LiveWire

PARKINSON SOCIETY CENTRAL & NORTHERN ONTARIO

Summer/Fall 2010

Inside

This year, as Parkinson Society Canada celebrates 45 years of supporting Canadians with Parkinson's, we can proudly look back on some of our accomplishments in our four pillars—support, education, advocacy, and research.

Our proud tradition of funding Canadian-based research has made us the largest private sector funder of Parkinson's research in the country. In the past year alone, we invested over $1 million in 26 research projects.

We are making progress. Our researchers are gaining new insights into areas such as Parkinson's and pesticides (Dr. Shawn Hayley); swallowing and gum chewing (Dr. Mandar Jog); iron levels and other differences in the brains of people with Parkinson's (Dr. Alex Rauscher); loss of smell (Dr. Harold Robertson); and REM Sleep Behaviour Disorder (Dr. Ron Postuma).

These incremental steps move us closer to achieving our vision: A better life with a brighter future for Canadians living with Parkinson's today. A world without Parkinson's tomorrow.

Inside this issue, you will see examples of awareness and educational events that have gone on in the first half of this year across the province. Our staff members are hard at work on events still happening this year, and have already started plans for 2011!

Vision, Eye Movements, and Parkinson's

By Dr. Jason Barton

It is not uncommon for patients with Parkinson's disease to notice some problems with their eyes or vision. Fortunately, most of these are minor and can be treated with some simple approaches.

Dr. Jason Barton directs the clinical neuro-ophthalmology program at the University of British Columbia, the Human Vision and Eye Movement Laboratory, and the Canadian Neuro-ophthamology Website (www.neuroopthamology.ca). Dr. Barton received the 2005 Norman Geschwind award for research in behavioural neurology from the American Academy of Neurology.

One of the most frequent complaints reflects **dry eyes.** In parkinsonian conditions, this condition may be due in part to reduced blinking, which normally helps keep the ocular surface moist. Patients may note a burning sensation in the eyes, or a gritty feeling, as if sand was in their eyes. If uncomfortable enough, this may stimulate a pain reflex that causes the eye to tear, creating the paradoxical situation where patients with tears running down their cheeks are told they have dry eyes! Vision may blur intermittently as well, if the cornea dries out. Examination of the tear film or corneal surface by an optometrist or ophthalmologist using a slit lamp can easily confirm dry eyes. There are three treatment options: First, artificial tears can be used regularly through the day and when symptoms are bothersome. Second, if dry-eye symptoms are worse on awakening, then a protective ointment can be applied at bedtime. Both drops and ointments are available over-the-counter without a prescription, have few if any side effects, and don't cost much. Third, punctual plugs can be inserted to reduce the normal drainage of tears from the eyes to the nose.

The second most frequent complaint is difficulty with reading. Sometimes this is also due to dry eyes, as people blink less when they read. Other times, though, patients may notice a blurring or actual double vision, with the images side by side, either of which goes away if either eye is closed. This story immediately suggests **convergence insufficiency**. When we look at objects close to us, as when reading, our eyes normally cross slightly, so that both eyes are targeted at the same object or place on the page. In convergence insufficiency, the eyes do not cross enough: because the two eyes are pointing at different parts of the page, the words are blurred or doubled. Convergence insufficiency does not fluctuate or respond to medication. Rather, it can be treated by one of two simple physical methods: First, an eye specialist can put prisms into reading glasses that compensate for the misalignment. This is sometimes tricky to measure and get right, and the

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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 & Northern Ontario office 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.

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The Art of Living Well with Parkinson's Disease

Toronto Conference, October 30, 2010, at the BMO Financial Group, Institute for Learning

Our final conference of the year is coming up in the fall! Plan to join us to hear from Dr. Galit Kleiner-Fisman, Movement Disorder Specialist; Dr. Naomi Visanji, Parkinson's researcher; and Theresa Moore, RN, from the Markham Centre for Movement Disorders, on alternative and complementary therapies, driving and Parkinson's, and more!

Watch for registration flyers to be mailed in the Toronto area; find out information through your local support group; or visit www.parkinsoncno.ca

We reached attendance capacity quickly last year, so register early to be guaranteed a spot! Only $55 per person, including lunch and materials!

To RSVP, please call Elizabeth McCaw at

1-800-565-3000, ext. 3377, or 416-227-3377.

Do you live in Downtown Toronto?

As we continue to grow our regional support groups we have identified the need for a group in the Downtown Toronto area.

If you live in downtown Toronto, and would like information on this new support group, contact Elizabeth McCaw at 416-227-3377.

Support Group meetings will begin in September.

The LiveWire newsletter is published to provide people affected by Parkinson's in Central & Northern Ontario with helpful information. It is not meant to be medical advice and does not necessarily reflect the view of the Parkinson Society or the LiveWire Editorial Committee. Readers should contact their doctors in all matters relating to health concerns and/or medication.

The Editorial Committee is made up of volunteers and staff. The Committee welcomes feedback on current and past issues, as well as suggestions and submissions for future issues.

LiveWire is offered in both hardcopy and electronic form: **please let us know if you prefer to receive it electronically.**

Contact us at 416-227-3372 or 1-800-565-3000 ext. 3372 or email to livewire@parkinson.ca

Next submission deadline is October 15, 2010.

LIVING with Multiple System Atrophy (MSA) “With a Little Help from My Friends”

By Paul Walsh

When I went to the February 26 Rain concert in Toronto, I didn’t expect to come away with a theme song for coping with my degenerative neurological disease MSA. [Rain performs “A Tribute to the Beatles”—an anthology of the best Beatles music from 1964–1970.]

MSA is a rare, incurable brain disease that combines many symptoms of Parkinson’s and ALS, with cerebellar ataxia (e.g., feeling clumsy, dropping things, unable to balance without support) and autonomic failure (e.g., bladder problems, erectile dysfunction, constipation, cold hands and feet). MSA is so rare that many cases are wrongly diagnosed as Parkinson’s or other similar diseases.

2008 was a time of highs and lows. In March, I was skiing with my son in BC, and tackling the steepest slopes I could find. I had only one health concern—speech dysarthria—which I had had for three years. I had to speak slowly to articulate and be better understood. It was considered a neurological condition, but no diagnosis had been rendered.

In April, my wife wondered: “If Andy Barrie [a prominent CBC radio host with Parkinson’s] can benefit from dancing lessons, would singing lessons help your speech?” Despite my non-singing history, I began lessons, and within two months, people noticed a marked speech improvement! However, in May, I fell off my bicycle twice and my leg muscles started to become rigid.

After a thorough examination, my neurologist diagnosed MSA. I was so stunned that I don’t remember what she said about MSA. I do remember going home and Googling “Multiple System Atrophy.” What I read was not pretty, especially the predictive progression to wheelchair, bed-ridden, and death within 7–10 years. Speech dysarthria had been my presenting symptom. I was devastated. Thinking back, the relevant Beatles’ song was “Help!”

Help, you know I need someone, help.
… Won't you please, please help me?

That summer, I was preoccupied with several things that helped me ignore my new reality. Work, a trip to France to help our daughter prepare for the birth of her first child, and an Alaskan cruise with friends distracted me. I delighted in the birth of our first grandchild in August.

In September, I discovered and joined the Voices of Hope choir, whose members are mainly Parkinson’s patients and caregivers. The weekly practices and occasional concerts fed my newfound joy in singing and my spirit. So did a 10-day trip to Paris to see our new granddaughter.

Meanwhile I was experiencing a lot of pain, resulting in significant loss of sleep, and my risk of falling was increasing. Paul McCartney’s “Yesterday” echoed my feelings:

Yesterday, all my troubles seemed so far away.
Now it looks as though they're here to stay.
…Suddenly, I'm not half the man I used to be,
There's a shadow hanging over me,
Oh, yesterday came suddenly.

In 2008, the disease was managing me—it was time to change, to meet MSA head-on. I resolved to resume learning and playing duplicate bridge, and also took on a new consulting project. (I have retired from paid work now, but the bridge is going strong.) I discovered the value of water therapy via aquafit classes at a city pool. By Fall 2009, three aquafit classes per week stimulated my muscles, choir practice kept my voice happy and my spirits lifted, and duplicate bridge challenged my brain.

However, my speaking voice was deteriorating, so I returned to my speech pathologist, Bonnie Bereskin, with whom I had worked since my speech dysarthria had begun. Bonnie challenged me on two new fronts: to write about my experience in a blog and to consider forming a Communication Circle to intensify my speech therapy.

In December, I started my blog ‘LIVING with MSA’ (http://livingwithmsa.com/). I wanted to focus on things I could still do, rather than on my symptoms or what I had lost. Personal reflection was very new for me, but, strengthened by my faith and supported by the immense love surrounding me, I was motivated to reach out to others with MSA and their caregivers.

When a life-changing event impacts your quality of life, friends frequently ask, “What can I do?” Too often you have no answer—but the Communication Circle provided an opportunity. I emailed family and friends to ask for volunteers to spend 40 minutes with me every few weeks to coach me through specific speech exercises. The objectives were to improve my speech volume and articulation (via neuroplasticity concepts), and to ensure social interaction when communication and mobility issues might other-

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2010 PSCNO Volunteer Awards

On May 4, 2010, we held a Volunteer Tea, where we came together to celebrate all of the contributions of our volunteers. Our annual Volunteer Awards were presented, and it was so nice that all of the award winners could be present.

The Ian Davidson award is presented in recognition of individuals who have Parkinson's disease and have been role models in providing guidance and support that improved the lives of others living with Parkinson's in Central & Northern Ontario, and/or increased public understanding of their situation through such activities as leading support groups, public speaking, advocacy, volunteering, and fundraising. The 2010 award was presented to Margot Bartlett. Ian's daughter, Monica, attended once again to present the award in memory of her father.

L to R *Monica Davidson, Margot Bartlett, Debbie Davis, Robert McNutt*

The Derek Curwen Volunteer Award is presented in Derek's memory to volunteers who exemplify his fundraising expertise, ability to inspire and lead others, and whole-hearted support of Parkinson Society Central & Northern Ontario. The 2010 award was presented to John Scaini.

L to R *John Scaini, Debbie Davis, Stella Recchiuti*

Wednesday, April 21, 2010—Parkinson Society Opens the Market

Parkinson Society Central & Northern Ontario and event sponsor McLean Budden were honoured to open The Toronto Stock Exchange on Wednesday April 21, 2010. Before ringing the bell, Steven Bull, a journalism graduate, adventurer, and philanthropist, gave a keynote presentation of his journey up Mount Kilimanjaro and Mount Kenya. Founder of "Two Peaks, Two Causes" in honour of his late grandfathers (www.legacyclimb2010.com), this 28-year-old has climbed two of the world's tallest mountains to raise funds for two Canadian charities, one of which is Parkinson Society Canada.

The Marilyn Forbes Volunteer Award is presented in Marilyn's name to volunteers nominated by their peers who exemplify Marilyn's dedication to their chapter, support of people living with Parkinson's, and the work of Parkinson Society Central & Northern Ontario. The 2010 award was presented to A.B. Rustin.

L to R *Debbie Davis, A.B. Rustin;* ***Front*** *Mary Martin*

The Power of a Tulip—a True Story

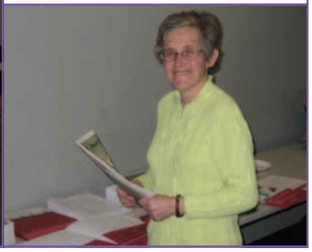
A young man came in to make a donation in memory of his father. He was given some tulips as a thank-you for his donation. On the way out of the building, the young man handed the tulips to a woman in the lobby and said, "These are some Tulips for Parkinson's."

The woman was in the building for a meeting elsewhere, but as it turned out, her mother had *just* been diagnosed with PD and was wondering where to start getting answers.

She stopped in at the CNO office to sit with staff, and obtain some information on Parkinson's disease—all because of a tulip and the generosity of a stranger!

Tulip-Powered Advocacy!

Seen below are some of the volunteers who put together tulip arrangements, which were delivered to all Ontario MPPs, to kick-off Parkinson's Awareness month in Ontario!



Wired for Success: Toward an Ontario Brain Strategy

By Kent Bassett-Spiers, Chair, Ontario Neurological Joint Working Group; and Shannon MacDonald, Director, Policy and Partnerships, NHCC

It is estimated that over three million Ontarians are currently living with a neurological, psychiatric, or developmental brain condition. These conditions are often progressive and affect every age and stage of life. At the same time, they create a significant and often catastrophic impact on the individuals with the condition, as well as on their families and caregivers. For all of society, the health, social, and economic costs of brain conditions are enormous, yet there has been no cohesive and integrated strategy for addressing these impacts across Ontario to date.

In 2009, Neurological Health Charities Canada (NHCC), a group representing neurological charities, and a division of the Ontario Ministry of Health and Long-Term Care (MOHLTC), came together in a spirit of mutual cooperation to identify ways to address these issues and create the first steps in an Ontario Brain Strategy.

Although there have been many examples of governments working together with charities and organizations to address issues, the opportunity for NHCC and the MOHLTC to work together from the start has been viewed by some to be a relatively unique partnership. It is clear that the working arrangement is proving to be a very successful pairing of expertise and skill. It has resulted in some strong and forward-thinking outcomes. Although the diversity of brain conditions is clear, what may not be as obvious are the commonalities that bind them together. At the root is their relationship to the brain—the most complex, and, to many, the most important organ of the body.

Each distinct condition also has in common a dependency on a large and complex health and social system of generalized knowledge and services. While the bodies of knowledge and expertise vary for each condition, system design prerequisites are often either similar or identical for most conditions. A third commonality among neurological conditions are the social consequences of experiencing a profound change in how one is engaged in society and can participate as a valued citizen. People with brain conditions are challenged on a daily basis to find ways to ensure that these basic opportunities are realized. To address these commonalities and the needs of our collective communities, the Ministry and NHCC developed a joint-planning process that involved broad consultation with experts and stakeholders, literature reviews, background data collection, and a formal long-range scenario planning process that identified key themes.

Wired for Success: Toward an Ontario Brain Strategy is an important first step in developing an integrated approach to addressing these important issues. Five dominant themes emerged from this consultative work. People expressed a need for having the following:

Personal choice

- Direct control of decisions regarding medical care, social supports, and shaping their living environment

An inclusive culture

- An Ontario that has a focus on health over illness
- Reduced stigma achieved by shifting public values and attitudes
- Employment opportunities and flexible work arrangements

Enabling technology

- Assisted living technologies to enable better living
- Smart homes, accessible education and workplaces
- Flexible transportation systems

Supported caregivers

- Whose role is valued
- Who are supported sufficiently to maintain their own health and financial stability

Shared knowledge

- Commitment to research and to moving evidence into practice
- Reliable medical and decision support information
- An engaged online community

Secondary themes also emerged, including integrating systems, designing the built environment, engaging the private sector, and taxing and funding.

Living well with a brain condition in Ontario is much more than a "health" issue. It requires the active engagement of the private sector, non-profit sector, and key government ministries, including the following: Finance, Health Promotion, Education, Community and Social Service, Child and Youth Services, Municipal Affairs and Housing, Labour, Research and Innovation, and Transportation. In short, it requires a thoughtful response from government, industry, and the non-profit sector that addresses all aspects of an individual's life: family relationships, education, income, employment, housing, and social participation.

NHCC and the Ministry will continue this work to examine these dominant themes, conduct a broad consultation across key stakeholders to generate support and feedback, and, through a prioritization process, identify areas of opportunity that will

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Wired for Success, Continued from pg 5

allow breakthrough solutions to be developed, implemented, and sustained.

The evaluation of our success will not rest with the completion of this report but, more importantly, with the work we can accomplish for Ontarians living with a brain condition. It is for them, along with their families, that this work is necessary. It is for them that our collective efforts now, and into the future, are so important.

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Debbie Davis, CEO of Parkinson Society Central & Northern Ontario, is part of the NHCC committee.

For more information on the work of NHCC, please contact Debbie at

1-800-565-3000 ext. 3373 or

debbie.davis@parkinson.ca

NeXus I, II, and III Rollators—Association with Falls and Serious Injury

Dana Douglas Inc. has initiated a voluntary recall of certain neXus I, II, and III rollators, which may break during use, resulting in the user falling and suffering serious injury including bruising, broken bones, or death.

Any cases of serious or unexpected adverse incidents in patients using Medical Devices should be reported to Health Products and Food Branch Inspectorate.

http://www.hc-sc.gc.ca/dhp-mps/medeff/advisories-avis/public/_2010/nexus_pc-cp-eng.php

THE ALEXANDER TECHNIQUE AS A TOOL FOR MANAGING PD

For many people, the onset of Parkinson's means a gradual process of learning to live within limitations. While medication and conventional treatment have much to offer in managing symptoms, the progress of the disease often leads people to seek out additional strategies for maintaining freedom and autonomy in their everyday lives.

The Alexander Technique is a process through which people learn to use their bodies more efficiently. It is not exercise-based—rather, it teaches people to pay attention to their movement habits in simple, everyday activities like standing, sitting, and walking. By reorganizing the way a person approaches these tasks, the wear and tear on the nervous system decreases, resulting in greater ease and comfort, both at rest and in movement.

In 2002, a study was published in the *Journal of Clinical Rehabilitation* on the effect of lessons in the Alexander Technique on idiopathic Parkinson's disease. Those who received lessons in the Alexander Technique alongside normal treatment were better able to perform everyday activities, both at best and worst times of day. The study was investigating not only the physical benefits of the Technique, but also whether it had any bearing on a person's attitude toward the disease. Again, those who received lessons in the Technique reported lower incidence of depression, and a more positive outlook overall.

This study was first brought to my attention by a woman recently diagnosed with Parkinson's. Her main interest in pursuing lessons was to try and diminish the amount of shaking that she was experiencing as a result of the disease. She was finding it particularly troublesome in social situations. After working together for a few months, and by putting the principles of the Technique into practice, we were able to quiet her shaking within the lessons. A few months later, she reported that she was increasingly able to reproduce this effect on her own. At her annual physical that year, her doctor reported that she had "grown" an inch; in essence, we had reversed some of the stooping that often accompanies the disease.

Since that time, I've worked with a number of people at different stages of their journey with PD. Every case of PD is different, but among the Parkinson's sufferers I've worked with, I've witnessed improvements as varied as a decrease in stiffness, improvement in walking, greater facial expressivity, and increased vocal resonance. So far, none of the cases I've worked with have failed to show marked improvement.

"I feel more like myself," says a man who sought out the Technique to help him address some of the symptoms of early-onset Parkinson's. "Sometimes I feel stuck in my body, and practising what we work with in the lessons helps me to move better. I'm much more flexible than I was before I started lessons."

In 2006, the National Institute for Clinical Excellence (NICE), an NGO in Great Britain that periodically reviews the research on major diseases, included the Alexander Technique in its recommendations for treating Parkinson's. They honed in on research demonstrating that people with Parkinson's who were having Alexander lessons tended to increase their medication less, *because their symptoms did not worsen.* In its Clinical Guidelines, NICE stated that "the Alexander Technique may be offered to benefit people with PD by helping them to (...) affect both the physical nature of the condition and the person's attitudes to having PD."

Although it doesn't offer a cure, the Alexander Technique can be invaluable in managing the symptoms of a challenging disease, and helping people continue with life as they know it to the greatest possible degree.

Tanya Bénard is a Certified Teacher of the Alexander Technique practising in Toronto. She maintains a private practice, in which she has worked with a number of people with Parkinson's. Tanya is also a frequent presenter on the Technique in a wide range of settings, from small support groups to large national conferences. In addition, she created an Alexander Technique programme for the Royal Conservatory of Music, which she currently teaches. For more information (including a link to the above mentioned research related to PD), please see www.alexandertech.ca © Tanya Bénard, 2010. ***Tanya will be conducting a workshop on the Alexander Technique at this year's Toronto conference.***

Hope in Bloom Campaign Blooms to New Heights!

The 2010 Hope in Bloom campaign had two goals; to increase the awareness of Parkinson's disease and to raise funds for Parkinson Society Central & Northern Ontario. We are happy to report that we did just that! Over 81,000 tulip stems were sold across our region. Throughout April, Parkinson Society Central & Northern Ontario took over malls, local businesses, and major corporate office buildings raising $120,000 to benefit support services, research, advocacy, and education for people living with Parkinson's in our region. Our Community Development Coordinators worked tirelessly to organize and support each district's local volunteers. This campaign is not possible without the dedicated volunteers who devote their April each year to promote the Society and sell a tulip or two.

Community Development Coordinators: West—Karen Dowell, Toronto/East—Elizabeth McCaw & Nada Loughead, York/Simcoe—Jon Collins, and North—Sandra Willock

District Tulip Wrap-Up

GREATER TORONTO AREA—What a year! Hope in Bloom volunteers came together to sell tulips at 24 major GTA venues this year. Union Station remains the largest one-day sale raising over $9,500 and selling over 1,700 tulips in a single day. The GTA venue campaign would not be possible without the amazing volunteer base. This year's venue captains/support staff were Robert McNutt, Jim Long, Noreen Searson, Helen Cox, Cathy Graham, Marg/Don Turner, Derek Quin, Steve Plumley, Saghi Samino, Nota Bountis, Sara Lawson, Brian Rogers, Shane Curry, Mary Inniss, Kathy Raponi, Jim Lynge, and the over 50 additional volunteers participating in the campaign.

EAST—Our East District chapters have continued their commitment to the Hope in Bloom campaign again this year. Durham Region, Peterborough/Kawartha Lakes and Kingston all increased their campaigns in 2010 making the "East" the second largest fundraising district in Central and Northern Ontario. The Northumberland chapter, under the fundraising direction of Andy Haynes, outdid themselves again, reaching new heights in community fundraising! Andy had this to say about their efforts: "This year's Hope in Bloom campaign was our most successful yet. In 10 years, sales have increased every year. This year we sold almost $18,000. The potted tulips were increased from 600 to 900 pots and we still did not have enough to satisfy demand. This brings the total amount raised over the last 10 years to over $150,000. All of these proceeds are used to further Central and Northern Ontario and chapter activities."

WEST—Sales in the west were up overall and a special thank-you goes out to Bert Kamphuis of the Brampton Support Group for heading up the sale for over 10 years. The Georgetown group were sold out by noon again for the sixth consecutive year. The tulips were a hit at the annual education evening at Royal Botanical Gardens. Next year, the Guelph group will visit some retirement homes in the area.

YORK/SIMCOE—The Hope in Bloom campaign made its first major foray into the York-Simcoe region and had some great success. With venue sales in two major malls and a central hospital, along with targeted fundraising in the City of Vaughan and surrounding areas, we had significant success.

Special thanks to our tulip captains at Upper Canada Mall, Georgian Mall, and Markham Stouffville-Hospital, and to our Barrie and North Simcoe chapters that each made a contribution.

Additionally, we had three individual fundraisers in the district that had different approaches but all had great success. Thank you to John Scaini for managing four venues, to Maria D'Andrea whose database of supporters and energy for the campaign seems never-ending, and to Lara Duffy who continues to support each and every fundraiser we offer.

NORTH BAY—Pre-selling is the key! The North Bay Support Group doubled their order this year from last year. Not many tulips made it to the Northgate Mall, but many thanks to the Support Group members who were pleased to provide aware-

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Around the Region—For more information on support groups in your area, please contact 1-800-565-3000 ext. 3372.

West District

Mayor Susan Fennell of **Brampton** declared April as Parkinson's Awareness Month at the March 30 Council meeting, and 12 group members were on hand as Rogers Cable captured the event (above). Next meeting is September 28 at 1:30 p.m. at Holland Christian Homes.

Etobicoke Support Group members had their wrap-up BBQ on June 9 and were pleased to meet Matthew Okell who will cycle across Canada this summer to raise funds for Parkinson's research. Follow his progress at www.livelifeoutdoors.ca

Chris Young and Margaret Swain were honoured at the June meeting for their outstanding service to the **Guelph** chapter. Several members of the group have offered to play a role as the group moves forward.

The **Mississauga** Support Group they distributed 300 bookmarks to the local libraries, attended the City of Mississauga Health Fair, sold fresh-cut tulips at Humbertown mall, and attended Hope on Display at the Origin Evergreen Retirement Community where they meet. Pictured is resident and group member Mavis Floyd playing piano at the event (right).

The **Niagara** Chapter hosted a talk on May 1 by Dr. John Adams with 90 people in attendance. The highlight was Dr. Adams answering everyone's questions.

Central District

Barrie Chapter

In the first five months of the year, we've had a lot of activity. We started the year with a presentation from Revenue Canada's regional director, who fully discussed and answered all questions on medical and disability tax information.

In March, we had a visit and presentation from Lynda & Jim MacKenzie. Lynda is an outstanding example of the power of positive thinking as she walks you through her 23-year journey with PD. Have Lynda and Jim visit your chapter—it's a great experience!

Also in March, Rogers Cable TV station in Barrie interviewed Jon Collins. Jon talked about April being Parkinson's Awareness Month.

In April, Sandie Jones visited, speaking of positive people. She is always informative with a great attitude.

The Cut-a-thon in April raised $2900. Our sincere thanks to Sandra Mikulski for her great effort.

In April, our chapter's prayers and thoughts were with Mavis and Bruce Warren, as Bruce underwent Deep Brain Stimulation surgery, which was successful—fantastic, Bruce!

In May we had an education session and a Hope On Display evening with Dr. Mark Guttman, an outstanding PD specialist along with Sheri Corkum, Occupational Therapist both from the Markham Centre for Movement Disorders. Also, the Barrie Tai Chi group did a demonstration, explaining the benefit of this type of exercise. This event was well attended, with 150 from the Georgian Bay area.

Collingwood Support Group

Once again, our annual Cut-a-thon proved to be a big success with many returning customers. Business was brisk; there was a lot of activity, laughter, goodies, and stunning transformations throughout the day.

Terrific news was received at our May meeting. A representative from The Order of the Eastern Star visited and advised us that Parkinson Society Canada will be the recipient (via our local chapter) of the proceeds of their upcoming year's fundraising activities!

Sandie Jones visited us for our June meeting for a question-and-answer period, primarily about medications: always an area of considerable interest.

North Simcoe Chapter

Our members look forward to four annual events, two social and two fundraising: Lawn Bowling in June, both our Potluck Dinner and Tag Day in August, and our SuperWalk in September.

Peterborough Chapter

Bill and Vivian Heinmiller had a "Plants for Parkinson's" sale at their home at the end of May and raised over $2,000 for SuperWalk. They would like to thank Don and Marg Turner for donating plants from their Toronto garden for the sale. Several members of a Toronto electro-funk orchestra, *A.M.,* which their son, Andrew, belongs to, entertained on the lawn during the sale. That evening, 10 members of the group raised $500 at the Montreal House Pub for the Peterborough chapter.

Hope in Bloom, continued from pg. 7

ness and education in the Mall for the day. We are grateful to Wal-Mart for graciously providing a television to play our educational DVD. Special thanks to Bev and Ralph Stapley, who stored the tulip deliveries, and to Jack Latourneau, who single-handedly sold 103 fresh bunches and 34 potted plants, mostly to scores of wonderful employees of the Ontario Northland Rail. Those employees even asked for more after the sell-out: bless their hearts! Nigel Wood, Support Group Facilitator, very much appreciated totally-free awareness and tulip sales advertising through these media events: 1) Julie Perry at the North Bay Nugget provided a full page "red-tulips" colour ad; 2) Linda Holmes at CTV interviewed Nigel for an hour in his home and featured the edit as a special on the CTV news; and 3) John Intof, at CJTK, 103 FM, also aired an interesting 10-minute interview with Nigel.

SUDBURY—Peter Higham, Sudbury Chapter President, skilfully acquired no-charge full-page tulip sales advertising in *The Sudbury Star*, while in the *Northern Life*, member Nora Lea Arcand wrote of "Three Learning Opportunities," and Denise Maki, Certified Kinesiologist and Parkinson Mobility Group leader, contributed "Exercise & Parkinson's Disease —Opposites Attract." Grade 8 Entrepreneur Emmah Cacciotti, granddaughter of Support Group members Art and Donna Connor, enhanced slow Sudbury tulip sales; she painted twin tulips with the words "Together Standing Tall" and "Parkinson's" and then "fired" all that paint onto 53 attractive glass mugs. With her grandparents' donation of the mugs and Emmah's donation of obvious talent and meticulous labour, the mugs easily sold at $8 each. Emmah's profit for this school project was on paper only! Special thanks to the many chapter members who willingly and graciously manned the awareness and tulip sales table at the New Sudbury Shopping Centre, and especially to Chris Sheridan, who volunteered and bought so many tulips. The chapter is exceedingly grateful to Brenda Leclair, who single-handedly prevented a sales project loss by selling many bunches of not-the-freshest tulips to the wonderful employees of Sudbury Regional Hospital Dialysis Unit. Unsold potted tulips were delivered as thank-you gifts to organizations and businesses that support Parkinson's, as well as to some of the chapter members who were "under the weather" at the time.

Passing of a Friend

Stanley Fujarczuk was a long-time supporter of Parkinson Society Central & Northern Ontario through the Parkinson's Golf Classic. He and his family organized the annual event and have raised over $150,000 to date. Stan passed away on May 19.

Family and friends braved the cold and rain on June 9 to honour his memory and raise funds for the cause he championed. Many players had taken part since the event started 14 years ago. That is the kind of commitment he inspired.

Stan will be missed.

Cut-a-thon raises $12,000 in Central & Northern Ontario

Cut-a-thon for Parkinson's is one of Parkinson Society Central & Northern Ontario's most anticipated annual events. This year, Cut-a-thons were held in four locations across the region including Barrie, Collingwood, Guelph, and Toronto.

Thank you to all of our supporting salons and their participating stylists:

Barrie

ABSTRACT the salon

Audies Hair Design

Envision Hair Studio

Giovanni & Perri

Hairscape

i.d. Salon

Shapes Hair Studio

Shear Illusions Hair Design

Hosted by The Barrie College of Hair & Esthetics

Collingwood

Headlines Salon

L'Attitudes Studio

Strands Salon &Spa

Waves Hairstyling

Guelph

Aqua Hair Salon

Apple Hair Salon

Eros Hair Studio

Salon Gii

Toronto

Paul Pecorella Hair Salon & Spa

Robin Barker Hair'Sociates

Salon Intrigue

Thank you to our key sponsor, **JOICO,** who provided fabulous gift bags to all participants and salon stylists, and to **PIZZA NOVA,** who generously donated pizzas to feed the Toronto stylists!

Hope on Display

Hope on Display is in its fourth year and this April, a new show was held in Mississauga at Origin Evergreen Retirement Community in their lovely art studio. We had live music by Mavis Floyd on piano and Dave Sanderson on one of his handmade guitars, and work on display from three artists.

Debbie Lecavalier, pictured, was one of six artists who shared their paintings, wire sculpture, jewellery, etc., at the YMCA in Oakville again. Hope on Display is an opportunity for the artists to share not only their work, but the story of their journey with Parkinson's disease and how it inspires or challenges their creativity. Thank you all for sharing your work.

Garden of Hope

Tulip bulbs can be ordered now for delivery in early September. Consider purchasing 100 bulbs to receive a free Garden of Hope sign as pictured here.

We have the "Parkinson" tulip, which is red with white tips, as well as limited quantities of yellow or white tulips. They are $6 for a bag of 10 or $50 for a bulk box of 100. Shipping costs may apply. Contact your local chapter or Community Development Coordinator for more information. Call 1-800-565-3000 and ask for Karen (west), Elizabeth (Toronto and east), or Amanda (York Simcoe).

Education Events and Conferences

1,300+ people attended one of our education events and conferences so far this year. For some, it was the first time to hear from an expert in the field of Parkinson's, and for others, it was new insight into the disease they have lived with for years.

Thank you again to all our speakers, for generously giving of their time and their expertise with us!

Paul Passmore of the Niagara chapter, with Sandie Jones, and Dr. John Adams

Attendees at the North Bay Conference at a session presented by Dr. Fox

Dr. Mark Guttman and Dr. Mandar Jog shared their views with 400+ attendees at RBG.

For more on our education events this year, please see page 11.

Vision, continued from Pg. 1

prisms may only work for a short time, if the misalignment gradually worsens, which it can. The other treatment method is to simply patch one eye (it doesn't matter which one) when reading.

In some other parkinsonian conditions, there can be other eye problems. In progressive supranuclear palsy (PSP), a condition first described by Toronto neurologists in the 1960s, patients have problems moving their eyes up and down (**vertical gaze palsy**), but not sideways. This can create another type of difficulty with reading, since we tend to hold books down on our lap or on a desk surface. To deal with this, it can help to move reading material higher or to put prisms in reading glasses, so that patients do not have to move their eyes as far down to see down. Problems looking down can cause difficulty with other tasks, such as going down stairs or eating meals.

Progressive supranuclear palsy is often accompanied by frequent small eye movements that interrupt steady gaze (**square wave jerks**). The more of these unwanted movements, the slower reading becomes. Unfortunately, there is no known way to reduce square wave jerks, with the exception that deep brain stimulation of the subthalamic nuclei can reduce these in a few patients.

The treatments for Parkinson's disease can also have effects on the eyes. Patients with advanced disease and who are taking Sinemet may notice that during their "on" phases (when the medication is working), they have unwanted movements of their head, arms, or legs—so-called drug-induced dyskinesia. Similarly about 15 percent may have brief upward or sideward deviations of their eyes (**ocular dyskinesia**). Although having one's eyes roving in an unwanted manner can obviously disrupt visual processing, patients don't tend to complain of these movements, perhaps because they are more focused on the unwanted movements of their limbs or head. Presumably, these movements might respond to the same treatment strategies as limb dyskinesia. Last, some patients with sub-thalamic stimulators may notice sustained deviation of their eyes to the side opposite the stimulator that is turned on, which ceases when the stimulator is turned off.

Most of the visual symptoms discussed to this point reflect problems with eye movements, which is not surprising given the predominantly motor manifestations of Parkinson's disease. However, there is interest in whether deficiencies in dopamine may also be reflected in sensory disturbances. Dopamine is a neurotransmitter that is used by some cells in the retina, and research has suggested that there may be subtle problems with retinal function. It has been argued that this can reduce visual acuity above and beyond the natural changes in acuity with aging, and possibly also interfere with functions like contrast sensitivity (the ability to appreciate subtle changes in brightness) and colour vision. There are even some suggestions that there may be problems with the function of brain regions involved in visual processing, which may lead to problems with sophisticated processes like remembering faces, recognizing facial expressions, or orienting in the environment. Overall, though, these sensory deficits are still subject to debate and if present, may not be evident until the disease is advanced. In general, they are more experimental curiosities of theoretical interest to neuroscientists than likely sources of difficulties in daily life for patients.

The above article was written and submitted by Jason J S Barton, MD, PhD, FRCPC; Director, Clinical Neuro-ophthalmology; Canada Research Chair and Professor of Neurology, Ophthalmology and Visual Sciences; Psychology; University of British Columbia.

Originally printed in Parkinson's Update *magazine, issue 50.*

Living with MSA, continued from Pg. 3

wise cause me to withdraw.

I received 30 "count me in" responses! Family and friends told me that it was a "win-win" to learn about speech therapy concepts and help me at the same time. Bonnie trained all volunteers in an energized evening in our new condominium—no stairs! Now, after three months of intensive, repetitive speech therapy (four sessions per week), my voice is definitely stronger and, I'm told, more articulate. The generosity of my friends and family has gone way beyond speech coaching, and I continue to be surprised by offers to drive me to classes and appointments or just enjoy time together.

So where am I now? Well, I've "graduated" from my cane to a walker to increase my stability (and reduce falls), and MSA continues its inexorable march. You might say that my body is hopelessly "out of tune." But somehow I'm hopeful. Why? I finally get to my new theme song:

What would you think if I sang out of tune,
Would you stand up and walk out on me?
…Oh I get by with a little help from my friends,
I'm gonna try with a little help from my friends.

Certainly no one has "walked out on me," and I intend to beat the MSA longevity odds with my proactive endeavours, with the love that surrounds me, and "with a little help from my friends." Quoting from my 65th birthday card sent by a dear friend, "Attitude is everything!"

Paul Walsh is a brand new senior citizen who has only just discovered the joy of writing out of personal reflection. His writing is informed by the experience of coping with a neurodegenerative disease (Multiple System Atrophy—MSA) and also by the love and support of close friends and family. Prior to his retirement, Paul focused on technical writing and training as an IT consultant for the final third of a widely varying work career.

Highlights of the Spring, 2010, Educational Events

In all, over 1,300 people living with Parkinson's, carepartners, and healthcare professionals attended educational events and sessions in April and May across central and northern Ontario.

The Barrie Educational Session and Hope on Display had 160 people in attendance to hear two presenters from the Markham Centre for Movement Disorders. Dr. Mark Guttman presented an update on Parkinson's, and Occupational Therapist Sheri Corkum gave a presentation entitled *Buttons, Buckles & Bows: Practical Tips for Activities of Daily Living*. There was a Tai Chi demonstration, and a screening of *Impoverished Places*—a look at struggles with Parkinson's through dance—preceded the education session.

The Royal Botanical Gardens Education Session in Burlington had over 400 people in attendance as Dr. Jog and Dr. Guttman each shared their individual thoughts on hot topics such as *Stem cells are/are not the future of Parkinson's disease.*

The Belleville Education Session had 175 people attending this all-day conference with a focus on *Life After Diagnosis*, featuring four speakers including keynote speaker Dr. Stuart Reid from the Kingston Movement Disorder Clinic; a motivational speaker living with young onset Parkinson's, from Halifax; a family doctor also living with young onset Parkinson's, sharing her experiences; and a lawyer discussing future planning.

The Niagara Education Session had 90 people in attendance to hear Dr. John Adams from the Markham Centre for Movement Disorders.

Special thanks to our corporate supporters Teva Canada Innovation and Novartis Canada for helping to cover costs for these impactful events.

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Increasing Awareness and Access in Northern Ontario

The North Bay Conference had 175 people in attendance for this all-day event sponsored by The Boedecker Foundation. In the morning, Dr. Fox, a Movement Disorder Specialist from Toronto Western Hospital, spoke and answered questions. In the afternoon, there were three sessions: a physiotherapist, a speech language pathologist, and a break-out session for care-partners.

Sandie Jones, a Registered Nurse from Parkinson Society Central & Northern Ontario, presented 40 sessions to 363 health care professionals, both medical and nonmedical, about the complexity of issues in dealing with the treatment and management of Parkinson's disease, thus improving the quality of life for people living with this chronic, progressive disease.

The Boedecker Foundation looks to *inspire, impact, and improve* in all of their partnerships. Funding will be also used to increase access through technology by providing DVDs to those in the area who could not attend, as well as exploring how video conferencing can increase access to educational sessions in more remote regions.

boe

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If you are interested in planning an event with proceeds benefiting Parkinson Society Central & Northern Ontario, please contact us at 1-800-565-3000 ext. 3301, or 416-227-1200, or by email at info.cno@parkinson.ca

☑ ***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 Canada) or ☐VISA ☐Mastercard ☐Amex

Please complete the following information:

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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).

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☐I would like to receive The Legacy, a free newsletter on financial and estate planning

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 $20 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 prefer not to have your name traded, please tick here: ☐

LF10C

CNO staff at their team day —June 2010

Front row L to R: Sandie, Lorelei, Amanda
Middle row L to R: Karen, Debbie, Robert, Elizabeth
Back row L to R: Louise, Melissa, Jon, Stella

The CNO team welcomes back Amanda Stanton from her maternity leave. We are also happy to keep Jon Collins, who had been standing in for Amanda on contract for the past year. Jon will be working with Melissa for a few months on SuperWalk, and then in the fall will join Client and Education services, where he will be developing and rolling out *Get It On Time!*, which is a new education program geared toward front-line health-care staff on the importance of PD medications (more on *Get It On Time!* in the next issue of LiveWire).

Sadly, we say goodbye to Nada Loughead. Nada had a uniquely funded position, working part-time for Parkinson Society, ALS, and Huntington's. Nada has relocated in the province, and accepted a full-time position with ALS Ontario, where we know she will bring the same enthusiasm she gave to our team. Good luck, Nada!

We also say goodbye and thanks to Sandra Willock for her extraordinary performance on the CNO team. Sandra took on a short-term contract with us, covering a leave of absence. Sandra brought a unique perspective to the work done in northern Ontario, and made a memorable contribution to our successful northern Ontario conference.

Parkinson SuperWalk 2010

Don't forget to register for Parkinson SuperWalk 2010! This year, Parkinson Society Central & Northern Ontario is hoping to raise $900,000 for research, education, support services, and advocacy. Help us reach our goal by registering online at www.parkinsonsuperwalk.ca

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