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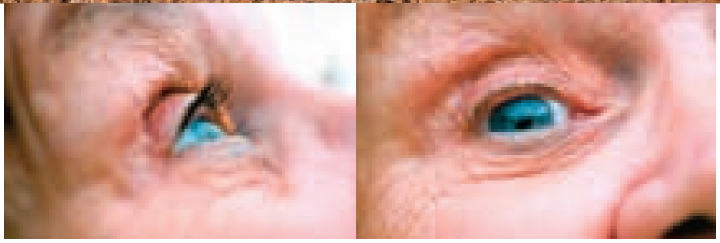
DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

celebrating 30 years of serving all dystonia-affected persons

Dystonia Canada

A Newsletter of the Dystonia Medical Research Foundation Canada

Winter 2006



Dorothy Klassen *can again see the distant prairie horizon. Health Sciences Centre (HSC) Winnipeg's Dr. Jerry Krcek performed stereotactic surgery to implant stimulators that now keep Dorothy's blue eyes open and the dystonia in check. (Turn to page 3…"Seeing Is Believing")*

** Photo Courtesy of Health Sciences Centre (HSC)-Winnipeg*

DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

The Dystonia Medical Research Foundation Canada is a non-profit health organization founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. It is dedicated to serving people with dystonia, a neurological movement disorder. The Foundation's headquarters resides in Chicago, Illinois with the Canadian office serving as its sister organization—sharing the same mission in advancing dystonia research for more effective treatments and ultimately a cure; promoting awareness and education; and, supporting all dystonia-affected individuals and their families.

Dystonia Medical Research Foundation Canada Board of Directors

Canadian Donations should be sent to:
Dystonia Medical Research Foundation Canada
8 King St. East, Suite 106
Toronto, ON M5C 1B5
English Line: 416-488-6974 or 800-361-8061
French Line: 800-787-1015
Fax: 416-488-5878
Email: info@dystoniacanada.org
www.dystonia-foundation.org

A Message From The National Director

Seasons greetings, to all. The holidays are here, and we turn our attention to celebrating with family and friends. While much support comes from close family and neighbours who have come to understand the daily challenges of living with dystonia, I realize that many people feel alone in their battle with this disease, particularly at this time of year. This is where it is increasingly important to maintain hope. Of course, what we all want more than anything is a cure, but while we wait for that, I hope we find a way to ease the burdens of daily living for all those experiencing pain and discomfort.

Canadians with dystonia and their families continually rank educating the wider community as one of the top ways to keep hope alive and improve their quality of life-just behind finding a cure and improving access to supports and services.

Imagine what might happen if government and corporate decision-makers really understood the complexity of issues facing Canadians with dystonia and their families? What kind of investment would they make in research for a cure and better treatments? How would policy change if they knew what we know? What could that mean for the dystonia community in Canada and the world?

Advocating for change is a key focus for DMRFC and for this *Dystonia Canada* issue. Inside you will read about the progress we have made as a result of our advocacy efforts on Parliament Hill. You will read about one persistent man who took it upon himself to educate folks who process Canada Pension Plan Disability applications, and won his appeal case because of it. And, you will read about ways people are stepping up to become leaders in their community to support others with dystonia.

I appreciate the loyalty, dedication and the sacrifices that so many of you make to keep this organization going and growing. As we continue to build understanding and support, the tiny glimmers of hope will one day appear to be one giant leap in finding a cure.

On behalf of DMRFC, I wish you all a hopeful year filled with peace, prosperity and happiness.

Sarah Smith
National Director

*** Special Note:** In the *Dystonia Canada* Summer Issue, DMRFC extended its deepest condolences to the Mintz Family for the loss of their daughter, Julie. Furthest from the truth, Julie is alive and well. Please accept our heartfelt apologies for this administrative error. We are so very sorry for any pain--emotional or otherwise--that may have resulted from this misprint.

Seeing is Believing

The thought of undergoing this type of surgery didn't scare her.

"I wasn't nervous," says Dorothy Klassen, one of few people in the world to have Deep Brain Stimulation to relieve her Meige's syndrome – blepharospasm combined with oromandibular dystonia. "I just wanted to be rid of these symptoms. What have I got to lose?"

Dorothy, a Manitoba native, was diagnosed with craniofacial dystonia in 1991, and for years, her symptoms forced her to slowly withdraw from her life.

"Each day, my eyes would close longer and longer," ultimately rendering her functionally blind, she says. Dorothy also experienced extreme twitching; she couldn't straighten her neck or control her jaw, became tired easily.

"It got to the point where I didn't want to go anywhere," she says. "I couldn't go shopping because I kept bumping into people. It was a very frustrating life."

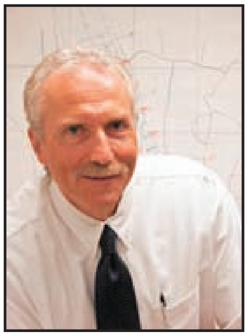
Dorothy and Peter Klassen Post DBS surgery

For 10 years, she relied on Botox® treatments, until her body began to reject the drug. It was then suggested she was a candidate for Deep Brain Stimulation (DBS), a procedure where three-dimensional coordinates are used to locate the point (or points) in the brain that are triggering the condition.

Having seen videos of the effects DBS had on other patients, Dorothy felt this was the right choice for her.

"This is how we at Health Sciences Centre (HSC) Winnipeg came to know Dorothy," explains neurosurgeon Jerry Krcek, Ph.D; M.D.

Krcek and his team found one other case in the world like Dorothy's, where DBS was performed on a patient with craniofacial dystonia. In that case, in Germany, only one side of the brain was operated on at a time. In Dorothy's case, both sides were done at once.



Dr. Jerry Krcek is HSC Winnipeg's stereotactic neurosurgeon.

The vast majority of people treated with DBS have generalized or segmental dystonia. But Krcek thought that the surgery might be successful for Dorothy.

Like all patients who undergo DBS, Dorothy lay awake on the operating table while Krcek and his team stimulated areas of her brain. It wasn't until post-surgery though, when the battery pack inserted under her skin, just below her collarbone, was programmed, they realized the extreme success of the operation.

"It was amazing," says Krcek. "In Dorothy, it was like a light switch went off. We got it right away."

Today, more than a year and a half after the surgery, Dorothy leads a normal life. She has regained her independence and with her battery pack, has deemed herself a "bionic woman."

Krcek presented Dorothy's case at the Canadian Conference of Neuroscience this year, and his team is working to write up her case for publication.

For Dorothy, she is thrilled with the outcome and hopes her story is an inspiration to others. "I found it very difficult to go on with my life, but now that I have had the operation, I feel like a different person," she says. Many people with different forms of dystonia are not good candidates for DBS. But Dorothy says she "would recommend it to anyone who is a candidate."

Manitoba Opens New Movement Disorder Clinic

Education and patient care are the priorities at a new multi-disciplinary Movement Disorder Clinic that opened in Winnipeg this summer.

The new facility, housed in a heritage building in Deer Creek Lodge, will implement group educational sessions for patients, work to educate a variety of healthcare professionals as well as assist with various support groups.

The area this new clinic will serve is vast and includes Manitoba, Eastern Saskatchewan, Northwestern Ontario, Northwest Territories and Nunavut.

The Clinic focuses its practice and research mainly on dystonia, Huntington's disease and Parkinson's disease. Parkinson patients make up to approximately 60 per cent of the Clinic's patient population. The Clinic also caters to general neurology patients.

L-R: Neil Fast, Board Chair WRHA, Keith Penhall, Board Chair Deer Lodge Foundation, Dr. Douglas Hobson, Premier, Gary Doer, Premier of Manitoba, Bonnie Korzeniowski, MLA St., James Winnipeg, Dr. Brian Postl, CEO President WRHA, Réal Cloutier, COO Deer Lodge Centre

The staff includes Movement Disorder Specialist, Doug Hobson, M.D.; Neurosurgeon Jerry Krcek, Ph.D; M.D; Neurologist Andrew Borys, M.D.; and Neuropsychologist Dr. Andrea Kilgour, as well as a team of nurses, nurse clinicians, research co-ordinators, social workers and administrators.

The team is also looking to add a physiotherapist, occupational therapist, speech therapist, dietitian and geriatrician in the near future.

Spotlight on the West

Revitalization and growth around dystonia support and awareness continues to build in Western Canada. Please meet some of the people who are making a difference and see how you can join them in their pursuits.

Dorothea Gensch

Diagnosed with cervical dystonia just one year ago, Dorothea is eager to make a contribution to the dystonia cause.

A lifelong learner, Dorothea completed courses in fundraising and philanthropy, as well as marketing and public relations. These programs have provided her with the knowledge to raise awareness – and money – for dystonia research and programs.

She has also previously contributed to advancing the goals of other non-profit organizations, including the United Way and Canadian Cancer Society. “I find it very rewarding to help others,” she says.

Dorothea hiking along her favourite trails

Dorothea is an outdoor enthusiast and an avid reader and one of her favourite quotes, by Sydney J. Harris, is: "The whole purpose of education is to turn mirrors into windows."

Dorothea is interested in creating an informal support network of individuals with dystonia in the Vancouver area or anyone who is interested in helping out the cause. She can be contacted via email: dgensch@shaw.ca

Interested in meeting people in your area to talk about dystonia?

Support groups and informal support networks are building momentum in the West. To join, please contact one of the listed representatives:

Victoria – Janet Cauthers – jcauthers@shaw.ca; Remy Campbell – remycampbell@yahoo.ca
Vancouver – Dorothea Gensch – dgensch@shaw.ca
North Shore – Barbara Smith – Ladybar@shaw.ca
Chilliwack/Sardis/Abbotsford – Arlene Czop – (604) 858-8931
Kelowna – Brian Hoar, M.D. – bbhoar@shaw.ca

National Advocacy Day a **HUGE** Success

Key Initiatives Moving Forward

By John J. Heney
Member, National Dystonia Advocacy Committee

Advocacy Day in Ottawa has become a valuable and exciting part of the Dystonia Medical Research Foundation Canada's strategy to raise awareness about this debilitating disorder.

Daring to enter the sometime daunting parliamentary halls of Ottawa, Dystonia Medical Research Foundation Canada (DMRFC) first took action in 2004. The highlight that year was hosting a reception and dinner off Parliament Hill that was attended by a handful of MPs and a Senator.

In 2005, we graduated to more meetings, honing our literature and our requests to MPs. DMRFC held a reception in the private chambers of the Speaker of the House of Commons and also conducted our first national news conference with the Parliamentary Press Gallery.

With DMRFC National Director Sarah Smith leading the way, the DMRFC National Advocacy Committee--comprised of Stu Higdon, Kelda Whalen and myself--continued to move forward in 2006, experiencing an extremely exciting and successful year that unfolded with lots of promise for the future.

The inroads we've made and the paths we now walk are thanks in no small way to past and current participation by Canadians with dystonia, including Ian Boudreau, Remy Campbell, Mary Guy, Kathleen Gregoire, Suzanne Hebert, Tracy Henry, David Jaakkola, Shirley Morris, Cathy Rochford and Kelda Whalen.

Top: Special thanks to M.P Yasmin Ratansi (4th from left) and M.P. Steven Fletcher (centre) for co-hosting DMRFC's 2006 Advocacy Day Reception on the Hill.

Middle: (L-R) M.P. Robert Merrifield, DMRFC Advocacy Committee member John Heney, DMRFC Advocacy Committee member Kelda Whalen, Hon. Raymond Simard.

Bottom: (L-R) M.P. Paul Szabo; Hon. Judy Sgro; DMRFC member Ian Boudreau, M.P. Steven Fletcher, DMRFC member Remy Campbell.

(cont'd John Heney)

Thanks to our continuing momentum, look at what we're able to report as a result of our Dystonia Awareness Days held in Ottawa October 16-18, 2006!

This year, a moving presentation on the effects of dystonia had a significant impact on the **Canada Pension Plan-Disability** staff, including its Chief Medical Officer. DMRFC now has an invitation to help educate CPP adjudicators in the field about the real need for disability benefit support. (Read about Tim Williston on page 8 who is already benefiting from this success.)

A **Private Member's Bill** seeking to declare the first week of June as National Dystonia Awareness Week is now making its way through parliamentary protocol.

A **DMRFC e-bulletin** has been developed for major stakeholders, including legislators, health officials and researchers. Our publication will expand its reach as crucial participants continue to be identified. If you would like to receive DMRFC's quarterly e-bulletin, please contact DMRFC to be placed on the distribution list.

A **dystonia caucus** on the Hill is expanding, and currently includes staff, political party health critics and members of crucial committees including health and finance.

Greater teamwork with the **Canadian Institutes for Health Research**, has already seen us obtain a matching grant to strengthen the research supporting capacity of the Foundation, increase our connection to dystonia health researchers in Canada and increase the visibility of dystonia in government and across Canada. We're on track to participate in a CIHR symposium on movement disorders, planned for 2007.

The first DMRFC presentation was made before a full **House of Commons Standing Committee** – in this case, Finance-- in the interest of awareness and increased research funding.

We were thrilled to have the support of Remy Campbell of Victoria, BC, who is featured in the poignant documentary ***TWISTED***. Video clips we had on hand of Remy before and after her dramatic DBS surgery, as well as with her implant turned on and off, had a significant impact on awareness and understanding of dystonia.

We continue to explore new opportunities as they arise, including discussion with the Canadian Medical Association, working with provincial caucus groups in Parliament and the development of tools to enable us to collect data on dystonia in Canada.

Left: (L-R) Speaker of the House Hon. Peter Milliken; DMRFC member David Jaakkola.

Middle: (L-R) Hon. Bryon Wilfert; M.P. Paul Szabo; DMRFC member Mary Guy; M.P. Ken Boshcoff.

Right: (L-R) M.P. Raymond Bonin; DMRFC National Director Sarah Smith

CPP-D **VICTORY**!!!

New Brunswick resident with dystonia receives disability benefits after lengthy appeal process

New Brunswick resident, Tim Williston, who suffers from cervical dystonia, was recently awarded CPP Disability (CPP-D) benefits after a lengthy appeal process.

Williston, who is currently recovering from Deep Brain Stimulation, is relieved to receive CPP-D benefits after a seven month battle.

Due to the rapid progression of his dystonia, Tim was forced to close his business, The Lobster Barn, in December, 2005. In March, 2006, he underwent a successful Deep Brain Stimulation surgery, but he was surprised the recovery process would be so long.

"I was so optimistic I would be back to work by May, but it soon became clear my recovery was going to take longer," he says.

In April, Tim reluctantly filed for CPP-D benefits, to help pay for his medical expenses.

"I didn't want to be a burden on society," he says. "I'm a proud man."

Tim's wife Nancy, thoroughly filled out the four page application and was stunned, when three months later, they received a letter stating that while Tim was eligible for benefits as he had contributed to the program, his claim was rejected as his dystonia was not "severe or prolonged", as deemed by CPP-D medical adjudicators.

"It was unacceptable," says Nancy. "They didn't call to ask any other questions or visit him to see his limitations. They just said no."

So the couple wrote a lengthy letter as an appeal outlining Tim's dystonia and how it affected his ability to work.

Tim and Nancy Williston

While Tim's appeal was underway, DMRFC representatives and member-advocates met with the top CPP Disability policy advisors and the Chief Medical Advisor at Advocacy Day in Ottawa, to inform them about the severity and chronic nature of dystonia.

DMRFC members also met with the Honourable Andy Scott, Member of Parliament – Fredericton, New Brunswick, who was extremely supportive of dystonia-affected individuals and their families. Scott wrote a letter to his local CPP official informing them of the difficulties individuals with dystonia often have in receiving benefits.

Meanwhile, Tim and Nancy continued to lobby for their cause, flooding their local CPP office with valuable information regarding dystonia.

In November, their calls were answered when a nurse from the CPP Disability office called Tim to discuss his abilities and limitations, ultimately granting him CPP benefits on the spot.

"It was just such a relief, that the battle is finally over," says Tim of the victory. "We hope this has helped pave the road for others struggling with the same battle."

"I do truly believe that with the right attitude, I will be able to go back to work and contribute to society," he says. "But for now, this will help me recover."

Tim is adamant that education is the answer and he says it is everyone's role to educate our decision makers about dystonia, as it is often the case they have no idea the impact this disease has on people's lives.

"Too often, CPP-D denies applications from individuals with dystonia because CPP-D officials are not aware of the chronic, disabling characteristics of the disease," said Sarah Smith, National Director of the Dystonia Medical Research Foundation Canada. "Tim's success demonstrates the impact pressuring our legislators has in creating more awareness around dystonia and influencing legislation. Your actions make a difference!"

JUST THE FACTS

Dystonia is approximately six times more common than ALS (Lou Gehrig's Disease).

ALS patients received $7.55 million in CPP Disability Benefits in 2004 and $7.7 million in 2005.

Dystonia patients, on the other hand, received only $1.17 million in 2004 and $1.26 million in 2005.

Increasing awareness about dystonia influences legislation.
Your actions make a difference!

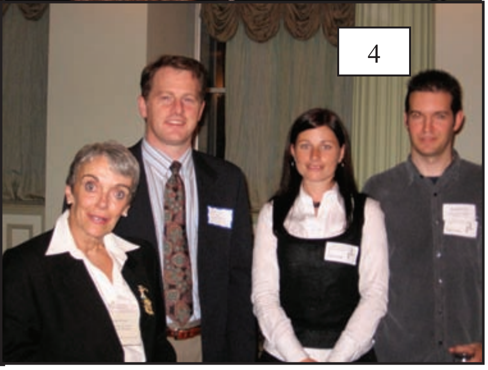


Photo #1
(L-R) DMRFC Advocacy Committee member Stu Higdon; Hon. Andy Scott.

Photo #2
(L-R) DMRFC member Remy Campbell; Hon. Andy Scott.

Photo #3
(L-R) DMRFC National Director Sarah Smith; M.P.Nancy-Karetak-Lindell; M.P Yasmin Ratansi.

Photo #4
(L-R) DMRFC Advocacy Committee Member Kelda Whalen; Neurologist Dr. Grimes; Allergan Rep Andree-Michele Daigle; DMRFC member Ian Boudreau.

We're Raising Awareness!

Hamilton Support Group

Jeanne Spencer and Laurie Bell of the Hamilton Support Group, hosted their third annual Buskerfest in support of dystonia at Dunnville's Sobeys on Oct. 28, 2006. Fifteen musicians gathered in Sobey's foyer to perform while the group distributed dystonia pamphlets and greeted customers. Spencer was instrumental in organizing the local talent from the high school. Bell comments that "the event is designed as a fundraiser but is really all about raising awareness." A total of $908 was raised in five hours from their supportive community. Congratulations!

Buskerfest

Left: Heidi Dawson; Mike Bell.

Celtic Group: (L-R) Brianne Pottie, Wayne Faulkner, Brad Faulkner.

Top: (L-R) Dave Bell: Rob Lamothe; Carolyn Van Nort & Son; Joan & Bryan Melick.

London Support Group

On September 23, 2006 the London Support Group set-up an awareness booth at the St. Julien Park Community Festival. Dystonia was featured among many other displays concerning wellness, AIDS, and mental health issues. The day highlighted many fun activities including a dog show and dancing. The group donated $500 to DMRFC. Many thanks for your awareness efforts!!

London Support Group Leaders

(L-R) Connie Vandeloo; Michelle Goodhue; Margaret Palmer

Calgary Chapter

Lil Faider, known as a "lil dynamo" to some, has summoned 36 volunteers for their Calgary Casino fundraiser to be held on January 5 & 6, 2007. In 2005, the group raised in excess of $80,000! They hope to champion this amount in the new year. What a team!!!!

Toronto Support Group

Mixing fun with philanthropy has proven to be a winning combination for the Toronto Chapter. Its signature soiree, the 17th Annual Toronto Chapter Dinner and Silent Auction, earned the reputation as the party to attend this year. Held on Nov. 25, approximately 60 people attended the fun-filled evening featuring live entertainment by DMRFC's very own elegant hoofer, William Orlowski. His outstanding performance with Susan Cuthbert, lead singer of Phantom of the Opera, was breathtaking (see photo on page 12). After a remarkable comeback from DBS surgery, William's determination to grab hold of life again is to be commended. Funds raised in support of dystonia research to be announced in the next issue. Hats off to such a fabulous evening!

Ottawa Support Group

Stu Higdon, leader of the Ottawa Support Group, has a brother in Newfoundland long challenged by dystonia, and the reason Stu stepped up to coordinate the Ottawa group. He works tirelessly to raise funds for dystonia and has been a major player on the National Advocacy Committee for three years. Stu reports that his group has raised almost $8,500 to date in 2006. What an excellent year!

Manitoba Support Group

Brian and Barbara Crow, leaders of the Manitoba Support Group, report that raffle ticket sales are positive with well over 2000 sold! The group has sent more than $4,000 to DMRFC this year. Thank you for your commitment and dedication.

Golden Triangle Support Group

Delectable gift baskets, dolls, and porcelain lanterns went up for sale at the Golden Triangle's Christmas Auction. Judy Harsch, leader of the Support Group, announced that a great time was had by all and proceeds will be sent to DMRFC. Thank you for your continued support!

TWISTED

A sensitive and revealing documentary of not only the experience of individuals with dystonia but also universal themes about the human condition.

DVD copies of TWISTED are scheduled to be delivered to each Support Group Leader in the Spring of 2007. For those who just can't wait, copies can be purchased from the DMRF by phoning 312-755-0198 or e-mailing twisted@dystonia-foundation.org . The cost is $43 Canadian (includes shipping and handling). The film is 54 minutes in length and will broadcast on PBS through Independent Lens on January 30, 2007. Only those who receive the American channels will be able to pick it up.

To bring unprecedented awareness to dystonia in Canada, DMRFC will showcase TWISTED in 4 sites across the country in 2007-08 (Sites TBD and contingent on grant funding). A screening of the film, along with a reception and educational panel, will take place in the selected sites. MPs, government officials, neurologists, physicians, social service agencies, media, individuals with dystonia and their families will receive invitations. Stay tuned and find out more in the new year.

Season's Greetings & Happy New Year From Your Friends at DMRFC

A breathtaking performance by DMRFC/Toronto Chapter Member, William Orlowski, and Susan Cuthbert--lead singer of Phantom of the Opera--captivate an inspired audience at the Toronto Chapter Annual Dinner.