Spring 2004 ▪ Volume 4 ▪ Issue 1
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ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Finding the *parkin gene*

Why Dr. Mizuno is one step closer to a cure

How much do you know about Parkinson's?

Meet four award-winning volunteers

PLUS:
Canada to host World Parkinson's Day

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

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Photo: CP Images

SuperWalk for Parkinson's 2004 is just around the corner

…….so start collecting pledges now! This September over 75 walks will take place across Canada and there are various ways to get involved:

Become a SuperSTARWalker – raise over $1,000 and receive a special SuperSTARWalker hat then start collecting SuperSTAR pins to show how many years you have reached this goal!

Walk as a team – Get together a group of 4 to 10 of your friends, family members or co-workers and walk as a team. Each individual team member is still eligible for all individual prizes and incentives but the team who raises the most is collectively eligible for team prizes nationally and locally!

Register On-line – Many regions across Canada offer on-line registration. Visit www.superwalk.com to see how easy it is, send out requests to your friends and family, get immediate receipts and have a great time seeing your pledges grow!

Volunteer – Call your regional office closest to you (see pages 5 & 6 for regional office numbers) and see what you can do to help make the walk in your area successful!

Visit **www.superwalk.com** for details about the SuperWalk near you and to learn about our great prizes and incentives. **See you in September!!**

SuperWalk
for Parkinson's

Letter from Parkinson Society Canada

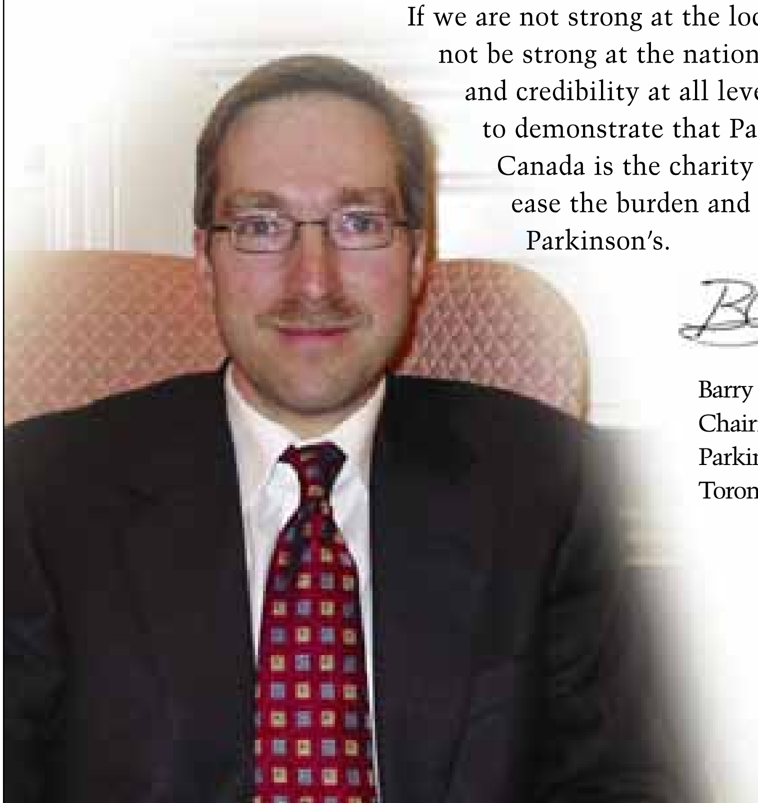
Building a strong community at all levels

In November 2003, I began my two-year term as Chair of the National Board. My experience with Parkinson's began not as a patient or caregiver but as an engineer in the oil and gas business in Calgary. In 1993 a colleague invited me to join the board of The Parkinson's Society of Southern Alberta (PSSA). I agreed to attend a few meetings and soon realized that this was a good fit for me. The organization was well run and had a very committed group of staff and volunteers. The meetings were lively and cooperative and we discussed funding, programs and services, caregiver issues and the interaction with the local medical community. I quickly learned how important a strong Parkinson's organization was to the community.

In 1995 I became Chairman of the Board of PSSA and began to work closely with the Executive Director. Over four years we grew and expanded our services to the Parkinson's community. In 2000 I joined the Board of the Parkinson Foundation of Canada (now PSC) and have been involved since then with policy issues around research and the raising and sharing of revenue on a national basis.

During the next two years, you will see continued change within PSC as we pursue the goals of the ambitious but achievable Strategic Plan that was adopted in June, 2003. We are working together to develop our smaller regional partners and to ensure that we meet the local needs of people with Parkinson's and their caregivers right across Canada. This will require the cooperation and commitment of every regional Parkinson's organization in Canada as we look at ways of collectively increasing revenue to fund more research, education, advocacy and support services.

If we are not strong at the local level, we cannot be strong at the national level. Strength and credibility at all levels are important to demonstrate that Parkinson Society Canada is the charity of choice that can ease the burden and find a cure for Parkinson's.



Barry Johnson
Chairman,
Parkinson Society Canada
Toronto, ON

Parkinson Society Canada
Société Parkinson Canada

ON OUR COVER:* *Dr. Donald Calne (right) and Dr. Yoshikuni Mizuno take a break after Mizuno's presentation at the recent PSC Annual General Meeting in Montreal, QC.

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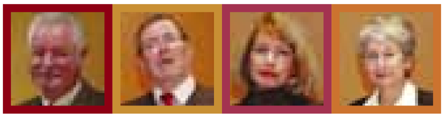

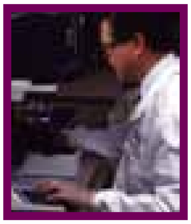

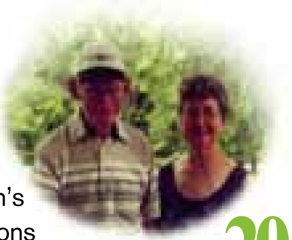

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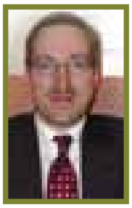

ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

Parkinson Post Vol. 4, Issue 1, Spring 2004

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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

- Our Annual Membership campaign began in December with some large gifts. In 2003, we had 1,168 members. Our Corporate campaign kicked off in January.
- Support Services Coordinator Carmen Dyck has been visiting support groups on Vancouver Island, in the Fraser Valley and on the Sunshine Coast doing in-services.
- In 2003 PSBC had 1,256 calls to the toll-free line and filled 720 information requests.
- Partnering with the Vancouver Coastal Health Authority and University of Victoria, PSBC offered a six week session on chronic disease self-management.

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

- Recent education events included: 'New Developments in Parkinson's' by Dr. Jon Stoessl from UBC, 'Hot Topics in Parkinson's', by Dr. Ted Rosenberg, specialist physician with expertise in movement disorders, and 'Speech and Swallowing Changes' by a speech-language therapist.
- A practicum nursing student will be exploring access to physician services for those with neurological conditions and how to advocate for quality care.

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

- Melanie Ozdoba, 11-years-old, was honoured for her outstanding fundraising efforts at Edmonton SuperWalk. She received a $500 ROOTS gift certificate for raising $2,100 as the Top Fundraising Student across Canada.
- Held our Annual Member Christmas Social. Volunteer Shirley Bailey presented a tulip oil painting in recognition of our 30th Anniversary.
- Praveen P. Nekkar, doctoral student at the U of A, was presented with the Daniels/Rabin Parkinson's Society of Alberta Graduate Scholarship for the third year.

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

- The Brain Gym fall pilot program was very successful. Now running a winter program.
- Physiotherapist Diane Lyders-Reid is running three community exercise programs for different levels of ability for people with Parkinson's.
- Porridge for Parkinson's was held in Calgary in November by Beth Carter and family, and raised over $2,500!
- Red Deer's young-onset group have signed up with the city's new 'Therapeutic Exercise Centre'. The new 'Coping with Chronic Illness' group in Olds is well attended.
- The Classic Antique Bicycles exhibition in Calgary, a new venture for PSSA, is being held February 13–16.

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

- We have seven support groups across the province. Diane Hewitt, our Acting President, is planning to visit with all these groups.
- We look forward to our Regina Curling Classic. The Auction is on Friday, April 2, at Victoria Club; the Curling is on Saturday, April 3 at the Callie Club.

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

- The Manitoba Region office held its official open house on December 5. Members came to see the new office and review our large selection of resources.
- We are hoping to re-start a support group for Brandon and the surrounding region. If you are interested, please call the office and

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

leave your name and number.

PSC Central and Northern Ontario Region

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

- Held a tea to recognize volunteers in December with 45 of our extraordinary volunteers.
- Sold holiday cards and fruitcakes, raising $23,600.
- Had a December regional meeting with chapters and support group leaders to discuss future plans for Ontario.
- Plans are underway for two conferences for people with Parkinson's and care partners: April 3 in Thunder Bay and May 1 in Toronto.
- Planning fresh cut tulip campaign for April – hope to sell 70,000 tulips.
- Congratulations to our volunteers who recently won awards: Bill Harshaw, Jan Duff, A.B. Rustin, Marilee Weisman, Judy Hazlett and Roger Buxton.

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

- Forwarded $221,000, from seven SuperWalks, to PSC National.
- Developed a new special event, 'Spell The End of Parkinson's', a Scrabble® tournament to be launched in March 2004.
- Developing a Parkinson Education Program to educate and support large numbers of people about Parkinson's in a consistent, continuous and cost-effective manner by 'training the trainer.'
- A volunteer drive has reinforced existing committees, and recruited new committees and office volunteers, including two students.

Parkinson Society Ottawa

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

- Dr. Tilak Mendis' presentation on Cognitive Deficit in Parkinson's drew over 80 people.
- A new popular support group has been formed in Winchester, facilitated by social worker Vicki Larsen.
- A new monthly workshop has been set up. In January, chiropractic care and Parkinson's was discussed.
- A 'Pictures for Parkinson's' Contest was launched at SuperWalk as part of our 25th anniversary celebrations. Children were invited to illustrate the tulip and SuperWalk. Over 50 entries now grace our walls as our 'Tulip Garden.' Winners were awarded at the annual holiday party.
- Launched the annual Volunteer-of-the-Year Award, named for Ruth Hall-McMillan, the founding president of PSO, and awarded to Alexandra Howard, a dedicated event and office volunteer.

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

- A committee is studying the difficulties faced by people living with Parkinson's and to develop a more appropriate intervention strategy in Quebec.
- The Montreal chapter raised over $5,000 with its Art for Charity event. Participants discovered local artists living with Parkinson's.
- PSQ hosted Parkinson Society Canada's Annual General Meeting in November. A memorable event, 'Wine and Insects', was held at the Montreal Insectarium and drew 200 people.
- Participated in a meeting with nurses from the movement disorders clinics in Quebec to build relationships and exchange information.

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

- New tulip note cards, featuring a painting by New Brunswick artist Jeff Burns, are $10 for eight cards.
- The Maritime Region congratulates George Turnbull on winning the 2003 *David Simmonds Award*.
- Paul McNair has been named Executive Director for the region effective November 2003.
- A major new Awareness Month fundraiser is in works for late April.
- Working to confirm a vision, objective and strategies for the Maritimes.

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

- Sponsored information sessions in Corner Brook, Grand Falls and Clarenville in October 2003 with presentations by neurologists, and physio, speech and occupational therapists.
- Held a Regional Planning Day on November 8 to help set our priorities for the next five years.
- The College of the North Atlantic will again sponsor a sumptuous breakfast for the Society on April 3 at the St. John's Campus.
- Congratulations to Denise Murphy on winning the 2003 *Mimi Feutl Award*.
- In January, we mourned the loss of one of our founding members, Anne Rutherford. Anne will be sadly missed.

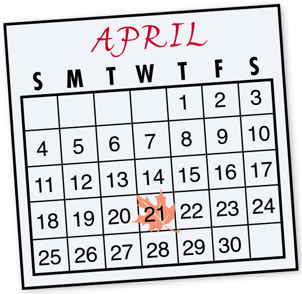
Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

Canada hosts World Parkinson Day 2004

Wednesday, April 21 is **World Parkinson Day 2004.** Representing 'The Americas' and hosting the world, Parkinson Society Canada (PSC) will welcome members of the international Parkinson's community to Canada for the signing of the World Health Organization's Global Declaration for Parkinson's Rights.



In honour of World Parkinson Day, PSC will launch a series of initiatives in 2004 to bring national attention to Parkinson's issues and to directly impact the quality of medical care for people with Parkinson's across Canada.

Look for more information in the next issue of *Parkinson Post*, or log-on to www.parkinson.ca for event highlights and updates about World Parkinson Day programs throughout the year.

In 1997, the Parkinson's Disease Working Group of the World Health Organization (WHO) celebrated the first World Parkinson Day. Since then, this annual conference has been hosted by the United Kingdom, Argentina, India, Japan, Russia, Spain and the United States.

How can you raise Parkinson's awareness locally?

April is Parkinson's Awareness Month (see our detailed story on pages 16 and 17). Consider purchasing a subscription to *Parkinson Post* for your local library. You'll be ensuring Parkinson's is front and centre and that accurate information is available to everyone.

New privacy legislation in Canada

Parkinson Society Canada (PSC) maintains your right to privacy. When you share your personal information with us by contacting us in any way – whether via mail, the telephone, connecting to our website, supporting our organization through donations or being a part of our volunteer base – our commitment is to the protection of your personal information and your right to privacy.

We are complying with the 10 Privacy Principles that cover the protection, collection and use of your personal information.

If at any time you want more information on this subject, please feel free to contact our Chief Privacy Officer by calling **1-800-565-3000.** As well, a copy of our *Privacy Policy* is available at 4211 Yonge Street, Suite 316, Toronto, Ontario, M2P 2A9 or www.parkinson.ca

Ease the Burden; Find a Cure

Health Tip

Here comes summer!

By Susan M. Calne, CM, RN

The urge to head outside when the warm weather arrives is irresistible. Many people with Parkinson's report better symptom control in the warm weather; however, sunlight and excessive heat can create problems for people with PD. Here are some simple precautions to ensure good health in warmer weather.

Wear a wide-brimmed, comfortable hat that shades your whole face, neck and ears. A baseball cap is popular and provides shade over the eyes and to some extent the face, but it does not protect the end of the nose, ears or nape of the neck from the sun's harmful rays. The nose and ear are prime targets for basal cell carcinomas. If you wear a baseball cap, use a sunblock with a sun protection factor (SPF) of at least 15 on exposed areas before leaving home and re-apply it every two hours while outside.

Wear good sunglasses with UV lenses. A lens with a blue tint may sharpen contrast when negotiating sidewalks and pavements.

In hot weather, fluid loss through perspiration and breathing can be a problem, especially if you have dyskinesia. Maintain a higher than normal fluid intake and don't wait to drink until you are thirsty.

Dehydration causes several problems: 1) Confusion and disorientation, 2) Drop in blood pressure which causes sweating and dizziness, and increases the risk for fainting, falls and fractures, 3) Constipation, which is uncomfortable and dangerous, and 4) Increased fatigue which leads to increased symptoms.

Stay indoors between 11 a.m. and 3 p.m. when the temperature is highest if you can. When watching sports outdoors, wear a hat, use a sun umbrella and seek available shade.

Susan Calne, CM, RN, is a Coordinator with the Pacific Parkinson's Research Centre, UBC Hospital, in Vancouver, BC.

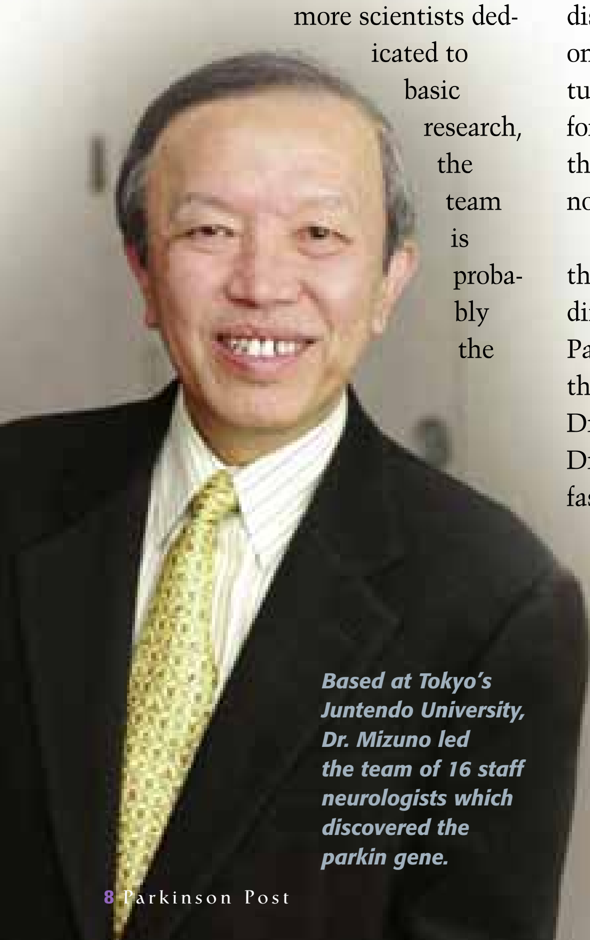
Of genetics and genes…

Dr. Yoshikuni Mizuno discusses the latest in Parkinson's research

By Ian Corks

At its 2003 Annual General Meeting in Montreal, Parkinson Society Canada (PSC) was proud to sponsor the inaugural *Donald Calne Lecture*, which was delivered by one of the world's foremost Parkinson's researchers, Dr. Yoshikuni Mizuno.

Dr. Mizuno is currently Chairman of the Department of Neurology at Tokyo's Juntendo University. With 16 staff neurologists working primarily on the diagnosis and management of Parkinson's patients and more scientists dedicated to basic research, the team is probably the largest, and certainly one of the most influential, academic groups in the world devoted to Parkinson's disease. Dr. Mizuno is also President of the 8,000-member Japanese Neurological Association.



Based at Tokyo's Juntendo University, Dr. Mizuno led the team of 16 staff neurologists which discovered the parkin gene.

Dr. Mizuno is dedicated to the cause of Parkinson's and has led pioneering research in many aspects of the disease. One of his greatest accomplishments came in the late 1990s, however, with his identification of a new gene that is implicated in familial forms of Parkinson's disease. This discovery has shed light on how dopamine cells die prematurely and has implications not only for familial Parkinson's but also for the more common sporadic (i.e. non-hereditary) form of the disease.

Much of Dr. Mizuno's work throughout the years has been directed at the role of genetics in Parkinson's disease. Introduced to the distinguished audience by Dr. Donald Calne himself, Dr. Mizuno directed much of his fascinating lecture to the significant progress that is being made in this area, including his own contributions. What follows is an overview of Dr. Mizuno's presentation on genetics.

The genetic link

Although it is not a true hereditary condition, as many as one in 20 people with Parkinson's have an inherited form of the disease. This is often referred to as familial Parkinson's disease.

Parkinson's can be 'inherited' through two pathways. In so-called autosomal dominant Parkinson's, the disease is passed down from grandparents to parents and then to children and grandchildren. In autosomal recessive Parkinson's, the parents remain apparently unaffected; yet can pass on the condition to several of their children.

Researchers have identified 11 distinct forms of familial Parkinson's disease involving both autosomal dominant and autosomal recessive inheritance pathways. These have been named Park 1 through Park 11, according to the order of their discovery.

The first of these, Park 1, was identified among families living in the Contursi region of southern Italy. Park 1 is an autosomal dominant form and the age of onset is slightly younger than normal. One of the great advantages for researchers studying familial Parkinson's is the ability to identify and study the causes of the disease at the molecular level, something that can't currently be done in other types of the disease. This kind of molecular study has enabled researchers to determine that

Park 1 occurs in the long arm of chromosome 4 and is caused by mutations of the alpha-synuclein gene and protein.

Alpha-synuclein is an important protein that also plays a role in the causes of cell death in the substantia nigra in non-familial Parkinson's. In the case of Park 1, it was found that altering a single amino acid within alpha-synuclein – specifically changing alanine to threonine – could trigger the complex condition that is Parkinson's.

Discovering a new gene

Park 2 is an autosomal recessive form of the disease and was detected in a small population in Japan. Park 2 usually occurs around the age of 40, and while people with the condition respond well to levodopa, they tend to develop dyskinesias and motor fluctuations from the treatment more easily than other groups.

Dr. Mizuno's team located Park 2 on the long arm of chromosome 6 and, perhaps more importantly, has identified a new gene – which they named the *parkin gene* – as the causative factor.

This identification of the parkin gene occurred in a relatively short period of time by normal research standards. While investigating the manganese superoxide dismutase gene as a potential target gene for a genetic risk factor for Parkinson's, Dr. Mizuno's team came across a family in which four out of six siblings had young onset Parkinson's. All affected individuals had two alanine molecules in their chromosomes, compared to one in the general population. Using a process called linkage analysis, 12 similar families were identified and analyzed.

This provided data that eventually allowed the team to locate the disease gene on the long arm of chromosome 6. Next, the team encountered a patient who seemed to be lacking one of the DNA markers being used in their linkage analysis. They theorized that this marker might be within the disease gene itself. They then employed an experimental technique called molecular cloning – something Dr. Mizuno compares to fishing – trying to find one molecule (in this case one that absorbs a substance known as D6S395) among thousands.

Dr. Mizuno was able to catch that 'fish' and the parkin gene was discovered.

When the blood from patients within the families was analyzed, many different kinds of mutations in the parkin gene were found. It has since been discovered that mutations in the parkin gene usually result in the absence of the parkin protein. In patients with Park 2, parkin protein is usually low or absent, while in people with regular sporadic Parkinson's there is abundant parkin protein.

In Park 2, therefore, the researchers determined that the lack of parkin protein is the cause of nigral neuronal cell death. They discovered that parkin protein is an enzyme called ubiquitin ligase, which plays a role in a cell 'cleaning' system (called the ubiquitin proteasome system) that removes unnecessary proteins or proteins that are no longer needed from the cells. Without the existence of this ubiquitin ligase, the system does not function properly. Therefore, without the parkin protein, the proteins that should be removed instead accumulate in the cells. Dr. Mizuno compared it to dust and dirt accumulating in a carpet if you don't vacuum regularly because you don't have a vacuum cleaner.

Finding a piece of the puzzle

This accumulation of abnormal protein eventually kills the cells. By putting together this process, researchers have found a significant piece of the puzzle – the molecular mechanism by which the lack of parkin protein kills nigral neuron cells.

The discovery of the parkin gene and how it is linked to cell death represents a significant advance. It has helped shed light on how dopamine cells die prematurely in familial Parkinson's, which, in turn, has important implications in all forms of Parkinson's disease. Similarly, the work done on other types of familial Parkinson's disease have also provided valuable data that is currently being used by researchers around the world.

Closer to the cause

Dr. Mizuno emphasized the importance of research into familial Parkinson's. He believes that, in the near future, researchers will be able to find the precise cause of regular sporadic Parkinson's disease using the information obtained from the studies being conducted on familial Parkinson's. And once that major goal is achieved, we will be that much closer to finding effective ways of stopping the disease process in all forms of the condition.

If you would like to borrow a videotape of Dr. Mizuno's full lecture, please contact the PSC regional partner near you (see pages 5 and 6 for contact information). Videos are available in English only.

Meet four outstanding PSC volunteers

By Carol Jamieson

It is a daunting challenge each year to select recipients for the prestigious volunteer awards presented at Parkinson Society Canada's (PSC) annual general meeting. So many incredible people serve the Parkinson community across Canada in unique, selfless and courageous ways.

Here is a small tribute to the most recent award winners: Dr. George Turnbull, Halifax, Nova Scotia (*David Simmonds Parkinson's Leadership Award*), Bill Harshaw, Toronto, Ontario (*Dr. Morton Shulman Award*), Denise Murphy, St. John's, Newfoundland and Labrador, and Jan Duff of Mississauga, Ontario (joint winners of the *Mimi Feutl Award*).

1 Investing in the future

As Professor of Physiotherapy at Dalhousie University's Faculty of Health Professions, **Dr. George Turnbull** insisted his students learn about Parkinson's and its management. He conducted workshops for health professionals in Canada and overseas and continues to be an internationally recognized lecturer on Parkinson's. He was instrumental in establishing a one-of-a-kind clinic in the Maritimes which focuses on the prevention of secondary complications from Parkinson's. He has contributed to an understanding of problems associated with gait (walking) in the elderly and those with Parkinson's to help reduce falls. As volunteer Chair of Parkinson Society Canada, Maritime Region, Dr. Turnbull worked with staff and volunteers to increase membership from 300 to 1,300 and developed a wide array of services for people with Parkinson's. He also brought stability to the organization while it was refocusing its mission.

Dr. Turnbull's nominators say: "He offers unconditional support, respect and knowledge of Parkinson's to his clients." According to David Simmonds, "George is a man known by his principles – empowering people with Parkinson's and demonstrating respect for the role of volunteers." Dr. Turnbull volunteers because he "firmly believes everyone has a responsibility to help those less fortunate – the cornerstone of a civilized society. Volunteering allows me to enact that philosophy."

David Simmonds (left) presents the award named in his honour to Dr. George Turnbull.

2 Leading the way

Bill Harshaw was diagnosed with Parkinson's in 1981 at age 37. Since then, he has lived his life according to the old motto: 'Some people look at the world as it is and ask Why? I look at the world as it might be and ask Why not?' He designed, and then persuaded the Ontario Government to implement, the Ontario Trillium Drug Plan, which provides drug benefits to the self-employed and working poor who cannot afford expensive drug therapy for chronic illness. Bill had successful experimental neurosurgery in 1993 and 1994 to relieve severe Parkinson's symptoms. As the first North American to undergo Deep Brain Stimulation (DBS), he wrote *Neurosurgery for Parkinson's Disease: A Patient's Perspective* for surgical candidates around the world, and a memoir, *My Second Life: Living with Parkinson's Disease*. He also served on PSC's National Board of Directors and is involved with the Toronto chapter.

Bill's nominator says, he "serves as an inspiration and role model for people with Parkinson's. He has always displayed indomitable optimism and courage and is a strong advocate for research fundraising." With characteristic humour, Bill says his late mother would look on his award with "puzzled amazement." She would be thinking, "We always knew he would amount to something. But an award for being a troublemaker …"

Meredith Saunderson presents Bill Harshaw with the Dr. Morton Shulman Award.

3 Lending support

Denise Murphy joined the staff of St. John's Movement Disorder Clinic in 1992 as Nurse Coordinator and Neurology Research Coordinator. A supporter says Denise quickly gained "a tremendous understanding of the complex array of problems faced by people with Parkinson's." She volunteered to assist members of Newfoundland's regional chapters develop an outreach program for people with Parkinson's in remote areas where specialized medical services were non-existent. Denise is involved in clinical research trials, provides educational programs for nurses in nursing homes and travels the province offering clinical support. She serves as patient services advisor to Parkinson Society Newfoundland and Labrador's Regional Advisory Board and volunteers at fundraising events in the area.

Denise's nominator says Denise "personifies all that is best in her chosen profession. She has incredible compassion for people with Parkinson's and their families, spends countless hours listening to their concerns and imparts information in a gentle, quiet, thoughtful manner." Denise volunteers because "it is a pleasure to work with people who have a common goal to make life better for people with Parkinson's. I feel it is important to do my part and assist wherever I can."

Patricia Morrisey (left) presents the Mimi Feutl Award to Denise Murphy.

Parkinson Post is sad to announce that **Anne Rutherford**, one of the recipients of the first *Mimi Feutl Award* in 2002, passed away in January 2004.

Anne was dedicated to the Parkinson cause and contributed in numerous ways in Toronto, ON, and later in St. John's, NL. She willingly shared her vast knowledge, set up and assisted support groups, helped establish the Movement Disorder Clinic in St. John's, started a Parkinson exercise class, organized many special educational events and launched the Newfoundland and Labrador Parkinson's newsletter. Her contributions have been immeasurable and she will be deeply missed by the Parkinson community.

Parkinson Society Canada Awards

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

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

***Dr. Morton Shulman Award*:**

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

***Mimi Feutl Award*:**

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

4 Educating others

For many years, **Jan Duff** was a nurse at Toronto Western Hospital. She now works for a company where she manages clinical trials for drugs relating to the central nervous system, such as Parkinson's. She collaborated with the creators of the STOP program for York Region – training police on how to recognize a person with Parkinson's, often mistakenly thought to be inebriated. She was part of the original group that designed the Parkinson's Impact Scale, served on Parkinson Society Canada's Board and was involved in the initial development of the Movement Disorder Surgery program. She is Chair of PSC's Clinical Assistance and Outreach Program Committee. She is considered an expert on Parkinson research and lectures frequently on Parkinson's to professional and support groups. Jan sees people with Parkinson's as people first – then as people who happen to have Parkinson's.

Jan Duff's nominators comment, "She is the benchmark against which many of us measure our own professional competence." Sandie Jones, a fellow nurse who has known Jan for more than 30 years, says, "She combines superlative clinical skills with a total devotion to her patients and a true loyalty to her friends and colleagues." Jan mentions, "I reap tenfold more than I expend as a volunteer. I've met a wonderful group of people, especially nurses, at clinics totally committed to the spirit of giving."

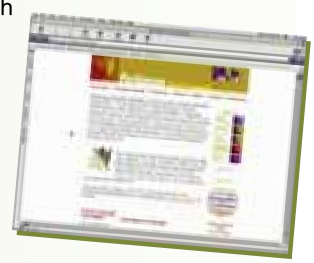
Jan Duff (right) receives her Mimi Feutl Award from Sandie Jones (left).

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca

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

- For anyone interested in learning about how Parkinson Society Canada's research program operates and what kind of research is being supported, there is now an informative and easy-to-understand information package on the website. **(See Parkinson's Disease/Resource Materials/National Research Program)**
- There is an improved Disability Tax Credit Certificate T2201 form that may be useful when you file your 2003 taxes. Get the details on how to apply or re-apply. **(See What's New/February 2004)**
- If you are interested in reading PSC's Privacy Policy, it is now available on our home page.



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

Photo: CP Images

Support groups provide an opportunity for people to share ideas and help others. Pictured above, members of a group in St. Lambert, Quebec, share practical advice during one of their regular meetings.

Starting a support group

Five steps to help you get going!

By Ian Corks

So you're thinking about starting a Parkinson's support group?

Let's assume that you have done your homework and determined that there is no local group that meets your needs, and that there are enough people in the area who may be interested in joining such a group.

Here's a useful five step process – the Five P's – to help you get rolling.

STEP 1: PEOPLE

Start by identifying two or three people who share your interest (and commitment) and are willing to help out. Although it is possible to run a group by yourself, it is much easier if you have other people assisting you, even if it is with simple tasks.

STEP 2: PLACE

Decide where to hold the meetings. A home with a large room can suffice for smaller groups. Church halls, community centres or local schools are other generally available alternatives. Make sure the location is relatively central to, and easily accessible by, group members.

STEP 3: PLANNING

You need to decide how often your group will meet. Consider monthly meetings, at least to start. If your group meets less frequently, it runs the risk of losing momentum and focus. Meeting more often may be difficult for some people to manage.

You will also need to determine your overall focus. There are many kinds of support groups, each with its own style and approach. For example, will the main focus be educational, social, supportive or a combination? Will it be restricted to certain types (e.g., newly diagnosed or young onset)? If possible, separate ages and stages of Parkinson's so people can relate to others in the group.

While it is good to have a basic plan ahead of time, it is not unusual for the final format of the group to be 'fine-tuned' at the first meeting with input from members. Avoid the temptation to be all things to all people. Go with a plan that's best for the group as a whole.

STEP 4: PUBLICITY

Since it is unlikely that you will know all potential group members personally, publicity can play a major role in starting a support group. There are plenty of free ways of promoting the group. Produce a flyer outlining the basics – date, location, time and a brief description of the group's purpose – and send it to as many relevant organizations as you can think of. Start with churches, community centres and local school halls; community newspapers; the PSC regional partner near you; your health care professional (they can spread the word to other Parkinson's patients) and friends and colleagues.

STEP 5: PROGRAMMING

The focus of the group that you determined in the planning stage should help direct the programming. For example, if education is a major mandate, consider inviting an expert or showing an educational video.

Concentrate on the first meeting, then seek input from attendees to program future meetings. Members are an excellent resource for information. Some may have special skills and insights on certain topics that may be useful.

Remember, running a meeting is a learned skill, so don't feel discouraged if you're not perfect at it right off the bat. Keep at it – you'll get better and your group will prosper.

Editor's note: For some personal reflections on support groups, see the article in the Winter 2003 issue of Parkinson Post.

PSC can help

Parkinson Society Canada and its regional partners are excellent starting points and can help with speaker referrals and educational materials (for example, see booklet on page 23). They can also help you promote your group. See pages 5 and 6 for a list of partners.

Research Report

A look at current Parkinson's research arou

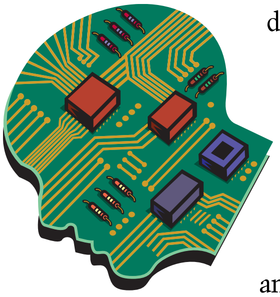
Research Editor: Dr. John Wherrett

The scope and pace of research into Parkinson's disease makes it a challenge to attempt to even summarize the many fascinating projects currently underway. For example, an Internet search through the National Library of Medicine in Washington yielded about 400 papers on Parkinson's published in the last three months alone. Thus, the research summarized here reflects a few of the recent advances that may have a wide impact on our knowledge of the causes and treatment of Parkinson's.

Rebalancing the brain's circuitry

An abstract presented in New Orleans at the annual meeting of the Society for Neuroscience describes a fresh approach to treatment of Parkinson's symptoms.

The investigators described the use of gene therapy to 'rebalance' the disordered circuitry in the brain of Parkinson's to relieve symptoms and reduce the dependence on dopaminergic drugs. As a result of the inactivity of the nigrostriatal tract, another relay station downstream, called the subthalamic nucleus, becomes overactive. This is the area of the brain where deep brain stimulators are implanted. During surgery conducted at the Toronto Western Hospital, it was shown that injection of tiny amounts of a drug which stimulates neurotransmitter receptors called GABA receptors resulted in suppression of the overactive nucleus and mimicked the effect of deep brain electrical stimulation.



Other investigators decided to see if they could boost the activity of the cells that release GABA by inserting an extra amount of the gene that makes it. Experiments using models of Parkinson's in mice and, subsequently monkeys, proved to be successful. Cautious trials in human patients have now begun and initial results are expected in a year. If successful in humans, this treatment represents a new way of adjusting brain circuitry for therapeutic benefit not only in Parkinson's disease but also in other brain disorders.

Reference: National Library of Medicine, www.ncbi.nlm.nih.gov/entrez/query.fcgi

Advances with adenosine

Step-by-step progress over the last 30 years in studies of the neurotransmitter adenosine have resulted in a better understanding of the function of its system and are now culminating in remarkable new approaches to improved drug therapy.

Adenosine (which is actually found in DNA) acts through receptors. A particular form of receptor, called A_{2A}, is specifically localized in, and is important for various functions of, the basal ganglia affected in Parkinson's disease. These receptors are involved in a number of actions that enhance the long-term responses to dopamine. In addition, their over-activity promotes Parkinson's symptoms and by blocking these receptors not only diminishes the symptoms of Parkinson's, but prevents progressive cell damage and can prolong the effect of levodopa. Some A_{2A} receptor blocking drugs are already available and have been found so far to be free of side effects. Controlled clinical trials are underway for a drug that is hoped to have multiple beneficial effects. *(Editor's note: Caffeine is also a blocker of adenosine receptors and some readers may be aware of studies that link consumption of caffeine to a decreased chance of developing Parkinson's disease.)*

Reference: *Neurology* 2003, Vol. 61, Supplement 6

Extra gene provides clue to cell injury

An observation that may be central to understanding the cause of injury to nerve cells in Parkinson's disease has been provided in a brief paper describing a gene abnormality occurring in a particular family affected by familial Parkinson's disease.

Members of this family, known as the 'Iowa kindred', are affected in early adulthood in succeeding generations. This suggested that the affected members might harbor mutations in the a-synuclein gene, as was found in the Contursi kindred of Southern Italy – the family in which a genetic form of Parkinson's disease was first identified. While no mutations were detected in the Iowa kindred, it was discovered that affected

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

nd the world

members carried three extra copies of the normal a-synuclein gene. In these individuals, excessive production of a-synuclein would be expected to occur which suggests that an overabundance of this protein is injurious to nerve cells.

This phenomenon is analogous to the situation in Down's syndrome where there is overproduction of a protein called the Amyloid b protein that is injurious to nerve cells and causes Alzheimer Disease, as Down's individuals age. This overproduction of Amyloid b occurs because there is an extra copy of the 21st chromosome that carries the gene for this protein.

The discovery in the Iowa kindred is further evidence of a toxic protein effect. As is the case in several neurodegenerative diseases, strategies are being developed to suppress the toxic effects of the proteins involved. Other investigators have shown that a-synuclein can be found in blood and are determining whether measuring its levels in the blood could be used for diagnosis.

References: *Science, FASEB Journal.*

Dr. Takahashi awarded Boehringer Ingelheim Fellowship

Parkinson Society Canada is pleased to announce the results of our autumn research competition for the July 2004–June 2006 cycle.

Dr. Jennifer Takahashi of Edmonton, Alberta, has been awarded a *Boehringer Ingelheim Clinical Movement Disorders Fellowship*. Dr. Takahashi will be studying under the supervision of Dr. Mark Guttman at the Centre for Movement Disorders in Markham, Ontario. This $45,000 fellowship will run for one year commencing July 2004 and will provide training and expertise in the diagnosis and management of Parkinson's disease and possibly other movement disorders.

This Fellowship program is funded through a generous donation by Boehringer Ingelheim.

Review calls for more research into advanced care

A valuable review of the disabilities and complications occurring late in the course of Parkinson's, conducted by the Pacific Parkinson's Research Centre in BC, highlights the many areas in which further research in advanced care is needed.

While research towards prevention and treatments to reverse symptoms show great promise, we know that many people with Parkinson's either do not benefit from, or may eventually lose the benefit of, current treatments and become progressively disabled. From diagnosis, these people and their families are greatly concerned about what the future may hold for them. They wish to be assured that, whatever the response to antiparkinson treatment might be, they will be well cared for, they will be safe, the myriad of complications that can occur to aging individuals will be expertly managed, their social needs will be met and community supports will be there when needed.

The review also notes that not only is there a pressing need for research in this area but there is also a great need for education about what already is known.

Reference: *Journal of Neuroscience Nursing*

Focus on…

Dr. Cindy Zadikoff

PSC Boehringer Ingelheim Clinical Movement Disorders Fellow

As the current PSC Clinical Movement Disorders Fellow, Dr. Cindy Zadikoff has the opportunity to study all aspects of Parkinson's disease in the company of some of Canada's leading experts.

It's an opportunity the neurologist relishes. "Only by seeing the varied expressions of Parkinson's can one ask appropriate clinical and basic science questions to not only treat but, one day, prevent the disease," she notes.

In choosing neurology as her specialty, Dr. Zadikoff followed in the footsteps of her father, a neurologist who moved the family to the U.S. from their native South Africa in order to complete his residency.

Following education at the University of Pennsylvania and New York University, Dr. Zadikoff earned her medical degree at Ohio State University. Her own neurology residency was completed at Harvard Beth Israel Deaconess Medical Center in Boston. After completing her residency, she was eager to learn more about Parkinson's disease and other movement disorders.

The decision to join Dr. Anthony Lang's team at the University of Toronto was a relatively easy one. "The work of Dr. Lang and the University of Toronto team is known worldwide," Dr. Zadikoff explains. "And I had a colleague who did a fellowship here a couple of years ago. She couldn't say enough about it."

At present, Dr. Zadikoff is involved in a full spectrum of Parkinson's specific activities, from involvement in Phase I through III clinical trials of new pharmaceutical products, to participation in epidemiological studies, to collaborations with other departments of the hospital. She also spends considerable time consulting with patients in the Toronto Western Hospital Movement Disorders Clinic.

"It's a wonderful experience," Dr. Zadikoff relates. "It is an excellent program here, with much to offer Parkinson's patients and physicians like myself who want to learn as much as we can about this condition and to make a contribution to its treatment."

By Ian Corks

April is Parkinson's Awareness Month

How much do you know about Parkinson's disease?

The man behind the name

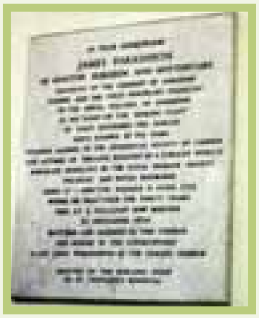
Dr. James Parkinson, 1755–1824

Physician, surgeon, apothecary, educator, scientist, founding member of the Geological Society, author, political and social reformer – though he was born 200 years too late, Dr. James Parkinson was a true Renaissance man.

Among Dr. Parkinson's many accomplishments, however, he is undoubtedly best known today as the first person to acknowledge the characteristic symptoms and provide a description of the disease that bears his name.

Born in Hoxton, England, in 1755, James Parkinson was the son of a family doctor. He apprenticed to his father and was one of the first students to attend London Hospital Medical College. Dr. Parkinson became a prominent London physician and took a particular interest in medical education.

In 1817, at the age of 62, Dr. Parkinson wrote and published *An Essay on the Shaking Palsy*, in which he recorded his observations on what he called a "tedious and most distracting malady."



He began this ground-breaking work with this definite and concise description of the condition: "Involuntary tremulous motion, with lessened muscular power in parts not in action and even when supported; with a propensity to bend the trunk forwards and to pass from a walking to a running pace."

Dr. Parkinson did not speculate on the causes of the disease and noted: "Until we are better informed respecting the nature of this disease, the employment of known internal medicines is scarcely warrantable."

It was not until more than 50 years after his death, in 1868, that the condition he termed "the shaking palsy" was first described as Parkinson's disease by Jean Martin Charcot.

Parkinson's quiz

Think you know a lot about Parkinson's disease? Test your knowledge of the many aspects of this condition.

1. Parkinson's disease and Alzheimer Disease are part of the same condition. True or False?
2. What is the 'official flower' of Parkinson's disease?
3. Which famous athlete, who has Parkinson's disease, lit the flame at the 1996 Summer Olympics in Atlanta, GA?
4. At what age was Canadian actor Michael J. Fox diagnosed with young onset Parkinson's disease?
   A. 30 B. 35 C. 40 D. 44
5. The annual direct health-related costs of Parkinson's disease in Canada are estimated to be:
   A. $750 million B. $1 billion
   C. $1.75 billion D. $2.5 billion

Cracking the Parkinson's code: Recent advances

1957 Carlsson and colleagues propose dopamine link to Parkinson's

Laboratory studies led Swedish researcher Dr. Carlsson to theorize that L-dopa could reverse the Parkinson-like symptoms caused by the drug reserpine. In 2000, he shared the Nobel Prize for his work in this area.

1960 Hornykiewicz and colleagues identify 'pharmacological hallmark'

Dr. Hornykiewicz, a neuropharmacologist in Vienna, studied post-mortem human brains. He showed that the concentration of dopamine in the human brain was severely depleted in Parkinson's patients. He proposed dopamine deficiency as the pharmacological hallmark of Parkinson's and coined the term 'striatal dopamine depletion syndrome', which led to a new understanding of Parkinson's.

1961 Hornykiewicz and colleagues the first to give L-dopa to humans

1967/1968 Cotzias and Yahr and colleagues in New York confirm benefits of levodopa

Between 1961 and 1967, researchers questioned levodopa's benefit due to its side effects. In separate studies Dr. Cotzias and Dr. Yahr confirmed the drug's effectiveness. Both described "a dramatic benefit" when patients were started on low, slowly increasing doses of levodopa, which minimized side effects.

1983 MPTP provides an animal model of Parkinson's and evidence of sub-clinical damage to the brain

The 'accidental' finding that the chemical MPTP induced Parkinson-like symptoms in humans opened up new fields of research. Dr. Langston and colleagues in California studied heroin addicts who had injected MPTP, believing it to be heroin. Some of them rapidly developed Parkinson-like symptoms. This 'accident' led to the development of unique animal models of Parkinson's. Later, Dr. Stoessl and colleagues in Vancouver showed that although others appeared not to have developed symptoms, they had abnormal PET scans – the first evidence of 'sub-clinical' damage (i.e. without obvious symptoms).

1989 Rajput shows Lewy body is not a pathological hallmark of Parkinson's

In postmortem pathological examinations of levodopa-responsive Parkinson's patients, Dr. Rajput, based in Saskatoon, failed to find Lewy bodies in the substantia nigra. His discovery dispelled the myth that Lewy bodies were essential diagnostic requirements.

2001 Mizuno and colleagues propose alpha-synuclein link

After years of research, Dr. Mizuno from Tokyo, Japan, discovers the *parkin gene*. Further studies reveal that high tissue concentrations of alpha-synuclein are associated with neuronal death in patients with the parkin gene who do not have Lewy bodies. This leads to a new theory, proposed by Dr. Calne in Vancouver, that Lewy bodies are not the cause of neuronal death, but rather that the formation of Lewy bodies may be an attempt by the body to sequester a noxious protein.

2004 Research closing in on cure

In Canada and around the world, scientists are closing in on improved treatments and even ways of preventing and curing what Dr. James Parkinson called a "tedious and most distracting malady."

6. Approximately how many Canadians currently have Parkinson's disease?
   A. 50,000 B. 75,000
   C. 100,000 D. 250,000

7. Parkinson's disease affects twice as many men as women. True or False?

8. A deficiency of which chemical in the brain has been closely linked to Parkinson's disease?

9. The average age of onset of Parkinson's disease is:
   A. 50 B. 55 C. 60 D. 65

10. Parkinson's disease almost always runs in the family. True or False?

11. How much did SuperWalk for Parkinson 2003 raise for Parkinson's research and support in Canada?
    A. $543,000 B. $1.11 million
    C. $1.46 million D. $2 million

12. Do researchers believe a cure will ever be found for Parkinson's disease?

For answers, see page 22.

Stem cells: Expanding research horizons

By Dr. Laurie C. Doering

Since the isolation and cultivation of human embryonic stem cells in 1998 by James Thomson of the University of Wisconsin and John Gearhart of Johns Hopkins University, the scientific community and popular media have linked stem cells with the promise of new therapeutic strategies to treat a wide variety of conditions ranging from arthritis on.

Parkinson's disease is no exception and early results are encouraging. Initial studies at the basic research level have shown that stem cells can form the dopamine cells that are lost in Parkinson's and can produce restorative functional effects when tested in laboratory animals.

Embryonic versus adult: Which is better?

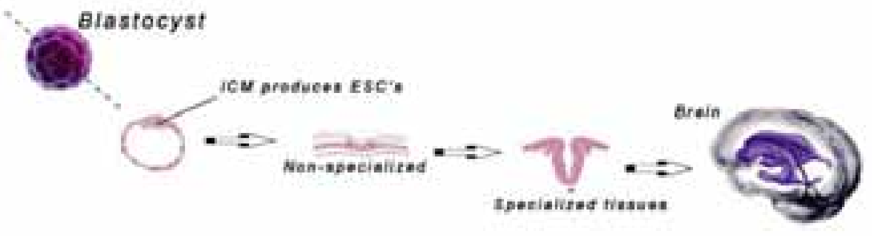
Cells are the smallest units of living matter in our bodies. Assemblies of cells form tissues and organs.

A very small percentage of our cells are classified as stem cells. These exist from the very first stages of life to the last moments of our life span. Stem cells have received an incredible amount of attention because they have the capacity to renew themselves and, depending on the signals they receive from their environment, can turn into a wide variety of specialized cells.

There are two broad classifications of stem cells, based on the time of their origin: embryonic stem cells (ESCs) and adult stem cells (ASCs).

The true ESCs are found in the earliest stages of human development in an area called the inner cell mass (ICM). The ICM transforms into three layers of cells. Through a series of developmental stages, these layers eventually form our entire body. The ICM is part of the blastocyst – a spherical structure that is only visible with the aid of a microscope (see Figure 1). At the blastocyst stage, no tissues or organs have developed, and it is at this stage that ESCs show the greatest potential to form all the cell types that make up our body. The therapeutic potential of ESCs is the source for the high levels of excitement. Research on ESCs is the only way to realize the unique advantages of these cells and move these cells to human therapy. On the down side, ESCs are extremely difficult to control in terms of getting the exact desired cells and they can be extremely unpredictable. Some ESCs also show uncontrolled multiplication when transplanted back into the body.

Figure 1



Adult organs like the liver, brain and skin also produce small numbers of stem cells. It is these cells that are commonly referred to as ASCs. Like their embryonic counterparts, ASCs have also been shown to form cell types that are different from the organ in which they reside. While it is more difficult to direct ASCs into a wide variety of cell types, they are easier to coax into a limited pool of the desired cells. The ability to isolate ASCs from the brain and body permits scientists to study the conditions, within tissue culture, that regulate the potential of stem cells to develop into specific types of cells. Another advantage of ASCs is that if these cells were taken from the patient, grown in tissue culture to the specified cells and then transplanted back into the same patient, the cell rejection would be minimized if not eliminated. The same could be said of the ethical issues surrounding stem cells.

Brain stem cells: Where are they?

There are numerous locations within

the brain and spinal cord that have been identified as hot spots for the isolation of ASCs. We are able to obtain stem cells from both the young and old nervous system. A reliable source of ASCs is the layer around the brain ventricles that contain cerebral spinal fluid (see Figure 2). ASCs may exist in the lining of the ventricles that is bathed with cerebral spinal fluid or the cells may be present in the deepest cell layers just outside the ventricles.

The positive identification of the cell type(s) within this layer is yet to come. Indeed, there just may be more than one type of cell in this layer capable of producing stem cells. Evidence is also emerging that mature cells in the brain, like astrocytes (supporting cells), can adopt stem cell characteristics.

Figure 2

Part of the problem in determining appropriate stem cell candidates relates to the lack of specific markers for the identification of these cells. Many of the original markers thought to be specific for stem cells have now been discovered to overlap with other types of mature brain cells.

New directions from promising research

It is important to study both ESCs and ASCs as the information gained from one type of stem cell can often be transferred to another type of stem cell. In essence, the science needs to focus on the entire stem cell spectrum from the earliest to the latest time points. The questions answered help us to piece together the stem cell puzzle and learn what activates stem cells to form new cell types in the process of repair.

Perhaps there may be certain types of stem cells or stem cell combinations that are most applicable to a stage of Parkinson's. At this time we do not know what type(s) of stem cell(s) will be best suited for Parkinson's. Only through this type of comprehensive research will we learn the answers.

In the last couple of years we have witnessed additional and unconventional possibilities for the generation of stem cells. Different characteristics, like de-differentiating (cells changing from a mature state to an immature/stem cell state), trans-differentiation (cells adopting the characteristics of alternate cell types) and cell fusion (stem cells combining with adult cells), have surfaced under rigorous experimentation. These new reprogramming possibilities may be removed from the natural developmental process that we are accustomed to, but enhance our awareness within the spectrum of stem cell biology and therapy.

Researchers are now thinking about more imaginative ways of working with stem cells. For example, we may apply our knowledge to activate stem cells produced within the body to move to the sites of brain cell death or damage, detect what is required and repair the area, thus improving or correcting function.

We will continue to focus on the potential for self-repair in the nervous system as an end goal. Our knowledge of the stem cell and what it can do is helping to bring new treatments from dreams to reality. Stem cells are indeed painting new horizons and creating possibilities that were completely unforeseen just five years ago for the treatment of neurodegenerative disorders like Parkinson's.

DON'T MISS AN ISSUE!

Coming in the Summer 2004 issue of *Parkinson Post*

Preventing falls

Many people with Parkinson's worry about falling. We'll explain the risks and give you practical advice on how you can improve your balance, reduce your risk of falling, prevent falls inside and outside of your home and more.

First person

Read about a geologist in St. John's, Newfoundland and Labrador, who was recently diagnosed with Parkinson's. He describes what he has learned in his first year with Parkinson's and shares his coping strategies.

SuperWalk 2004

This year over 75 SuperWalks across the country are in the works for the fall! Read about the prize winners from 2003 and learn about the prizes lined up for 2004. You'll see how you can get a jump-start on fundraising and read about other ways to get involved.

Parkinson Society Canada
Société Parkinson Canada

The Parkinson's journey: Lessons from the road

By Jean Strachan, Hamiota, Manitoba.

Fixing a door knob with a screwdriver, helping to hang curtains or eating food that is a challenge to get to your mouth – all of these supposedly easy tasks became almost impossible for my husband Garth who was 71-years-old. That was seven years ago. For the previous few years we had spent our winters in southern Texas where we had our own mobile home.

Garth eventually quit golfing because his coordination had become so out of whack that he didn't know where his ball might go. He loved playing shuffle but soon found that didn't work too well either and he couldn't figure out the score. What was happening to this man who thrived on excellence in whatever he did?

He withdrew from friends and activities and avoided anything that would give his secret worries away. Was it just his age, early dementia or, most frightening, something worse? He finally admitted to me under duress about his feelings and his worries.

The journey begins

We drove home to Manitoba from Texas that winter and immediately went to see our family doctor who after a few preliminary tests in his office said he was setting up an appointment with a neurologist. Our first question was "Why?" The doctor explained that he was pretty sure my husband had Parkinson's disease. He mentioned that he knew as soon as he saw the way my husband walked and when he looked into his eyes. We had heard of the disease before but had no knowledge of symptoms or prognosis.

After tests with the neurologist and a CAT scan, Garth was diagnosed with Parkinson's and put on Sinemet®. At least now we knew what we were dealing with. He had been a provincial winner in curling at the Senior and Master level and was well known for his skills in curling and in other sports. Now, because of his inability to perform at his own personally high standards, he withdrew from everything he loved best.

Garth (left) and Jean have learned to depend on one another as they face life with Parkinson's.

The end of the road?

Since it would be too difficult for us to go to our mobile home in Texas for the winters, and not be able to participate in all the activities he had loved, my husband (despite my reluctance) decided to sell it. It sold immediately. Our oldest son drove us down to Texas and then our other son came down to bring us and our possessions home to Manitoba. With many tears I accepted it was the best way to keep peace in our already disrupted lifestyle.

Later that winter, my husband was awarded a curling distinction award from the province. Our oldest son spoke on my husband's behalf and explained publicly that his father was suffering from the immobility of Parkinson's.

The signs ahead

Our life was to take another surprising turn as I started showing signs of trembling and weakness in my right side. I could not write and was not able to do my different crafts and needlework.

"What is this? Have I been living with my husband so long that I began imitating him?" I thought to myself. I went to the neurologist, had an MRI and a CAT scan to rule out other causes and then the diagnosis was confirmed: Parkinson's disease. I explained that I could not have that because my husband already had dibs on that!

I was 62. How could this happen? We asked our doctors and searched for any information I could find on the internet and from Parkinson Society Canada. Seldom did I find any reports of both husband and wife having Parkinson's and in such close proximity at onset.

Help along the way

We didn't have a local doctor to help us monitor our medications or progression so after some research we found out about Dr. Ali Rajput's clinic in Regina. We were accepted as patients and our son drove us out the 300 kilometres where we were given complete checkups and put on medication that was best for each of us. We continue to visit twice a year and can be in touch if we have concerns or serious problems, which gives us a sense of security.

We are able to manage most things and have support and help from family. We still maintain a garden and I enjoy my potted plants and flower garden, but we hire help for the bigger yard maintenance. We require a lot of rest but stay mobile by walking, using our treadmill and doing stretching exercises.

With the support of family, the couple is successfully adapting to Parkinson's. Pictured with Garth and Jean are their son and grandson.

My husband also has dementia so I am essentially a caregiver as he needs direction in most things. I took a 12-week course last winter in stress management, which helped improve my coping skills.

I am a firm believer in taking advantage of resources that are offered and doing lots of research when a health problem arises. My son set up a computer for me when I couldn't write well by hand. This has been a source of more independence for me.

We live in a town that has several cases of Parkinson's so I have been closely following the findings related to 'cluster Parkinson's' and environment. I would like to form a local support group but so far have not had any positive responses from others.

Lessons from life's travels

We still enjoy watching our grandchildren play hockey in winter and baseball in summer. We look forward to visits with them telling us about their activities and we appreciate the help they can give us doing odd jobs. Living close to your family is a bonus when you have a debilitating illness and minor jobs become major ones. Our sons have become 'Mr. Fixits' in our home and yard.

Most people know very little about Parkinson's and think that medication keeps it completely under control, but they don't know about the difficulty of getting in and out of bed, showering, dressing, cleaning your teeth or the loss of coordination of your hands. As Parkinson's progresses these ordinary tasks become even harder.

We are accepting our fate slowly and have a difficult time when we see our friends doing all of the things that we used to enjoy. I also have arthritis which limits participation in the sports I loved. We miss visiting our friends as much as we used to because it is hard for my husband to communicate. I miss going to a lot of things because of social anxiety and we miss the companionship of each other.

However, we admire and love our friends and family who accept us the way we are and help us out with things we always thought we would be able to do for ourselves forever. This is the road we must take and we will strive to

Ask the Expert

Q ***I've heard that there are some medications that may interact with my Parkinson's drugs. What medications should I avoid?***

A Medications for Parkinson's disease have undergone considerable advances in recent years. People with Parkinson's disease often require combinations of medications not only to directly improve their symptoms but to treat other disorders. This is particularly a concern in older people who may have changes in their ability to absorb and break down medications.

Medications used for the management of the symptoms of Parkinson's disease include drugs that increase dopamine or mimic its actions in the brain. Levodopa combination therapy (with carbidopa or benserazide) and dopamine agonists (bromocriptine, pergolide, ropinirole, pramipexole) are the most effective in improving movement. Other drugs with different or additional effects include amantadine, anti-cholinergic medications (e.g., trihexyphenidyl) and selegiline. All of these medications have common side effects such as nausea, light-headedness and sleepiness. Most people do not have any problems, especially if medications are started gradually.

Careful titration is often the key to achieving an effective dose. The principle of 'start low and go slow' applies to medications in older people and makes sense for people with Parkinson's disease. New problems that start after initiating a new medication might be due to that medication and should be discussed with your doctor and pharmacist. You should discuss potential side effects and interactions with these health professionals if you are starting any new medication.

Different types of drug interactions can occur. These can be classified as drug–drug, drug–disease or drug–food/herbal interactions. Drugs can interact at their site of action (in the brain) or by affecting each other's absorption, breakdown, protein binding or elimination from the body.

Combinations of drugs that have similar actions on the brain are often used in order to best manage symptoms of Parkinson's disease. A downside to such combinations is that side-effects due to increased dopamine effect on the brain can occur. Common combinations include levodopa preparations with dopamine agonists or with entacapone. Anti-cholinergic medications are used for parkinsonism, but many over-the-counter preparations have anti-cholinergic side effects such as dry mouth, constipation and confusion. These are best avoided in older patients. Confusion, delusions (false ideas) or hallucinations (false perceptions) can be related to drugs or to a new medical problem, such as a urinary tract infection, so discuss changes in your health with your doctor. Some drugs such as ciprofloxacin or Zantac® might increase the amount of ropinirole in the blood by decreasing its breakdown in the liver.

Combinations that have opposing effects should be avoided. Some drugs that are used for nausea (such as metoclopramide) can block dopamine and worsen parkinsonism. This is an example of a drug–disease interaction. Similarly, some anti-psychotic medications used to treat hallucinations can worsen parkinsonism.

Over-the-counter medications and natural products can also interact with prescription medications. Herbals such as St. John's Wort and Valerian are sedatives that can increase sleepiness. Alcohol can have similar effects.

Foods with a high protein content can interfere with levodopa getting into the brain, while iron supplements can decrease absorption from the intestine. These problems can be managed by diet changes or dose adjustment.

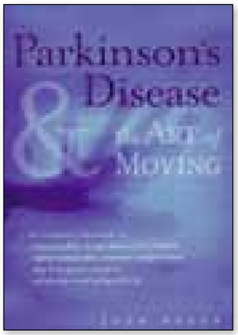
In summary, careful use of medications can improve function in people with Parkinson's disease. Problems can be avoided by careful titration and monitoring. Discussion with your pharmacist and doctor is important. If you start a new drug, get all the information you can about potential problems. If, after starting it, you notice new symptoms which might be drug related, consult your doctor and pharmacist.

Richard Camicioli, MD, FRCPC
Associate Professor,
University of Alberta, Edmonton, AB

Parkinson's **quiz:**
answers from pages 16–17

1. **False.** There is no direct connection between the two conditions.
2. A red and white tulip named the **Dr. James Parkinson bulb**, developed in 1981 by renowned Dutch horticulturist J.W.S. Van der Wereld, a person with Parkinson's.
3. Three-time World Heavyweight Champion, **Muhammad Ali**.
4. **A.** Fox was diagnosed in 1991 at age 30.
5. **D.** The estimated cost of treating Parkinson's is $2.5 billion a year.
6. **C.** Nearly 100,000 Canadians have Parkinson's disease.
7. **False.** Parkinson's is found relatively equally in men and women of all ethnic groups.
8. A deficiency in the chemical **dopamine**, which helps direct muscle activity, has been closely identified with this condition.
9. **C.** Though Parkinson's can occur as early as 30, the average age of onset is 60.
10. **False.** There is a direct family connection in only a small percentage of cases of Parkinson's disease.
11. **C.** Last year's SuperWalk raised over $1.46 million and we hope to do even better this year.
12. **Yes!** The international research community continues to make significant progress and with ongoing research funding believes that more effective treatments, and even a cure, for Parkinson's disease is achievable in the near future.

Resources



Parkinson's Disease & the Art of Moving

Parkinson's Disease and the Art of Moving

By John Argue

Reviewed by Judy Murray, Physiotherapist

Parkinson's disease affects the automatic actions and movements that are vital to independence. Using his experience as an actor and acting coach, and principles of yoga and Tai Chi, John Argue presents a series of 10 lessons that teach exercises to gain control of everyday movements in a "graceful, mindful and complete" manner.

The program holistically progresses from warm ups in sitting, to voice production, to functional exercises on the floor and in standing as well as providing valuable movement strategies. It demands the time and effort of a dedicated caregiver and the motivated patient for the most beneficial result – mobility.

Available at bookstores for $26.95. You can also visit www.parkinsonsexercise.com for more information and the accompanying videotape.

Parkinson Society Canada
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National Research Program

PSC's National Research Program: Championing the Search for a Cure

Parkinson Society Canada has produced a new information package on its National Research Program. The eight-page package provides a basic overview of the research program and includes information on:

- what categories of grants and fellowships are available for funding;
- what grants and fellowships are currently being supported;
- how our Scientific Advisory Board conducts their review and adjudication of applications;
- the history of the program and Canada's contribution to Parkinson's research, and
- why your donations make a difference.

For anyone interested in learning about how PSC's research program operates and what kind of research is being supported, this is an informative and easy-to-understand overview.

To order a free copy, call PSC at 1-800-565-3000, ext. 225.

The EnableLinker electronic newsletter

Reviewed by Jill Pritchard

If you are looking for a Canadian source of information for people who live with disabilities – and you want it delivered to your computer's in-box, be sure to visit www.enablelink.org and click on '*The EnableLinker*.' This monthly e-zine, published by the Canadian Abilities Foundation, is an excellent way to keep up with the latest news.

A recent edition included news about the new Compassionate Care Benefit and a link to HRDC's site; links to two new disability reports and a website of the month featuring a collaborative project to monitor the human rights of people with disabilities worldwide. While the site isn't Parkinson-specific, I recommend it to anyone living with, or interested in, disability issues.

To subscribe, go to http://enablelink.org/Ezine/enablelinker.htm or visit www.enablelink.org and follow the on-screen instructions.

HOW TO START A PARKINSON'S DISEASE SUPPORT GROUP

How to Start a Parkinson's Disease Support Group

The American Parkinson Disease Association

Reviewed by Suzanne Tobin

Although this publication originates in the U.S., it is full of useful information about what a support group can do for people and how to start one. In 24 pages it includes details on where to meet, how to plan and promote the first meeting, how to organize the group, how to plan the program and invite speakers, how to solve potential problems and ways to cover expenses. The templates at the back are particularly helpful: a support group site checklist; a sample letter to hospitals, churches, etc. to request meeting space; and a sample letter to invite speakers.

To order a free copy, call PSC at 1-800-565-3000, ext. 225.

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.

THE
Parkinson
LEGACY

A GIFT OF *hope*
FOR TODAY AND TOMORROW

Parkinson Society Canada
Société Parkinson Canada

We Need Your Support

When you make a planned gift through ***The Parkinson Legacy***, you provide **Parkinson Society Canada** and its regional partners with resources to support research into a cure as well as Parkinson's support programs across Canada.

Through ***The Parkinson Legacy***, there are numerous ways you can make a Planned Gift to **Parkinson Society Canada** or one of its Regional Partners:

Bequest in Your Will
Gift of Life Insurance
Charitable Remainder Trust
Gift of Residual Interest
Gift Annuity
Commemorative Gifts

To become a part of The Parkinson Legacy, or for more information about making a Planned Gift, please contact any of the following offices:

Parkinson Society Canada National Office
To discuss a planned gift or request an information kit, please call:
(416) 227-9700, ext. 227
Toll Free: (800) 565-3000, ext. 227
www.parkinson.ca/donating/theparkinsonlegacy.html

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

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

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

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

Saskatchewan Parkinson's Disease Foundation
Ph: (306) 477-4242

Parkinson Society Manitoba
Ph: (204) 786-2637
Toll Free: (866) 999-5558

Parkinson Society Canada Central & Northern Ontario Region
Ph: (416) 227-9700
Toll Free National:
(800) 565-3000

Parkinson Society Canada Southwestern Ontario Region
Ph: (519) 652-9437
Toll Free Ontario:
(888) 851-7376

Parkinson Society Ottawa
Ph: (613) 722-9238

Parkinson Society Quebec
Ph: (514) 861-4422
Toll Free: (800) 720-1307

Parkinson Society Canada Maritime Region
Ph: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468

Parkinson Society Newfoundland & Labrador
Ph: (709) 754-4428
Toll Free (NFLD / Labrador):
(800) 567-7020

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Ease the Burden; Find a Cure