



Dystonia Canada Report

A Newsletter of the Dystonia Medical Research Foundation Canada

Winter 2010/11



Ed Smith of Vineland Ontario performing at the Hamilton Area “Buskerfest”
(See story on page 7)

Research Updates	Twisted Winnipeg & Ottawa	Fundraising & Awareness Updates	Financial Statements & Donor Recognition
Pages 2,3,5	Page 6	Page 7	Page 10

DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

The Dystonia Medical Research Foundation Canada (DMRFC) is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRFC funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families. DMRF Canada works in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partners with the Canadian Institute of Health Research (CIHR) in funding excellent dystonia research in Canada.

Board of Directors

President

Samuel Belzberg

Vice President

Frances Belzberg

Secretary/Treasurer

Pearl E. Schusheim

Directors

Lil Faider

Dennis Kessler

Rosalie Lewis

Connie Zalmanowitz

Scientific Director, ex officio

Mahlon R. DeLong, M.D.

Executive Director, ex officio

Diane Gillespie

Staff

Executive Director

Diane Gillespie

Office Administrator

Loretta Jacques

Canadian Donations should be sent to:

Dystonia Medical Research Foundation Canada

100 Adelaide St. W. Suite 909

Toronto, ON M5H 1S3

English Line: 416-488-6974 or 800-361-8061

French Line: 800-787-1015

Fax: 416-488-5878

Email: info@dystoniacanada.org

www.dystoniacanada.org

It is the editorial policy to report on developments regarding all types of dystonia but not to endorse any of the drugs or treatments discussed. We urge you to consult with your own physician about procedures mentioned.

A Message from the Executive Director



DMRF Canada has had a landmark year in awareness and research activities. Our support groups continue to thrive under strong and dedicated leadership. Our relationships with DMRF in the United States and the Canadian Institutes of Health Research continue to help further outstanding dystonia research both in Canada and worldwide.

DMRF Canada continues to assist people with dystonia and their families and friends through its toll free support line 1-800-361-8061 in English and 1-800-787-1015 in French along with our on-line support in both English and French. These are critical outreach activities that enable people with dystonia to access medical and community resources. Our website www.dystoniacanada.org is a valuable tool that presents up-to-date dystonia information including Movement Disorder Clinics across Canada and each of the provincial health on-line sites.

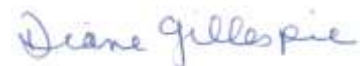
On the cover of this issue we are featuring a performer at the Hamilton Area annual Buskerfest, Ed Smith of Vineland, Ontario. More on this story on page 7.

This Fall, DMRF Canada participated in a number of awareness activities. Dr. Sylvain Chouinard chaired a half day session on dystonia at the Notre Dame Hospital in Montreal, and Dr. Melanie Langlois chaired a similar presentation in Quebec City. These sessions were presented for the benefit of the dystonia francophone community. The film Twisted was screened in both Winnipeg, with Dr. Doug Hobson chairing, and in Ottawa, with Dr. David Grimes chairing. All sessions were very well attended and received.

Our financial statements are presented on page 10, and we are pleased to report that our income in 2009 once again surpassed the income from the previous year. This is only made possible through our generous supporters and volunteers.

Thank you to all.

Sincerely,



Diane Gillespie
Executive Director



Dystonia on the Green

Golfers with the Yips May Have Focal Dystonia

From Dystonia Dialogue Winter 2010

It's the sort of thing that makes even the caddy cringe: A golfer is poised on the green, about to make the kind of short putt he could easily do in his sleep, and inexplicably blows it. And no one is more baffled by the missed shot than the putter himself. *What happened?*

Why is Studying Golfer's Dystonia Important?

Certain dystonias make good models to help scientists better understand all forms of the disorder.

Task-specific, focal dystonias such as golfer's dystonia and musicians' dystonia occur only when an individual attempts a specific series of movements. This provides clues about how the brain functions under the influence of the disorder.

These dystonias may also point the way to potential new treatment approaches.

Task-specific, focal dystonias reinforce the belief that dystonia is a 'circuit' disorder, meaning that the problem lies in how the brain learns to coordinate a movement or task.

Rehabilitative and physical therapy methods are being used to 're-train' the nervous system to complete tasks without symptoms.

Lessons learned from these dystonias may be relevant to treating primary and secondary dystonias.

Like musician's dystonia, golfer's cramp is a good model to use because the symptoms only happen under specific circumstances, making it easier to work backward and track the origins of the disorder in the nervous system.

'Yips' is a term used by golfers to describe an involuntary jerking, twitching, freezing movement usually when putting or chipping. The cause of the yips remains unclear. Most golf instructors, sports psychologists, magazine articles, and the golfing public think that it is a form of 'choking' or psychological disorder. This is very similar to how many types of dystonia were viewed for years.

A group of researchers believe that yips may be a form of focal, task-specific dystonia: golfer's cramp. This would be similar to writer's cramp or musician's dystonia but affecting golfers. It is well known that stress and anxiety worsen involuntary movement symptoms in many individuals with dystonia, so the fact that the yips occurs mainly in tournament or other pressure situations is not surprising.

Charles Adler, MD, PhD from Mayo Clinic Arizona led a study with colleagues John Caviness, MD at Mayo Clinic and Debbie Crews, PhD, Marco Santello, PhD, and Kanav Kahol, PhD at Arizona State University. They studied 50 golfers, 25 complaining of the yips and 25 not complaining of the yips, on an outdoor putting green at Arizona State University.

While putting, golfers wore a Cyberglove, a device that measured movements at 18 different joints of the wrist and fingers as well as electrodes pasted on the forearm to monitor muscle contractions.

Further research in identifying golfers that have golfer's dystonia, and then research in treating these golfers is needed. It is expected that research on the yips and golfer's dystonia will not only help golfers but will also contribute significantly to helping musicians and individuals with dystonia, especially task-specific forms.

DMRF Co-sponsors Grants with Dystonia Coalition

In August, the Dystonia Medical Research Foundation in the United States announced the co-funding of two Career Development Awards as part of its partnership with the Dystonia Coalition. The Dystonia Coalition is a National Institutes of Health-funded collaboration of scientists, institutions, and patient organizations worldwide (including Canada) formed to advance the pace of clinical research for dystonia.



The Dystonia Coalition's Career Development Award Program supports junior investigators in their pursuit of clinical research projects relevant to dystonia. The award is geared toward advanced post-doctoral clinical research fellows, senior clinical fellows, or junior faculty members who will be independent investigators within one or two years. The DMRF supports this program as part of its ongoing commitment to encourage and inspire young investigators to establish careers in

the field of dystonia. DMRF Canada is pleased that a Canadian investigator was the recipient of one of these awards.

Mateusz Zurowski, MD at Toronto Western Hospital is improving up on a dystonia assessment tool doctors use to evaluate an individual's symptoms by adding measures for emotional and mental health. Dr. Zurowski is incorporating psychiatric measures into the "TWSTRS" dystonia scale used to evaluate patients with cervical dystonia in a project entitled "Dystonia Coalition – Psychiatric Assessment." Inclusion of these new measures will help neurologists obtain a more complete picture of an individual's treatment needs and more accurately recognize the effects of emotional and mental health issues on the quality of life of people with cervical dystonia. The results from this study will lead to improved treatment and better outcomes for patients.

Tri-County Support Group Now in Chatham, Ontario **By: Tracy Henry, Support Group Leader**

I started the Tri-County Dystonia Support Group in 1995. The group started with Chatham and area with about 13 members and it just grew from there to about 60. Some of the guest speakers we have had include physiotherapists, chiropractors, massage therapists, Pharma representatives, and pharmacists.

I organized our first walk in Chatham and invited the Windsor people to come. I think we raised about \$1000.00 that first year about 14 years ago. Then I tried to have two walks on the same day – in Windsor in the morning and Chatham in the afternoon. I did that for two years and I found it too much; so we continued to run it in Windsor. We often have a barbeque which I haul down in my trailer, along with hotdogs and water and juice. I appeal to the rest of the group to bring potluck. I haul church tables and chairs to set up for our many door prizes that the members bring along with tablecloths, the banner, cleaning equipment and



even the weed wacker when the Windsor Parks were on strike. I picked up the coffee and timbits from Tim Horton's who have always donated to the event.

My four kids and their spouses helped me a great deal. They travelled from Collingwood and Toronto to help but now that they have little ones running around it is different to lend a hand but they still come to support me. This is one of the main reasons I am downsizing to a smaller group. Each year we raised our goal and we almost raised \$10,000 one year with church donations and Green Shield. That is with about 12 active members.

Every dystonia awareness week I did something different. Just some of the activities I did each year have been: newspaper articles in different papers, like the Windsor Star, Wallaceburg Paper, and Chatham Daily News. We had an article printed in the Windsor Living magazine one year. I have been on different radio stations like CKSY, CFCO, and CBC. I was even on TV twice with a medical doctor who did a three minute talk on different health issues.

I call the support group, my dystonia family. We may all have dystonia, but as the song goes WE ARE NOT DYSTONIA. We will continue to support each other in any way . Tracy Henry

I set up my display board in a different hospital every year. I gave presentations to all sorts of groups throughout the years –women's church groups, nursing students from different hospitals including Petrolia, Newbury, Chatham and Wallaceburg. I gave an all day presentation in Windsor Met Hospital one year. It was in their education room and I just kept playing our DVD and speaking with medical staff and lay people as they came during their breaks. It was a long day but well worth it for awareness.

I think my greatest accomplishment was organizing a regional symposium in Windsor in 2003. I had five different doctors from Montreal, Ottawa, Toronto and London as presenters. Having attended several symposiums myself I hated going to one and not know the city very well. Since I really don't know Windsor well myself I walked the area and found restaurants for people to eat at and activities for people to do after the day hours. I wanted to make sure everyone had a pleasant time in Windsor. My husband even did a taxi service for people who were coming in on the train or the plane so they wouldn't have to call a cab. Dr. Moro was so impressed to have that personal touch and Dr. Jog said it was one of the most organized symposiums he had ever been to. (It was after this symposium that Dr. Jog started to come to Windsor to give Botox so patients would not have to make that drive to London.) I even made small jars of jam for the leaders who came in for the leader's day. Joaney from Allergan was a huge help with the technical end of it. My daughter who had only been married one week was on the registration table, my husband also was my tech guy and my youngest daughter worked the table where we sold t-shirts, and other dystonia merchandise. We had 120 people come and they came not just from Canada but also from Michigan, Mexico and New York. People stayed right downtown on the waterfront.

When a new patient learns he has dystonia I can spend sometimes an hour with them clarifying what the doctor has said to them. When people read articles about dystonia and they don't know if that is what they have, they call me and I steer them in the right direction where they can get a proper diagnosis.

When I look back at the years it has been busy for me but my family has always supported me. Even when my own dystonia hits hard and I am bed ridden they are there and I am truly thankful. My five grandchildren are only little for a short time and I want to be with them as much as possible. I am expecting three more grandbabies next year in January, May and June. So it will be busy again. I find that I must scale down my dystonia group activities. We will still have a walk in Chatham next year hopefully and I will get the Sarnia people on board. Meetings will be in Chatham or Sarnia hopefully and my one page newsletters will continue.

If you are touched by dystonia and living in the Windsor area and would like to consider a volunteer leadership role, please contact Diane Gillespie, 1-800-361-8061.

DMRFC Funded Research

Ottawa Hospital Research Institute

The Dystonia Medical Research Foundation partners with the Canadian Institutes of Health Research (SHOPP Program) in funding fellowships in dystonia research. In this issue we are presenting two DMRFC/CIHR funded researchers (fellowships) at the OHRI.

Dr. Amanda Smith



I am from Ottawa and then moved to Kingston Ontario to do my undergraduate degree at Queen's University where I studied Life Science. In 2000 I graduated with a Bachelor of Science Honours degree. I then began a Master's program at the University of Ottawa in the department of Cellular and Molecular Medicine in the laboratory of Dr. Marie-Andree Akimenko at the Ottawa Hospital Research Institute. The main interest of this laboratory was studying signaling pathways involved in zebrafish fin development and regeneration. Eventually I transferred to the Ph.D program and graduated in 2009. I am currently doing a postdoctoral fellowship in the laboratory of Dr. Dennis Bulman. The main focus of the Bulman laboratory is identifying the cause and understanding the pathophysiology of genetic disorders. My research project is looking at a neurological disorder called Myoclonus dystonia. The goal of my research is to elucidate the function of a gene called ϵ -sarcoglycan (*SGCE*), which is found to have mutations in 40% of patients with Myoclonus dystonia. By determining the function of *SGCE* we will determine the reason mutations in this gene cause Myoclonus dystonia.

Dr. Scott Ryan

I completed my undergraduate degree at Memorial University in Newfoundland, where my training focused on nutritional biochemistry and fatty acid mediated activation of transcription factors. Throughout my Doctorate at the University of Ottawa I pursued the hypothesis that aberrant lipid metabolism activates the signaling pathways that underlie neurodegeneration. By analyzing cortex from post-mortem Alzheimer Disease patients and transgenic mouse models of Alzheimer disease, I found that specific lipid second messengers are aberrantly metabolized in the disease condition. Furthermore, I traced the signal transduction pathway initiated by these second messenger and determined that they contribute to Alzheimer pathology by disrupting organelle function. As a postdoctoral fellow at the Ottawa Hospital Research Institute, I am pursuing my interest in organelle function while expanding his understanding of neurodegeneration. As a member of the Kothary lab, my research focuses on sensory-motor neuropathy resulting from mutation of large cytoskeletal linker proteins that manifest in dystonic phenotypes. This work evaluates the contribution of cytoskeletal instability and transport defects to disease onset in the hopes of identifying novel mechanisms for disease intervention.





The Medtronic Foundation has granted the funds to screen the movie Twisted in major centres across Canada. To date, DMRF Canada has held screenings of the award winning documentary in Halifax, Ottawa/Gatineau, Toronto, Waterloo, Winnipeg, Edmonton and Calgary.

In the film TWISTED the producer and director Laurel Chiten, at age 17, hopped in a friend's car and woke up in an ambulance. Months later, her head began to twitch. But it was more than 20 years before she was diagnosed with dystonia. The film takes us on a journey into the lives of four courageous people and their experiences with dystonia.

Winnipeg

DMRF Canada hosted by Dr. Doug Hobson and the Winnipeg Support Group held a Twisted screening and luncheon on November 23, at the University of Manitoba Basic Health Sciences building with over 140 in attendance. A panel discussion followed, moderated by Dr. Doug Hobson, BSc, MD, FRCPC Neurology, Co-director



The Wieler Family and Dr. Doug Hobson

Movement Disorder Program at Deer Lodge Movement Disorder Clinic in Winnipeg and movement disorder neurologist and accompanied by Ms. Joanne Malenko, RN at the Deer Lodge Movement Disorder Clinic. Dr. Hobson and Ms. Malenko were joined by Cara Windle, BMR (PT) physiotherapist.

Ottawa

On December 3, DMRF Canada hosted a luncheon and screening of Twisted supported by Dr. David Grimes and the Ottawa Dystonia Support Group. Over 200 people filled the Amphitheatre at the Ottawa Civic Hospital. The panel following the screening was moderated by Dr. David Grimes, Associate Scientist, Neuroscience, Ottawa Hospital Research Institute Associate Professor, Division of Neurology, Department of Medicine, University of Ottawa Director, Parkinson's Disease and Movement Disorders Clinic at

The Ottawa Hospital, Co-Director of the Parkinson Research Consortium, Ottawa Health Research Institute, joined by Kathryn Sullivan, Deep Brain Stimulation patient



Dr. David Grimes, Kathryn Sullivan



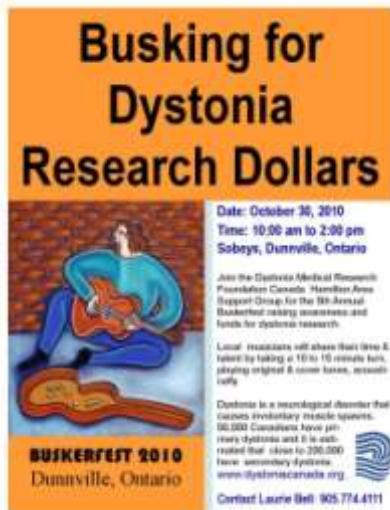
Hamilton Area Support Group – Buskerfest

By: Laurie Bell, Co-Leader/Liaison

Rose Gionet, Laurie Bell & Bryan Melick

On Sat., Oct. 30, 2010, members of the Hamilton Area Dystonia Support Group held its sixth annual Buskerfest in Dunnville, ON. This unique awareness and fundraising event is held yearly in the foyer of the Dunnville Sobeys grocery store, on the last Saturday before Halloween.

This year, 14 local musicians played acoustic instruments for 15 to 20 minutes each. The musicians have always been very generous & enthusiastic with their time and talents. And, they are exceptionally good sports, as they play with the crashing of grocery carts and chatter in the background. Always, there are a few people who come to just hear the music and musicians often stay to listen to or back up each other.



Support group members handed out pamphlets to shoppers as they entered the store, stopping to chat, without holding up traffic. In turn, the shoppers dropped any change into an open guitar case, as they leave the store.

Our hosts at Sobeys have been nothing less than warm and welcoming. This foyer is a favourite spot for local fundraisers and after we had our first successful day five years ago, we enjoyed a standing invitation to return.

The event runs from 10 AM until 2 PM, as shopping traffic is highest in the middle of the day. Over \$1000.00 is raised every year during these four hours. Periodically, bills are removed from the guitar case, for safety reasons. Four hours is about the limit the support group members can stay at it, for various symptomatic reasons. The

results of this event, the fun that is had and positive feedback make us all look forward to our next year's event. (Pictured Chad Brown & Rob Lamothe)



This event could not happen without the help of Bryan and Joan Melick, Rose and Roland Gionet, Jeanne Spencer, Myrtle Gowans and her pal, Flo Johnston, Diane Gillespie and Loretta Jacques, at the DMRF Canada office, have always been supportive and encouraging, supplying posters and handouts without question.

My right hand man, Dave Bell, helps with everything from carrying heavy loads to providing some music and counting the coin the day after. The most successful events are those that are simple, fun, and shared by people who enjoy working together.

It is heartwarming to receive such encouragement and support from my small community.

2010 Dystonia Awareness and Fundraising Activities



Toronto

The weather threatened early morning with rain and winds, but by the start of the Freedom To Move 5K Run/Walk in High Park on June 5th, the skies opened. Almost 200 participants enjoyed a great run/walk through the park while raising an all-time high of \$42,000. Special thanks to all the volunteers from the Toronto Chapter, especially Chapter President Wendy Paul and her family, Deloitte, Region of Peel, Grenadier Restaurant and to our sponsors, Deloitte, Allergan, PDF Architects, Grenadier Group, One King West, The Hilton Toronto, The Hilton Garden Inn Toronto and Sheraton Hotel and Resorts. Very special thanks to the organizing committee, David Jaakkola, Dan Buganto, Jessica Kasparian and our Honourary Co-Chairs, Bill and Paul Saundercook.

David Jaakkola and Bill Saundercook at the start line

Calgary

The Calgary Chapter managed to get the only dry day in weeks for their walk in June. Those participating enjoyed a neighbourhood walk and the delicious picnic that followed at Marg Roy's home. The funds raised were about \$3,900. Thanks to the Casino Day, organized by Lil Faider the Calgary Chapter was proud to forward a cheque for \$64,798 to DMRF Canada research and awareness.

Hamilton Area

The Hamilton Area Walk organized by Rose Gionet with assistance from Laurie Bell, had a very successful walk with NO RAIN! There was a higher attendance this year with 104 people signing in. More raffle tickets and 50/50 draw tickets were sold than in previous years. The Group raised a record \$12,000. Buskerfest in October raised \$1,000.



IODE walks for dystonia

Gagne with family and friends. Her son Beckham was diagnosed at 11 months with dopa-responsive dystonia which can be treated with dopamine. It was a long hard struggle to get the diagnosis and Beckham is the youngest person that doctors polled at a recent neurology conference had heard of. Corinne and Beckham were sponsored for \$500 by the committee that runs the Rick McDonald Memorial Ball Tournament and we are thankful to them. Rick, a police officer, killed in the line of duty, was Corinne's first husband. Corinne's family & friends brought in an additional \$1,507."

Sudbury

The Sudbury Support Group led by Mary Guy, raised a record \$15,000. Mary Guy says "special thanks go to Dwayne Backer who had another personal best collecting \$4,056. He approached 315 people of which 190 were Wal-Mart employees. Wal-Mart matched the employees donation with a \$1,500 donation. Also attending was Corinne Fewster-



Gagne family and friends

Ottawa

This year the Ottawa/Gatineau Support Group held their annual Walk at Vincent Massey Park, on June 11. A small but dedicated group enjoyed the both the Walk and the picnic while raising over \$4,000. In 2010 the Walk will be moved to Britannia Park. Thanks to all who participated and volunteered to help the DMRF Canada staff, Diane Gillespie and Loretta Jacques in organizing this fun event



Kathryn Sullivan and John Heney at the Freedom To Move Walk & Wheel in Ottawa

Tri-County

Congratulations to organizers Tracy Henry and Claire Matthieu and all participants on a successful and rain-free Walk. Over \$6,000 was raised at the Windsor event. Other Tri-County fundraisers raised \$1,300. Special thanks to Kym Kell and the other dedicated volunteers who ran events ranging from car washes to pasta dinner nights. A special thank you goes out to Green Shield Canada who held a staff dress down day and raised \$1,000.

Golden Triangle

The group held its annual Walk with 13 in attendance and 11 walkers. Afterwards, everyone enjoyed lots of food and good conversation. A good time had by all and \$900 was raised



Anne Skomedal and Gisela Rentmeister

Kelowna Awareness Week

In 2010, the Kelowna Support Group held its Dystonia Week booth at Orchard Park Mall with their own poster featuring dystonia member and patient Carla Costain.



Dr. Josephe Tsui and Carla Costain

While in Vancouver for her bi-monthly Botox treatment, Carla presented Dr. Tsui of the UBC Movement Disorder Clinic, the book, "Living Well with Dystonia", on behalf of the Kelowna Dystonia Support Group.



Montreal and Quebec City Dystonia Awareness Presentations

Two half day sessions on what patients need to know about dystonia were hosted in Montreal at the Hospital Notre-Dame on September 11, with Dr. Sylvain Chouinard chairing and in Quebec City on October 23 with Dr. Melanie Langlois chairing. The presentations were presented entirely in French. Supporting the presentations were Dystonie Quebec, (DMRF Canada support group), and Merz Canada.

Montreal Presenters: Dr. Sylvain Chouinard, Dr. Michel Panisset, Dr. Jean Rivest, Dr. Valérie Soland.
Quebec City Presenters: Dr. Melanie Langlois, Dr. Pierre Naud, Dr. Marc Petitclerc

DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA
STATEMENT OF FINANCIAL POSITION
YEAR ENED DECEMBER 31, 2009

ASSETS	2009	2008
Current Assets		
Cash	220,113	\$323,724
Guaranteed investment certificates	200,000	42,243
Amounts receivable	2,515	7,307
Prepaid expenses	1,857	2,365
	424,485	\$375,639

LIABILITIES & NET ASSETS

Current Liabilities		
Accounts payable & accrued liabilities	27,135	\$27,353
Net Assets		
Invested in capital assets		Nil
Unrestricted	397,350	348,286
	424,485	\$375,639

STATEMENT OF OPERATIONS & NET ASSETS

REVENUE		
Donations	406,937	\$388,294
Interest	1,191	5,017
	408,128	\$393,311
EXPENSES		
Research grants & activities	156,561	\$127,541
Awareness, Education & Services	106,725	126,675
Fundraising	48,858	49,311
Administrative and professional costs	38,980	41,861
Advocacy	7,940	9,227
	359,064	\$354,615
EXCESS of revenues over expenses	49,064	\$38,696
NET ASSETS, beginning of year	348,286	309,590
NET ASSETS, end of year	397,350	\$348,286

Thank You

The Dystonia Medical Research Foundation thanks its many supporters, donors, sponsors and benefactors in 2009. This support provides the funds needed to support our mission to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well being of affected individuals and families.

\$50,000 to \$100,000

Bel-Fran Charitable
Foundation
Edmonton Dystonia
Support Group

\$25,000 to \$49,999

Calgary Chapter - DMRFC
Canterbury Coffee Corporation
DMRF Toronto Chapter
(In participation with DMRFC
Freedom to Move
5k Walk/Run)

\$10,000 to \$24,999

Allergan Inc.
Anonymous
Hamilton Area Support Group
Jet Equipment & Tools
(Canada) Foundation
Ottawa Gatineau
Support Group
Peter & Joanne Brown
Foundation
Sudbury and District
Support Group
Tri-County Support Group

\$5,000 to \$9,999

BML Group
Deans Knight Capital
Management Ltd.
John W. S. Preston
Charitable Foundation
The Lutsky Families
The Alvin And Mona Libin
Foundation
United Way of Calgary,
Donors Choice Program
Wedgwood Hotel & Spa

\$2,500 to \$4,999

Curry's Art Store Limited
Deloitte and Touche
Foundation Canada
Diamond Foundation
Merz Pharma Canada Ltd

\$1,000 to \$2,499

505707 Ontario Ltd.
Brian and Barbara Crow
Walter Ewenson
Golden Triangle
Support Group
Lil Faider
Fredericton Support Group
Max Fugman
Hotspex Inc.
Marilyn Kanee
K.C. Whalen Memorial Fund
Bob and Lily Lee
Terry and Linda McBride
RSG Corporation
Manitoba Support Group
McInnes Cooper
Glenn Munro
PDA Architects
Michael Scholz
Siteworks Development Inc.
Barry Slawsky
St. John the Apostle Parish
The Joseph & Fanny
Tanenbaum Charitable
Foundation
United Way Of The
Lower Mainland
Wal-Mart Canada Corp.
Witten LLP
Barry Zalmanowitz &

June Ross

Danny & Connie Zalmanowitz
Kelly Dip

\$500 to \$999

Richard Cummins
James Dennison
Goldie Feldman
Lloyd and Yvonne Frazer
Green Shield Canada
Murray and Tracy Henry
JMC Building Developments Ltd.
Kalmar Family Foundation Inc.
Marilyn Luffman
Heather MacLellan
Myguy Management Services Ltd.
Quebec Eastern Townships
Dystonia Support Group
Runnymede Healthcare
Centre Volunteers
Sonamguy Inc.
Tsu Jan Holdings Limited
Christine Woodhouse
Hal Zalmanowitz

\$250 to \$499

A A Vacuum Doctor
Robert Abells
Thomas Allen
BB7 Machining Inc.
Dennis Bedard
Cheryl Blinick
Mary Burke
Earl Consky
Côté Davignon Avocats
Richard Currey
Jennifer Guy
Gary Bluestein Charitable
Foundation

Gracian Retirees
Greg Saari Merchandising Ltd.
Lynn Johnston
Danielle Kain
London Support Group
Melcor Developments Ltd.
Douglas Menard
Joanne Menard
David Oldroyd
Oxbow and District
Donor's Choice
Anita Pearlman
Dorothy Pearsall
Provincial Employees
Community Services Fund
Royalty General Construction Ltd.
SaskTel Telcare
Employee Charity Trust
United Way Centraide, Ottawa
United Way of Greater Victoria
United Way of London
and Middlesex
St. John The Apostle
Bridge Club
Ralph Stoecker
The Hydrecs Fund
Bobbi and Glen Timmerman
NadiaToski
Lauren Woods
Doug Willis
Jeffrey and Beryl Zeifman

\$100 to \$249

Sandra Adams
All Charities Campaign
Blume Alexander
Tony Alonzi
Joanne and Gary Appelt
APS-Antian
Professional Services
Shirley Avery
Elizabeth Baker
Gary E. Balmer
Pat Balmer
Michael and Jennifer Barnett
Fritz Becker
Michael Bernard
Lucille Germaine Berube

Donna Biderman
Lauraine Blais
Brenda Blakey
J. Leigh Blonde
David Bookhalter
Ghislain Boudreau
Alyssa Boyd
Fatima Bregman
Anne Brown
Murray Brown
Shirley Brown
Timothy Brown
Darlene & Gordon Bushewsky
Ann Marie Caldwell
Paul Christie
Canadian Millwright Services
Lou Canton
Janet Cauthers
Nancy Carr
Lola Casey
Hugh Chapman
Mary Chong
Tim Christmann
Dale Clemmer
Laurence Cohen
Bernie Colterman
Alison Cook
Laurine Cowie
Elizabeth Coyne-Dubeau
Don Cramer
Suzanne Creighton
Paulet Cyr
Sami Dabliz
Colin Davies
Carol Dean
Jackie Dann
DeCaria Engineering Limited
Andrew Dencs
Joe Diciccio
Hilton & Michele Dinner
Len & Catherine Dolgoy
David Douglas
Dunn United Church Women
Don Eby
Errol Raff P.C.
Lillian Fairhurst
Lyle Falk

Anne Fanning Binder
Cathy Farnell
Marleen Ferguson
Sean Fleming
Robert Ford
Ann French
Shirley From
Joyce Gainsford
Fleurette Gallen
Greer Gardner
Dr. E. Gauk
JM Ghent
Roland & Rose Gionet
Glover Customs Brokers Inc.
Mildred Good
Evelyn Goodwin
Carol Gordon
Jim Gowans
Myrtle Gowans
Elizabeth Graham
James & Margaret Graham
JK Gray
Alain Gregoire
Ernie Gutstein
Adam Guy
Frances Guy
Mary Guy
Reta Haarsma
Nash Hall
Barbara Hampe
Roberta & Norman Hanson
Judy Harsch
Darlene Hart
Ross Harrison
Kimberly Henry
Karen Hering
Nick Hertz
Stu and Mary Higdon
Jeremy Hill
Iona Hind
Debbie Hoffman
Bob Hollingshead
Eileen Hudson
IATSE Local 58
Jean Hutton
William Jago
Joan Johnston

Samuel & Susan Jones
Lynda Joyce
Sherry Julien
Juniper Networks'
Company Matching Gifts
Just Lubes
Lyle Kanee
Chester Kajdas
Yosuke Kawasaki
Keith Tankel Professional
Corporation
Bernard Kleinberg
George Konrad
Marc Landry
June Lajoie
Asheef Lalani
George Langois
Gaston Larose
Jill Lawrie
Leon & Jennifer Lenchener
Ellery Lew
Arnold Lindquist
Ruth Liston
Moe & Sandy Litman
John Little
Doris Littleton
Jane Loehr
Tony Lopes
Barbara MacAulay
Eric Macklin
Malting Industry Association
Dr. S. Marcushamer
Ginette Martel-Gauthier
Margo Lindener and
Nicholas Mattison
Eric McCarthy
Eleanor McChesney
Rae McConnell
Helen McCuaig
Peter McDermott
Joyce McGeachy
Anne McGuire
Walter & Marcy McKall
Midevco Commercial
Arliss Miller
Josh & Michelle Miller
Vera Milner

Radmilo Milutinovic
Mirkwood Engineering
Kate Mitandis
Elaine Mollema
Kathy Moorcroft
Rick Moorcroft
Mary Ellen Mortier
Brian Mullen
Dan Murphy
Gwyneth Murray
Julie Noorden
Anne Marie O'Brien
Patricia Omer
Ontario Power Generation Inc.
John & Nancy Page
Reno Parisotto
Earl & Reeva Parker
Irene Patry
Tom Patterson
Elaine Perry
Personnel By Pro-Staff
Asher & Sharon Pertman
David Petretta
Sheryl Plantinga
Norm Pollock
Polytec Quality Consulting
Portfolio Management
Corporation
R.V. Anderson Associates Ltd.
Michael Rae
Clarence & Anne Ramme
Cindy Rapley
Carolyn Readman
Jim & Vivian Redmond
Stephen & Susanne Resar
Respiratory Department,
St Bonafice Hospital
Aharon Revah
Sherrie Richards
Frank Ries
Robert R. Pokroy
Professional Corporation
Marianne Robitaille
Robson Communication Inc.
Royal Bank of Canada
Margaret Roy
Mary Rukavina

Evelyn Russell
Ray Rutman
Elaine Samuel
Sasktel
Elizabeth Saundercook
Paul Saundercook
Douglas Schade
Eric & Elexis Schloss
Francine Schutzman
Jack & Betty Sharp
Howard & Reeva Shein
Kayla Shoctor
Leonard Shymkiw
Shari Silverstein
Leah Sinclair
John Skogstad
Mary Smiley
Claire Smith
F. Smith
T. Bradbrooke Smith
Renee Smith
Howie Sniderman
Lorne Sorge
Ronald Sorokin
Matthew John Standish
STC Construction Group Inc.
Les Steiner
Mark & Lorraine Stillman
Mark Stoneburgh
Kathryn Sullivan
Barbara Surplus
Sweetnam Farms
Keith Tankel
Cheryl Tanner
Thunder Bay Terminals
Anne Treling
Barbara Trepanier
Union Gas, A Spectra
Energy Company
United Way Of Greater Toronto
Daniel Vallee
Cornelis Van Velzen
Connie Vandelloo
Lynn Van Demham
Frank Van Humbeck
Venchiatritti Gagliardi
Architect Inc.

Joanne Volden
Rob Vorps
Audrey and Tom Wakeling
Gitta Wallen
Marvin Waxman

Mary Weaver
William West
Bill West
Iris Weverman
Neil Wilson

Norman Witten
Joseph Wohlgelernter
X+1 Technologies Inc.
Mary Yannakis
Leo Zalmanowitz

Yogatonica Comes to Ottawa

A gentle form of yoga designed for people with movement limitations can help people begin to experience more relaxation as well as some other benefits. An introductory workshop will be offered at the Rama Lotus Yoga Centre starting January 19th 2011. This pilot project will run for 5 weeks until February 16th. The price of this five-session workshop series is \$75.

Lucille Smeltzer-Legault, who will be teaching the class, is a certified yoga teacher who has been teaching Kundalini and Hatha yoga for ten years. She is also a registered social worker at Family Services à la famille Ottawa. (for further information: 819-827-1278)

Rama Lotus Yoga Centre: 342 Gladstone, Ottawa, Ontario
January 19- February 16: Wednesdays at 1:30 until 3:00 pm (13:30-15:00)
To register call: 613-234-7974

How to Get What You Need

An Advocacy Workshop for individuals living with dystonia, friends, family and caregivers



- **Effective communication skills**
- **Developing your own advocacy plan**
- **Strategies for creating changes in your life**

If you are interested in learning more about how to advocate for yourself or someone you care about then this is the workshop for you. To register and for more

information please call: 1-613-725-3601 ext, 132 or email

etroy@familyservicesottawa.org Website: www.familyservicesottawa.org

Date: February 7, 2011
Time: 5 p.m. to 8 p.m.
Location: 312 Parkdale Avenue,
Ottawa, Ontario

WORKSHOP IS FREE

Volunteer Leaders and Area Contacts

BC	Anne	Skomedal	Kelowna Support Group Leader	250.763.7739	rskomedal@shaw.ca
	Brian	Hoar	Kelowna Area Contact	250.764.5005	bbhoar@shaw.ca
	Cindy	McKay	Kelowna Area Contact		cansoda@shaw.ca
	Arlene	Czop	Chilliwack Area Contact	604.824.9849	rczop@telus.net
	Grant	Kaiser	Vernon/Salmon Arm Area Contact	250.542.8509	cgkaiser@telus.net
AB	Margaret	Roy	Calgary President/Support Group Leader	403.271.4438	roymg@telusplanet.net
	Brenda	Lewis	Edmonton Support Group Leader	780.474.5320	
	Joanne	Alford	Northern Alberta Support Group Leader	780.752.8604	jealford@shaw.ca
SK	Jean	Palmquist	Regina Area Contact	306.352.1442	jpalmquist@accesscomm.ca
	Diane	Haugen	Saskatoon Support Group Leader	306.477.0577	dystonia@sasktel.net
MB	Barbara	Crow	Manitoba Area Contact	204.255.2633	bcrow@mts.net
ON	Monica	McCool	Co wall Area Contact	613.936.1356	ashleymccool@live.ca
	Judy	Harsch	Golden Triangle Support Group Leader Kitchener/Waterloo/Guelph	519.767.9721	jjmarie@rogers.com
	Laurie	Bell	Hamilton Area Support Group Co- Leader	905.774.4111	landbell@mountaincable.net
	Rose	Gionet	Hamilton Area Support Group Co- Leader	905.575.3534	rgionet@mountaincable.net
	Margaret	Whittaker	Kingston Area Contact	613.345.2115	
	Jane	Soules	Kingston Area Contact	613.498.1472	soules1@sympatico.ca
	Michelle	Goodhue	London Area Contact	519.455.7457	bgood137@sympatico.ca
	Bruce	Goodhue	London Area Contact	519.455.7457	bgood137@sympatico.ca
	John	Heney	Ottawa Area Contact	613.224.6888	jjheney@netrover.com
	Brian	Hall	Peterborough Area Contact	705.932.3111	bdh333@gmail.com
Mary	Guy	Sudbury Support Group Leader	705.524.0606	maryguy@personainternet.com	
Wendy	Paul	Toronto Pres./Chapter Group Leader	416.789.0154	dmrftoronto@rogers.com	
Tracy	Henry	Chatham-Kent, Sarnia-Lambton Support Group Leader	519.354.6833	tracyhenry1224@yahoo.ca	
QC	Ginette	St-Hilaire	Quebec On-Line Support Group	http://dystonie- qc.org	webmaster@dystonie-qc.org
	Chloe	Belisle	Montreal Support Group Leader	514.696.0949	honeylocas@sympatico.ca
	Queenie	Grosz	Montreal Area Contact	514.223.2394	
NB	Edna	Jordan	Fredericton Area Contact	506.453.0708	
	Tim	Williston	Fredericton Area Contact	506.457.2388	tim.williston@hotmail.com
	Shirley	Sharkey	Moncton Support Group	506.204.2722	j.s.sharkey@rogers.com
NS	Marcellin	Chiasson	Port Hawkesbury Area Contact	902.625.1811	marcellin.chiasson@ns.sympatic o.ca
	Marion	Nauss	Queen's County Area Contact	902.677.2506	
NU	Sharon	Gee	Nunavit Area Contact	867.979.3791	candsgee@northwestel.net

Plan a Gift—Support Dystonia Research  **DYSTONIA**
MEDICAL RESEARCH FOUNDATION CANADA
Association of Dystonia-related groups



There are a number of ways you can help

- *Leave a bequest in your will...
- *Make a gift of life insurance or securities...
- *Donate property or goods...

Ask your financial advisor how, or contact DMRF Canada at:

TOLL FREE: 1.800.361.8061 FRENCH: 1.800.377.3978
 info@dystoniacanada.org

www.dystoniacanada.org

We Need Your Support More than Ever!

Clip and return this form to: **Dystonia Medical Research Foundation Canada,**
909-100 Adelaide St. West, Toronto, ON M5H 1S3

- I wish to renew/start my Dystonia Canada Report/Dialogue subscription (\$40)
- I wish to make a donation in honour of _____, Please send an acknowledgement letter/card to this person
- I would like information sent to me regarding DMRFC Planned Giving Program
- I wish to make a general donation \$1,000 \$500 \$250 \$100 \$25 Other \$ _____

PAYMENT OPTIONS

- Please charge my credit card: VISA MasterCard American Express

Name on Card: _____ Card Number: _____

Expiry Date: _____ Signature _____

INFORMATION

Name	Address	
City	Province	Postal Code
Phone	Email Address	

Charitable Registration Number 12661 6598 RR0001