as high as 30 per cent if you are of African decent.

For the past year, the LRRK2 gene has been one of the most active areas of Parkinson's research, with 48 scientific papers published. Researchers have shown that different mutations can occur on different locations on LRRK2. What these mutations are and where they occur could account for the very specific clinical features and pathological abnormalities that are seen in different families.

Discovering and interpreting this type of genetic data could point the way to the eventual development of treatment and even prevention strategies. As Dr. Wszolek notes, "Just like the Rosetta Stone provided our key to the translation of ancient hieroglyphs, genetic studies hold the key to the treatment of diseases such as Parkinson's."

In the case of LRRK2, the studies started with a single patient, then led to a family tree, then to pathology information that provided data on chromosome abnormalities. From there, the specific gene in question was isolated and numerous mutations were discovered. The next step will be transgenic animal studies towards the development and investigation of specific therapies for individuals with familial PD—treatments that could conceivably benefit anyone who suffers not only from familial PD, but from the more common sporadic form of the disease.

An inspiration to others

A native of Poland, Dr. Zbigniew Wszolek received his MD from the Silesian University. He began his research on the genetics of Parkinson's disease in 1987 while a neurology resident at the University of Nebraska.

Since then he has established a reputation as one of the world's leading Parkinson's researchers, and his work has inspired and influenced many. He is a co-recipient of the prestigious M.K. Udall Parkinson's Disease Center of Excellence Award from the National Institutes of Health and has more than 300 publications to his credit. Dr. Donald Calne describes Dr. Wszolek as being like "the conductor of an orchestra of interdisciplinary researchers working in the area of genetics and PD."

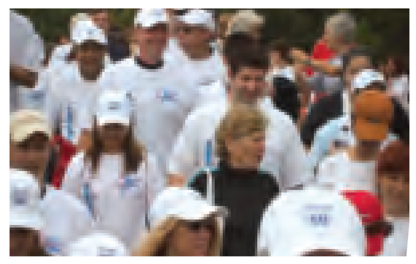
Today, Dr. Wszolek is Professor of Neurology, College of Medicine, Mayo Clinic, Rochester, Minnesota, and Consultant at the Mayo Clinic, Jacksonville, Florida. He is currently researching the Tau gene and Lewy Bodies in PD.

Join us at SuperWalk

Each September, thousands of Canadians across the country join together to raise funds for Parkinson's. In 2005, revenue from SuperWalk for Parkinson's reached an all-time high of $1.75 million! To the many dedicated volunteers, staff and walkers who participated, thank you!

This September, take up the challenge and walk with us as we continue our streak of breaking each previous SuperWalk record. Bring your family, friends and co-workers and walk with us toward a cure. Tom Cochrane, our honourary chair, will be joining us again this year.

Parkinson Society Canada is honoured to have the consistent support of many sponsors who give money, send company teams and volunteers, and provide the fantastic prizes and incentives that make walk day great for our supporters. They each contribute so much as we strive to make a difference in the lives of those around us with Parkinson's. Because of them, our goal is closer every day.



Don't forget to visit **www.superwalk.com** and register on-line for any walk in Canada. This is an easy way to send invitations to friends asking them to join in or send you a pledge. Registration is free and fast—in 2005 we had more on-line walkers and donations than ever before! While you're on-line, don't forget to check out the great team and individual prizes and incentives.

See you in September!

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SuperWalk for Parkinson's

Thanks for your support!

Here's what you'll receive in return for supporting SuperWalk:

RAISE $100–$999

- $10 in **ROOTS** gift certificates for every $100 raised
- one Grand Prize draw ticket for every $100 raised
- two free **Solstice Beauty** products (retail value of $30) with any minimum $20 on-line purchase–free shipping

RAISE $1,000–$2,499

SuperSTARWalker

- a blue SuperSTARWalker hat and pin
- one chance to win in the draw for an **AQUOS LCD Television, courtesy of SHARP**
- $10 in **ROOTS** gift certificates for every $100 raised
- one Grand Prize draw ticket for every $100 raised
- four free **Solstice Beauty** products (retail value of $70) with any minimum $20 on-line purchase–free shipping

RAISE $1,000–$2,499

SuperSTARWalker Supreme

- a red SuperSTARWalker hat and pin
- one chance to win in the draw for an **AQUOS LCD Television, courtesy of SHARP**
- $10 in **ROOTS** gift certificates for every $100 raised
- one Grand Prize draw ticket for every $100 raised
- seven free **Solstice Beauty** products (retail value of $125) with any minimum $20 on-line purchase–free shipping

RAISE $5,000+

- everything listed for the SuperSTAR Supreme plus...
- **MindFit,** a new easy-to-use computer software program that provides a comprehensive program of mind-fit exercises (retail value $175)
- a basket of **Deep Cold** products (retail value of $100) courtesy of the Mentholatum Company of Canada

GRAND PRIZE DRAW

1. 10-day Costa Rica Rainforest Adventure, **courtesy of ElderTreks**
2. Two Hospitality Class Airline Tickets to any scheduled international Air Canada destination, **courtesy of Air Canada***
3. Cineplex Entertainment VIP Card, one year of unlimited movie admissions for two, **courtesy of Cineplex Entertainment**

* Some time restrictions on travel may apply. Qualification for national prizes is not open to any employees of Parkinson Society Canada and its regional partners or to any member of their immediate families. Parkinson Society Canada reserves the right to substitute an alternate prize.

Team challenge

Joining the walk as a team makes a great day even better! Friends, family and co-workers can all join together. For more details, ask your regional office for a team book.

- Each qualifying team member can be eligible to be part of the draw for **ROOTS leather bags**, valued at $400 each, and still get their individual prizes.
- All **corporate teams** can be part of our **SuperSTAFF** for SuperWalk campaign and get their team name, company name and total funds raised listed on our website.

SuperSTARWalkers

Raise $1,000 or more, become a SuperSTARWalker, and get even more exciting prizes and incentives. In 2005, SuperSTARWalkers across Canada raised close to half-a-million dollars.

Spreading the word about Parkinson's

April is Parkinson's disease awareness month in Canada, and each year Parkinson Society Canada (PSC) and its regional partners host, promote, participate in and encourage an exciting range of events aimed at increasing the understanding of PD and the role of PSC.

Here are just a few highlights of the many April Awareness 2006 activities.

Photo: George Bashiri

Guardian Angel students (left to right) Taylor Rawn-Kane, Kaitlin McCutcheon, Franklin Turkson and Gabrielle David show off their April Awareness tulips.

Angelic art

Students at Guardian Angels Catholic School in Brampton, Ontario, put their artistic talents to work by creating pictures of tulips, the symbol of PSC and the fight against Parkinson's.

At the invitation of PSC Central and Northern Ontario Region, 22 kids from Ms. Stoker's grade two class produced some colourful and beautiful images. "The students really enjoy expressing themselves," comments a Guardian Angels staff member. "It's nice to be able to help a charity at the same time."

Passing the baton

The first annual Pass the Baton for Parkinson's was held at Berrigan Elementary School in Barrhaven, Ontario, to help educate elementary school students on PD.

This event was designed and coordinated by Shelby Hayter, who, last year, raised awareness and over $36,000 for the Parkinson's Research Council (PRC) by running in the grueling Boston Marathon—just one month after being diagnosed with young onset Parkinson's at age 40.

The idea was to demonstrate how a doctor, a scientist, a patient and caring people in the community (including children) can work towards a common goal such as finding a cure for Parkinson's.

With the assistance of Dr. David Grimes and Dr. David Park of the PRC, Shelby led students in a series of exercises highlighting the four common physical abilities affected by Parkinson's: strength, balance, flexibility and speed. Each class participated in a 15-minute circuit before they passed the baton to the next class. At an assembly the previous day, students helped to simulate a few of the effects of PD through a series of walking and running drills, first wearing running shoes, then oversized winter boots, and finally oversized ski boots.

The original event raised almost $3,700 for the PRC and generated awareness for Parkinson's through television and local newspaper coverage.

Shelby Hayter tells students that everyone needs to work together to find a cure for PD.

Jean Kristjanson (left) accepts the framed tribute to her late husband, Dr. Leo Kristjanson, from Manitoba's Minister of Education, Citizenship and Youth, Peter Bjornson.

Manitoba MLAs get the message

Parkinson Society Manitoba hosted a special reception for Members of Legislative Assembly (MLAs) to raise awareness among legislators and health officials about the devastating effects of the condition.

Attendees learned about PD and had a chance to review and sign the *Global Declaration on Parkinson's Disease*. In addition, the Honourable Peter Bjornson (MLA Gimli), Manitoba's Minister of Education, Citizenship and Youth, presented a framed copy of his private member statement to Jean Kristjanson, widow of the late Dr. Leo Kristjanson, a long-time resident of Gimli. The statement addressed the burden of PD and paid tribute to Dr. Kristjanson, the former President of the University of Saskatchewan and Member of the Order of Canada, who passed away in 2005 after a long battle with PD.

Education Maritimes-style

Parkinson Society Maritime Region held a week-long series of interesting and informative lectures on various aspects of Parkinson's disease. Guest lecturer Sandie Jones, Director of Client Services and Education, PSC Central and Northern Ontario Region, made seven presentations in five days, speaking in Saint John, New Brunswick; Summerside, Prince Edward Island; and Sydney and Pictou, Nova Scotia.

The Bridgewater, Nova Scotia, Chapter organized a full day workshop on April 11 to mark World Parkinson's Day. The event attracted over 100 people, who participated in seven practical sessions.

Keep on rocking!

For three days straight, Newfoundland's 83-year-old Burt Fudge "rocked" for Parkinson's.

The Grand Falls-Windsor resident sat and rocked from nine to five on April 20, 21 and 22. It was the second year for Burt's "rock-a-thon," and this year he raised $525 for Parkinson's research.

Piggies for Parkinson's

Parkinson Society Newfoundland and Labrador (PSNL) put a herd of pink piggies to work in their April Awareness campaign.

Adorable custom-made Parkinson's piggy banks were put up for "adoption." The idea is to use the bank to collect spare change, and return it to PSNL when full. The piggy will be emptied, then returned to its owner and put back to work for another year. To date, about 150 Parkinson's piggies are in circulation.

Jessie Goodyear proudly shows off her newly adopted Parkinson's Piggy.

And much more

Calgary: The One Enchanted Evening Progressive Dinner fundraiser was a sell-out, with over 100 guests enjoying champagne, wine-tasting and an excellent meal.

Edmonton: The 28th Annual Annie Wyley Memorial Lecture was delivered by Dr. Richard Camicioli of the Edmonton Movement Disorder Clinic.

Montreal: Journee modiale de la maladie de Parkinson (World Parkinson's Day) was marked by an art exhibit at Complexe Desjardins–Grande Place. Six artists displayed their works and raised funds through sales of a calendar.

Winnipeg: A Parkinson's Awareness ad campaign, featuring the tag line "You are not alone," appeared on a Winnipeg city bus.

Parkinson's research around the world and

Research Editor: Dr. John Wherrett

Explaining nigrostriatal tract degeneration

German investigators used a variety of techniques and strategies in attempting to understand why the nigrostriatal tract degenerates in Parkinson's disease (PD), while an adjacent dopamine tract (the ventral tegmental tract) is less affected.

In mice models of PD, investigators found that channels in the substantia nigra cells that regulate the passage and excitability of the ion potassium into the cell were open. However, the channels in the adjacent tract were not. These channels (termed K-ATP channels) are regulated by ATP, the energy molecule, so that they open when the concentration of ATP is reduced. ATP is generated in the mitochondria, the energy-producing units in a cell. If the mice had channels that were genetically altered so that they could not be opened, the Parkinson models could not be produced.

This finding further supports evidence for an energy failure in parkinsonian nigrostriatal cells, and shows that the potassium channel is necessary for degeneration of cells. It now becomes important to determine if there are drugs (such as CoQ10) that might affect the energy generation in the mitochondria or might activate the potassium channel to prevent or delay neurodegeneration.

Reference: *Nature Neuroscience*, Dec. 2005

How levodopa treatment works

Thirty-six years after the discovery that levodopa could reverse the symptoms of PD, uncertainties remain as to how it actually works. However, recent advances in neurobiology and genetics have opened up new opportunities to seek answers.

Investigators from Scotland and the U.S. have applied a number of advanced approaches to genetically engineered mice models and a rat model of PD in an attempt to assess the effect of dopamine deficiency on brain circuitry beyond the site of the damaged and dopamine deficient nerve cells (the nigrostriatal tract). The mice were created by the American National Institute of Neurological Diseases and Stroke, and the rat model was developed by a Canadian investigator (and former member of PSC's Scientific Advisory Board).

It has been known for about 18 years that there is an imbalance between two motor control systems that are normally muted. One system—called the "indirect" pathway—develops an abnormal pattern of activity in a fashion that shuts down motor activity. Treating Parkinson's with deep brain stimulation appears to partially block a "way-station" in this pathway, thus reducing the abnormal activity.

The investigators studied mice in which specific nerve cells, known as medium spiny neurons that are targets for dopamine in the large nucleus or "way-station" called the striatum, were labeled according to which of two variants of dopamine receptor they contained. The "indirect pathway" neurones contain only the so-called D2 form of receptor, whereas the "direct pathway" neurones contain only the D1 form. The researchers found that when dopamine was deficient, there was a marked loss of the D2 receptors but not D1 receptors. These spines also serve as the receptor region for nerve inputs that use glutamate, a neurotransmitter that acts to increase activity. However, the loss of spines and glutamate input appear to create an abnormal pattern of increased activity in the "indirect" pathway.

The connection between the dopamine deficiency and the loss of spines was shown to be a channel that controls the movement of calcium into the cells. If the channel was removed or blocked, dopamine deficiency did not result in a loss of spines. Thus, in the medium spiny neurons of the initial link in the "indirect pathway" that were subject to a reduction of dopamine, a calcium channel was affected that resulted in a distorted activation by glutamate neurotransmitter.

Drugs that block calcium channels are in common use for treatment of high blood pressure and angina. Further studies are underway to determine if any of these calcium channel blockers could be considered for trials in PD to reduce the effect of dopamine deficiency.

Reference: *Nature Neuroscience*, February 2006

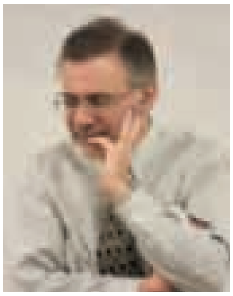
EDITOR'S NOTE: Please remember that clinical studies, research findings and other information featured in *Research Report* are often of a preliminary or investigative nature. Results may not be applicable to all cases and actual treatments resulting from findings can take time to be developed. The information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

here in Canada

Renowned scientist recognized with Donald Calne Lectureship

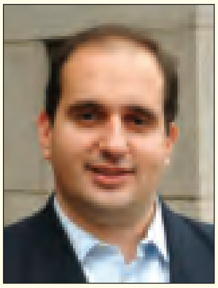
Parkinson Society Canada (PSC) is pleased to announce the award of the fourth annual Donald Calne Lectureship to Dr. Jon A. Stoessl, Director of the Pacific Parkinson's Research Centre at the University of British Columbia (UBC) in Vancouver.

A native of London, U.K., Dr. Stoessl moved to Canada in 1960 and obtained his MD from the University of Western Ontario in 1979. His post-doctoral work focused on movement disorders, PET technology, Alzheimer disease and neuropharmacology. Dr. Stoessl's current research is focused on understanding basal ganglia disorders, particularly Parkinson's disease, including complications of long-term therapy. Dr. Stoessl's lab uses positron emission tomography (PET) to study the natural history and progression of Parkinson's disease, compensatory changes that take place during the course of the disease, and changes associated with the development of motor complications. Dr. Stoessl and his colleagues have used PET to demonstrate dopamine release as a mechanism underlying the placebo effect in Parkinson's.


Dr. Jon A. Stoessl.

This lectureship was established in 2002 to honour Dr. Donald Calne for his outstanding service to the Parkinson's community as Professor of Neuroscience, UBC, and past chair and long-time member of the Scientific Advisory Board, PSC.

Each year PSC awards a distinguished neuroscientist, whose work is primarily in the area of Parkinson's disease, with this lectureship. The recipient will deliver a "state of the illness" lecture on Parkinson's disease to PSC's Annual Meeting. This year's lecture will be given in Ottawa on Friday, November 3, at "Bridging the Generations," PSC's Annual Conference. To register, watch for information at www.parkinson.ca.



Focus on …

Dr. Oury Monchi

PSC New Investigator Award

Centre de Recherche de l'Insitut de Geriatrie de Montreal, Montreal, Quebec

Along with his colleagues at the Centre de recherche de l'Insitut de Gériatrie de Montreal (CRIUGM) and the Montreal Neurological Institute, Dr. Monchi is studying cognitive problems in PD. To be more specific, he is using functional magnetic resonance imaging to compare the mechanisms responsible for the cognitive and motor deficits associated with the disease.

"The neurobiological dysfunctions in the brain responsible for these deficits are not well understood," explains Dr. Monchi. "We can use new functional brain imaging techniques to identify the neural circuits responsible. This will help us to understand how these problems evolve–to track their pathophysiology. It may help us to predict and perhaps prevent them."

It is highly specialized work and requires specialized expertise. Dr. Monchi has that expertise, earning a PhD in computational neuroscience modeling at King's College, University of London. Returning to the Montreal area where he previously lived, he served post-doctoral fellowships at the Montreal Neurological Institute and the CRIUGM in order to develop an expertise in functional neuroimaging. He is now assistant professor at the University of Montreal and lead researcher on this Parkinson Society Canada-funded project at the CRIUGM.

"We are making progress," states Dr. Monchi. "We were first to show differences in neural circuit activity depending on whether or not the striatum was involved. Cortical activity was decreased if the striatum was involved and increased if it wasn't. Our work will also allow us to measure cognitive and motor deficits together and correlate data, something that has not been done previously."

In addition, Dr. Monchi's work could have added significance in emerging areas of Parkinson's research. "For the last 20 years, nigrostriatal dopamine depletion has been thought to be the cause of PD," he explains. "Now, some prominent researchers are speculating that it is time to 'look beyond nigrostriatal dopamine.' They suggest there may be additional pathophysiologies. Functional neuroimaging could be important in identifying these."

Staring down Parkinson's

By Alistair Thomson, Oshawa, ON

An avid reader, Alistair researches as much as he can about Parkinson's disease.

Parkinson's introduced me to my new self, and I like the person I've met. I've been lucky. I'll tell you why.

Shortly after I was diagnosed, I began a study of what causes Parkinson's disease. Early in my research, I discovered the idea that the body is affected by the mind. Time and again, research studies prove that stress and conflict cause serious illness.

My life was a history of stress and conflict, so it's obvious why Parkinson's struck: I set myself up for it. However, in my search for answers, I discovered a cause for hope. In reading many medical histories, I learned that when patients let go of anxieties and achieved peace of mind, they recovered or dramatically improved the quality of their lives.

Time to change

If ever there was a man who lacked peace of mind, it was me. Faced with Parkinson's, I knew I had to change. Now, I'm at least in the process of changing. After all, it isn't a passive process. I have to work at it. Fortunately, I have learned that the way I react to stress is more important than the stress itself.

There is a connection between peace of mind and the ability to love oneself. Psychiatrists confirm that children who are unloved grow into adults who do not have the ability to love themselves or others. Yet loving oneself is basic to acquiring peace of mind.

Science has shown that people can recover from incurable diseases, so I am convinced that I can get well no matter the odds. I know the mind can work near-miraculous cures. However, recovering from Parkinson's is my second goal. My first goal is to achieve true peace of mind. I am told it is achieved only by making a commitment to a more loving and accepting outlook—this sounds good to me.

A marvelous adventure

I've always been convinced that life is a marvelous adventure. In support of my optimism, I have a loving, patient, understanding wife, I have no financial worries, I am happily retired, and I come from a long line of tough Scots. I have nothing from which I wish to

Alistair appreciates the support of Joan, his wife, as he learns to live with the disease.

escape. My point is that I refuse to be a victim. I want to live to be at least 100 years old and, along the way, to become an expert on Parkinson's.

Alternate causes and cures

In my research on Parkinson's disease, I've encountered many suspected causes. However, there is one condition that studies have not mentioned. In fact, I'm reasonably sure this night visitor may have been responsible for causing my Parkinson's, but I have no research to support my conclusion. Although there are many studies of sleep disturbances and the disease, I have found none that say conclusively that sleep apnea, over the long term, may cause Parkinson's. Sleep apnea causes the person to stop breathing while asleep. Overnight monitoring of my sleep pattern at a sleep clinic recorded that I had stopped breathing 97 times in an eight-hour period. Adequate blood oxygen levels depend on a normal breathing pattern. Surely decreased blood oxygen levels, over the long term, must damage brain cells.

The most effective remedy for sleep apnea is to use an air supply when asleep. For more than a year, I experimented with air pumps and face masks. It was frustrating because the mask would not seal properly against my face; as a result, I would awaken several times in the night, as the air leaking through the seal emitted a loud Bronx cheer. After spending hundreds of dollars on masks that were often barely functional, I found a system that has two short tubes which are inserted in the nostrils. This system works better than a mask and allows me to have nine hours of sleep a night. The pump holds a steady quarter-pound of air pressure in my upper air passages, thus ensuring that I breath normally and maintain a viable blood-oxygen level. Solving the sleep apnea problem has alleviated many of the Parkinson's symptoms. I no longer have a tremor, my balance is restored, I no longer have daytime fatigue, and my ability to concentrate is restored.

Let's talk about available drug therapy for Parkinson's disease. I have been experimenting with alternatives. In my experience, my anti-depressant seems to act as a facilitator for my Parkinson drug and allows it to work more efficiently. I have also consulted with a Chinese doctor of herbal medicine, and he recommended an herbal remedy that has no side-effects. Medical doctors are often skeptical of herbal treatment, but because of the herbal medicine, I have cut my medication dose in half. My wife and I are happy with the reduced side-effects, and I feel I have control of my medication.

Alistair enjoys playing the piano, one of his many hobbies.

I am also in control of my health, as Parkinson's has encouraged me to be physically active. I walk for an hour each day on an indoor track at the Oshawa YMCA, and I usually cover four miles. After my walk, I work with weights or swim a few lengths of the pool. The exercise helps me fight the disease.

Life is a gift

Life is many things. It's certainly a challenge. An extra 10 pounds lifted on a bench-press or an additional length in the pool can help to lift one's spirit. Life is also an opportunity to make a contribution to humanity. And life is a gift.

To others with Parkinson's, I say don't accept that there is nothing you can do. You can research. You can hope. You can find sources of alternative treatment. You can talk to Parkinson's patients. You can re-organize your life. You can meditate. You can pray. Use every resource that you believe in.

You may think it unusual for a Scots Presbyterian to quote Harold S. Kushner, a Jewish rabbi, but his words are profound:

"No one ever promised us a life free of pain and disappointment. The most anyone promised us is that we would not be alone in our pain, and that we would be able to draw on a source outside ourselves for the strength and courage we would need to survive life's tragedies and life's unfairness."

That's promise enough to stare down Parkinson's.

Editor's note: The experiences described in First Person are personal and not necessarily appropriate for all individuals. You should always consult your physician before making any changes to your medical treatment.

Ask the Expert

Q ***"Can you tell me more about massage therapy and how it can help with my Parkinson's symptoms?"***

A Massage therapy is the hands-on manipulation of the body for the purpose of healing. It is one of the oldest forms of therapy in the world. In fact, massage therapy has been documented as early as 1552 B.C. in Egypt "as a form of medical treatment."

Massage therapy is now ranked third among the most frequently used forms of alternative health care, according to a survey of alternative medicine that was published in the *New England Journal of Medicine.*

Studies since then have found that massage therapy is beneficial for patients with Parkinson's disease. For example, at the Touch Research Institute at the University of Miami, 16 patients with Parkinson's disease were divided into two groups: one group received 30 minutes of massage therapy sessions twice a week for five weeks (10 sessions total), and the other group received progressive muscle relaxation exercises for 30 minutes twice a week for five weeks (10 sessions total). Physicians then rated participants in the massage therapy group as having shown an improvement in the Activities of Daily Life Scale (Schwab and England, 1958) and showing slight improvement in increased independence and functioning on chores. The massage group also reported more effective sleep and less sleep disturbances.

The Saint John Chapter of the Parkinson Society Maritime Region is presently experiencing the value of massage therapy as a complementary therapy in the treatment of Parkinson's disease. For the past six months, massage therapy students from Compu College have been providing one-and-a-half hour massage therapy sessions to those with Parkinson's. The sessions are held in conjunction with the Parkinson's exercise class. These sessions are always full, and often there is a waiting list for the next session. Persons with Parkinson's who have participated in the exercise and massage therapy sessions have reported less stiffness in their muscles, greater flexibility and range of motion in their movements, and better sleep.

Sheree Trecartin, RN
VON Parkinson Nurse, Saint John, NB

Article reprinted with permission from Down East Parkinson News.

WEBSITE HIGHLIGHTS

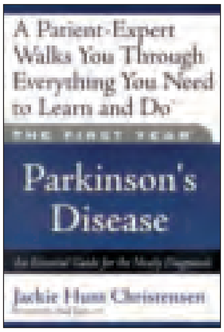
Visit us on-line: www.parkinson.ca

Our website is being updated regularly. Please watch for more changes in the months ahead. Some of the new material includes the following:

- Learn about April Awareness activities in your region. **Click your region on the map of Canada.**
- Check out our newest grants for Clinical Movement Disorders Fellowship and Boehringer Ingelheim Clinical Movement Disorders Fellowship starting in July 2006. **Click on Research.**
- Read your region's latest newsletter. **Click your region on the map of Canada.**
- Learn about the coming 2006 SuperWalk. **Click the SuperWalk icon on the right hand side of any page.**

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

Resources



Parkinson's Disease: An Essential Guide for the Newly Diagnosed

By Jackie Hunt Christensen

Reviewed by
Rosemary Craig

Jackie Hunt Christensen, a Parkinson's patient/expert, walks you through everything you need to learn and do. This book does indeed cover a large number and range of topics, from signs and symptoms and diagnosis, through treatments (conventional and complementary), to family issues and life planning.

Overall, this book gives an overview of PD and the issues that people with Parkinson's have to come to terms with. The book's strong points are lots of information and resources. The book's weak point is the lack of depth of information and explanation (e.g., "what is PD?" was efficiently described; however, I was left asking "Where exactly in the brain is the substantia nigra?")

A good starter book for the newly diagnosed, with lots of resources for the next level of learning.

Visit your local bookstore to order your copy.

Managing Parkinson's: Straight Talk and Honest Hope

By American Parkinson Disease Association

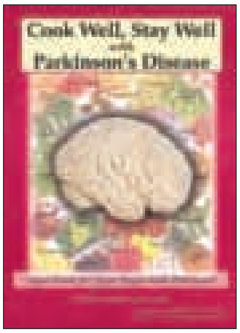
Reviewed by Barbara Snelgrove

The newest resource from the Washington State chapter of the American Parkinson Disease Association is a comprehensive guide to maximizing quality of life for people with Parkinson's disease.

The hour-long DVD contains interviews with prominent doctors, health care professionals and people living with the disease.

The DVD is divided into several modules so people can select their own topic and learn at their own pace. Part one covers the disease and treatments. Part two covers ways to help maintain quality of life. Part three introduces people living with Parkinson's disease who share their wisdom. An extensive resources section is also included.

The free DVD is available for ordering online at www.waparkinsons.org/DVDRequest.asp.



Cook Well, Stay Well with Parkinson's Disease

By Kathrynne Holden, MS, RD

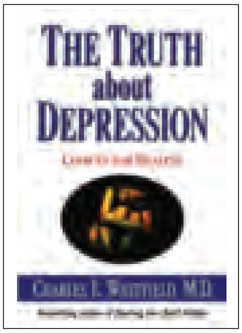
Reviewed by Ian Corks

Kathrynne Holden is a dietitian specializing in nutrition for people with PD, and when it comes to cooking for this condition, she obviously knows what she is talking about.

This practical book presents almost 200 "PD friendly" recipes, covering everything from salads and snacks to entrées and desserts. The recipes are chosen based on their nutritional value and ease of preparation. Each one comes with a quick checklist identifying features such as "Easy-Fix," "Easy-Chew," "High Fiber," and other useful indicators. In addition, Holden concisely and knowledgeably sets the stage in the Getting Started section, discussing why and how these recipes can contribute to better health.

This book's no-nonsense, easy-to-follow approach makes it an invaluable resource for anyone preparing meals for a person with PD.

You can order the book on-line at www.nutritionucanlivewith.com.



The Truth About Depression: Choices for Healing

By Charles L. Whitfield, MD

Reviewed by
Alistair Thomson

This book should be on your "must read" list if you have depression. It explores the theory of childhood trauma as a cause of adult depression. Dr. Whitfield says that if a child is repeatedly abused or neglected, his or her brain and nervous system will be damaged.

Whitfield questions conventional wisdom regarding depression. For example, he does not believe that depression is caused by faulty genes or brain chemistry. He believes that doctors must discover the trauma and stressors which cause a person to be depressed.

Written in clear and understandable language, *The Truth About Depression: Choices for Healing* is published by Health Communications Inc. Visit www.hci-online.com.

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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