LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

June 2008

INSIDE...

Region Names Recipients of Volunteer Awards

From Karen Dowell
Community Development Coordinator

Dr. Mandar Jog, BSc. MD,FRCPC with Jim and Elaine Forbes of Thunder Bay

Each April is not only Parkinson's Awareness Month, but also Volunteer Appreciation month.

We could not touch the number of people living with Parkinson's the way we do without the help of so many volunteers who serve in support groups, on regional committees and during our fundraising events all year round. Staff provide much of the structure, coordination and administration within the region but the many volunteers who help out are fundamental to our success. People with Parkinson's, caregivers, family members and members of the community who want to provide support to a good cause all bring important knowledge and expertise to the organization.

Each April we honour three of the many volunteers with a special award. This year we have five winners.

The Derek Curwen Award for fundraising and chapter support this year goes to Andy Haynes of the Northumberland Support Group. Andy has grown tulip sales in the Cobourg/Port Hope area from 750 bunches in 2000 to 1,320 bunches and 408 pots this year. He also designed, sourced a supplier for and distributed fridge magnets to pharmacies throughout the district via the chapters to be placed in with the prescriptions of Parkinson's patients. This year he initiated a "sponsor page" for his area and worked with Peterborough and Durham Region in an attempt to have those communities also acknowledge Parkinson's Awareness Month in that way.

The Marilyn Forbes Award for chapter leadership and support of people living with Parkinson's goes to Jim and Elaine Forbes of Thunder Bay. Jim and Elaine have

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Cut-a-Thon for Parkinson's 2008

On Sunday April 27th, stylists from six premiere Toronto Salons volunteered on their day off and worked their magic on over 100 clients. Many participants gathered up family members or girlfriends to make a day of it. We extend our thanks to the salons who generously donated their services and to Pizza Nova who kept the stylists energized with delicious pizza.

Thanks to:
Claus Feser Haute Coiffure
416-962-3355
Paul Pecorella Hair Salon
416-924-2751
Purple Hearts – 1-877-678-7753
Raffaello Salon & Spa
416-929-0021
Robin Barker Hair'sociates
416-960-5545
Salon Intrigue – 416-926-8827
Pizza Nova – 416-439-0000

We encourage you to support them throughout the year!

Parkinson Society Central & Northern Ontario
Société Parkinson du Centre et du Nord de l'Ontario

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MISSION STATEMENT

Parkinson Society Canada is the national voice of Canadians living with Parkinson's. Its purpose is to ease the burden and find a cure through research, education, advocacy and support services. The Central and Northern Ontario Region of the Society contributes to the national research program while offering support services, information, and specialized programs to ease the burden for those living with this chronic, degenerative neurological disorder in the region.

REGION ADVISORY BOARD

Bruce Ireland	Chair
John Parkhurst	Vice Chair
Dr. Gordon Hardacre	Member
Sherri Kinch	Member
AB Rustin	Member
Kate Pitfield	Member
Chuck Tellett	Member

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SUPPORT AND SERVICES

- Advocacy
- Individual Support (RN on staff)
- Educational Seminars and Conferences
- Resource Lending Library
- Website
- 1-800 Bilingual Information and Referral Line
- Quarterly Newsletter
- Scientific Research Funding
- Newly Diagnosed Education and Information Sessions
- Fundraising Events
- Presence at Health Fairs
- Personalized Information Packages
- Education In-services
- Support Group Network

provided outstanding leadership and inspiration for the group in Thunder Bay since 2000. They initiated fundraising events to bring Dr. Jog to the North on a regular basis. Under their leadership that chapter has been active in raising funds, organizing their own SuperWalk, selling tulips bulbs in the fall, and organizing other fundraising events.

The Ian Davidson Award, in honour of the late Ian Davidson, was established in 1990 to recognize individuals in the Toronto area who have made a significant contribution towards the Society in helping persons with Parkinson's and increasing public understanding of Parkinson's. The 2008 award goes to a deserving couple, Judy Hazlett and Roger Buxton. Together, over the past few years, Judy and Roger have developed and presented the STOP and Assist Program to educate Police about Parkinson's and facilitated the Markham Stouffville Support Group. In addition, Judy, with Roger's support, presented at World Congress Day and at the Toronto conference and Judy also performed a moving dance with a partner about overcoming Parkinson's. Judy and Roger show how a team effort can ease the burden of living with Parkinson's.

Congratulations to the recipients of this year's volunteer awards. The awards will be presented at the annual Volunteer Tea, Tuesday June 17 at the Parkinson Society Central and Northern Ontario office in Toronto. These awards serve as a reminder that

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there are many, many other volunteers who are making important contributions. Without them people living with Parkinson's would not be as well served as they are now. On behalf of everyone in Central and Northern Ontario I express a very big "Thank You".

TrainingBIG™, for Improved Mobility in Parkinson's

A new physiotherapy treatment program for people with Parkinson's, "TrainingBIG™", is now available in Ontario.

There is growing evidence that regular exercise can not only improve the quality of life of people with Parkinson's but also reduce the rate of progression of the disease. For some people with Parkinson's, TrainingBIG™ may be a good addition to their regular exercise program.

One reason why people with Parkinson's have trouble moving normally is that they have a problem with "cueing" themselves to produce a movement of sufficient magnitude. TrainingBIG™ provides a cueing strategy, one that can be generalized for different types of movements in different situations. In addition, it is a standardized protocol for teaching patients to think big. Initial results of research funded by the National Institutes of Health (U. S.) show that it leads to:

- faster walking with bigger steps,
- better balance,
- increased trunk rotation, and
- improved quality of life, and that these benefits are sustained for at least three months.

Traditional physiotherapy for Parkinson's usually has multiple goals - flexibility, strength, balance - and requires patients to remember multiple instructions for each goal. In this new approach, patients simply focus on one goal - Think Big! For 16 therapy sessions they are encouraged to take big steps, make big gestures, and make a big effort. The objective is for them to learn to expend more effort in everything they do - standing, dressing, walking, cleaning, etc. Focusing on one goal also makes it easier for patients to participate in the intensive, repeated practice required in this treatment program.

TrainingBIG™ is based on a proven treatment for the speech motor system in people with Parkinson's, the Lee Silverman Voice Treatment (LSVT). Like TrainingBIG™, LSVT has a simple focus - think loud. Research on LSVT use over the last 15 years has shown that it results in improvements in speech intelligibility and voice loudness.

With TrainingBIG™, rehabilitation gains a novel standardized movement intervention to help the person with Parkinson's to function optimally.

You can get more information about TrainingBIG™, including a list of certified therapists, at: www.gleecoinc.com or from Jan Goldstein Elman and Rebecca Gruber in Toronto at (416) 783-7175.

The Readers Write

I find your newsletter very interesting and helpful. I enjoyed *Hope Springs Eternal* and These are a few of my favourite things. I was very touched by James W. Forbes' article – *One Man's Odyssey*. I will be going to the next meeting of the Belleville-Quinte support group and I look forward to hearing others speak of their journeys.

My Journey with PD

Three years ago I began to see
that something was happening to me.
When I walked it wasn't the same,
and my trembling I just couldn't tame.

Sleep patterns much worse than before;
my doctor didn't agree with me anymore.
My symptoms were not caused by my pills,
but from PD pamphlets I knew I was ill.

Finally, he gave in to my plea
and a neurologist I went to see.
To find out what I already knew;
every symptom I had, it was true.

With his treatment I felt more like myself;
no reason to sit on a shelf.
So I do all my tasks the same way;
work and play and write poems every day.

In the future I know not what will be,
but it's important to live in the now, don't you see?
And with the Lord at my side,
He'll be my guide;
with Him at the wheel, it'll be a great ride.

By Margaret Rose Larrivée

Variety is the Spice of Life

Gordon D. Hardacre, MD, CCFP, FCFP

An identifier many of us share is the label – Parkinson's, which connotes that our nervous systems are characterized by a subnormal amount, or function, of dopamine. Our own disease experience – its onset and progression; its clinical features; symptom severity; resultant quality of life; and medication in type, dose and timing – can be as different as A is from Z. What perplexes or confounds you? Is it wearing off or dyskinesias? Tremor or lack of stamina? Bradykinesia or rigidity? Your speech or your balance? Freezing or sleep upheaval? Your mood or changes in your work life? Not to mention the differences in our physicians' experiences, opinions and preferences.

In 1999, three years after my diagnosis, when I was 53, my neurologist allowed me to make my own choice of dopamine agonist drug. It was I, not he, who voiced the need for a therapeutic boost. An agonist is now and was then commonly selected over Levodopa as early treatment for someone in my age bracket. I chose Requip and, with dosage-tailoring over nine years, got a "good run" out of it. Such is my verdict, even though I experienced its not uncommon problems of leg swelling, impulse control, and occasional daytime sleepiness. Currently, my dopamine needs are met by about 1200 mg of Sinemet per day, without Requip. Your body's requirement for Sinemet may be zero to 2,000 mg or more per day. This degree of Sinemet variability truly exists among us, even without our consideration of Requip or Mirapex or other agonists. This variability exists even without factoring in Comtan, Azilect, Amantadine or an anticholinergic, antihistamine or additional symptom suppressants; or a long-acting controlled release (CR) pill of some kind.

Dr. G. Hardacre

My current medication "cocktail" fits me, and probably, in the minutiae of its detail, only me. A friend's morning Sinemet CR fulfils, he says, his need. My only CR is taken at bedtime, to help me get through the night and to be reasonably flexible upon awakening. To each his own regimen; both are okay given our individualized circumstances and perceived drug responses. My daytime status seems to demand a drug dose at about three-hourly intervals; yours may be entirely different.

Yet we are said to bear the same condition! This is precisely why it is important that you, with your GP, neurologist, pharmacist, or other advisor, discuss what your own requirements appear to be. Even then, they will undoubtedly change over time. Such meetings deserve your careful preparation beforehand by listing your other conditions and medications beyond Parkinson's. Do the same exercise regarding your PD symptoms, including its onset features and triggering factors, its duration, its alleviation, and worsening, and its effects on your life. Finally, relate any possible drug side-effects. These may be hard to tell from aspects of Parkinson's itself.

Parkinson's is an unusual medical condition which is characterized by so specific a "core" description while at the same time being accompanied by such a person-to-person variation in appearance or management. Your outlining to your doctor of any small and rational therapy change, which is met with success but performed of your own volition, will more often than you might expect be met with acceptance. Your doctor's further suggestions may follow. Learn about your symptoms and your medications!

Even though our lives have become more challenging ("spicier") than we might have chosen, we must each cope with our own variety of this spiciness conferred by Parkinson's and importantly, share our experiences and observations with each other. Variety is indeed the spice of our lives!

Garden of Hope

Plant a 'Garden of Hope' this Fall to enjoy in the Spring. When you buy 100 bulbs, you will also receive a 'Garden of Hope' marker for that bed of blooms.

Contact Stella at
1-800-565-3000 (ext. 3301)
or check our website.

It's A Family Affair

Janis Miyasaki, MD, MEd, FRCPC

Parkinson's disease directly affects approximately 100,000 Canadians but it also, indirectly, affects their families and partners, business associates and friends. And yet, I am surprised how often my request for family to attend visits is met with surprise or "whatever for?"

I am well aware that patients have the right to self-determination, to participate in decision-making and to make fully informed choices. However, choices are not fully informed when incomplete information comes from the physician or from the patient to the physician. The therapeutic relationship is just that – a relationship. This is why physicians do have the right to "fire" patients, though such action should be reserved to where there is a breakdown in the physician-patient relationship. Each side needs to respect the other and to provide complete information for the best possible care to occur.

The best possible care looks different to each person. Comparisons by individuals in a support group are likely to lead to as many treatment regimens as group members. Every treatment decision is based on treatment and patient factors. Treatment factors include the side effect profile, ease of use, complexity of dosing, strength of benefit, cost, and the risk of serious adverse events (side effects that are severe and unexpected or result in hospitalization). Patient factors include gender, sometimes race, age, body mass, activity levels, expectations, tolerance of side effects in the past, etc. Some of these factors will be easy to identify while others rely on information that you might have overlooked.

Monitoring response to medication includes not only how well it worked, but what didn't go well – such as side effects. Some are easy to spot and report, such as vomiting - either you did or you didn't. Others are more subtle, particularly change in behaviour or cognition (thinking or reasoning and memory). Recent behaviour that is disturbing in PD are impulse control disorders – compulsive gambling, shopping, hypersexuality, binge eating or in fact, any behaviour that is repetitive or compulsive and interferes with functioning or relationships.

Janis Miyasaki, MD

Other behaviour that is important to report is confusion or hallucinations. To the patient visual hallucinations (seeing things or people that aren't there) are quite real and therefore may not be reported. They can, though, be a sign of dementia, urinary tract infection, pneumonia, or medication change.

Typically patients report 1/3 of what informed others (usually the spouse or other family member) report, and remember only 3 things from any visit – and they aren't necessarily the things of most importance.

When family members are involved in visits there will be more than one person listening and remembering. A family member can help by writing down instructions and information. Family members may also have some different questions and can learn much from visits, including what to expect from the regular follow-up visit. Even discovering what is due to PD and what isn't can be a revelation.

Typically, patients spend 15 minutes with their specialist and often less with their family physician. Words are flying fast and furious to squeeze in as much as possible. Academic centres may have longer visits, but, because of additional information collected, may seem to be more time pressured. This is not a time to assert independence – it's the time to have as many resources as possible to maximize the benefit from an appointment. Autonomy can be supported in other arenas. Separate social networks and activities or hobbies can reinforce independence.

Often, people don't want to impose upon family members, particularly children. But here's a secret – most children would love to come to their mom or dad's medical appointments. They have questions, too.

As PD progresses, the usual update "everything's great" or "the doctor didn't say anything" just doesn't cut it. Patients' children frequently call to tell me I'm 1) incompetent 2) not aware of their mom/dad's problems 3) haven't done anything to help them, or 4) am generally useless. I imagine that this is the same for most physicians. The surprise for them is that I have documented in my charts the numerous times I've asked questions and not received accurate information, had my suggestions shot down or my concerns about their function downplayed – in the words of one patient "the doctor doesn't know what she's talking about". I recognize that this is often the patient's way of coping with continuing deterioration and fear of what is coming – family members who do not attend visits have no idea of these exchanges. Having

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support from family means that over the months between visits information from the physician visit can be gently reinforced. Working together with the physician, patients and the family can learn to realistically face PD.

My job is to advise – based on seeing thousands of people with PD, having some ability to predict what's coming and what can be done to minimize the effects of passing time and increasing disability. For patients to follow through with suggestions, they have to accept that it is necessary. They have to accept the reality of their illness. The role of the family is crucial in this process which must be repeated at each stage of PD.

For spouses and family members: don't be an absentee family.

For patients: don't be a roadblock to your family's participation in keeping you going.

There is no I in team. And that's what your family and social network are, your team, your posse, your protectors. Invite them on your journey and welcome their company.

Dancing with Parkinson's

By Carolyn Jackson

It isn't always pretty, but it is always fun. The sound of twenty-five PD people shouting "Olé!" rises above the tango Igor plays on his keyboard as Dancing with Parkinson's founder, Sarah Robichaud, glides around the room yelling "Wonderful! Fantastic! You all look so beautiful!"

Beauty must be in the eyes of the beholder, I think to myself as I struggle to move my balky left leg in time to the music. Beside me in the circle, Allen chuckles. "*She* looks fantastic," he says. "Me, I'm just staggering around." We laugh. And this, perhaps, is as important as the movement that is going on around the room. No matter how people look and move as they arrive for the Wednesday afternoon class, they leave an hour later with a spring in their steps and big grins on their faces.

Sarah is one of those people whose energy and spirit just lift everyone in her presence. That energy and spirit led her to study with New York's Mark Morris Dance Group after she started working as a personal trainer with CBC Radio's Metro Morning host, Andy Barrie, who had been diagnosed with PD. She didn't know much about the condition, but started researching. A professional dancer and choreographer, she introduced Andy Barrie to ballroom dancing and then took herself off to New York to learn how the Mark Morris dancers develop routines for people with PD.

She says it was the most moving weekend of her life, watching people arrive with walkers and then experience the joy and emotions of dance. Back home in Toronto she became a woman with a mission, determined to start free weekly dance sessions for people with PD. "This is my chance to give back," she says.

Now neurologists are sitting up and taking notice of the way dancing to music helps their patients. Dr. Tiffany Chow, a neurologist at Baycrest says music is "getting movement going through the back door of the brain." Sarah admits she had no idea the medical world would be so interested, but she is now giving presentations to the medical community. My own neurologist, Dr. John Adams, told me he was so impressed with her presentation that he asked her to start a class at his Centre for Movement Disorders in Markham. "Unfortunately," he says with a sigh, "she is just too busy right now."

Enter Sarah's new mission. While her class is a first in Canada, she doesn't intend for it to be the last. In April, she and her friends organized a Dancing with Canadian Celebs fundraiser, which included a hilarious stage show, a silent auction, and raffles for donated prizes. The event raised $17,000. "I realize now that there is such a need for this," Sarah says. She has enough people on a wait list to start another class in Toronto and hopes the funds will allow her to promote classes across the country.

Meanwhile, for us "dancers" Wednesdays have become a weekly highlight. Hardly anyone misses a class—even on one Wednesday in a wretched winter blizzard the hall was full. The chance to move to an hour of live music with Sarah and her volunteer helpers is exercise with a difference. Behind his keyboard, Igor Vassine watches Sarah's every cue and delivers marches, waltzes, cha chas and tangos with ease and flair, while we try to imitate the grace and beauty of Sarah's steps. We are all different—Joe freezes, Mary loses her balance, Doris's arms move to their own rhythm, and I try madly to make my left leg behave—but to a person, we are all smiling, and maybe that's what makes us beautiful in Sarah's eyes.

You will be able to see Sarah's dance class in action in a CBC documentary, tentatively scheduled for the fall. For information: www.sarahrobichaud.com.

Plan Ahead

By Sandie Jones, RN

Sandie Jones on her 10th Anniversary celebration in April

As I gathered my thoughts for this article on the importance of planning ahead and Parkinson's, it occurred to me that a large percentage of our time each day is spent planning. We plan when we're going to get up, what we're going to wear, what we're going to eat, and what we're going to do. We plan our careers, our weddings, our family, our vacations – we plan so that our lives will go as smoothly as possible and end up where we want to be.

Recently it has been pointed out to me that perhaps I haven't accomplished as many of my goals here as I would like because I haven't had a formalized plan of action. As a result, I have been in reactive mode, with ideas floating around in my head instead of down on paper. So I end up doing same old, same old. Now I have a plan. I'm being proactive.

Even the most organized individuals and fastidious planners can't possibly know everything that life is going to throw their way. No matter how many plans we make, there are times when we simply aren't prepared for events that will have a huge impact on our lives – being diagnosed with Parkinson's is a good example. I have yet to meet anyone who had that as part of a life plan. Of all the descriptions I have heard about this life-altering event, the one that sticks in my mind is that Parkinson's is like an uninvited guest who suddenly shows up on your doorstep and insists on staying permanently, in spite of being made to feel extremely unwelcome. Regardless of your best attempts at ignoring it or pretending it has gone away, this intruder insists on invading and interfering with everything you do.

Like it or not, it becomes part of your life. Failure to plan how you are going to take this journey, what equipment you need, or what you need to do to live well with Parkinson's can result in your facing obstacles that seem insurmountable and that will make your journey more difficult than it has to be.

One of the first people with Parkinson's I met when I started to work at Parkinson Society Canada ten years ago said to me, "Parkinson's lives with me, I don't live with Parkinson's." Read that again. It's a mantra that puts you back in control. You need to take charge. Someone else said, "Difficult as it may seem, do not let Parkinson's daunt your fortitude. Parkinson's only slows down the timing of your accomplishments."

Regardless of where you are on this journey, you need a plan – maybe several different plans – for how you are going to meet the challenges that will inevitably come. It's your choice: you can let the uninvited guest take over and run your life or you can confront the intruder head on, and let it be known you are not going to back down, but are ready to face up to the fight of your life. In the next few issues I will talk about Roadblocks and Detours – all part of PLANNING AHEAD.

Doctor's Convention

Around the Region

Barrie Chapter
In January, Dr. John Adams from the Centre for Movement Disorders in Markham gave an entertaining presentation to a group of more than 100.

In March, we had a Getting to Know You meeting that turned out to be a great event. Other chapters should try it.

Barrie declared April Parkinson's month and on the 1st, Karen Dowell organized a Hope on Display presentation in the city hall rotunda that included art, music, and tai chi by PD patients.

On April 16th we had a group luncheon at the Kempenfelt Centre and on the 27th many local hair salons donated time and money to the Cut-a-Thon fundraiser.

In May we planned a garage sale and a Parkinson Golf tournament at the Innisbrook Golf Club. We will close out the first half of the year on June 9 with a Pot Luck Lunch at St. Vincent Park.

Jim Duffield

Belleville-Quinte Chapter
Our group would like to thank Shoppers Drug Mart at 405 Dundas St. East in Belleville for hosting a Cosmetic Gala on our behalf on Saturday, April 19th. The day-long event included makeovers, demonstrations and skin consultations. Tickets were $10, with half going to our chapter and half to be used toward purchases made on that day. Information on Parkinson's was handed out to those keen to learn about the condition. More than 80 tickets were sold. Perhaps other groups could approach Shoppers Drug Marts in their areas about doing something similar. It's a great way to raise money, provide information, and have a good time as well.

Bev Hanna-Jones

Burlington Chapter
It's been a busy spring. We sold 100 fresh tulips and delivered tulips to 20 of our friends who are no longer able to come to our meetings.

On April 9th we were fortunate to have Dr. Susan Fox of Toronto Western Hospital speak at the Third Annual Education Awareness series at the Royal Botanical Gardens. She shared the current status of research and what the future may hold. For the 400 attendees, it was very exciting news. Several vendors supported this evening both financially and educationally.

All are welcome to our monthly meetings. Please visit our web site at www.uelearn.com/Parkinsons

Maureen Thun

Maureen Thun receives the proclamation of Parkinson's Awareness Month from Burlington Mayor, Cam Jackson.

Hamilton Chapter

The following presentations were very interesting and we always come away with new knowledge:

March: Canada Revenue program on medical disabilities re: the 2007 Income Tax.

April: Spring Speakers Series was a great success thanks to Karen Dowell, from the regional office.

Tulip sales and Open House.

May 10: Mary Sutherland, Friends of Avery.

May 24: Support Meeting.

June 7th: Summer Luncheon

June 17th: Annual summer trip to Warplane Heritage Museum. Call Vivian at 905 387 0129

Sept 6th: Start up.

Sept 13: SuperWalk.

Get your pledge forms at www.superwalk.com

Vivian Wilson & Christina Mills

Hamilton Halton Early Onset Parkinson Support Group
Meetings are held the last Sunday of each month from 2 – 4 pm in different members' homes. Meetings are open to anyone who has been diagnosed with PD prior to age 60. Members are encouraged to attend with a spouse, friend, or significant other. Call: Debbie or Michel Lecavalier at 905 332 2367

Tanya Benard, a certified teacher of the Alexander Technique attended our April meeting. Tanya feels this technique can assist anyone with PD to improve coordination and balance; and experience greater ease of movement. Contact Tanya at: 416 405 9893 or Tanya@alexandertech.ca

Debbie Lecavalier

Kingston Chapter

About 50 attended April's meeting with a timely topic: how to prepare your income tax with special attention to medical and disability related information.

Other news:

Monique Desrocher has been appointed the chair for SuperWalk to be held in Kingston, Saturday September 13th at Lake Ontario Park.

The Chapter staffed information tables at the health fair at Olympic Harbour and at the Movement Disorder Centre at Kingston General Hospital and sold tulips as part of Parkinson April Awareness Month.

The 13 original Shirley Hulley 2007 Parkinson Calendar watercolours have been listed on e-Bay with a reserve bid of $5000. Funds raised will go to the Parkinson Society. Check it out on E-Sell-4u.com.

May 24th, we held a one-day conference at the Holiday Inn.

Felicity McKendry

Leaside Support Group

Sandie Jones, Education Coordinator at the regional office was the guest speaker at our May meeting. Sandie was in attendance for the full two hours and answered many questions and offered much professional advice.

Dr Gordon Hardacre will be the speaker at our June 9th meeting at the Presbyterian church on Eglinton, east of Bayview. Anyone reading this is welcome to attend.

We won't be meeting again until September 8th. Have a great summer!

Ron Penwarden

Muskoka Support Groups

Huntsville and Bracebridge support groups gained knowledge about preparing Powers of Attorney from Jo-Anne Boulding. She stressed that it is important to discuss your future plans with family and to choose wisely when appointing your attorney. The Ontario government publishes a free booklet with the forms which you can fill out and you can also consult your lawyer.

Sept 13 – SuperWalk in Bracebridge from 9 am – 11 am.

Twins, Tina Webster and Tammy Taylor, who was diagnosed with PD six years ago, are the movers and shakers behind the initiative to bring the Walk to Muskoka. The SuperWalk will bring some newly needed public recognition about Parkinson's.

Karen Boyer

North Simcoe Chapter

We've come a long way, baby, in so many ways in the last year. Education: with excellent speakers on Swallowing, Medications, CCAC local support, Tax savings and more. Share & Care: getting to know each other, sharing tools and hints and experiences. Awareness: Weekly events in April with member, community and media involvement, selling tulips handing out literature and chatting with folks to raise awareness. New this April was our booth at the Midland Home, Auto and Recreation show.

We also held a Parkinson's Information Day in Midland with featured speakers Dr. John Adams and Theresa Moore of the Centre for Movement Disorders, Markham.

Our annual BBQ Social will be held June 26, hosted by one of our members. Fun begins at 5pm, dinner at 6pm.

With the enthusiastic guidance of Val MacLean and George Heathwood our 2nd Annual Midland-Orillia SuperWalk will take place Sept. 14 at the Midland Town Docks. We're determined to exceed last year's total of $33,000.

Penny McDowell

Northumberland Support Group

We have enjoyed a very successful 8th annual April Tulip Sales Campaign. The 2008 Campaign raised about $5,000, an increase of about 20%. Over 1,320 bunches and 400 pots were sold in Port Hope, Cobourg, Colburne, and in a new campaign in Campbellford.

Our efforts are organized by our super salesman, Andrew Haynes, who has led all eight campaigns. Many thanks to Campaign organizers Lawrence and Joanne Massey, Len and Jurina D'Agnostino, Paula and John DeGraauw, Barbara and Peter Higgs, Jane and Charles Coon and Jim Hamilton. Our success would not have been possible without the dozens of friendly, caring volunteers from all the communities.

Claire Lloyd

Oakville YMCA Parkinson's Group

The "Y" is a charitable association open to all, dedicated to providing life-long opportunities for health enhancement and personal growth.

Of the 16 people with Parkinson's at the Y, you'll find an engineer, electrician, film producer, pharmacist, teacher, university professor and a dispatcher, among others. With the help of leaders, Pat Broughton and Marcella Mailing, this group engages in exercise, mutual support and much laughter three times a week. "Each person experiences the disease differently," says Pat, "but everyone in our program says it has helped them not just physically, but emotionally too." "Socialization is an important part of the program," says Marcella.

During the first half hour, the PWP walk the track, performing fairly strenuous feats along the way – touching hand to heel, for example. During the second half hour, they'll perform chair exercises, work on the floor mats, or float around the pool.

Many of the PWP come to work

out beyond the program; some have teamed up with a personal trainer. People with different kinds of abilities can improve their physical condition, find new friends and make their spirits soar.

Peter Sanci retired from teaching five years ago due to Parkinson’s. Unwilling to let the disease get the best of him he works hard at his program at the Y. “It gets me out of the house,” he says, “and I definitely feel better on the days I come here. The program is helping me with my balance.” He adds with a smile, “Pat and Marcella are great. They push us a little.”

Donna Papacosta

Peterborough/Lindsay Chapter

In April, about 125 people attended an excellent presentation by Dr. Mark Guttman and Theresa Moore from the Centre for Movement Disorders, Markham.

Ruth, our program chair, continues to find wonderful speakers for our meetings. Especially rewarding was a presentation from the Community Access Centre. These are located across Ontario and provide a single point of access for info and referral to community and in-home health services and admission to long-term care homes and programs,

In Peterborough, we sold 240 bunches of tulips in April—next year 300! Lindsay sold out their 20 bunches—next year they’ll order 40.

Our chapter has reorganized in an effort to duplicate the work of Vivian and Bill Heinmiller, the dynamic duo who have given many years of dedicated service. They will be “relaxing” but still deeply involved. Thank you, thank you, Bill and Vivian.

John Wood

FOR MORE INFORMATION ABOUT SUPPORT GROUPS CALL
1-800-565-3000 ext. 3372

South Simcoe Support Group (former Alliston support group)

Some of the members of the Group met in the Cedar Kitchen Restaurant in Tottenham in March. Karen Dowell from the Regional office kindly offered her help to revive the group. We renamed the group, see above, and changed the day and time that we meet.

We hope the new name better reflects our area that includes Alliston, Tottenham, Beeton, Palgrave, Adjala-Tosorontio Township, Ivy and Cookstown. We welcome anyone in the surrounding area who would like to attend. The meeting room is on the ground floor and is wheelchair accessible.

The format is very typical of a support group: self-help discussion, question and answer, news related to Parkinson's and social chat. Our small size does not justify a guest speaker, but we hope to visit Barrie Chapter to hear some speakers.

We will again be holding a SuperWalk at the same location: Riverdale Park, Alliston (starting at the Lions Pavilion on Fletcher Crescent) on Saturday, Sept. 13th. Start time is 9 am.

Les Stevens

Thunder Bay Support Group

"When it rains it pours," but it was a spring snow storm that hit hard. Our turnout to hear Dr. Mandar Jog MD was about a third of what we had expected.

After the Mayor, Lynn Peterson, proclaimed April as Parkinson's month, we heard from Dr. Jog, our guest speaker extraodinaire. He's been coming to Thunder Bay for ten years and he is more of a good friend than just a doctor. His style is relaxed and he has the ability to explain technical terms. He built on the analogy of Parkinson's being like a huge iceberg in that there is a whole lot going on beneath the surface. Thank you Dr. Jog, you are always welcome in Thunder Bay. For the Parkinson's support group in Thunder Bay, I'm Jim Forbes.

PS: Jennifer Roland's concert in a Thunder Bay church was a sell-out. She is a very talented performer who also has a mission to raise awareness of Parkinson's. With her mom in the audience, Jennifer spoke of how difficult it was to watch her dad deal with Parkinson's. The Parkinson Society couldn't have a better ambassador.

Jim & Elaine Forbes

People Really Do Care!

When Vivian Heinmiller of Peterborough set up to sell tulips at the Ministry of Natural Resources in April she had no idea what a heartwarming experience it was going to be. That very day Jake Forsma had taken early retirement and not told his many friends and co-workers as it was just too hard after 31 years. They all knew he had Parkinson’s but were not aware of his plans. Seeing the tulips gave some of his co-workers an idea. They bought 31 bunches to send home with Jake’s wife who also worked at the Ministry. The picture they took will be signed, framed and presented to Jake. The group also decided to enter a team in his honour in the Peterborough SuperWalk. “This is a great example of how people really do care” say Vivian.

Upcoming Educational Events in Various Parts of the Region.

More information in our September Issue.

Giving Back

Stanley Fujarczuk surrounded by (left to right), nephew Ted Fujarczuk, children Ed Fay and Susie Klamut, and son-in-law Henry Klamut.

When Stanley Fujarczuk was diagnosed with Parkinson's, it didn't take him long to do something about it. A tenacious family man and founder of the Unifay-Fedar Group, Stanley contacted Parkinson Society Canada and offered to help. Twelve years later his Parkinson's Charity Golf Classic is a great success, having raised more than $150,000 for research!

Recent research advances have led to a better understanding of the disease, offering hope to families affected by Parkinson's. Increased funding has enabled researchers to broaden their scope beyond motor symptoms like tremors and rigidity, providing a better understanding of non-motor symptoms like depression and anxiety.

The generosity of people like Stanley and his family makes these research advances possible. As Stanley says, "With our unfaltering support of medical research in Canada and around the world, a cure for Parkinson's can be found."

In its first year the tournament attracted eighty players – mainly family members, friends, and business associates. This core group continues to attend, making the tournament "a big reunion of family and friends" claims Stanley's daughter Susie. With the support of Stanley's children, Ed Fay and wife Sue, Susie and husband Henry Klamut; niece and nephew Teresa and Ted Fujarczuk; and five grandchildren, the tournament has grown and last year celebrated its best attendance with over 140 people!

But it was a bittersweet celebration. Stanley's wife, Stella, had sadly passed away. It was a difficult year for the family. Stanley and Stella raised their children in an environment where everything centered on family. It's no surprise then, that the family comes together to do good in the community.

For the family, giving back to the community that has been good to them is important – a lesson that's passed on to younger generations. From children to grandchildren, everyone lends a hand with the event. As Ed believes, "We've done well and we want to give back."

Other charities also benefit from the family's hard work. Annual golf tournaments and other events are held for charities that have touched the family's lives. For the Fujarczuks giving back is only natural. "Giving back is a wonderful feeling that has to be experienced firsthand," Susie believes. "I recommend trying it out."

To sign up for the 12th Annual Parkinson Charity Golf Classic on Wednesday, June 11, 2008, contact Felicia Migliore at 1-800-565-3000 ext. 3378 or felicia.migliore@parkinson.ca. Registration is $150 (includes lunch, dinner, round of golf). A tax receipt will be issued for a portion of the fee. Save the date! Next year's tournament is Wednesday, June 10, 2009.

☑ ***Yes,*** I will help support the people affected by Parkinson's in the community.

I've enclosed my gift of: ☐ $35 ☐ $50 ☐ $100 ☐ $250 ☐ Other $____

☐ Cheque (payable to Parkinson Society Central and Northern Ontario) or ☐ Visa ☐ MasterCard ☐ Amex

Card No.: ______________________ Expiry Date: _____ / ______ Signature: ______________________

Please complete the following information:

☐ Mr. ☐ Mrs. ☐ Ms. ☐ Miss ☐ Other:_________ First Name: ____________________ Last Name: ____________________

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☐ **Please sign me up as a monthly donor. I have completed the information above and understand the amount indicated will be charged to my credit card or deducted from my bank account on the 15th of each month (please enclose a void cheque for monthly direct withdrawals).**

☐ I would like to receive e-mail updates about Parkinson Society Central and Northern Ontario's activities

☐ Please contact me about how I can make a legacy gift.

Please return your reply form with your gift today in the enclosed prepaid envelope.

Thank you for your support!

Tax receipts are issued for donations of $10 or more, or upon request.

From time to time, we trade our mailing list with like-minded charities in order to find new donors to support our work. However, if you still prefer not to have your name traded, please tick here: ☐

LS09C

LiveWire is published four times a year to provide people affected by Parkinson's in Central and Northern Ontario with helpful information. It is not meant to be medical advice and does not necessarily reflect the views of the Parkinson Society or the LiveWire Editorial committee. Readers should contact their doctors in all matter relating to health concerns and/or your medication.

The LiveWire Editorial committee is made up of volunteers Carolyn Jackson, Ron Penwarden and Ian Russell and staff member Sarah Roojee. The committee welcomes feedback on current and past issues as well as suggestions and submissions for future issues. Contact the Regional office at 416-227-3372 or 1-800-565-3000 ext 3372 or by email to livewire@parkinson.ca.

	Material required by
March Issue	January 23
June Issue	April 23
September Issue	July 23
December Issue	October 23

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Thank you for your support!

For more information call Sara Lawson @ 416-227-3377 or 1-800-565-3000 ext.3377

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