



Dystonia Canada Report

A Newsletter of the Dystonia Medical Research Foundation Canada

Summer 2011



Jared Subel of Thornhill, Ontario with his school project on Dystonia (See story on page 7)

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**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.

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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



The Year 2011 signifies the 35th anniversary of the Dystonia Medical Research Foundation. The Foundation has its roots in Vancouver, Canada where its founders Sam and Fran Belzberg started DMRF in response to their daughter Cheri's dystonia diagnosis. Today, DMRF is a world-wide leader in facilitating and funding dystonia research.

The Dystonia Medical Research Foundation Canada exists to help people with dystonia. The Foundation has support groups across Canada led by a group of very dedicated volunteers. These groups hold patient/neurologist forums so that people with dystonia can learn more about their particular form of dystonia. The support groups hold regular support meetings to facilitate one-on-one discussions and provide encouragement to people with dystonia and their families. The groups get involved during Dystonia Awareness week, the first week in June, by creating awareness through newspaper stories, booths at Malls and other venues, and by raising much needed funds for research through various events, such as Freedom to Move walks.

DMRF Canada salutes all of the wonderful efforts of our Support Groups and Chapters. The Foundation could not exist without this Canada-Wide volunteer effort.

Most importantly the goal of DMRF Canada is to find effective treatments and a cure for dystonia. In the year 2011 the Dystonia Medical Research Foundation has doubled its research contribution.

It is a privilege to partner with DMRF in the United States, a world leader in dystonia research, in providing increasing funds for their ground-breaking research program and related research efforts.

DMRF Canada's strong partnership with the Canadian Institutes of Health Research (CIHR), SHOPP, allows us the unique opportunity to have our research dollars equally matched by the Canadian government. This year, DMRF Canada is proudly funding six dystonia research fellowships through this program.

Thank you to all.

Sincerely,

A handwritten signature in blue ink that reads "Diane Gillespie".

Diane Gillespie
Executive Director

A Special Message from Our Founders

Dear Friends,

The year 2011 marks the 35th anniversary of the Dystonia Medical Research Foundation (DMRF). It is a bittersweet occasion for us. In as much as we take pride in DMRF's years of steadfast commitment to the dystonia community, our proudest moment will be the day we close our doors because a cure is discovered and no individual or family is ever again burdened by this devastating neurological disorder. The anniversary is not a celebration. It is a moment to reflect on our 35 years of dedication to the dystonia community and a time to reaffirm our promise to continue until a cure is found. We are working hard to put ourselves out of business.



Sam and Fran Belzberg

When we finally obtained a diagnosis for our daughter Cheri, we discovered there was no treatment, no research, and no support services. So we decided to take action, for the benefit of our child and all individuals facing the same diagnosis. Within the first year of operations, DMRF funded research grants, recruited the world's experts to work on dystonia, and built a network of affected families. DMRF was the first to disseminate information, and we brought together several disparate local groups into a larger, cohesive organization.

Our first Head Office opened in Vancouver and one of our initial research grants was given to a team at the lab at the University of British Columbia. Over the years it became apparent that there were a larger number of Dystonia patients outside of our area, and indeed Canada. As the DMRF patient list grew we moved our head office to Chicago and in time created Dystonia Medical Research Foundation Canada with its Head Office located in Toronto with a dedicated Executive Director supporting the dystonia patient and medical community across the country.

DMRF was there when dystonia was of little interest to the medical and scientific community. DMRF was there when patients were routinely cast into a wilderness of misdiagnosis somewhere on the outskirts of psychiatry. The work of DMRF led directly to the improved visibility and understanding of dystonia as a neurological disorder. One of our most dramatic and important gifts to the Dystonia Family was the discovery of dystonia genes, which has led to procedures that allow parents to conceive children born without the risk of certain dystonias.

The Foundation continues to be a powerful catalyst for change. We value collaboration with organizations that share our goals because it strengthens our cause and serves the greater good. We will be here as long as it takes, and we are unwavering in our drive to accelerate scientific progress and improve the lives of those affected.

Though we regret there is still a need for the Dystonia Medical Research Foundation because it means we have not yet fulfilled our promise, we also know this is a vibrant medical research foundation that continues to contribute valuable resources toward improved treatments and a cure. The Foundation could not have persevered throughout these years without the support of our Dystonia Family. We are grateful for each and every one of you.

Thank you so much for your faith and support of DMRF over the years.

Sincerely,

Samuel Belzberg
Chairman of the Board/Co-founder

Frances Belzberg
Director/Co-founder

DMRFC Funded Research

Toronto Western Hospital

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 newly funded DMRFC/CIHR funded researchers (fellowships) at the Toronto Western Hospital. (TWRI).

Dr. Kaviraja Udupa



After my Bachelors degree in Medicine & Surgery, I studied Medical Physiology during Masters Degree (MD Physiology) and senior residency at Pondicherry University, India. My research interests in the field of neurosciences led me to pursue PhD in Neurophysiology from National Institute of Mental Health & Neuro Sciences, Bangalore, India. During my PhD, I studied the modulatory effects of repetitive transcranial magnetic stimulation (rTMS) on cardiac autonomic functions in patients with major depression and compared the effects with those of antidepressant medications. After my PhD, with the aim to explore and understand the physiology of brain, using TMS as a tool, I pursued post doctoral research fellowship at Dr Robert Chen's laboratory at Toronto Western Research

Institute (TWRI, University of Toronto), Canada. This laboratory explores the motor cortical networks and plasticity using TMS in patients with movement disorders including dystonia and Parkinson's disease. The proposed research study plans to investigate the clinical improvement following deep brain stimulation in patients with primary generalized dystonia. In addition to measuring neuroplasticity in the motor cortical circuits, this study has been designed to investigate brain derived neurotrophic factor single nucleotide polymorphism which is one of the factors determining the neuroplasticity. Thus, this study aims to investigate the predictors of clinical improvement to deep brain stimulation based on the neurophysiologic measures and genetic profile of the dystonia patients.

Dr. Akihiro Yugeta

I graduated from School of Medicine, Kanazawa University; passed the National Examination for Medical Practitioners in Japan, and obtained my MD degree. I received postgraduate medical trainings in University of Tokyo and became a Board Certified Member of the Japanese Society of Internal Medicine after which I started my research on the human brain using techniques of clinical neurophysiology. My studies focused on the involvement of the basal ganglia in the control of eye movements during my Ph.D. at University of Tokyo. I also obtained board certification in Neurology by the Japanese Society of Neurology. After completing my Ph.D., I worked as a neurologist in Tokyo. In April 2010, I started my postdoctoral fellow in Toronto Western Research Institute.

Throughout my research career, I have studied the neural circuits and connectivity in the human brain using techniques of clinical neurophysiology to examine eye movements

which are regarded as indicators of the output from the basal ganglia. At Toronto Western Hospital, I am studying neural activity changes related to eye movements recorded from electrodes for deep brain stimulation implanted in the basal ganglia in people with dystonia and Parkinson's disease. My research goal is to characterize the neuronal mechanisms and the role of the basal ganglia in the initiation and inhibition of movements. Abnormalities in the inhibition of movement are currently believed to be a major feature of dystonia.



NEW! Going Global: a Research Update –

From the Dystonia Dialogue

By Jan Teller, MA, PhD, DMRF Science Officer

Everyone is busy in the field of dystonia. Scientists are working in their labs trying to understand the disease mechanisms. Neurologists continue to be amazed by the many different forms of dystonia and strive to come up with better treatments for their patients. Pharmaceutical companies are attempting to design and develop new drugs that specifically target dystonia. And patient organizations like the Dystonia Medical Research Foundation (DMRF) are doing everything in between. This is particularly true since dystonia organizations have begun to collaborate more effectively and speak with one voice on behalf of the community.

In 2010, the National Institutes of Health (NIH) awarded a five-year grant to form the Dystonia Coalition, a collaboration of medical researchers and patient advocacy groups that is working to advance the pace of clinical and translational research in the dystonias to find better treatments and a cure. The European Dystonia Federation recently joined the DMRF and other US-based foundations and became a member of the Dystonia Coalition.

Why is it critical that we all unite in our efforts to find a cure for dystonia? First, dystonia is a relatively rare disease and does not receive enough attention. Second, although there are many forms of dystonia, they most likely share common mechanisms. Third, development of new treatments requires not only money but above all collaboration and communication between all involved. Therefore, we should welcome every effort to coalesce the field. And we are certainly on the right path!

Yet, what really counts is research and progress being made in solving the dystonia puzzle. What is new? Where are we heading? How can we help promote and support research?

New genetic techniques combined with painstaking analyses of familial cases of dystonia resulted in the discovery of new disease-causing genes. Just one of these genes, DYT6, sparked numerous new explorations into the general mechanisms of dystonia. Initially it was identified in a few families, but many novel mutations of DYT6 have since been discovered demonstrating unexpected connections between various forms of dystonia. Several other attempts are being made to understand complex dystonia genetics, from screening of whole genomes with the hope of finding associated genes to systematic screening of engineered cells to find novel targets for drug discovery and development.

While genes give us clues about the underlying mechanisms of dystonia we always have to look at this disorder in a much broader way. Research in other areas of neurology and neuroscience continuously provides novel insight into dystonia. Since dystonia can be considered as a neural circuits malfunction, there is great hope that it can be corrected by interventions putting these circuits back in order. There are many ways to achieve this. One of the most spectacular is deep brain stimulation (DBS) which has proven capable of restoring 'normal' function of the basal ganglia. Its success offers an unprecedented framework for future translational research. If electric stimulation of precisely selected areas of the brain can restore proper motor function, then developing pharmacological agents targeting the same areas should also be possible. What is needed is a much better understanding of the basal ganglia and other brain structures involved in movement control. Substantial progress is being made in the area of dissecting neural pathways that are pivotal for movement. The role of the cerebellum in dystonia regained its importance through human brain imaging and animal studies. Neurophysiological studies revealed the critical role of specific neurons in the striatum. Since these neurons are the centerpieces of the striatal neurotransmission involving complicated dopamine and acetylcholine pathways, researchers pharmacologically target their receptors. Unfortunately, there are not many suitable drugs or drug candidates that are specific enough to precisely, and without side effects, modulate these receptors. Many dystonia patients using currently available medications are acutely aware of this.

2011 DMRFC/CIHR/SHOPP Dystonia Research Fellowships

Dr. Behzad, Elahi, Toronto Western Hospital, Fellowship (DMRF Canada) Regulatory effect of intra cortical inhibition on Paired Associative Stimulation (PAS) induced sensory-dependent, motor cortex plasticity

Dr. Manon Le Bel, Université Laval (Quebec), Fellowship (DMRF Canada), Study of the involvement of relaxing glutamate and expression levels of neurotransmitter transporters in dyskinesia induced by L-DOPA

Dr. Scott D. Ryan, Ottawa Hospital Research Institute, Fellowship (DMRF Canada) Cytoskeletal linker proteins mediate organelle functioning neurons

Dr. Amanda Smith, Ottawa Hospital Research Institute, Fellowship (DMRF U.S. 2010, DMRF Canada 2011- 2014) Investigation into the Cause of Myoclonus Dystonia

Dr. Kaviraja Udupa, Prediction of clinical improvement by deep brain stimulation surgery in primary generalized dystonia using clinical, genetics and neurophysiologic measures

Dr. Akiro Yugeta, Saccade-related beta band activity in local field potentials recorded from human basal ganglia

The John H. Menkes Children & Family Dystonia Symposium

August 19-21, 2011 – Holiday Inn Mart Plaza - Chicago, Illinois

Join the DMRF (United States) for a special symposium to bring individuals and families together to learn about dystonia, interact with experts, and find support among one another.

This meeting includes sessions designed for:

- Dystonia-affected children (ages 6 and up) and teenagers
- Parents & siblings of affected children
- Dystonia-affected parents
- Dystonia-affected 20- and 30-somethings

FRIDAY AUGUST 19

3:30 PM - "19 & Up" Forum Registration
4:00 PM - "19 & Up" Forum - Discussion session for younger adults (20s & 30s) about the challenges of living with dystonia.
5:00 – 6:00 PM General Registration & Reception - All Attendees
6:00 PM - Greetings & Welcome Dinner
7:00 - 9:00 PM - DJ & Dancing

SATURDAY AUGUST 20

8:30 AM – 4:30 PM Presentations & Sessions
Dinner on your own
7:00 – 9:00 PM Pool Party
9:00 - 11:00 PM Teen Movie Night

SUNDAY AUGUST 21

8:00 – 11:30 AM Presentations & Sessions



Look for more detailed information and online registration at <http://www.dystonia-foundation.org>

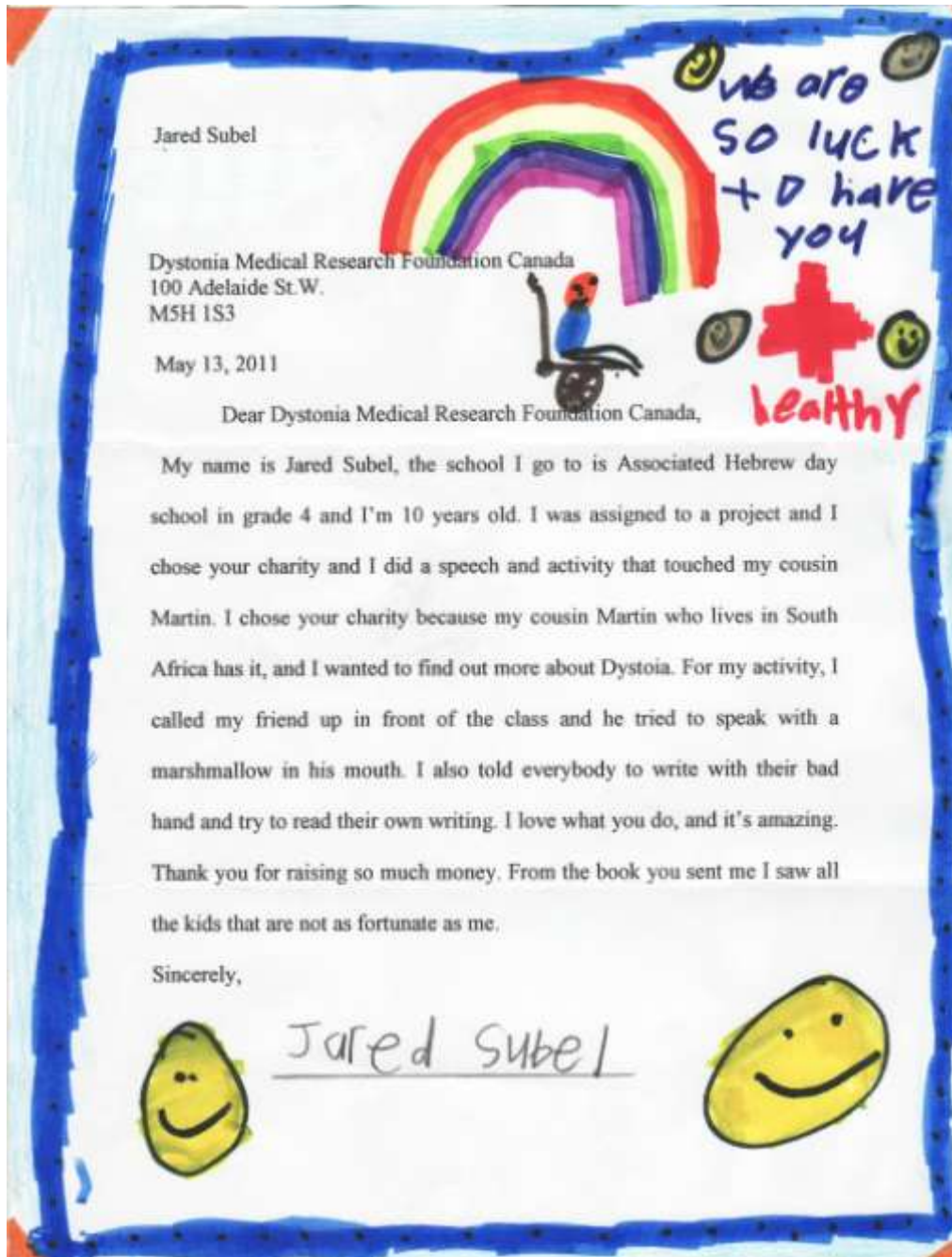
Questions? Contact the Dystonia Medical Research Foundation at 800-377-DYST (3978) or dystonia@dystonia-foundation.org

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Ten Year Old Jared Subel Raises Awareness and Funds for Dystonia

Thank you to 10 year old Jared Subel of Thornhill, Ontario for raising awareness and funds to help people with dystonia in honour of his cousin Martin who lives in South Africa and who has dystonia. Jared shares his letter to DMRF Canada and his school project. Jared and family also attended the DMRF Canada Toronto Freedom to Move 5km Run/Walk June 5, 2011.



Curry's Art Auction, Liberty Grand, Tuesday, October 25, 2011 in Support of Dystonia Awareness & Research

In 2011, Curry's is celebrating its Centennial Anniversary!

As part of its Centennial celebrations, Curry's is borrowing from its roots as an Art Gallery to sell art again – that is for one special night. Curry's is thrilled to be holding an Art Auction on October 25 at the Liberty Grand that will feature inspiring Canadian artistic talent. Dystonia Ambassador and acclaimed musician Bill McLaughlin will be performing. But the real emphasis of this Art Auction is to raise awareness and funds for the Dystonia Medical Research Foundation of Canada.

Dystonia has affected a significant number of musicians & artists, making it a cause close to Curry's heart. Since Dystonia can be caused by repetitive motions, artists – Curry's customers - may be at risk. For the past three years, Curry's has worked to raise awareness of Dystonia and the DMRFC through its retail flyers and online promotional vehicles.

Curry's appreciates that many Canadians may be affected by Dystonia and are completely unaware that they are. Receiving a diagnosis and appropriate treatment can be challenging. Therefore the key message in Curry's awareness campaign is "If you have frequent, unexplained cramping or uncontrollable muscle spasms in your fingers, hands, forearms, or elsewhere in your body, or if you want to be involved in finding a cure and treatments for dystonia, please contact Dystonia Medical Research Foundation Canada".

Unfortunately Curry's has learned about the challenges of receiving a proper diagnosis of Dystonia by experience. It took numerous doctor appointments, tests and referrals for Fred Curry's great, great granddaughter to be accurately diagnosed with Dystonia. As a result, Curry's is honoured to be able to, in some small way, assist in raising awareness and funds to help those affected by Dystonia.



If you wish to attend or be involved in this upcoming event please visit www.currys.com or e-mail CurrysAuction@rogers.com.

Cathy Lynch, Artist, Creates Dystonia Greeting Cards –Me and My Dystonia

Cathy Lynch of Richmond Hill, Ontario was an Accountant for over 30 years when she was suddenly struck down in a matter of days with dystonia in March of 2009. No longer able to work she has been focusing her efforts on getting better including art as a form of therapy.

"Me and My Dystonia is my interpretation of my personal battle with Dystonia. Dystonia for me is like playing a game of Snakes and Ladders on a daily basis. The ladders detail the treatments I take and steps taken to improve my condition, the snakes describe the events that aggravate the symptoms. Being involved in dance throughout my life, I start off in the first box, in the dark, broken and in pain and hopefully reaching my goal at the end, in daylight and back to normal. I painted it with Guache." To order Cathy's greeting cards go to <http://www.dystoniacanada.org/Toronto>. To view Cathy's art go to <http://cathylynchpaintingsanddesign.blogspot.com/>



Wendy Paul, Toronto Chapter President

“My Dystonia Journey”

My journey with dystonia is similar to other’s experiences. I first experienced a drop-foot/scuffing of my right foot when I was pregnant with my first child. I soon figured out that I could run and walk backwards perfectly, but I could not walk forward on a sidewalk.

It took eight years to be diagnosed. I saw three neurologists: one suggested that my problem was due to my being “a housewife.” A sports medicine doctor gimped and mimicked my movements beside me, as we walked to his examination room.



By chance, a mother of my third child’s friend suggested I see a brilliant diagnostician at The Toronto Western Hospital, while we stood in line to pick up our kids at nursery school. Dr. Vern McMillan diagnosed me with focal dystonia, when I walked toward the chair in his office. It was 1992.

I immediately signed up and began to receive DMRF and Toronto Chapter newsletters. I was functioning well, wearing a brace and raising three kids. I did not feel impacted enough by my symptoms to seek further support.

Years passed and my symptoms progressed though they never spread. I twisted, had spasms and had a great deal more difficulty having my foot listen to what my head was telling it to do.

My dystonia progressed at the right time of my life. Though giving up work as a pre-school teacher was difficult, retirement gave me the time to be the president of the Toronto Chapter, its support group leader and newsletter writer. I spend each morning at the gym; practicing mindful walking, following my personal trainer’s recommended routine and playing on the BOSU ball to improve my strength balance. Just today another gym member told me that my middle name should be “determination”. I do not feel like the “inspiration” that I am frequently told I am. My afternoons’ focus is, as needed, on the DMRF Toronto Chapter.

The Chapter’s mandate is three-fold: we support patients and families at support group meetings and through our newsletter; we spread awareness by setting up Awareness Tables twice a year; and we raise funds for scientific research into dystonia at our annual dinner, at the High Park Run and through sales of “dystonia and me” greeting cards.

Dystonia has taken me on a long emotional and physical journey. There are many activities that I have had to give up and the rest take a REALLY long time to accomplish. However, feeling sorry for myself just does not help. My husband Sid, my kids, parents and friends are an amazing help... I do what I can do (slowly)!

Ways to Help People with Dystonia

Your generous support and participation are critical to our ability to serve the dystonia community. Getting involved is empowering and provides an opportunity for you to contribute to the DMRF's unrelenting quest for a cure and commitment to serving the needs of affected people and families.

There are a number of ways you can help.

- Donate Now
- Plan a Gift
- Spread awareness
- Advocate
- Volunteer
- Fundraise

Create Awareness

Promoting public awareness of dystonia is one of the most important aspects of the DMRF mission. In addition to improving society's recognition and understanding of dystonia, increased awareness directly impacts our ability to fundraise for research and identify people and families who need our help.

There are many ways in which you can create awareness:

Distribute our *What Is Dystonia* brochures to friends, acquaintances, local doctors and hospitals. Contact info@dystoniacanada.org to order brochures

Participate in Dystonia June Awareness week activities. Dystonia Awareness week is celebrated the first week in June. [Contact your local support group for details.](#)

Set up awareness booths at local fairs, schools, shopping malls and stores. [Contact us to find out how.](#) 1-800-361-8061.



Contact local radio, newspaper or television outlets to encourage them to promote dystonia in a special news piece

Donate

We thank the thousands of individuals, corporations, foundations and groups across Canada who help the DMRFC ease the burden and find better treatments for dystonia through research, education, advocacy, and support services.

There are numerous ways you can make a difference:

- Make an online donation
- Make a donation by mail, phone or fax
- Plan a bequest gift, securities or life insurance gifts
- Make a monthly gift
- Make a donation in honour or memory of someone
- Participate in your local Walk and Wheel Freedom to Move event
- Corporate/Foundation Giving
- Employee Group Giving/United Way

Online donations are made through Canada Helps: www.canadahelps.org



Hold an Event or Participate in an Event to Help People Living With Dystonia
It's Fun and we can help you make it easy to do. There are many types of events that you can hold.

Golf Tournament · Dinner Party · Car Wash · Musical Gathering · Group Walk · Bowling Tournament
 Fashion Show · Pledging for Personal Achievements such as Running or Swimming

Contact us for information on event fundraising:

TOLL FREE: 1.800.361.8061 FRENCH: 1.800.377.3978

info@dystoniacanada.org

FREEDOM MOVE

Support Dystonia Research!

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 _____

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