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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Life in the lab: An inside look at Parkinson's research

Sharing the grief of your loved one's condition

Practical tips for the newly diagnosed

PLUS: "Parkinson's disease doesn't define me"

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

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Victoria Epilepsy and Parkinson's Centre Society
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The Parkinson's Society of Alberta
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Toll Free: (888) 873-9801

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

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Parkinson Society Manitoba
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Toll Free (NS, NB & PEI): (800) 663-2468

Parkinson Society Newfoundland & Labrador
Ph: (709) 754-4428
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Parkinson Society Canada
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www.parkinson.ca

Ease the Burden; Find a Cure

Letter from Parkinson Society Canada

Parkinson Society Canada
Société Parkinson Canada

Editorial Advisory Committee

***ON OUR COVER:* Dr. Anurag Tandon, a Parkinson's researcher, pauses during yet another busy day in his lab at the University of Toronto's Centre for Research in Neurodegenerative Disease.**

Together, we are stronger

It is with great pleasure and enthusiasm that I join Parkinson Society Canada (PSC) as President and CEO this September. PSC is on the move and is committed to fulfilling its mission of easing the burden and finding a cure for Parkinson's disease through research, education, advocacy and support services.

A national agreement, which forms the foundation of the partnership between the national and regional representative organizations, along with the adoption of a five-year strategic plan, form the roadmap to PSC's future success.

The work that is currently underway sets the stage for PSC to come together as a seamless national organization that will focus its efforts on effective and efficient delivery of service, clarification of national and regional roles, and integrated communications, marketing and resource development efforts.

PSC is well positioned to enhance its advocacy efforts to effect change. Through the hosting of World Parkinson Day 2004 in Canada, we have elevated the awareness and understanding of Parkinson's disease; we have opened the door to dialogue with government, medical professionals and other partners; and we have positioned PSC to influence federal and provincial health agendas.

Approximately 100,000 Canadians have Parkinson's disease, and this number is expected to double by the year 2016. Faced with a projected decline in practicing neurologists over the next five years, family physicians will experience an increasing demand to become more knowledgeable about Parkinson's. To address this growing need, we have committed to the development and delivery of a Parkinson's Medical Education and Support Program (MESP) for family physicians. The newly developed *Family Physician Information and Resource Kit* will be completed this fall and distributed to every family physician in Canada. We will also present a Parkinson's disease symposium at the Family Medicine Forum in Toronto, Ontario, in November. We understand the needs of those affected by Parkinson's; we are responsive and we take action.

We have accomplished much. We have a road map, but the road is long with many opportunities and challenges ahead. Success will be marked by our ability to work together to improve service delivery, adopt best practices and present a cohesive and consistent brand to our stakeholders.

I look forward to working with all of you to ease the burden, find a cure and continue to positively impact the lives of those living with Parkinson's. Together, we must be mission-focused and accountable. Together, we are stronger and we will achieve our vision.

Joyce Gordon

Joyce Gordon,
President and CEO,
Parkinson Society Canada
Toronto, ON

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ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

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Our mission

Parkinson Society Canada/ Société Parkinson Canada is the national voice of Canadians living with Parkinson's. Our purpose is to ease the burden and find a cure through research, education, advocacy and support services.

Parkinson Society Canada
Société Parkinson Canada

Regional Partners/Roundup

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
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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

- The Parkinson Society/Ballet BC Golf Tournament netted $20,000.
- Eight BC communities will host a SuperWalk. To date, we have $13,250 in cash sponsorships and $26,250 of in-kind donations.
- Our fall education meeting is on October 16 with Dr. Martin McKeown, who will speak on his work with functional MRI.
- Our annual conference for the newly diagnosed is taking place on November 6.

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

- Over 100 people attended Susan Calne's presentation in April. We are most grateful for her expertise and her compassion for those with PD and their family members.
- Many of our PD education services use chronic disease self-management (CDSM) content. We will be assessing whether to tailor our programs further after reviewing other CDSM programs in BC.
- The Society is undergoing a strategic communications process, which includes a review and updating of its existing logo and keywords.
- Fundraising initiatives continue to raise significant funds with minimal expense, providing excellent value to donors and sponsors.

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

- First annual Parkinson's Golf Classic on June 17 was a great success, with over $16,000 raised.
- The fourth annual speech-program "Education in Action" sessions will run from mid-September to December. The program is in conjunction with the University of Alberta, Faculty of Rehab Medicine, Speech Therapy Department.
- SuperWalk for Parkinson's will be in Edmonton on September 25 and Grande Prairie on September 26. Vicki Gabereau will be at both walks.
- A major research survey will be conducted with the Faculty of Nursing, University of Alberta, this fall.

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
www.parkinsons-society.org

- Annual General Meeting held on April 23 with speakers Dr. George Turnbull and Dr. Bin Hu.
- Annual Tulip Tournament, held in July, raised $35,000.
- SuperWalks planned on September 18 in Red Deer, on September 19 in Medicine Hat, September 25 in Calgary, and September 26 in Lethbridge.
- New support group started up in Nanton.

Saskatchewan Parkinson's Disease Foundation
3502 Taylor St. E., Suite 108B
Saskatoon, SK S7H 5H9
Ph: (306) 477-4242
Fax: (306) 477-4243

- SuperWalk on Sunday, September 26, 2004.
- Parkinson's Clinic in Regina held two days each month. Phone 1-306-966-8009 for an appointment.
- Our seven support groups have books and videos available for lending. Please call for information.

Parkinson Society Manitoba
171 Donald Street, Suite 302
Winnipeg, MB R3C 1M4
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 975-3027

- Hired a Community Development Co-ordinator and Administrative Assistant.
- SuperWalk 2004 expansion to three sites: Winnipeg, Brandon and Morden.
- We've moved right next door! Our number remains as Suite 302, 171 Donald Street.
- Byron Jones, Chair, has resigned his position with our Regional Advisory Board. He will remain past-Chair and Advisor. We gratefully acknowledge his years of service to the organization.
- The Regional Advisory Board is pleased to announce the appoint-

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Parkinson Society Canada
Société Parkinson Canada

ment of Terry Snell as Chair.

- We sincerely thank Joanne Malenko and Sandra Funk as our Nurse and Social Worker (respectively) for their years of service.

PSC Central and Northern Ontario District

4211 Yonge Street, Suite 321
Toronto, ON M2P 2A9
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Toll Free National: (800) 565-3000
Fax: (416) 227-1520

- Toronto held this year's "Taking charge: What you can do to conquer the challenges of Parkinson's disease" conference on May 1, 2004, at the Inn on the Park Hotel. The conference had a record 375 delegates attend.
- Eighth annual Granite Ridge Golf Tournament held on June 9 raised $15,000.
- Fourth annual Bolton Soccer Tournament took place on June 12 and 13, and raised $10,000.
- Fifteenth annual Pitch-in for Parkinson's on June 23 raised $17,000. Justin Speier was the Toronto Blue Jays Honorary Chair.
- "Education and Information Sessions for Newly Diagnosed Individuals" is being offered for the third time.

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

- Raised over $55,000 through Parkinson's awareness events, including a new Cut-A-Thon for Parkinson's in Kitchener/Waterloo.
- Initiated fundraising efforts specifically geared towards the Parkinson Education Program (PEP).
- Attracted 235 people to the Annual Regional Parkinson's Conference. Dr. George Turnbull and Dr. Gordon Hardacre were plenary speakers.
- Hired two summer students, Paul McHenry and Rachel Butler, through the Human Resources Development Canada Summer Career Placements Initiative.

Parkinson Society Ottawa

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

- A second young onset support group began in April.
- The HOPE Volleyball Beachfest in Ottawa is the world's largest charitable, beach volleyball tournament. This year, they chose PSC to be its national charity partner. PSO provided over 50 volunteers and profited with lots of awareness.
- We held our first annual Volunteer Appreciation Ice Cream Social to thank our dedicated volunteers.
- Our April awareness activities included mall displays over three weekends, 10 in-service presentations, and media appearances on three local television stations and one local radio station.
- Several workshops and presentations added to our growing education program: Daily Living Aids (April); Services provided by the Ottawa Community Care Access Centre (May); and Your Money – the ABCs of Fraud (presented by the West Ottawa Rotary Club in May); and a hands-on Art Therapy Workshop (June).
- Held the third annual Dr. J. David Grimes Memorial Golf Tournament in June. Jerri Southcott, from The NewRO, was the dinner emcee and also interviewed a PSO client and Dr. David Grimes Jr on TV.

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

- Eight walks have been scheduled for the ninth annual SuperWalk.
- A new Executive Director, Lucie Demers, was hired in August. She has excellent experience and will bring a sense of revival to the SPQ.
- A *Speech Therapy Exercise Guide*, developed in collaboration with a speech therapist, is in preparation for publication.

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

Parkinson Society Newfoundland and Labrador

The Ashley Building
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

- The Regional Advisory Board recognized World Parkinson Day by sponsoring an event on April 21 to honour the Society's volunteers and sponsors. Mr. Ross Wiseman, Minister of the House of Assembly and Parliamentary Secretary to the Minister of Health, signed the World Parkinson Declaration.
- The Regional Board presented Dr. Alan Goodridge, a neurologist with the Movement Disorders Clinic, with a cheque to cover the cost of a video camera for the Clinic. The camera will be used in clinical assessments and as a teaching aid for medical students.
- A five-year strategic plan has been prepared that will guide the Region's operations.
- In September, four SuperWalks will be held at Deer Lake, Grand Falls-Windsor, Carbonear and St. John's.

Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

PSC to deliver valuable information to Canada's 32,000 family physicians

At World Parkinson Day this past spring, Barry Johnson, Chair of Parkinson Society Canada's National Board of Directors, spoke about the need to enhance family physicians' knowledge and understanding of Parkinson's. He committed Parkinson Society Canada (PSC) to the development and delivery of a Parkinson's Medical Education and Support Program for family physicians.

At the College of Family Physicians of Canada's annual conference in November, PSC will provide information to family physicians in the form of the newly developed *Family Physician Information and Resource Kit.*

For more information, visit **www.parkinson.ca** or call **1-800-565-3000** and speak with Peggy Yates, National Director of Communications.

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Mark your calendars

Our National AGM will be held in Toronto at the Delta Meadowvale Resort and Conference Centre on November 7, 2004.

As part of our AGM, PSC is pleased to announce the award of the second annual *Donald Calne Lectureship* to Dr. Oleh Hornykiewicz of Vienna. Widely recognized as one of the world's leading neuroscientists, Dr. Hornykiewicz will deliver a "state-of-the-illness" lecture on Parkinson's on Sunday, November 7, 2004. The lecture will be filmed and will be made available to interested persons who cannot attend.

For more information on this year's lecture, please contact Lysa Toye at **lysa.toye@parkinson.ca** or **1-800-565-3000**.

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Canada Revenue Agency to revoke Parkinson Support and Research Society status

After many months of confusion for the Canadian public, the Canada Revenue Agency (CRA) is in the process of revoking the charitable status of the Parkinson Research and Support Group (PSRS).

We have received calls from across Canada from concerned donors, volunteers, stakeholders and the general public, and we thank each and everyone who wrote or called the Charities Directorate on our behalf.

The appeal that PSRS made to the CRA in response to the government's attempt to close them down has been dismissed by the courts and the process for revoking their charitable status has begun. PSRS can no longer solicit charitable donations that involve the issuance of receipts, accept charitable donations that involve the issuance of a receipt and can no longer issue or distribute receipts that contain their charitable registration number.

The last step for the Canadian government in revoking an organization's charitable status is to publish the name and charity number in the *Gazette*, a Government of Canada publication available on-line at http://canadagazette.gc.ca/partI-e.html

Ease the Burden; Find a Cure

Health Tip

Computer-related solutions

By Jeffrey Burns

Difficulties with writing and typing were among the first signs that I had developed young onset Parkinson's disease. Fortunately, there are many strategies and an increasing number of assistive technologies that can keep people with Parkinson's e-mailing and generating reports with relative ease.

Voice recognition software helps me manage the rather dense flow of documents and correspondence that is part of my work as a university professor. Dragon NaturallySpeaking is a popular choice for PC users. Beyond word processing, the software allows for some hands-free navigation of web pages and spreadsheets, and for opening, closing and switching between applications. Voice commands are generally intuitive (for example, if you want to delete the last phrase you dictated, you say "scratch that"). The range of functions and the adaptability of the software are quite amazing.

Getting set-up cost my employer several hundred dollars. Nearly half of this was put toward the recommended "preferred" version of the software, and almost $300 went for a good microphone (very important). I have the Philips SpeechMike Pro 6274. The computer must have ample memory and a relatively fast processor.

You'll need a quiet working environment, and you'll probably want privacy. You can speak naturally and quickly (you can dominate conversation in an on-line chat), but clear speech is critical. Above all, you'll need patience. Correcting mistakes takes time and effort, but this is an important part of how Dragon NaturallySpeaking "learns" your vocabulary. Accuracy improves as it saves "voice files."

You won't find them at the mall, but there are other useful computer-related products for persons with many kinds of physical challenges. For some relief from strain, I bought an iGesturePad by FingerWorks, a marvelous device that replaces your mouse and reduces much keyboarding. A Canadian company called ErgoCanada.com sells dozens of such innovative products.

Life in the lab

Behind the scenes of a Parkinson's research project

By Ian Corks

The war against Parkinson's disease is being fought on many fronts and by many people. On the frontlines are the dedicated physicians, specialists, nurses and other experts who each day must deal with the symptoms and physical and emotional toll that the condition takes. These experts are joined by individual families and people with Parkinson's. Together, their fight is for the present and the years directly ahead.

Behind these frontlines, however, is another group of individuals. Their fight, for the future, is being conducted in research labs, hospitals and universities across Canada and around the world. And while their work is complex and often deals in theories and terminologies beyond the comprehension of the average person, these individuals are just as dedicated to beating – in one way or another – the condition known as Parkinson's disease.

Parkinson's researchers come in all shapes and sizes. Some specialize in clinical research, working closely with patients and studying the effects of certain medications and treatments through clinical trials. Others never leave the lab and spend their time analyzing tissue samples or tracking the movement of specific proteins at the cellular level.

Methodical research

Dr. Anurag Tandon of the University of Toronto's Centre for Research in Neurodegenerative Disease is a researcher from the latter group. In many ways, he is a typical research scientist and his current project illustrates the standard day-to-day workings of a complex clinical research operation.

The mere title of Dr. Tandon's project – The organization and disassembly of alpha-synuclein complexes in human cells – is a fair indicator of its complexity, at least to the lay person (for an explanation of the project, see

At age 39, Dr. Anurag Tandon is a recipient of the CIHR's **New Investigator Award.**

page 10). For his team, however, it's simply a measured, methodical study of cause and effect. And it requires a straightforward, albeit painstaking, approach.

"For one thing, it's certainly not glamorous," laughs Dr. Tandon, a recipient of the Canadian Institutes of Health Research's *New Investigator Award* for 2004. "What we are looking for is at the cellular level. We know that the protein alpha-synuclein is involved in familial Parkinson's disease, particularly in its interaction with other proteins in dopaminergic cells. We are trying to determine the 'hows' and 'whys.' It involves peering into microscopes, examining cultures and recording and analyzing data. It's not very thrilling to watch."

Important questions

But the work is important. As Dr. Tandon explains, "By the time the physical symptoms of Parkinson's disease begin to show themselves in a person with the condition, as much as 60 per cent of the damage to the brain has already been done."

"There are some excellent research teams in Canada and elsewhere looking at ways of slowing or halting the progression of the disease from that point and developing more effective treatments," he continues. "Our focus is on learning about the disease at an earlier stage, as much as five to 10 years before the symptoms take hold. We are asking important questions like How are the crucial proteins in the brain altered? Are there factors that pre-dispose some people to the condition? Are there bio-markers we can use to identify individuals with Parkinson's before it impacts their lives? If we can answer these types of questions, then we have taken a major step towards slowing or even stopping Parkinson's before it does any damage."

Like most research, the work is demanding and labour-intensive, requiring the efforts of a specialized team. Dr. Tandon's team at the University of Toronto (U of T) currently consists of one PhD student, one summer student and two research technicians. He is hoping to add a post-doctoral fellow and a Masters student.

According to Dr. Tandon, his role as team leader is the least glamorous of all and reflects the many facets of maintaining and running a research project of this type. "On the research side, my role is mainly supervisory," he notes. "I check results, answer questions and ensure things run smoothly. The rest of the time is spent in developing new ideas, keeping the projects funded, motivating my team and administration."

That's a big responsibility for a promising, young researcher like Dr. Tandon.

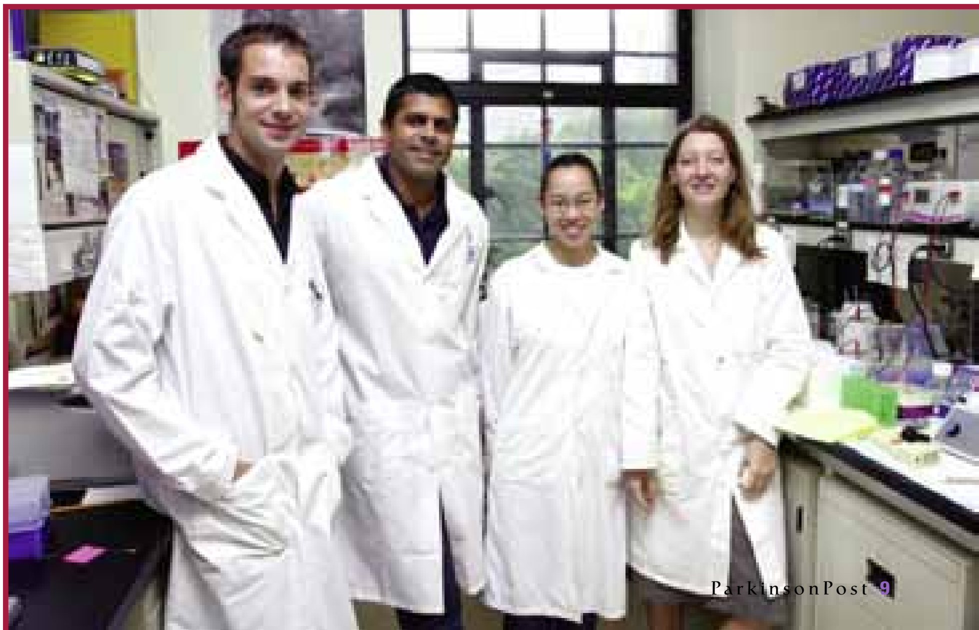
A passion for science

Born in India, Anurag Tandon spent his early childhood on an air-force base in Zambia, before moving to the U.S. and subsequently to Montreal, where he spent his youth. He credits his interest in biology and chemistry to a couple of his high school teachers. "They were so motivating," he recalls. "They really inspired my passion in these subjects. I hope my own kids have teachers like that when the time comes."

He translated that passion into an undergraduate degree in biochemistry and a graduate degree in pharmacology at McGill University. This was followed by four years of studying molecular neurobiology and cell biology at The Scripps Research Institute in La Jolla, California. When Dr. Anthony Lang was awarded the new Jack Clark Chair in Parkinson's Disease Research at the University of Toronto, Dr. Tandon was offered and accepted a research position at the U of T's Department of Medicine.

Beyond the lab

He has been at U of T since 2002 and has been successfully balancing his research duties with a busy family life, which includes raising two beautiful daughters, whose photos adorn the door of the lab fridge. "There's Leya, who is two and a half, and Sofi, who was born in June of this year," he smiles. "In fact, I'm a bit behind in some report writing as I took a brief parental leave. I won't deny that it's hectic, hurrying between day care



The University of Toronto team includes (left to right) technician Dave McIlwain, Dr. Tandon, student Fiona Wong and PhD student Melanie Dyllick. Other team members include technicians Linda Wang and Tammy Lang.

and the lab and wherever. But at least it keeps me active."

On top of all his work, Dr. Tandon also runs a karate school at York University with his wife, Isabelle Aubert. The two are both black belts (he is a first degree, and she is a second degree) and devote a few hours each week to teaching adults' and kids' classes.

Dr. Tandon and his wife have more in common than their black belts. Isabelle is also a researcher. She works at Toronto's Sunnybrook and Women's College Health Sciences Centre and studies the regeneration of neurons in the brain after trauma. While this has the potential to lead to some heavy conversations over the dinner table, Dr. Tandon assures that this is not the case. "We both leave our work at the lab," he chuckles.

The search for funding

And there is certainly plenty of work back at the lab, including one of the most important tasks of all – writing requests for research grants.

Writing research grant requests is a major priority for the simple reason that funding from grants is essential to the existence of the team and the research. The unfortunate truth is that this type of research is very expensive. As such, funds from organizations like Parkinson Society Canada and the Canadian Institutes of Health Research (CIHR) are crucial. "Our regular costs include team member salaries (which account for about 50 to 60 per cent of the total), laboratory equipment, consumables and countless other items, including paying room and board for 2,000 mice!" says Dr. Tandon. "Virtually every cent has to be raised from outside, including my own salary.


Dr. Tandon's role includes supervising the work of research team members, including summer student Fiona Wong.

"It can be difficult at the beginning," he continues. "You need results to attract grants, but it's hard to get real results without the funding to get started in the first place."

The good news is that the early results generated by Dr. Tandon's team have been encouraging enough to attract the continued interest of relevant groups, including Parkinson Society Canada.

"The funds we receive from Parkinson Society Canada are extremely welcome and crucial to our efforts," explains Dr. Tandon. "They provide us with the opportunity to move our research forward and hopefully find the answers we are looking for."

Those answers, when they do come, will represent another triumph in the ongoing war against Parkinson's disease, and one that, when combined with other answers from other dedicated research teams working around the globe, could move us closer to a final victory over this distressing condition.

Editor's note: This is the first in a series of articles that will look at the many aspects of the ongoing war against Parkinson's and the dedicated people who are fighting it.

A lay summary:

The organization and disassembly of alpha-synuclein complexes in human cells

The causes of Parkinson's disease are poorly understood, and current therapies that provide symptomatic relief, based on increasing dopamine levels in the brains of patients, do not alter the normal progression of the disease.

A key factor identified in Parkinson's is the involvement of alpha-synuclein, a small protein normally found in high abundance in all brains. In Parkinson's and other neurodegenerative diseases, alpha-synuclein aggregates into sticky insoluble deposits within neurons. At present, how or why alpha-synuclein forms these insoluble deposits is unknown.

Dr. Tandon's research project, with funding from Parkinson Society Canada, is attempting to characterize the cellular machinery that regulates alpha-synuclein interactions with intracellular membranes and with other proteins in human dopaminergic cells. The team's studies have shown that alpha-synuclein forms large protein complexes that are regulated by neuronal activity. These previously unknown alpha-synuclein complexes are detectable in human secretory cells, and in rodent and human brains. Their presence in normal neurons suggests that the complexes are important for alpha-synuclein's biological role.

Dr. Tandon postulates that these large alpha-synuclein-containing complexes are early pre-cursors to the sticky aggregates seen in the brains of people with Parkinson's. Understanding the organization and assembly of these novel complexes in dopaminergic cells will provide new and fundamental insights into alpha-synuclein function and dysfunction in Parkinson's disease.

Grieving – part two

Sharing the grief

Coming to terms with your loved one's condition

By Ian Corks

Parkinson's is a family disease. Not only does it affect the person with the condition, but also it can be devastating to family members and loved ones. As someone who cares very much for that person, it is only natural that you are deeply affected. And it is also natural that you feel grief.

"People don't just grieve when someone dies," explains Dr. Nancy Reeves, a Victoria-based clinical psychologist. "You can grieve over anything that represents a significant loss. In the case of a loved one with Parkinson's, the grief is over the perceived loss of that person as you know him or her – their physical strength, their mobility, their career, their ability to pursue hobbies and other things that you have become used to."

And Dr. Reeves affirms that grief is valid and is nothing to be ashamed of. It is essentially the manifestation of the thoughts, feelings and emotions that you experience within yourself at a very personal level in reaction to a major loss, either real or perceived.

Though a normal, very human reaction, grief can be difficult to handle, even for people who think they know what they are dealing with.

Rachel Thibeault is an Associate Professor in the Faculty of Health Sciences at the University of Ottawa, where she specializes in community-based rehabilitation and psychosocial care. In spite of her occupational therapy background, she recalls the tremendous grief she felt when her father was diagnosed with Parkinson's.

"My father had written textbooks on algebra and trigonometry – he was a brilliant man," says Dr. Thibeault. "I was aware of the evolution of Parkinson's and had worked for years with clients with this condition. But long before I was an occupational therapist, I was my father's daughter. I have an image of him that is not erased by a diagnosis of Parkinson's. It is not a question of awareness and knowledge, but one of shock and pain. My years of training have

Abe's story

Abram (Abe) Wiens from Calgary was the first to notice the symptoms of Parkinson's in his wife, Joanne, particularly in the way that she walked. He admits going through the various stages of grief during the 13 years since her diagnosis. "I especially remember being angry," he recalls. "I questioned how could this happen to such a nice lady. My grief was more for her than for myself."

Abe and Joanne researched the disease and found out as much as they could about what might lie ahead. He credits this and the support from outside resources, such as the caregiver's program at The Parkinson's Society of Southern Alberta, with helping him to deal with the grief.

"The grief still comes and goes as time progresses and we have had to give up things like our walks and hikes and to adjust to new ways of doing things," Abe adds. "But I have come to rationalize things. I believe in that prayer about changing the things I can and accepting the things I can't. I'm still human, and its tough to carry on at times, but I take strength in knowing that what ever I am doing, I am doing for Joanne."

nothing to do with it. I ached."

"Being a professional is of no use when it comes to grieving," she concludes. "I took months to come to terms with this fact. But finally, I accepted that my training was never meant to protect me from the pangs of mourning."

A healthy process

While it can be difficult, most experts agree that grief is essentially healthy. It is part of the process of recovering and "moving forward" with your life. In many ways, it is a physical, psychological, emotional and even spiritual journey we must undertake to come to terms with our loss.

Some people, however, are quite reluctant to admit to their grief. Occasionally, people dealing with a partner or close family member with Parkinson's have to struggle to even identify what they are grieving for.

"This type of grieving can be viewed as three-fold," notes Montreal psychotherapist Trudy Friedman. "You are grieving for what was, grieving for the present losses, and grieving for what is to come.

We call this third one, anticipatory grief." Realizing that the feelings you are experiencing are grief can be the first step towards a positive journey. Awareness of the typical process can also help.

When grief overwhelms ...

Grief is usually a natural and even positive experience. However, in some cases, it can overwhelm a person and evolve into serious anxiety and depression.

Warning signs include

- feeling "overwhelmed"
- low self-esteem
- constant feelings of panic
- feeling incapacitated by fear
- shunning friends and social activities
- an emotional numbness that does not go away,
- intense symptoms of depression, which may include chronic insomnia, lack of appetite, or loss of interest in relationships, hobbies and recreation
- thoughts of suicide

If you experience several of these symptoms, or feel any of them are becoming a serious problem, you should consult a therapist or your family physician.

Stages of grief

In 1969, while acknowledging the personal nature of grief, noted Swiss Dr. Elisabeth Kubler-Ross described some general patterns that most people will go through. These stages of grief have become generally accepted by most experts and serve as a useful overview of the grieving process.

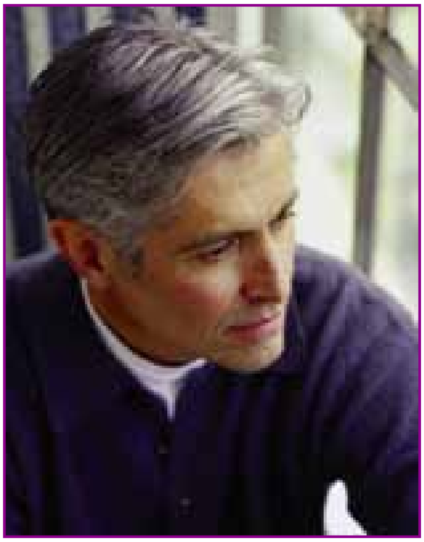
Shock and denial: These emotions can serve as psychological "shock absorbers," protecting you from facing the stark realities of the situation. Trudy Friedman explains that these emotions are not denial in the literal sense. "From my experience, people are not truly in denial," she states. "This period can be utilized as a healthy way to cope with the shock and keep life 'as it was' for as long as possible."

In some cases, these feelings begin early, when you first notice that something may be wrong with your loved one, but you choose to ignore the signs. This can often contribute to feelings of guilt when the diagnosis is finally made.

Fear: You may become afraid, not only of what will happen to your loved one but also what it will mean to you. This can be especially true if you have relied heavily on that person (e.g., to care for you, pay the bills, make decisions). You may feel suddenly helpless or overwhelmed by fear of what may lie ahead. Again, you may experience guilt over feeling this way, when it is the other person who has the disease.

Anger: You become angry at the world for inflicting this condition on someone you love. You may even find yourself searching for something or someone to blame. Dr. Thibeault recalls directing her anger at the chemical plants that for years had polluted the area in which her father grew up, blaming them for contributing to his condition.

For some people, anger is not a familiar emotion and can be quite upsetting. While anger may not be a "healthy" emotion, repressing it can be even less healthy.



Depression: Feeling down is natural and can't be avoided, but true clinical depression can be dangerous. Extreme feelings of loss, hopelessness and frustration can be almost crippling at times. To make matters worse, it is not unusual for both you and your loved one to suffer depression concurrently – adding to the overall sense of desperation. It is important to watch for signs of depression and be willing to acknowledge them and to seek professional help if necessary (see When grief overwhelms).

Acceptance: This is one of the most misunderstood stages of grief. While reaching acceptance can help dispel the negative emotions of the grieving process, it is not, as Dr. Thibeault puts it, "as if you suddenly reach a state of serenity and wisdom."

In most cases, the feelings of acceptance will come and go. In Parkinson's, they may be weakened by any new loss your loved one experiences. However, achieving some type of acceptance will allow you to move on with life and deal more realistically with the losses that you are facing.

"With time, I have come to realize that knowledge of the grieving process induces acceptance, even if sometimes I tried to cheat, rationalize and accelerate the progression," Dr. Thibeault offers. "Understanding the stages and their nearly immutable unfolding prompted my letting go. Since I could not avoid the steps, I chose to experience them and believe this led to much resistance and pain being spared."

Dealing with grief

Just as we all experience grief differently, the way we deal with it is also very personal.

Dr. Reeves suggests that awareness and understanding of grief is a good start. "People who take the time to become what I call 'informed consumers' of the grieving process find themselves better equipped to deal with their emotions," she notes.

Trudy Friedman believes in the benefits of moving forward with life. "Continue to do the things that you and your loved one did before for as long as you can, while at the same time modifying them," she advises. "For example, if the person with Parkinson's loved gardening but is having difficulties with the physical aspects, you could prepare the earth for him or her."

Trudy also recommends that you don't face things alone. "Allow other family members to become part of the team, and investigate outside resources like the local chapter of Parkinson Society Canada," she says.

If these resources don't provide the support you feel you need, you might find therapy useful. A therapist can help you understand the grieving process and provide a useful perspective. Your family physician can usually provide a referral.

The "loss" of a loved one to the symptoms of Parkinson's is not easy to take, and feelings of grief are understandable. Accepting and dealing with that grief in a positive manner can help you find the emotional and psychological strength to give your loved one the support and purpose they need at this difficult time.

Editor's note: This is the second of two articles on grieving in Parkinson Post. *In the previous issue (Summer 2004), we examined the grieving*

Gail's story

Gail Lindsay teaches nursing at Toronto's York University and her sister Lori is an occupational therapist, so by the time their father was officially diagnosed with Parkinson's disease, the two weren't terribly surprised.

"We had noticed the warning signs – his stiffness, gait and posture – so we were anticipating the diagnosis," she says. "I think this anticipation and the fact that the progression of the condition was quite slow for several years took the edge off the feelings of grief in the beginning."

In the last 18 months, however, things have changed for the worse, complicated by an unsuccessful hip operation, and Gail is dealing with the loss of some of her father's abilities.

"It's very poignant," Gail explains. "It's hard to see what the disease is doing and what he has to go through each day. We know that we can't stop it or make it better. All we can do is support him and that's what we do. Just spending time with my father and knowing we are doing whatever we can is comforting to us."

"Our ability to communicate also helps," she continues. "Dad has always been open and straightforward, and, as a family, we talk about things and share our feelings. I think it would be just too painful if we had to keep things inside."

Research Report

A look at current Parkinson's research arou

Research Editor: Dr. John Wherrett

Reviewing current and future therapies

Recently, two authorities on Parkinson's disease – Dr. Anthony Lang from Canada and Dr. Jose Obeso from Spain – took an objective look at the efficacy of standard and experimental therapies (both medical and surgical) currently used to treat the condition.

The following observations were made:

- Medical and surgical therapies directed to normalizing the functioning of the nigrostriatal dopaminergic system have been highly effective in controlling some of the motor symptoms of Parkinson's. These therapies provide most patients with benefits for 10 to 15 years.
- Improvements in the delivery of levodopa and direct agonists that allow for a steady flow to the nigrostriatal system (thus reducing fluctuations in response and dyskinesias), along with improvements in surgical techniques for deep brain stimulation that reduce dyskinesias, are needed.
- All of the ingenious techniques to provide steady dopaminergic stimulation to the nigrostriatal system by grafting various cell preparations seem unlikely to give more than marginal improvements.
- While therapies directed to dopaminergic systems, mainly the nigrostriatal system, have generated dramatic results, it has become apparent that not all features of the disease respond to this approach. Features that do not respond include disorders of postural stability and autonomic functions (blood pressure control, sweating, swallowing, bladder and bowel function) along with the dementia that may develop later in the disease.
- It is now obvious that the pathological changes in the brain affect important systems other than the nigrostriatal system that regulates movement. Recent neuropathological studies have confirmed the involvement of other systems that become apparent later on. Thus, it has become most important to understand not only why the nigrostriatal system degenerates, but also why other systems are affected.
- The very recent discovery of rare genetic errors that cause Parkinson's has focused investigators on the metabolism of specific proteins that can become toxic to cells, not only of the nigrostriatal system, but more generally. This approach is similar to that now taken in Alzheimer disease, where trials are already underway with agents that block the release, build-up and effects of toxic proteins.
- More than ever, the future of treatments for Parkinson's disease lies in the development of treatments that delay nerve degeneration or even prevent it.

References: *Annals of Neurology*, June 2004; *Lancet*; *Neurology*.

Dopamine deficiency and stem cells

Recent work by German and French investigators points to an intriguing relationship between stem cells in the adult brain, dopamine and Parkinson's disease.

The researchers have been examining the signals that trigger the proliferation of a kind of stem cell found lining the chamber of the brain in adult rats (these cells are also in humans). With appropriate stimuli, these cells multiply and assume the characteristics of various brain cells such as neurons. The investigators found that the cells had receptors for dopamine and required dopamine to multiply. Blocking the dopamine receptors also blocked the proliferation of these cells.

On finding this important role for dopamine, they questioned whether the reduction of dopamine in Parkinson's disease might play a role in the availability of stem cells. When examining the post-mortem brains of individuals with Parkinson's, they found that the number of adult stem cells was reduced. There is now strong evidence that nerve cells in various brain networks have a shorter life span than those in other parts of the body and require replenishment, not only to sustain pre-existing functions, but also to develop new variations in function. Thus, degeneration in dopamine networks, such as the nigrostriatal system (which is important for

nd the world

movement), may also limit the capacity of the brain to generate new nerve cells to maintain function of these networks.

Reference: *Nature Neuroscience*, June 2004.

Cerebrovascular disease and Parkinson's disease

Individuals with the typical features of idiopathic Parkinson's frequently have evidence of cerebrovascular disease, such as high blood pressure, diabetes and a history of strokes. It is therefore important to know whether vascular disease can cause Parkinson's and, if so, how to recognize it. This is important because treatment of the underlying vascular disease could delay or prevent progression of Parkinson's.

This issue has recently been assessed in both a detailed review and a clinical pathological study that, for the first time, has examined cases in a systematic fashion. British, Dutch and Australian investigators correlated findings from brains of individuals who had died with Parkinson's disease.

Specifically, they reviewed subjects that did not have either the pathological changes typical of idiopathic Parkinson's disease or any other disorder causing the Parkinson's symptoms, and they compared them to brains from control individuals with a history of only high blood pressure. They identified two categories of patient: one in which the Parkinson's clinical syndrome developed suddenly and could be attributed to isolated small strokes (called lacunar infarcts); and the other in which the clinical syndrome developed more gradually and was associated with evidence of many very small strokes widely affecting the central connecting regions of the brain.

From this, the investigators derived clinical criteria that can now be tested for their sensitivity and specificity in the clinical diagnosis of vascular Parkinson's disease.

In addition, while it has been widely assumed that vascular Parkinson's disease would not respond to treatment with levodopa, the researchers found that a majority of the subjects derived substantial and worthwhile benefit from levodopa. As such, patients with vascular risk factors should be considered for MRI, have their vascular risk factors carefully managed and should have a trial of levodopa therapy where otherwise appropriate.

References: *Journal of Neurology*, May 2004; *Movement Disorders*, June 2004.

Focus on …

Dr. Jeff Biernaskie

Hospital for Sick Children, Toronto, Ontario

Jeff Biernaskie's journey to his current position at Toronto, Ontario's Hospital for Sick Children (Sick Kids) hasn't quite taken him from coast-to-coast, but it's come pretty close.

A native of Brockville, Ontario, Dr. Biernaskie grew up in Lethbridge, Alberta, where he attended the University of Lethbridge, earning his undergraduate degree and receiving his first exposure to neuroscience. He then headed east to Memorial University in St. John's, Newfoundland, where he earned his PhD. His work at Memorial involved studying how the brain "re-organizes" – in other words, how it adapts and remodels itself – following trauma or damage, such as that caused by a stroke.

"This work led me to an important conclusion," says Dr. Biernaskie. "While the brain can adapt and compensate to some extent through rehab or other treatments, it is really not going to return to its original state or function unless the damaged cells are somehow replaced."

That conclusion sparked Dr. Biernaskie's interest in stem cells and their potential as a source of replacement cells that could be implanted in the brain. "I then met Dr. Freda Miller of Sick Kids at a conference and was impressed by the work she had done in this area," he recalls. "The chance to help continue this work was exciting, and I joined the team here at Sick Kids."

Dr. Biernaskie is currently on a Basic Research Fellowship program supported by Parkinson Society Canada. He is working on the Skin-derived Precursor Cells Project (SDPCP), in which researchers are studying the therapeutic potential of stem cells derived from skin in treating Parkinson's disease. "We have demonstrated the existence of stem cells on rodent and human skin," he explains. "This suggests that cells from a person's own skin could potentially be transplanted to replace damaged brain cells. Our first goal is to identify the genetic signals that prompt the stem cells to become neurons. The second goal – and one that is particularly relevant to Parkinson's – is to find ways to persuade the stem cells to become the specific type of neurons that produce dopamine."

The eight-person SDPCP team is making steady progress. And, as Dr. Biernaskie states, the answers they find could impact the treatment not only of Parkinson's disease but also of many conditions where there are damaged or malfunctioning cells in the brain.

Taking control:

How to get the help, support and information you need

By Carol Jamieson

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

First remember that you are unique. What works best for others with Parkinson's may not meet your individual needs and concerns. Start thinking about a basic plan to get help, support and information to make informed decisions about your future.

STEP 1:
Get information from reputable sources

You're at the supermarket checkout line and see a magazine article about Parkinson's disease. A celebrity on television is talking about surgery he had to control his symptoms. Your neighbour tells you about a relative who is looking into alternative therapies. The library has several books by people who claim to be experts on Parkinson's. All of this information can be overwhelming. What can you believe?

To find what resources are available in your community, start with Parkinson Society Canada. Contact one of our Regional Partners (see pages 5 and 6) or call our national toll-free Information and Referral Service at 1-800-565-3000. There are a variety of free resources including our latest comprehensive publication, *A Manual for People Living with Parkinson's Disease.*

STEP 2:
Start talking to your family and friends

When you're ready, discuss your diagnosis and share information with your family, and, as time passes, with good friends. Recognize that you feel a variety of emotions: anger, denial, frustration, fear and sadness. Proceed at your own pace (don't feel pressured), but make sure you stay connected with those close to you. Support each other and don't be hesitant to ask for help.

STEP 3:
Create a resource file

It can be a binder, folder or file box. Keep it in a convenient location (e.g., near the phone) and fill it with pertinent information, such as dates; locations and phone numbers of medical appointments; and questions for your doctors based on articles about Parkinson's disease, research findings and other reference materials you collect. Include a list of your medications (prescription and over-the-counter) should your health care providers, including your pharmacist, request a copy.

Take a family member or friend to your appointments to offer

moral support. Take notes to ensure that you don't miss any important information.

STEP 4:
Open a dialogue and maximize interaction

Make full use of your time at medical appointments. Don't feel rushed, and don't leave until all your questions have been answered. (This is where your resource file comes in handy.) If you don't understand certain terms, ask for an explanation in 'plain English.' Never be afraid to question the treatment you're receiving, if new medications that you've heard about could help you, whether you should consider alternative therapies, or pursue a 'second opinion.'

Find how to access your doctors' nurses or assistants between visits to answer your questions or ease your fears.

STEP 5:
Look for help and support

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

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

STEP 6:
Plan for the future

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

Go to **www.parkinson.ca** and click on *Parkinson Post*. You'll find a comprehensive guide called "Preparing for the years ahead: A guide to long-term planning" (Spring 2003). If you're working, you'll find practical advice in "Living and working with Parkinson's: Determining the best strategy for you" (Fall 2002).

Arm yourself with a variety of options, and discuss them with people you trust.

STEP 7:
Maintain an active social life

Don't isolate yourself from family and friends. Keep in touch by phone, visits or e-mail. You may feel depressed and anxious at times, so ask your doctor about available treatment to alleviate the symptoms.

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

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

Remember, you're not alone. Help is just a phone call or click away!

A Manual for People Living with Parkinson's Disease

Available free from Parkinson Society Canada. Contents include the following:

- What is Parkinson's Disease?
- Handling Your Diagnosis
- Your Health Care Team
- Managing Your Symptoms: Medications
- Managing Your Symptoms: Surgery
- Managing Your Secondary Symptoms
- Dealing with Speech and Swallowing Problems
- Dealing with Urinary and Gastrointestinal Problems
- Changes in Mental Status
- Sleep, Rest and Fatigue
- Diet and Nutrition
- Exercise
- Dealing with Motor Fluctuations, Dyskinesia and Freezing
- Maintaining Your Mobility and Independence
- Other Health Issues
- Special Issues for Young Onset Parkinson's
- Sexuality
- Financial and Legal Issues
- Long-term Care
- Research
- Issues for Caregivers
- Parkinson Society Canada
- Additional Resources

Need help? Go on-line.

Recommended websites include

www.parkinson.ca
Parkinson Society Canada

www.canadian-health-network.ca
Partnership between Health Canada and major Canadian health organizations. Features good articles on Parkinson's disease and caregiving

www.michaeljfox.org
The Michael J. Fox Foundation for Parkinson's Research. Under the heading, "About Parkinson's," is an excellent glossary with basic explanations of common, and not-so-common, Parkinson's-related words and terms.

Brain Waves

New program helps improve daily activities

By Jan Hansen

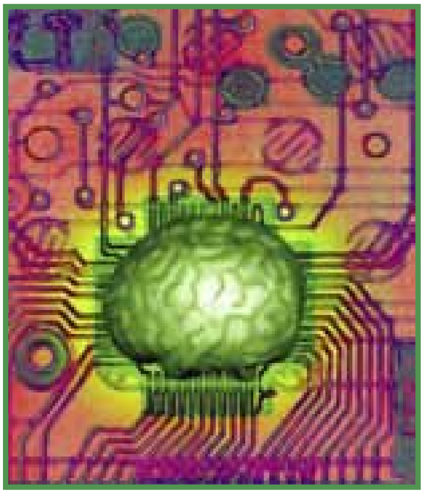
Having worked with families affected by Parkinson's over the years, I have always been interested in developing useful tools and acquiring strategies that might improve the situation for those living with Parkinson's.

A useful tool

Recently, while attending an introductory workshop on a program called Brain Gym® (otherwise known as Educational Kinesiology), I heard the instructor mention that there was a growing body of research backing up this series of activities. The program had been found to be helpful for individuals affected by various disorders of the brain such as dyslexia, Alzheimer disease, attention deficit disorder and autism. The improvement in memory seen in those with Alzheimer disease was compelling.

My training with Roselyn Elford, a local certified Brain Gym instructor who has stayed connected in order to assist with areas of the program, has been invaluable. Roselyn has a degree in Physical Education and a Masters in Psychology, specializing in gerontology. Her offer to our members to participate in a free two-hour workshop to assess our interest in starting a program has again been an invaluable resource for me and for The Parkinson's Society of Southern Alberta

Defying intuition



I naturally concluded that the program was relevant to Parkinson's. Initially, I saw this as an opportunity to help people better manage stress as it exacerbates Parkinson's symptoms. Later, I realized that it was more complex. For example, as muscles contract in response to a perceived danger, they activate something called the tendon guard reflex, which helps us prepare to escape a dangerous situation. Lengthening these muscles helps to re-educate the body to counteract contraction, resulting in positive changes, such as improved posture.

When our group did cross-crawls, the instructor gently corrected me and asked whether I had crawled as an infant. When my mother told me that I had not crawled due to her fear of the mouldy carpets we were exposed to in England (where we were living at the time), I came to some conclusions. First, it had been a toss-up between mould and brain deficits. Second, this stuff might help me too.

A test run

After training, I offered a program to 10 individuals with Parkinson's as part of a pilot project with the hopes of providing a program to others should the results prove positive. Run as a support group with a somewhat modified lineup, the program included adaptations for those individuals who were experiencing movement or balance challenges. It ended up being quite fun, and I saw some interesting results. During the class, one participant kept stating that it wasn't working for him, but the evaluation process uncovered that he was not performing the exercises between sessions. As motivation and dopamine are closely linked, follow-through can be an issue.

Over time and after reviewing publications in related areas, I changed the shape of the program to include additional activities, such as more acupressure points; breathing exercises and energy work were also included. One of our members, Bob Lee, came up with Brain Waves as a name for our group. While some initially envisioned this as a brain with a friendly wave, Bob saw it as ripples and even waves which emanated from the brain, depending upon how much change occurred. How large these waves become is essentially up to the individual.

Our program is drawn largely from the Brain Gym program, developed by Dr. Paul Dennison, an educator and pioneer in the area of applied brain research. This series of targeted activities is in use around the world, particularly within the teaching community and largely with learning-disabled individuals.

The activities are based on the premise that movement is closely linked to whole-brain learning and brain function. It involves activating various areas of the brain through a series of simple activities that make multi-sensory connections. And so, when we squeeze the upper trapezius muscle, while turning the head, breathing deeply and hooting like an owl, we activate several systems at once and get people laughing at the same time. It may seem silly, but it helps memory, vision and alleviates squinting.

Exercises are drawn from a variety of disciplines such as behavioural optometry, acupuncture, dance and educational kinesiology.

Positive changes

In January, I ran a program with 12 participants who were all within the mild to moderate stages of Parkinson's. When asked what changes had been experienced over the course of the 12 weeks, participants made the following remarks on the evaluations: improved balance, acceptance of life's challenges, improved energy, better sleep, lessened procrastination, a feeling of well-being, a more positive outlook, overcoming of the fears of the future, everything has improved, and "even my wife said that I am looking better." Having used some of the strategies on a one-to-one basis with a young onset member who has had Parkinson's for 15 years has also proven promising. Initially, Carolynne Scott wondered if the change she was realizing was all in her head; she started to engage in conversations without being asked to speak up or repeat what she had said. She feels that her writing is improving, and she has also experienced what for her is a victory: writing her own cheque without assistance. While she wonders if her sleep may also be improving, only time and practise will tell.

As I emphasized to participants in our program, these activities only take a few minutes per day, but they are to be added on to a regular exercise program (and not used as a substitute). Please remember that all exercise needs to include stretching.

On another note, I have noticed changes in myself as well. For one thing, I no longer have to suffer embarrassment when the poor guy at the co-op has to laboriously lug my groceries hither and yon while I attempt to hunt down my car, which I fear has been stolen. Apparently, this is all my mother's fault as I didn't crawl.

For courses near you, contact a certified Brain Gym instructor or access the Canadian website at **www.braingym.ca.**

Jan Hansen is the Support Services Director with The Parkinson's Society of Southern Alberta.

DON'T MISS AN ISSUE!

Coming in the Winter 2004 issue of *Parkinson Post*

A day in the life of a clinical nurse specialist

Clinical nurse specialists, who work in Movement Disorders Clinics and specialize in Parkinson's disease, provide expertise and real solutions to people living with Parkinson's. Explore how one specialist trains for this important career, and spend a day in his or her shoes.

Annual General Meeting 2004 and Donald Calne Lectureship

Read the highlights from the 2004 National Annual General Meeting plus excerpts from this year's awardee of the *Donald Calne Lectureship*, Dr. Oleh Hornykiewicz, who will deliver a "state-of-the-illness" lecture on Parkinson's disease.

Widely recognized as one of the world's leading neuroscientists, Dr. Hornykiewicz' international reputation was cemented early in his career when he determined that Parkinson's disease results from too little of the neurotransmitter dopamine. His subsequent development of L-dopa for the treatment of Parkinson's disease revolutionized treatment and remains the cornerstone of therapy today.

Launch of the Parkinson's Medical Education and Support Program (MESP) for Family Physicians

PSC National will introduce the newly developed Family Information and Resource Kit at the Family Physicians Forum in Toronto in November 2004. The program's purpose is to give family physicians the resources and tools to better diagnose Parkinson's disease and recommend treatment to patients.

Included in this issue will be highlights from the symposium delivered by doctors Anthony Lang, Janis Miyasaki, Susan Fox and Elena Moro. More information will be available on our website, **www.parkinson.ca**.

"Parkinson's disease doesn't define me"

By Cliff Burns, Edmonton, Alberta.

I breathe deeply. I smell the scent of the earth and ripening grain fields beside the road that I'm walking down. The prairie landscape and sky are iridescent with colours and sunlight streaking through the storm clouds that are rolling in.

My mind floats back to 1975 when I was 19. Another prairie dirt road west of Regina, Saskatchewan. Similar landscape and skies. On a long-distance run, I'm training as an RCMP recruit constable. I had survived a severe bout of homesickness over the first two months. The training was tough with four more months to go, but I was meeting the challenges when they came. As I ran, I remember wondering what my future would bring.

That same year, my mother, aged 44, was diagnosed with Parkinson's disease. She coped with the diagnosis by going farming with my Dad as soon as he retired from the military. They built a new house and farmyard from scratch while still raising my younger sisters and brother. Mom made the Energizer Bunny look like a turtle. They farmed until only a few years ago; Parkinson's was finally slowing Mom down.

Starting a family

My wife, Jeannine, and I will celebrate our 25th wedding anniversary this fall. We were married in November 1979 after a three-year long-distance courtship. We had been friends since high school. It was a "red serge" wedding at the church where her parents and her grandparents had also married. We still attend that church.

Jeannine and I were given the opportunity to buy a piece of land where her great grandfather homesteaded in 1891. We decided to put down roots, which meant an ending with the RCMP. I became a member of the Edmonton Police Service in July 1980. Since then, we have put down those roots, taking a bare patch of field, planting trees, saving for and then building a home, and raising four children. They have been able to get to know both sets of grandparents and a large extended family.

Warning signs

In August 1998, I developed what seemed to be a nervous tick in my right shoulder. By concentrating, I could stop the tick from moving, but otherwise it persisted. I was working in police communications (the 911 centre). We answered regular police complaints, evaluated emergency calls and dispatched all police-related calls. To keep fit and handle stress, I usually ran four or five days a week, often completing an eight-kilometre run during my lunch break at work. Prior to my shoulder trouble, I was still completing long runs, but, more often, I was bagged at the end of a run and took longer to recover. I knew some of the symptoms of Parkinson's, but I had no hand tremor.

I was referred to a neurologist at the University of Alberta Hospital in Edmonton. After being tested,

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

I learned I might have "Dopa responsive dystonia," but the results were not conclusive. Sinemet seemed to help control the movement and I had more energy. Further tests during the winter ruled out multiple sclerosis (MS). I was taken off Sinemet and put on Permax. In July 1999, Dr. W. Martin at the Glenrose Hospital confirmed a diagnosis of Parkinson's disease. I recall thinking that I was getting off lucky when compared to MS.

Persisting problems

The Edmonton Police Service and especially the people I worked with were excellent in helping me deal with the problem. I was still active but no longer running due to the exhaustion. More symptoms started showing up. As a dispatcher, it is extremely important to be able to multi-task. I found myself getting lost. I also found it more difficult to speak loudly and clearly. Stress caused these symptoms to become more severe. By the winter of 2000/2001, I was suffering from insomnia, depression and severe weight loss. I was no longer able to function well at work. I needed to get out, and my supervisor and Dr. Martin agreed. I went on medical pension in July 2001.

With the help of Jeannine, my family and medical specialists, I have recovered somewhat over the last three years. My depression took over a year to shake, and I still have to be careful. While I now get enough sleep, I still fight insomnia. Parkinson's has mostly affected my right side, with my right shoulder vibrating my whole body in crowd situations. I fight muscle rigidity and slowness in the morning. The symptom that bothers me most is "cognition-freezing," which comes with little warning and affects my speech and the speed at which I think.

Planning for the future

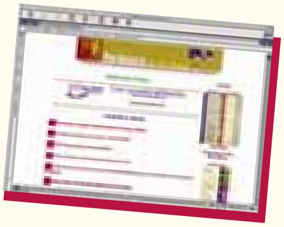
I call my Parkinson's the "Freedom 45" plan. It ended my career 10 years earlier than I had hoped. It has also given me a new career as a "home dad"; I'm able to be there for my kids as they have needed me. With my oldest three attending college but still living at home, I have spent many hours keeping their old clunker cars in good shape for school. While not totally domesticated yet (smile Jeannine), I am getting there.

As a family, the Burns clan has attended the Edmonton SuperWalk and sold tulips for fundraising in the spring for the last few years. I have met many other people and their caregivers who walk in the same shoes. Thanks Mary Chibuk and The Parkinson Society of Alberta! (There isn't sufficient space to thank all who have helped.)

I have learned that Parkinson's is a one-day, sometimes one-minute-at-a-time battle. In spite of the troubles of the moment, Parkinson's disease doesn't define me. I'm me and I only have Parkinson's disease. Parkinson's does not take away my thoughts, my memories or my ability to be who I am. I choose to participate. Find the moments in the day that make you smile, and cherish and remember them. Better yet, spread that smile

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca



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

- If you are prescribed Clozapine as part of your treatment, you should know about a recent Health Canada advisory regarding this drug. **Click on the Clozapine icon on our home page for more information.**
- Our National 2004 Annual General Meeting (AGM) will be held in Toronto, Ontario, on November 7, 2004, at the Delta Meadowvale. **Click on PSC Recognition Awards 2004 for nomination awards.**
- Working with family physician Dr. Gordon Hardacre and movement disorder specialists and doctors Dr. Anthony E. Lang, Janis Miyasaki, Elena Moro and Susan Fox, Parkinson Society Canada (PSC) will present a two-hour symposium on Parkinson's disease to family physicians attending the Family Medicine Forum in Toronto in November 2004. PSC National will also introduce the newly developed *Family Physician Information and Resource Kit.* **Visit our home page to learn more.**
- Parkinson Society Canada is pleased to announce the award results of its 2004–2006 Spring Competition Cycle for PSC's National Research Program. **Click on "What's New" for details.**
- Parkinson Society Canada welcomes Dr. A. Jon Stoessl as the new Chair of its Scientific Advisory Board. **Look in "What's New" section.**
- Parkinson Society Canada is pleased to announce the award of the second annual *Donald Calne Lectureship* to renowned, international, Parkinson's-disease scientist Dr. Oleh Hornykiewicz of Vienna. **Visit "What's New" for details.**

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

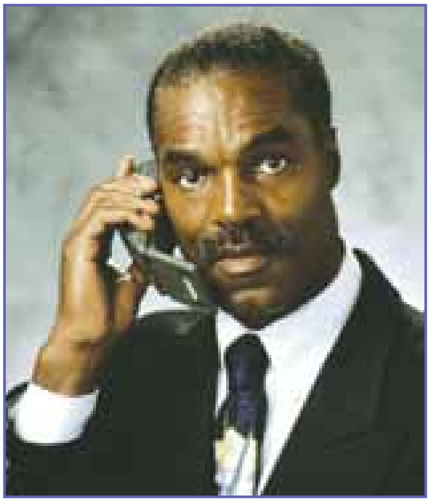
Ask the Expert

Q *My family can't hear me very well when I am talking on the telephone. Is there anything that I can do?*

A You are not alone in describing your trouble being understood by others. It is a frustrating problem and can lead to loneliness and isolation from friends and family. About 70 per cent of people with Parkinson's report speech problems, and it is often one of the earliest symptoms of the disease.

The difficulties identified in research studies include quiet voice, hoarse voice, slurred speech (imprecise articulation), monotonous voice, and "short rushes of speech" with long pauses. These changes are consistent with underlying Parkinson's symptoms: rigidity, tremor and slowness of movement. The quiet voice results from rigidity of the muscles of the vocal cords and respiration. Bradykinesia (slowness of movement) causes the "short rushes of speech." It may take awhile to begin speaking, but once the person begins to speak, there is trouble in controlling the rate of speaking. Occasionally, some people will begin to stutter as the Parkinson's worsens. Tremor can be heard in a tremulous voice.

Treatment depends on the severity of the impairment. As each person is different, it is helpful to have an assessment by a speech-language pathologist. For those with a quiet, monotonous voice, there are exercises to improve breath support, increase vocal-cord closure and maximize duration of speech. These exercises have been developed specifically for individuals with Parkinson's-related voice problems.



One of the best approaches in the scientific literature is the Lee Silverman Voice Treatment for Parkinson's, which, when practised regularly, has been found to be effective in maintaining a loud and interesting voice for many years. Ongoing practice is essential in maintaining voice.

For people who speak too quickly to be understood, it is helpful to learn a "rate-control program" to slow speech. The person with Parkinson's is taught to produce each word separately at a slow rate of speech, which can result in speech that is easily understood. However, the speech may be monotonous and may require sustained effort to slow its rate. This treatment is far easier to describe than it is to learn.

The rapid rate of speech in some does not seem to be under voluntary control. Like a person sliding down a steep hill, the speed gets ever faster. It requires a period of therapy – with emphasis on focused attention to the rate of speech – to achieve voluntary control the rate. There is a continuous need to "calibrate" the rate of speech or it can increase in speed.

It is important to begin treatment early, rather than wait until speech problems become more severe.

For those with significant speech and voice challenges, assistance is still available. Voice amplifiers improve the loudness of the voice. In some provinces, financial support to purchase these devices is available. As well, certain telephones are available that can amplify the speaker's voice.

A small percentage of individuals with Parkinson's have lost all functional speech. For this group, there is still hope in the form of alternative or augmentative communication devices (ACD). Such devices require an assessment by a speech-language pathologist and occupational therapist. ACDs can range from low-tech devices (such as a letter board) to sophisticated voice-output computers. For individuals without functional speech, ACDs provide ways of staying in contact with loved ones.

Many proven strategies are available to assist you with your communication challenges. Try to access a speech-language pathologist for guidance in treating the speech problems that often accompany Parkinson's. You can successfully deal with speech changes through speech therapy and regular practice.

Bonnie Bereskin, MEd, Speech-Language Pathologist (Reg. CASLPO); Lecturer (status-only appointment),
Graduate Department of Speech-Language Pathology,
University of Toronto
Toronto, ON.

Resources

Medscape from Web MD

Reviewed by Peggy Yates

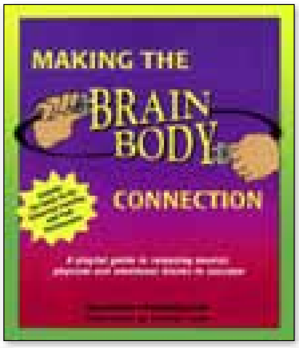
Containing the latest medical information, Medscape.com is a "subscribed website," meaning you need to register to join (free of charge). This enables Medscape to send you updates and the Medscape *Week in Review*, which details feature stories and top stories and information from the industry.

Website sections include Medscape Specialty, where you can go directly to neurology and neurosurgery; Medscape Today, which has daily news and feature updates; and the MedGenMed e-Journal Newsletter, which features 30 free newsletters.

The neurology and neurosurgery area has subsections on Information and Diagnosis, Treatment, Resources and more. The Highlights section features information on the eighth international congress of Parkinson's disease and movement disorders.

Medscape.com is a valuable resource on Parkinson's disease and other health or health care issues.

Visit www.medscape.com



Making the Brain-Body Connection

By Sharon Promislow.

Reviewed by Katherine Jacobs

This book will help you to "feel better, be more effective, … and handle change simpler and easier." It is written to clearly explain the brain's function. This function is not separated from the body's dynamics; instead, the pathways of the body are used to retrain the learning process. Many people should be credited for paving the road to brain function, and Ms. Promislow has covered all the areas.

There are a number of physical activities in the book which can be performed to make you feel better. The eye exercises, the emotional balancers and the "relaxers" (for just before bed) are a few. This most helpful and interesting book should be used daily. There is a bibliography and recommended material area in the index.

Available for $15.95 from Edu-Kenesthetics, Inc. Visit www.braingym.com to order.

www.ergocanada.com

Reviewed by Peggy Yates

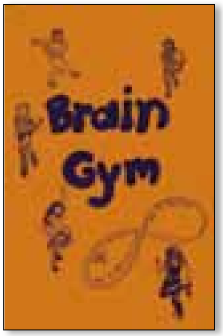
ErgoCanada is a Canadian website that offers a wide range of ergonomic products, including touchpads, trackballs, footswitches, keyboards (adjustable, separated, contoured, etc.), mice (contoured, left-handed, vertical, etc.), and more.

Website features include a product catalogue, a what's new section, info about the company and a search engine. If you are looking for an ergonomic professional to perform an assessment, you can use the free on-line Ergonomic Professional Locator Service to find geographically relevant information.

The site also contains links and references to many other products specifically designed to make your computing experience ergonomic.

ErgoCanada is an easy-to-use website that offers interesting and useful products, which are distributed by a Canadian company.

To learn more, visit www.ergocanada.com



Brain Gym: Simple Activities for Whole Brain Learning

By Paul E. Dennison and Gail Dennison

Reviewed by Katherine Jacobs

Brain Gym shares the message that movement and learning are necessary companions. Each page is full of activities that can be done by people of all ages. If you or someone you know has the ability or the information but can't seem to "get it out," you need this book.

Written in a bright, breezy manner, this book would be particularly useful if used together with the teacher's guide, which would advise how the exercises work, what their purpose is, and ultimately how to hold the attention spans of participants.

Sold for $9.00 by Edu-Kinesthetics, Inc. To order, visit www.braingym.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.

www.parkinson.ca

Parkinson Society Canada
Société Parkinson Canada

What affects 1 in 300 Canadians?

Parkinson's Disease

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

Symptoms may include:

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

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

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

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

Ease the Burden; Find a Cure