

DOWN EAST PARKINSON NEWS

INSIDE THIS ISSUE:

<i>Regional News</i>	2
<i>Maritime Region Awards</i>	4
<i>Board Nomination Form</i>	6
<i>Young Onset</i>	7
<i>Public Forums</i>	8
<i>East Coast Conference</i>	9
<i>Resource Centre</i>	12
<i>Chapters & Support Groups</i>	13
<i>Drug Approval Process</i>	14
<i>Research</i>	15
<i>Ask the Nurse</i>	16
<i>Bladder Dysfunction</i>	17
<i>Talking to Your Children</i>	18
<i>Caregiving</i>	19

ANNUAL GENERAL MEETING

Parkinson Society Maritime Region

Annual General Meeting

Sunday, October 23, 2005

Holiday Inn Select, Robie Street, Halifax

1:00 pm—2:00 pm—AGM

2:00 pm—2:30 pm—Reception

2:30 pm—4:00 pm— Chapter & Support Group Workshops

6:00 pm—CD Launch & Reception

Jennifer Roland, Cape Breton Fiddler

ALL WELCOME

7:00 pm—Keynote Speaker

Anthony Scelta Jr, Florida, US

OPEN TO PUBLIC

You Won't Want to Miss It!

2005 East Coast Parkinson Conference

October 23-25,

Holiday Inn, Halifax

Registration is limited, so don't delay

The Hotel is holding a block of rooms and offering a special rate for accommodations booked before September 20, you'll want to book early & don't forget to mention you're with the Parkinson Society to receive the reduced rate

Call the Holiday Inn directly at (902) 423-1161

(See complete details and registration form on page 9-11)



Check it Out

Maritime Region Awards Program - page 4

Maritime Region Board Nominations - page 6

Public Forums & East Coast Conference - page 8



SuperWalk 2005—Biggest Success EVER!

From September 9 to 11, hundreds of participants throughout the Maritimes took part in 15 SuperWalks. From the first-ever Corporate Walk in Halifax to events in PEI, NB and NS, SuperWalk set new records for attendance and funds raised!

While final results are pending, initial figures put the 2005 event at more than \$ XXX, surpassing last year's total by \$ XXX.

Special thanks to our walk coordinators who are to be commended for an outstanding job: Leon Fitzgerald, Jim Gates, Patricia Burke, Merton Geddes, Judy O'Brien, Cathy Barlow-Mitchell, Donnie Simmonds, Mary Langlois, Keith McCrory, Sheree Trecartin, Maxine Bell, Maureen Brisson, Millie Odo and Theresa Digioacchino.

A very special thanks to our 2005 Corporate Sponsor Medivie Blue Cross.

The Maritime Region also thanks Debbie Davis, the National SuperWalk Coordinator of her ongoing support. Special thanks to our media sponsors C100, ATV/ASN, the Daily News and the Halifax Herald.

Watch for the announcement of our prize winners in the next issue of Down East Parkinson News!

PICTURE

HOPE Volleyball

It was another wonderful day as hundreds of people gathered on the Garrison Grounds of Citadel Hill to play Volleyball in support of local charities.

The Parkinson Society is the event's national Charity and the Maritime Region receives funds from the event as part of a three-year agreement.

Many thanks to our 35 volunteers who provided assistance during the event. We are grateful to the Halifax organizing committee and HOPE Chair, Judy Thompson, for their encouragement and support of Parkinson's.

To recognize the \$25,000 grant provided to the Maritime Region by HOPE, the Society's Boardroom will be named in honour of HOPE's three year commitment from 2005 to 2008.

PICTURE

More Regional News

7th Annual Golf Tournament

2005 saw 18 teams take to the greens for the 7th annual Golfing for Parkinson's. Another great day of golfing was had by all and a great barbeque dinner followed the event hosted by Brian Phillips of CJCH.

Our sponsors included O'Regan's (hole in one car sponsor), Air Canada (trip for two, hoe in one), Big Dog and Cat Country, the Truro XXX and XXX

Prize Winners at the Tournament Included:

Top Team

2nd Place

Top Male

Runner Up

Top Female

Runner Up

Better Luck Next Year

Putting Contest

PICTURE

Region Receives 2 Community Outreach Grants

The Maritime Region received two grants from Parkinson Society Canada for 2005-2006.

The Maritime Parkinson Clinic received the E. Conner Community Outreach Grant to allow it to provide ongoing services for the year.

The VON Saint John received the CIBC National Community Outreach Grant which will fund the community nurse for the coming year.

Presentation of the awards will take place in September. The Maritime Region thanks Parkinson Society Canada, CIBC and E. Conner for their support of our programs.

PICTURE

Maritime Region Awards Program

Categories

- **Volunteer Achievement** (based on **volunteer contribution** to any group, Chapter, Support Group, program, activity in the Maritime Region)
- **Leadership** (based on **exemplary leadership** to the Region or Chapter / Support Group or donor, media, sponsors who have given outstanding support)
- **Health Care** (a **health care professional** serving beyond the call of duty to further the understanding of Parkinson's)
- **Chapter / Support Group** (a **community group** whose contribution furthers the mission and vision not only of the community but the Region and Parkinson's)
- **Lifetime** (recognizes **long-term contributions** of five or more years)

The selection committee may choose not to award any or all awards based on the nominations received. Only winners will be announced at either the annual conference or the AGM

Nominations are limited to the nomination form and two additional pages of text accompanying material. Winners may only receive any one award once.

Awards will be presented at the Maritime Region Annual Fall Conference or other appropriate venue.

PLEASE SEND MARKED *CONFIDENTIAL* TO:

All nominations must be received **NO LATER** than **SEPTEMBER 28, 2005** and will be accepted by Mail, Fax or Email

Executive Director
 Parkinson Society Maritime Region
 830-5991 Spring Garden Road
 Halifax NS B3H 1Y6
 Fax: 902-422-3797; Email: pmcnair@parkinsonmaritimes.ca

Eating Out

Sharing a meal was nice, But now I have to think twice,
 I know I am not the centre of attention, I have no control over my body's actions,
 Ridged body and trembling hands, I now obey my body's commands,
 Trapped in the broken frame, There are others who are the same,
 Spilled juice, dribbled sauce, I waste most of the cost,
 As a small child, this I once did, Now again I must wear a bib,
 My granddaughter, going on three, "Look Nana, you are just like me,
 I do the same as you, It is alright Nana, I dribble too".

*Elizabeth Rogers
 Living with Parkinson's
 St. Stephen, New Brunswick*

Maritime Region Awards —Nomination Form 2005

Award Category (please specify **ONE** only) _____
(Each nomination **MUST** be on a separate form. Nominations may be made in multiple categories but **MUST** be on separate forms as well.)

Submitted by (Name of contact individual AND/OR Chapter/Support Group)

_____ Email _____

Address _____ Tel _____

NOMINEE NAME _____

Address _____

Postal Code _____ Email _____ Tel _____

Description of what the nominee has done—time, talent, projects, results:

Description of the impact the nominee has had on the community or Parkinson's:

Up to TWO additional pages may be attached as supporting this nomination. No materials can be returned.

Additional people (2) we may contact, if necessary, to support the nomination:

1 _____ Tel _____

2 _____ Tel _____

Signed _____ Date _____

DEADLINE SEPTEMBER 28, 2005

AWARDS (Confidential)

830-5991 Spring Garden Road, Halifax, NS B3H 1Y6

Fax: 902-422-3797 Email pmcnair@parkinsonmaritimes.

Maritime Region Board of Directors Nominations



Nominations are sought for Directors to serve a 2-year term beginning Oct 2005. Elections will take place at the AGM in October.

The following Board positions will continue:
 Chair (Kelly MacKay)
 Treasurer (Mark Singer)
 Programs & Services Director (Tom Carew)

Positions eligible for nomination and election for a **2 year term**
 Prince Edward Island Rep
 New Brunswick Rep
 Nova Scotia Rep
 Chair Elect
 Development Director
 Director at large (nominations will be accepted as there may be duplication in positions)

Name of Nominee: _____

Address: _____

Postal Code _____ Tel _____

Email _____

Nominated by _____ Self Nomination _____

Position Nominated for (please see above) _____

Brief Bio on nominee (a resume may be attached)

Experience that may assist the Board / Region:

Additional Skills::

Additional Information:

There are 4-5 Board meetings each year. In addition, the executive meets 4-5 times. Board meetings may be attended in person or via teleconference. The Regional Office reimburses all telephone costs or travel. Interviews will be held with all nominees prior to the Annual General Meeting.

**Deadline for nominations is September 23, 2005. Please mail or fax to:
 Board Nominations 830-5991 Spring Garden Road, Halifax, NS B3H 1Y6
 Fax: 902-422-3797**

What Defines You!

REPRINTED FROM APDA YOUNG PARKINSON'S NEWSLETTER, SPRING 2005

What would you say if you were asked this question, and what does your response say about you? It says a lot. For those of us who deal with chronic illness on a daily basis, whether as a caregiver or one with the illness, this question becomes even more important. What defines you! Have you become the sum of your illness or role as a caregiver, or have you allowed the illness to just be a part of your life—one more component in what is essentially a full life?

Sure, easy for me to say, you might be thinking. I do not have Parkinson Disease, but I have lived with it for almost twelve years in the role of support spouse, eventually leading to that of a harried caregiver. I made a choice early on not to be a victim, not to let our lives be overwhelmed. This illness would not define what our lives could be.

So we carried on and did the best we could to move forward and keep our perspective. Our lives were nearly shattered by the discovery that I had non-Hodgkins lymphoma almost five years ago. Again, I had the choice of allowing an illness to define who I was and what my life would be like. I chose life and all it had to offer, good and bad. I learned very quickly that my reactions would be mirrored in the faces of my children. The impact this illness had on how I defined myself could be positive or negative. I opted for the positive.

So this is the question and perhaps the challenge we all face each day. What defines you. or better yet. What will you allow to define you? When you figure

that out. Think about what elements have led you to that conclusion. What happens when the mix changes or varies? Who will you be then? Will you continue to grow in a positive way or will you find yourself lost in search of who you now are?

If the sum of your life is your role as a caregiver, who are you when that role is no longer there? Have you continued to have outside interests, hobbies and most importantly, friendships and relationships? How much of your life is wrapped up in caring for someone else, exclusive of your own needs and desires?

If it is you that is ill, how much of your life is all about you? Do you think often of others, and how your actions and illness affect their lives as well? Do you rail at the gods and feel it is just not fair that you have to suffer this injustice? On the other hand, have you accepted this illness with dignity and strive to work toward the best health you can have? You can't control your illness, but you can control your reaction to it. We all have a choice.

Face it. Life is not fair. We all have so much to be grateful for, though. Our reactions to the things that happen to us, both good and bad, define who we really are and what we project to others. We may not be in control of what life deals us, but we can work on how we allow these things to define us. Give it some thought. It might change your life, for the better.

CORRECTION

We incorrectly printed material from Jan Duff's summary of the Awareness Month 2005 Sessions and apologize for any misinformation and confusion this may have caused.

"New Indications for already approved drugs"- It says that COMtan is not yet available in Canada, whereas it is the COMtan/Sinamet combination med -STALEVO- that is not yet approved in Canada. The second point also should read STALEVO, rather than COMtan.

Sunday, October 23rd Events Holiday Inn, Robie St, Halifax



An inspiring young fiddler from Alder Point, Cape Breton, with talent and experience well beyond her years, **Jennifer Roland** will begin Sunday evening at 6:00 by entertaining delegates with the launch of her 3rd CD.

Her new CD, entitled *“Wings”* is dedicated to her Father, who in addition to living with Parkinson’s, taught and inspired her the art of fiddle playing .

You can find out more about Jennifer at www.jenniferroland.com

PUBLIC FORUM—ALL WELCOME

A true inspiration not only to people living with Parkinson’s, but to anyone who has ever had to face a challenge. **Anthony Scelta Jr**, author of *Defying Despair* was diagnosed with Parkinson Disease at age 25

Anthony will speak at 7 pm and through his experience will inspire you with his strength and commitment to help other’s. To find out more about the work Anthony is doing to “knock out Parkinson’s” visit www.defythis.com. Reception to follow.

Anthony will be available to sign a 2006 inspirational calendar featuring celebrities & athletes who have defied illnesses and physical challenges to become shining examples of those who overcome adversity . We will have a limited supply available at the door!

Although there is no charge for this forum, we ask that you RSVP, if possible, to ensure we have adequate seating and refreshments.



Tuesday, October 25th

SOMETHING SPECIAL FOR HEALTH CARE PROVIDERS

8:30—12:00

Parkinson’s 101 for Health Care Professionals—Caring for Someone with Parkinson’s

Presenters: Dr. David King, Neurologist, Halifax, NS
Dr. George Turnbull, BPT, PhD, Halifax, NS
Jan Duff, RN, Toronto, ON
Dr. Ellen Hickey, Halifax, NS

An overview of Parkinson Disease will be provided followed by a panel of experts discussing specific topics and a question and answer period.

Discussion Topics: Communication/Speech & Swallowing ; Exercise, Posture & Gait ; Medication Management; Cognitive Impairment & Challenging Behaviours

2005 East Coast Parkinson Conference—October 23-25

REGISTRATION FORM

Breaking New Ground

Please note space is limited to 150 participants. Deadline for Registration is October 10

Early Bird Special: \$99 (prior to Sept 5)

Late Risers: \$125 (after Sept 5)

Registration Fee (includes 2 lunches; 4 nutrition breaks, Sunday evening Public Forum & Reception)

Name: _____

Organization: _____

Address: _____ Postal Code: _____

Phone: _____ Fax: _____

E-mail: _____

Please choose one workshop from each session

MONDAY, OCTOBER 24

The Faces of Caregiving

Importance of Exercise in Parkinson's

Newly Diagnosed: What Can I Expect

TUESDAY, OCTOBER 25

I am involved in the care of people with Parkinson's and will attend the special session for Health Care Professionals *

- I plan to attend the Public Forum & Opening Reception on Sunday Evening – October 23
- Please reserve a spot for Dinner/In-Costume Keith's Brewery Tour – October 24 (extra fee: \$40)

PARTICIPANT CATEGORY

Person with Parkinson's Family Member/Caregiver Health Care Professional Other _____

Method of Payment

Please make cheque payable to "Parkinson Society Maritime Region"

Cheque/Money Order enclosed \$ _____

Visa/MC _____ Exp _____

Cardholders Name _____

Full refund, minus a \$20 administration fee will be given for cancellations received in writing by **October 3**. If you reserve a seat and do not attend, you **WILL** be invoiced shortly thereafter.

Please return Registration Form/Payment to:
 Parkinson Society Maritime Region
 830-5991 Spring Garden Rd Halifax NS B3H 1Y6
 Fax: (902) 422-3797
 Email: dhubley@parkinsonmaritimes.ca

2005 East Coast Parkinson Conference—October 23-25

Holiday Inn, Robie St, Halifax , NS AGENDA

Sunday, October 23

- 6:00—7:00 Delegate Meet & Greet
Entertainment: Jennifer Roland launches her new CD
- 7:00—8:15 **Defying Despair: Diagnosis at 25**
Anthony Scelta Jr., Florida, US
- 8:15—9:00 **Reception**
-

Monday, October 24

- 8:00 – 8:45 Registration & Exhibits/Displays
- 9:00 – 9:15 **Welcome / Opening Remarks**
Paul McNair/Kelly McKay
- 9:15 – 10:15 **How Life Changes After PD**
Grace Griffith, PT, Folk Singer, Washington DC
- 10:15 – 10:30 Organized Stretch – Yoga
- 10:30 – 10:45 **Nutrition Break & Walkabout Exhibits/Displays**
- 10:45 – 12:00 **Panel: Research**
Facilitator: TBA
Panellists Cell Transplantation – Dr. Ivar Mendez , Halifax , NS
Stem Cell – Dr. Murray Hong, Halifax , NS
- 12:00 – 1:30 **Buffet Lunch & Walkabout Exhibits/Displays**
- 1:30 – 2:30 **Concurrent Sessions**
Panel Presentation: The Faces of Caregiving
Facilitator: Sheree Trecartin, VON, Saint John, NB
Panellists: “Caring for a Spouse at Home”, Leon Fitzgerald, Dartmouth, NS
“Caring for a Parent at Home”, Patricia Burke, Parrsboro, NS
“Caring for the Parkinson Patient, Louise Mosher, RN, Oceanview Manor, Dartmouth NS
- Exercise for People with Parkinson’s**
Janet Millar, Halifax
- Panel Presentation – For the Newly Diagnosed**
Facilitator: Patricia Morrissey, Executive Director, Parkinson Society Newfoundland & Labrador
Panellists: “What Can I expect”, Jan Duff, RN, Toronto, ON
“Start thinking about Financial Planning”, Keith Oickle, Grant Thornton, Halifax, NS
“Enjoy Every Day with PD”, Bill Perry, Saint John, NB puts a positive spin on daily living

2005 East Coast Parkinson Conference—October 23-25

Holiday Inn, Robie St, Halifax , NS AGENDA

Monday, October 24 (cont'd)

- 2:30 – 2:45 Organized Stretch—Tai Chi
- 2:45 – 3:00 ***Nutrition Break & Walkabout Displays***
- 3:00 – 4:15 **Parkinson's Disease in Old Age When the Pills Start to Fail?**
Dr. Colin Powell, Centre for Health Care of the Elderly, QEII, Halifax
- 4:15 Rest Period (and/or dinner on your own)
- 6:00 Optional – Dinner at Waterfront Warehouse & In Costume Brewery Tour
(approx \$40 depending on attendance—not included in the registration fee)

Tuesday, October 25

- 8:30 – 8:45 **Welcome Back**
- 8:45 – 9:45 **Questions to ask your Dr.: What he/she May Not Tell You**
Dr. Barbara Patterson, UNB, Fredericton, NB
- 9:45 – 10:00 Organized Stretch
- 10:00 – 10:15 ***Nutrition Break***
- 10:15 – 11:45 **Effective Management of Chronic Illness**
Facilitator: Patricia Morrissey, Executive Director, Parkinson Society Newfoundland & Labrador
Presenters: Stress Management through Humor, Bill Carr, Humorist, Halifax, NS
Psychosocial Issues, Jason Rogh, Psychologist, Halifax, NS
- 11:45 – 12:30 Exhibits/Displays & Hotel Check out
- 12:30 – 2:00 ***Sit Down Lunch & Awards Program***
Paul McNair / Kelly MacKay

Concurrent Morning Session

SPECIAL SESSION FOR HEALTH CARE PROVIDERS

- 8:30—12:00 ***Parkinson's 101 for Health Care Professionals—Caring for Someone with Parkinson's***
Presenters: Dr. George Turnbull, BPT, PhD, Halifax, NS
Jan Duff, RN, Toronto, ON
Dr. Ellen Hickey, Halifax, NS

An overview of Parkinson Disease will be provided followed by a panel of experts discussing specific topics and a question and answer period.

Discussion Topics: Communication/Speech & Swallowing ; Exercise, Posture & Gait ; Medication Management; Cognitive Impairment & Challenging Behaviours

PARKINSON SOCIETY MARITIME REGION'S RESOURCE CENTRE

New This Month

Resource Guide

Ever wonder about all of the resources the Maritime Region has in their resource centre?

To help you, we have developed a resource guide which includes all our brochures, videos and books.

The guide is user friendly, is broken down by topic and is cross referenced if they cover more than one area.

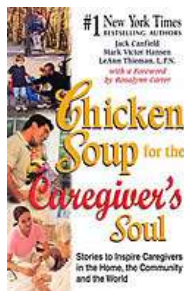
The guide can be used by everyone, including people with Parkinson's, their families and friends, Long Term Care Facilities, hospitals, Health Care Professionals, schools, etc.

If you or anyone you know would like a copy of the guide, please contact Denise Hubley at the Maritime Region office.

Chicken Soup for the Caregivers Soul

A dose of inspiration for the millions of souls who help care for family and friends and give of themselves to others through day care, eldercare, emergency and community service. While rewarding, care giving requires tremendous emotional, physical and spiritual stamina. This book offers a respite to those who give care through inspiring and uplifting stories about the work they do and its power to transform lives.

Through inspiring glimpses of real-life experiences, readers will find the motivation to overcome a challenging day, welcome recognition for their selfless contributions, and the encouragement to continue making a positive difference in others' lives.



Looking for Information related to Parkinson Disease, Stop by our Resource Library

In addition to the resources listed on the left, we have a number of books and videos available to the public on loan for a three week period. We also have a variety of brochures and booklets on Parkinson's available to the public.

or ...

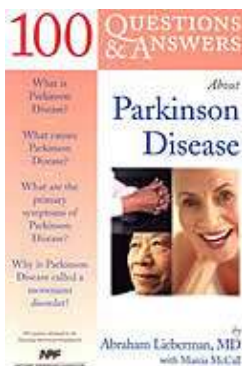
Check out our website

www.parkinsonmaritimes.ca where you'll find information on Parkinson's, volunteering, upcoming special events, support services in your area, links to our regional partners or why not leave a message on our online message board.

or ...

1-800-663-2468

100 Questions and Answers about Parkinson Disease: A patient-oriented guide to coping with Parkinson disease and the physical and emotional difficulties associated with the disease. This book is broken into sections and answers questions in plain language.



Call our toll free information line to speak with a staff member about your concerns and we'll be happy to provide you with information, support and referral and links in your local community.

CHAPTERS & SUPPORT GROUPS

NOVA SCOTIA

Hfx/Dart Chapter

Marion Cochrane
(902) 434-6638

Hfx/Dart Support Gr. (daytime)

Barbara Boudreau
(902) 443-8604

Caregiver Support Gr, HFX

Norma McPherson
Contact: Marion Cochrane
(902) 434-6638

Shelburne County Chapter

Keith McCrory
(902) 656-2332
kmcrrory@ns.sympatico.ca

Truro Chapter

Jim Gates
(902) 895-5227
jamesgates@eastlink.ca

Lun/Bridgewater Support Gr.

Maureen Brisson
(902) 543-4305
fmbrisson@ns.sympatico

Sackville/Bedford Support Gr.

Kevin McGuigan
(902) 865-9101
mcguigan1@ns.sympatico.ca

Cumberland Co. Support Gr.

Patricia Burke
(902) 254-2935
trishburke@ns.sympatico.ca

Cape Breton East Chapter

Mary Langlois
(902) 539-8592

Annapolis Valley Chapter

1-800-663-2468

Pictou County Support Gr.

Josephine Jollymore
(902) 752-6791

NEW BRUNSWICK

Greater Moncton Support/ Chapter

Jason Lewis, (506) 386-4969
annielew4js@hotmail.com

Fredericton Chapter

Sharon Simms
506-452-8909
rsleroux@nbnet.nb.ca

Saint John Chapter

Sheree Trecartin
(506) 635-1530, ext 503
trecarts@von.ca

Edmonston

1-800-663-2468

St. Stephen Support Gr.

Sandra Carson-Hanson
(506) 466-5444
hansonsm@nb.sympatico.ca

Grand Lake Chapter

Tom Leblanc
(506) 327-3205
sawalker@nbnet.nb.ca or
Maxine Bell (506) 385-2091

PEI

East Prince Support Gr.

Tom Carew
(902) 436-5231
tom.carew@pei.sympatico.ca

Queens County Support Gr.

Linda Skerry
(902) 566-2485
or Anne Wootton
(902) 569-1829

Prince Edward Island Chapter

Donald Simmonds
(902) 566-2301

Montague Contact

Gordon MacKenzie
(902) 838-4749



Members of our Pictou County Support Group, April, 2005

THE DRUG APPROVAL PROCESS IN CANADA

(PARKINSON PAPER, PARKINSON SOCIETY, OTTAWA, AUGUST 2004)

The therapeutic Product Directorate (TPD) of the Health Products and Food Branch (HPFB) at Health Canada is the Federal authority responsible for the regulation of pharmaceutical drugs and medical devices. They ensure that all drugs and devices used by the public are safe, effective and of high quality. To do this, they must ensure that manufacturers properly test drugs and devices and that the public is protected during each stage of the development process.

There are several strict steps involved in the development of a new drug in Canada and the average time between the initial laboratory tests and the marketing of a drug is about 12-15 years. The estimated cost of research and development required for each drug that reaches the market is \$1.3 billion.

Step 1 - Laboratory Research

Chemical and biological tests are performed on tissue cultures and then on a variety of small organisms to determine the effects of the drug. If the results show potential, the manufacturers can proceed to the next step.

Step 2 - Pre-clinical Development

More laboratory tests are conducted using animals over different time periods. If the drugs cause no serious or unexpected harm at the doses required to have an effect, the manufacturer may apply to TPD to proceed to Clinical Trials.

Step 3 - Clinical Trials - Phase 1

The drug is first tested on healthy human volunteers. These trials are carried out under carefully monitored conditions and usually consist of single doses given one at a time.

The process of identifying common side effects and the tolerated dose range begins here.

Step 4 - Clinical Trials - Phase 2

The drug is tested on people with Parkinson's who are otherwise healthy and have no other serious medical conditions. The goal is to collect information on the safety of the drug and to note if the drug makes a difference, compared to other treatments. Side effects are recorded and effective doses are identified. If successful, the manufacturer can apply to TPD for Step 5. ***The risk of failure is very high: on average, for every 5,000—10,000 compounds screened, two drugs will make it to Step 5 and one will be approved for Step 6.***

Step 5 - Clinical Trials - Phase 3

Many more people with Parkinson's (including people who have other medical conditions and who may be taking other medications) determine drug effectiveness and side effects in people who better represent the general population. More information is collected on how the drug should be used, the best dosage range and the possible acceptable side effects. If successful, the manufacturer can submit a New Drug Submission to TPD to sell the drug in Canada.

Step 6 - New Drug Submission (NDS)

TPD reviews all the information gathered during the development of the drug, decides how to test the drug themselves for safety and effectiveness, and considers the risks versus the benefits of the drug. If the benefits outweigh the risks under specific conditions, the Health Products and Food Branch (HPFB) may approve the drug by issuing a Notice of Compliance to the drug manufacturer. HPFB will also review and edit the Product Monograph. This is the document that is provided to physicians with the information they need to properly prescribe the drug.

Even after a drug or device is approved, Health Canada's Marketed Health Product Directorate (MHPD) continues to monitor the drug's effectiveness and safety because some side effects will only present themselves when the drug is marketed to a greater number of people.

Can a drug be obtained before it is approved in Canada?

Individual physicians treating patients with serious or life-threatening conditions (where conventional therapies have failed, are unsuitable, or unavailable) may be able to obtain a drug or device before it is approved by directly contacting the Special Access Program (SAP), which can authorize the sale of a drug or device not otherwise available in Canada.

www.pdtrials.org is a fairly new website that has information on Parkinson Disease clinical trials currently enrolling participants in the US (Many of the same trials run concurrently in Canada—please consult your neurologist.)

www.clinicaltrials.gov is the US National Institute of Health (NIH) site about clinical research trials.

RESEARCH UPDATE

VIEWPOINTS JUNE 2005, PARKINSON SOCIETY BC

Fracture rates in Parkinson Disease compared with age-and-gender-matched controls: a retrospective cohort study

Patients with Parkinson disease are not routinely tested for bone density or prescribed bone-protecting medication despite the fact that they are known to be at risk for falling. Researchers in the United Kingdom investigated whether subjects with Parkinson's were more at risk for fractures than other patient groups. They did this in order to establish whether fracture preventative measures should be taken routinely for those who have been diagnosed with Parkinson's.

The researchers studied the records of 200 Parkinson patients and compared them with 200 age and sex matched patients attending other medical clinics in the same hospital. Each age-matched counterpart being diagnosed with Parkinson's. They looked at the history of fractures before the entry into the study in both groups and then looked at each subject's record from date of PD diagnosis until April 2002 or death. They found that the percentage of fractures in the PD group was twice that of the controls (15% vs 7.5%). The commonest site of the fracture in the PD group was the femur followed by the forearm and the ankle. In the control group the forearm was the most common. Interestingly they did not show hip fractures but note that they are frequently fatal but preventable. The study showed that the increased risk comes about after the onset of the disease. Ninety percent of fractures occurring in the elderly are the result of a fall and people with PD tend to be older. As well people who have difficulty with personal care (bathing, dressing) balance, low blood pressure and walking are all more likely to fall and sustain a fracture and these problems are common in Parkinson's; however, the authors also discuss loss of bone density and low body weight as additional factors contributing to fractures. One study has shown that PD patients have lower bone mass than controls and weight loss is well described in Parkinson's. The authors argue for controlled randomized studies, which are indeed necessary but in the short term people with Parkinson's and those who provide their care should be paying more attention to reducing the risk of bone loss and fractures whether through medications, exercise or the use of safety equipment.

A mnemonic for Parkinson disease Patients considering DBS: a tool to improve perceived outcome of surgery

Michael S. Okun, MD and Kelly D. Foote, MD from the Movement Disorders Center, University of Florida, have developed a tool to help patients have a more realistic expectation of what to expect following surgery for Parkinson's. The authors recognized that patients considering deep brain stimulation for Parkinson's may be exposed to videotapes, media coverage, or literature, which show dramatic improvements in PD symptoms after surgical intervention. Patients look for the best centre at which to have surgery but afterwards they may be very disappointed after the surgery because it did not meet their preconceived and unrealistic expectations. In order to educate patients about the expected outcome following surgery they have developed a simple mnemonic device, which they suggest be taught to patients and families and then reviewed both before and after surgery. Using this tool may allow patients and families to develop an educated and realistic expectation of the benefit surgery may confer and help to ensure that the outcome meets or exceeds their expectations, and as a result they become a more satisfied patient with better symptom control

Does not cure

Bilateral DBS is often required to improve gait, although sometimes unilateral DBS has a marked effect on walking. **S**mooths out on/off fluctuations.

Improves tremor, bradykinesia (slowness), stiffness (rigidity), and dyskinesia in most cases, but may not completely eliminate them

Never improves symptoms that are unresponsive to your best "on". For example, if gait or balance do not improve with best medication response, it is very unlikely to improve with surgery

Programming visits are likely to occur many times during the first 6 months. There will be multiple adjustments in the stimulator and in the medications.

Decreases medications in many, but not all patients.

Ask the Nurse

Sheree Trecartin, VON Parkinson Nurse, Saint John, NB

Q: Why is it extra important for me to drink lots of water during the summer months, especially if I'm taking medication for the management of my Parkinson's?

*Sheree Trecartin
Parkinson Resource Nurse*



If you have a question about Parkinson's, it is most likely a question that many others may be wondering about also. Sheree our Parkinson Nurse is available to respond to questions via the newsletter. To pose a question to "Ask the Nurse" contact the Maritime Office at 1-800-663-2468 or 422-3656 or you can email it to dhubley@parkinsonmaritimes.ca.

Bladder Dysfunction

Viewpoints, June, 2005 Parkinson Society BC

Though Parkinson disease is defined by motor symptoms caused by the death of nigral cells within the brain, the shadow of disease is cast on the autonomic nervous system where it affects the bladder. In normal aging, the once elastic bladder loses its resiliency and may accommodate only half the volume of urine it did in its youth. Loss of elasticity or tone results in a frequent need to urinate. When the urge to visit the toilet occurs during the night, it is called nocturia and experiences by almost two-thirds of the elderly population. Other changes related to progressing age are increased residual volume after urination meaning the bladder does not completely empty, decreased peak urine flow, decreased average flow rate, and decrease volume voided. Studies show that while normal aging brings about changes in bladder function, people with Parkinson Disease are more likely than their healthier counterparts to report these issues. Researchers found urological symptoms followed motor symptoms by an average of 5.75 years. In other data, disease severity correlated with the presence of urologic symptoms, with more pronounced disease tending to have increased urological problems. The large category of bladder dysfunction can be broken into two distinctive camps of irritative and obstructive symptoms.

Irritative Symptoms include increased frequency, urgency and urge incontinence. Increased frequency is defined as urinating more than 7 times per day. Urgency is the desire to urinate. Urge incontinence occurs when there is an acute need to urinate followed by uncontrollable urine leakage. Irritative bladder symptoms frequently respond to anticholinergic drugs, Ditropan (oxybutinin), Pro-banthine (propantheline bromide), Cystopaz (hyoscyamine sulphate), Urispas (flavozate hydrochloride) and Detrol (tolteridone

tartrate). Side effects of the drugs include the appearance of obstructive-like symptoms, such as hesitancy and weak urinary stream. Other well-documented effects are dry mouth, impaired visual accommodation—difficulty shifting one's gaze from objects close in the field of vision to distant objects. Constipation and aggravation of glaucoma are also documented side effects.

Detrusor Hyperreflexia is the “hyper-active bladder”. The bladder is perceived as full at an early stage of filling. There are involuntary contractions in the detrusor muscle, which the individual is unable to inhibit. There is a very high incidence of detrusor hyperreflexia in patients with Parkinson Disease.

Obstructive Symptoms are weak urinary stream and urinary hesitancy. Obstructive uropathies include benign prostatic hypertrophy in men and stenosis of the bladder neck in women. Hypertrophy or enlargement of the prostate occurs frequently with aging in males. The prostate encircles the bladder neck, where bladder becomes urethral tissue and growth may impinge on the urethral opening creating impedance to urine flow.

Detrusor Arreflexia—“Detrusor” comes from the Latin verb detrudere, meaning to thrust down. The detrusor muscle is the thick muscular fiber of the bladder wall composed of smooth muscle fibers. In detrusor arreflexia there is decreased sensation as the bladder fills, an increase in bladder capacity and only a desire to urinate when the bladder is quite distended. The bladder does not completely empty; post-void residual volume is more than 100ml. Urodynamic findings associated with arreflexia re hesitance and weak urinary flow. Detrusor arreflexia is not common in patients with Parkinson Disease.

Telling Your Children About a Diagnosis of Parkinson Disease

TALK AMONG THE TULIPS, MANITOBA, JUNE 2005

You may be reluctant to tell your children that you have been diagnosed with Parkinson disease. Often this reflects a fear that your relationship with your children will alter and that you will be seen differently by them—no longer the strong, in-charge parent, but a weaker version of what you once were. A chronic illness impacts on children as well as a partner and telling them may enable them to cope with changes that they may be observing but do not understand. An open discussion can be beneficial to all concerned. Young children can understand if the information is presented simply and as a matter-of-fact. They will take their emotional cues from you. If you are matter-of-fact, children will not feel overwhelmed or burdened by the information. Children will benefit from the opportunity to ask questions, voice their fears (is it contagious, will you die?) and seek reassurance. You will benefit from

the opportunity to explain the changes that your children may be observing, explain why you may not be able to do certain things, and establish realistic expectations for what you can do with your children.

Adolescents, already often embarrassed by just having parents, may find it difficult to accept the physical changes that accompany Parkinson disease. Children may go through similar stages as yourself (denial, resentment, anger, acceptance) as they attempt to understand the changes in their life. If children are having difficulty in accepting the situation, professional counselling can be considered but is usually unnecessary. Help can also be found at the Parkinson Society Maritime Region through the resources available in video or print form. Please call Denise to find out what is available.

Music and Stress Management

WWW.YOUNGPARKINSONS.ORG

Music has been described as the universal language and is full of power to help you express your feelings and emotions. You may ask, how does music do this? Music is able to bring forward emotions and memories—the good and the bad of the past and the present. Once surfaced, the emotion can be identified, examined, confronted or tossed away. Identification of a problem is paramount in confronting its issues. Music is often used to enable the critically or terminally ill to express their feelings and emotions.

The lyrics of a song may reflect the listener's situation and in some cases identify a solution. Deforia Lane in her book, *Music as Medicine*, shares multiple examples of personalizing a song or even writing a song with patients or their families in the process of helping them to deal with serious illness or death. Lane says that "music has the unique power to do what often seems impossible: to open us precisely where we had shut down; to touch us where nothing had.music is a window where once was only a solid wall."

Music should eventually lead to relaxation and the enjoyment of being alive. Music also has the power to release "endorphins," or a natural high from chemicals produced in the body. The release of endorphins leads to feeling good, happy and peaceful, thus reducing stress and leading to relaxation. The addition of breathing skills, relaxation techniques, visualization or time management may further reduce or control the stress. So, put on some great music, learn some relaxation techniques and enjoy!

Government's Strategy to Support Caregivers

TONY IANNO, MINISTER OF STATE (FAMILIES & CAREGIVERS) (NOTES FROM CAREGIVERS NS LUNCHEON, MAY, 2005)

As we all know, unpaid caregivers are Canada's unsung heroes.

In every corner of this country, millions of caregivers are hard at work. They rake leaves and cut lawns. They shop for groceries and fix meals. They provide personal care and take care of medication. And they do all this, and so much more, while juggling the demands of their own work, their families, and their personal lives.

You might be able to estimate the economic value of unpaid care at more than \$5 billion a year. But you can't measure in dollars the value of a friendly voice, a willing ear, or a warm touch.

But unpaid caregivers can pay a huge personal price for their service through stress, physical illness, loss of income, and loss of privacy—name just a few possible consequences. We already know a great deal about the nature of caregiving today, but the context for the work is constantly evolving. We have to look at the impact of health care on caregiving, the increased prevalence of chronic illness, and the desire of ailing people to stay in their homes for as long as possible. And we have to respond to changing demographics: an aging population, smaller families spread out across the country and around the world.

That's why the federal government created a new department in 2003 called Social Development Canada to strengthen our social foundations. And that's why Prime Minister Martin created a

ministerial portfolio specifically to address the needs of caregivers and families.

The Government of Canada already has a range of measures in place to support caregivers, including:

- Tax credits to help offset out-of-pocket expenses;
- A compassionate-care leave-benefit that provides six weeks of income for family members who must stop working to care

“Caregivers are unpaid not because they're worthless, but because they're priceless”

for a dying relative.

- Special provisions of the Canada Pension Plan to help offset periods of low or no income;
- Labour legislation that provides caregivers some leave protection;
- Direct support for veterans, First Nations and Inuit;
- And of course, transfers to the provinces and territories for health and social services.

We also recognize these measures don't go far enough. We recognize the vital role of caregivers and are committed to offering more support. In the recent budget, the Government delivered on its commitment and increased support for home-based caregiv-

ers, doubling tax credits for medical and disability expenses to \$10,000/year. This was the first concrete step toward a strategy to increase support for family caregivers.

Through a series of roundtable discussions, there were seven priority issues identified, including the need to create information services for caregivers, to develop tools that could identify caregivers at risk of burn-out, and to deliver additional direct support to care receivers.

One message that came through loud and clear is that “no two caregivers are alike”. Some are concerned about out-of-pocket expenses and lost pension income. Others want more training, counselling and peer support so they can continue to deliver quality care.

There is now an online tool on the Social Development Canada Website for Canadian caregivers to tell their stories. Please take the time to share your stories. Not only will this help the government understand your challenges and solutions, it may also help one of your peers in another part of the country.

In the end, we're all in this together. The challenges associated with unpaid caregiving are immense—much larger than any single association or even government can solve on its own.

Parkinson Society Maritime Region

830-5991 Spring Garden Road
Halifax, Nova Scotia B3H 1Y6

Phone 422-3656
Toll Free 1-800-663-2468
Fax 422-3797
Email info@parkinsonmaritimes.ca

www.parkinsonmaritimes.ca

Canadian Publications Mail
Agreement No.

40025723



Parkinson Society Maritime Region
Soci t  Parkinson Regional Maritime

New Web Site
www.parkinsonshealth.com

A collaborative effort of Teva Neuroscience, Inc. and Eisai Inc. Designed to offer people with PD and their caregivers a variety of resources to empower them with knowledge about the disease and strategies for managing it.

We welcome submissions to Down East Parkinson's News. However, all submissions may be edited for content and space and used as appropriate. Please consult with your physician with regard to your treatment and health. Everyone's situation is unique. All opinions and articles expressed herein are those of the writers and do not necessarily reflect those of the Society.

Sharing Corner.....

Do you have a story to share?

We are always interested in short stories or articles involving our Parkinson community. If you have Parkinson's or are caring for someone with Parkinson's or are a volunteer, we'd love to hear from you. Also, if you have tips for living better with Parkinson's, please let us know so we can share these with our readers.

You can drop us a line either via phone (902) 422-3656, toll-free at 1-800-663-2468 or via email to dhubley@parkinsonmaritimes.ca.



Holiday Inn Select in Halifax have set aside a Block of Rooms at a **Special Conference rate up to September 20**. If you are planning on attending the **East Coast Parkinson Conference** in October, make sure you book your reservations with the Holiday Inn prior to September to ensure a spot at the reduced rate (902) 423-1161. **Hope to see you there!**