DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA
FONDATION DE RECHERCHE MÉDICALE SUR LA DYSTONIE CANADA
serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

Dystonia Canada Report

A Newsletter of the Dystonia Medical Research Foundation Canada September 2014

Chuck's Run/Walk: Jenny Mulkins, Diane Gillespie, David Jaakkola, Franco and John Mazzella, Alison Cook, Marisa Mazzella

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.

Canadian Donations should be sent to:
Dystonia Medical Research Foundation Canada
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Toronto, ON M5H 2K1
English Line: 416-488-6974 or 800-361-8061
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www.dystoniacanada.org

A Message from the Executive Director

I would like to say what a privilege it is to work with all of the wonderful and dedicated volunteers that support the dystonia cause here in Canada and beyond. Our volunteers are indeed the backbone of DMRF Canada working behind the scenes helping whatever way they can to spread dystonia awareness throughout their communities.

They can be found helping at events, working with media, volunteering at information booths, writing fundraising letters, and putting up dystonia pamphlets in doctor's offices and bulletin boards.

Our Support Group Leaders open their hearts to people newly diagnosed with dystonia, offering them information, hope and friendship. This issue features a new section that pays tribute to DMRFC volunteers. I hope you find their stories as inspiring as I did.

DMRF Canada a proud member of Neurological Health Charities Canada (NHCC) is pleased to announce the release of The National Population Health Study of Neurological Conditions. The study was jointly undertaken by NHCC and the Public Health Agency of Canada from 2009-2013 to address the lack of information about neurological conditions including dystonia in Canada and to understand the impact neurological conditions have on affected individuals, their families and the health care system. The study successfully engaged thousands of people with neurological conditions, caregivers, health charities, public policy leaders and over 130 academic and clinical investigators in Canada's first-ever population health study of neurological conditions, marking an unprecedented level of collaboration across fields, professions, jurisdictions, conditions, and interests, and generating a new level of understanding of the scope and impacts of neurological conditions. Thank you to all of our stakeholders who contributed to this study.

Sincerely,

Diane Gillespie

Diane Gillespie
Executive Director

Franco Mazzella– DMRF Canada 2014 Special Ambassador

John, Marisa and Franco Mazzella

Alison Cook/Jenny Mulkins

Unsung hero, thirty-one year old Franco Mazzella suffers constant pain caused by **Myoclonus Dystonia**, a rare form of dystonia, a debilitating neurological disorder that he has endured for more than half his life. A shining example of bravery in the face of adversity, his positive spirit carries on despite severe physical limitations. Franco was chosen as the 2014 Ambassador for Chuck's 5 km Run/Walk for Dystonia.

With a difficult disorder to identify, Franco, like so many others with dystonia, endured a seven-year long "diagnostic odyssey," before finally being diagnosed in 2008. After suffering for three more years with little to no medication to relive his constant pain, Franco and his family pursued the only treatment available to him – deep brain stimulation. While the surgery improved his symptoms, Franco still braves pain, muscle dysfunction and dystonic storms, which are described as intense with prolonged periods of muscle spasms. The toll it is taking on his life and his family's is massive.

"Research is the key to making advances in diagnosis and treatment for dystonia", says Dr. Dennis Bulman, Senior Scientist at the Children's Hospital of Eastern Ontario who specializes in myoclonus dystonia research. "While important progress is being made and new treatments are not that far off, we must continue to push forward, raising funds, through events like Chuck's Run, which are critical to the development of new treatments."

Despite his severe physical impairments and discomfort, Franco took part in the 9th annual Chuck's Run for Dystonia in High Park on Sunday, June 1st. Though his participation he hopes to motivate and inspire others to join him in his fight to live a pain free life.

Understanding Myoclonus Dystonia

Dennis Bulman Ph.D., FCCMG, FACMG
Senior Scientist, Children's Hospital of Eastern Ontario,
Associate Professor, Department of Pediatrics, University of Ottawa

Our current understanding of involuntary movement disorders remains poor, in large part due to our lack of insight into the disease process and this lack of knowledge is also reflected in the poor efficacy of currently available treatments. We are working towards understanding the causes of Myoclonus-dystonia (MD), a movement disorder that typically affects the upper half of the body. Affected individuals experience quick, involuntary muscle jerking or twitching (myoclonus) that usually affects their arms, neck, and trunk. More than half of affected individuals also develop dystonia, a pattern of involuntary muscle contractions that causes twisting and pulling movements of specific body parts. The onset of symptoms usually occurs before the age of 20 and people with M-D are at significant risk for developing psychological conditions such as depression, anxiety, panic attacks, and obsessive-compulsive disorder.

Myoclonus dystonia is a genetic disorder and the only known gene to cause this disorder is epsilon-sarcoglycan (*SGCE*). Mutations in SGCE account for only 40% of the cases of Myoclonus Dystonia and we would like to know what is responsible for the other 60% of cases. Recently we identified a new gene that when mutated also causes Myoclonus Dystonia. At this moment, nothing is known about the function of this gene. Our current research is basically divided into three parts. First, we want to determine the function of the gene. Second, we want to determine how the mutated version of this gene causes Myoclonus Dystonia. We have preliminary evidence to suggest that this new gene can effect the expression of other genes. Our third aim is to identify these genes and figure out how they are controlled by this new gene. We are collaborating with other research teams around the world as we try to figure out this complicated disorder.

DMRF-Funded Researchers Discover First TorsinA Chaperone Protein BiP Revealed as Potential Therapeutic Target

A study co-funded by the DMRF and published in the *Journal of Biological Chemistry* reveals a critical new clue about the origins of dystonia. Since 1997, scientists have known that a mutated protein called torsinA causes one of the most severe primary torsion dystonias, but the function of the protein remains unknown. A team of researchers has made important headway by uncovering a close relationship between torsinA and BiP a well-studied cellular protein that was not known to have an association with dystonia until now.

Dystonia is believed to result from improper signals in the nervous system that instruct muscles to contract involuntarily. Researchers do not yet fully understand the neurological mechanisms that cause the abnormal muscle contractions.

Jeffrey Brodsky, PhD, Professor and Avinoff Chair of Biological Sciences at the University of Pittsburgh and Michal Zolkiewski, PhD, Associate Professor of Biochemistry and Molecular Biophysics at Kansas State University, co-led a study that used a sophisticated yeast cell model to investigate several proteins that interact with normal torsinA and its dystonia-causing mutant. The cell proteins belong to a family of chaperones, which are molecules that help other proteins take shape and function properly or, in case of faulty proteins, disassemble and deactivate them. When torsinA is mutated, it cannot function properly and becomes a target for chaperones—and particularly for BiP, which appears necessary to degrade mutant torsinA. BiP stabilizes both normal and mutated torsinA in mammalian cells; it is the first identified chaperone to act on torsinA. The function of BiP is well-understood, and development of potential treatments based on its interaction with torsinA may now be possible.

Dr. Brodsky explains, "For the first time we identified a cellular protein—known as BiP—that helps torsinA attain its proper shape in the cell. Because drugs that target cellular helpers such as BiP are in development, we hope that these might someday be used to treat primary torsion dystonia."

The study also found that secondary mutations in torsinA, in addition to the specific DYT1 mutation known to cause dystonia, amplify the effects of the defective protein when the dystonia-causing mutation is present.

Brodsky laboratory is known for its expertise in studying cellular proteins in yeast. The yeast genome makes it possible to conveniently track genes and proteins, especially those that have human equivalents, making it a valuable model for research on human diseases. Although the discovery that the BiP protein modulates torsinA function was made in yeast, the researchers were able to validate the results in human cells.

"The next step is to identify other cellular helpers that impact torsinA," says Dr. Brodsky. This work is now conducted by DMRF research fellow Lucia Zacchi, PhD, Research Associate at Fundacion Instituto Leloir in Argentina, formerly a post-doctoral researcher in Brodsky lab. Dr. Brodsky adds: "Additional proteins from her continued analysis might one day also be targets of newly developed drugs to treat primary torsion dystonia."

To learn more about the DMRF research efforts, visit www.dystonia-foundation.org/research

Citation: The BiP Molecular Chaperone Plays Multiple Roles during the Biogenesis of TorsinA, an AAA+ ATPase Associated with the Neurological Disease Early-onset Torsion Dystonia. Zacchi LF1, Wu HC, Bell SL, Millen L, Paton AW, Paton JC, Thomas PJ, Zolkiewski M, Brodsky JL. J Biol Chem. 2014 May 2;289(18):12727-47.

Genes & Proteins Associated with Dystonia

Mutations in specific genes cause certain types of dystonia. Genes encode proteins, which fulfill specific functions in the body. Here is a chart of DYT-designated genes associated with dystonia, the proteins they encode, and forms of dystonia. *Please note that this is not a comprehensive list of all genes associated with dystonia. Many disorders in which dystonia is a consistent and dominant feature were described before the DYT labels came into use.*

Designation	Gene	Protein	Dystonia
DYT1	TOR1A	TorsinA	Early-onset generalized torsion dystonia
DYT2	Unknown	Unknown	Early onset segmental torsion dystonia
DYT3	TAF1	Transcription initiation factor TFIID subunit 1	X-linked dystonia parkinsonism
DYT4	TUBB4a	β-tubulin 4a	Primary laryngeal and cervical dystonia - whispering dysphonia
DYT5/ DYT14	GCH1/TH	GTP cyclohydrolase 1/ Tyrosine 3-monooxygenase	Dopa-responsive dystonia
DYT6	THAP1	THAP domain containing, apoptosis associated protein 1	Adolescent-onset torsion dystonia of mixed type
DYT7	Unknown	Unknown	Adult-onset focal cervical and laryngeal dystonia
DYT8	PNKD1/MRI	Myofibrillogenesis regulator-1	Paroxysmal nonkinesigenic dyskinesia
DYT9	SLC2A1/ GLUT1	Glucose transporter protein type 1	Paroxysmal choreoathetosis with episodic ataxia and spasticity
DYT10	PRRT2	Proline-rich transmembrane protein 2	Paroxysmal kinesigenic choreoathetosis
DYT11	SGCE	Epsilon-sarcoglycan	Myoclonus dystonia
DYT12	ATP1A3	Sodium/potassium-transporting ATPase subunit alpha-3	Rapid-onset dystonia-parkinsonism
DYT13	Unknown	Unknown	Multifocal/segmental dystonia
DYT15	Unknown	Unknown	Myoclonus-dystonia
DYT16	PRKRA	Protein kinase, interferon-inducible double stranded RNA dependent activator	Young-onset dystonia-parkinsonism
DYT17	Unknown	Unknown	Autosomal recessive primary torsion dystonia
DYT18	SLC2A1	Glucose transporter protein type 1	Paroxysmal exertion-induced dyskinesia 2
DYT19	Unknown	Unknown	Episodic kinesigenic dyskinesia 2
DYT20	Unknown	Unknown	Paroxysmal nonkinesigenic dyskinesia 2
DYT21	Unknown	Unknown	Late-onset primary torsion dystonia
DYT23	CIZ1	CDKN1A interacting zinc finger protein 1	Primary cervical dystonia
DYT24	ANO3	Anoctamin 3	Primary cranial and cervical dystonia
DYT25	GNAL	Guanine nucleotide-binding protein G(olf), subunit alpha	Primary dystonia of varied anatomical symptoms and age of onset

Thank you to the DMRF for providing the above research article and Gene/Protein Table

DMRF Canada Volunteering

Alison Cook & Jenny Mulkins, Communications & Media Relations Specialists

ALISON COOK

Alison Cook & Corey Tkachuk & family

Dystonia first entered my life in 1999 when I was diagnosed with vocal dystonia. I'd been searching for two years for an answer to explain my sudden inability to speak without sounding like someone had their hands tightly wrapped around my neck. Most doctors were mystified by ailment, concluding I was simply stressed, until finally Dr. Irish at Toronto General Hospital along with some doctors at Toronto Western concluded I had the third most common movement disorder, dystonia.

I began participating in Chuck's Run in 2007 and began volunteering for the Run in 2010. I was inspired to do more after seeing people at the event who were clearly suffering with seriously debilitating versions of dystonia. From younger to older, their situations moved me and I wanted to help support, in any way I could, research into finding a cure or better treatments for this life-altering neurological disorder. "More needs to be done" was the thought that kept circulating through my mind and I feel that even more so today. Leveraging my background as a communications specialist to help raise critical funds for dystonia researchers seemed the best way to do so.

As a volunteer, I've been working along with Jenny Mulkins on media relations. Our goal essentially has been to inform the media about dystonia while leveraging news-worthy stories in an effort to secure awareness-building coverage. While dystonia is such a worthy and important cause, securing coverage, with shrinking media budgets and the "clutter," as it's called in the industry, of media pitches, has been challenging. I feel though we've had some important success and I hope the coverage we've secured, such as CITY TV's three part series on Matthew Sheppard's DBS surgery and a health segment on Global TV have helped the public at large to better understand dystonia and what it means for those people suffering with it.

My participation has been an enriching experience. From meeting inspiring individuals like Matthew, Spencer Clough and Franco Mazzella who battle every day to perform some of life's simplest tasks; to having the opportunity to speak to Dr. Dennis Bulman, a bright and passionate researcher who is so amazingly committed to finding a cure; to working with the dedicated and focused individuals who make up the Chuck's Run team, it has been an life-altering experience in the best way possible.

I feel optimistic about the future for those of us ailing with dystonia. Important strides are being made on the road to a cure with researchers making vital progress every year. But until those critical discoveries are made and properly leveraged into new treatments and ultimately a cure, I know many of us will continue to make our own strides every year in June, walking or running in Chuck's Run.

JENNY MULKINS

My name is Jenny Mulkins, I have been volunteering with the Dystonia Medical Research Foundation for the past three years working on the fundraising event Chuck's Run/Walk for Dystonia.

Sisters: Christine, Catherine, Jenny

My older sister Catherine, was diagnosed with Dystonia at the age of 41, but she lived with symptoms undiagnosed for most of her life. She managed the symptoms privately and in her own way. Growing up I never noticed her Dystonia. She was my older sister; she could do anything and was good at everything. Other than the odd frustration with writing, she really never dwelled on it and it certainly never stopped her. In school, writing became her biggest frustration. Not understanding the reasons why her hand would shake and mark up her page, she would crumple up her paper and start over again. At the age of 19, she was misdiagnosed with Essential Tremor. In University, she taught herself to write with her other hand.
As she got older and was embarking on her career, she began questioning her condition more. Managing her tremors with exercise and yoga to "reduce stress" was not the answer – it was something more and she knew it. As the years went by, her symptoms began to impact her day to day functions and after having children of her own, she decided it was time to get to the bottom of what she was facing. Test after test, medication after medication, she persevered and battled to find the answer. Finally, after 30 long years of living with and managing her condition on her own, she was diagnosed with Dystonia. All of us were shocked, scared, and speechless. We had never heard of Dystonia and we didn't know what we could do; we felt helpless.

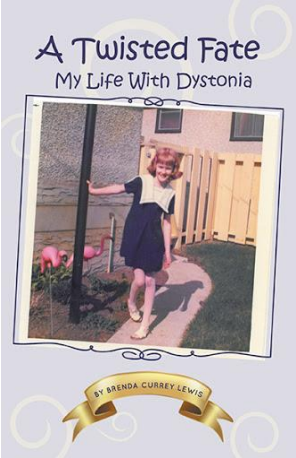
A few years after her diagnosis, I decided I needed to do something to help. So, on her 46th birthday, with my sister as inspiration, I called the Dystonia Medical Research Foundation to volunteer. It could be stuffing envelopes, answering phones, I was happy to do anything. It was supposed to be my gift to her. And as I discovered later, it also became a gift to myself. A few weeks later, I received a call to assist the Foundation with a large mailing. I was thrilled and ready to stuff! After a full day of stuffing, sealing and trips to the post office, I was able to sit and chat with Diane Gillespie, Executive Director of the Foundation. Our conversation led to my field of work as a freelance communications specialist. It just so happened that while they had an excellent communications specialist, Alison Cook, already volunteering, they could use another set of hands to help with Chuck's Run/Walk for Dystonia. It was a perfect fit and more than I could have hoped for. The rest is history.

The decision to volunteer with the organization was a personal one inspired by my sister. Feeling powerless, I chose to offer my help in a way that I hoped would allow me to feel I was doing something. While her diagnosis was what propelled me to become involved, realizing how many people and families are affected by Dystonia, I became inspired and wanted to help in a broader sense. Although my volunteer role is very small in the grand scheme of things, my reasons for volunteering are now not just about me and my loved one, but about helping this tremendous Foundation reach its goals.

These past years have been a phenomenal experience for me and for my family. We have all become more active in the organization, and have learned so much more about Dystonia. I have had the good fortune to meet many wonderful and inspiring people, all while working with a dedicated group who share a common goal. I believe the decision to volunteer is an individual choice and perhaps is not for everyone. It has enriched my life in so many ways and I hope to continue do so for many years to come.

A Twisted Fate

My life with Dystonia by Brenda Currey Lewis



Brenda Currey Lewis was a typical, active child. But when she was seven years old in 1974 her life changed dramatically. Generalized dystonia turned her muscles against her. With her mom's unwavering advocacy, she has navigated the unchartered waters of this baffling disorder Brenda started walking on the outer edge of her right foot, and within a year she was wheelchair bound. The symptoms gradually spread through most of her body. For almost forty years Brenda has experienced uncontrollable muscle movements that have wreaked havoc in her body, but not her spirit.

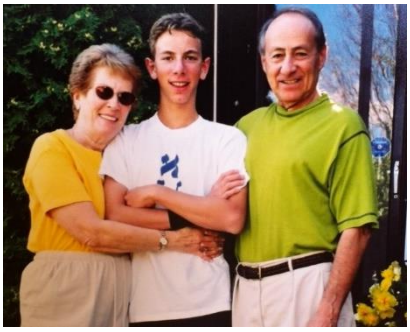
This is a story of resilience in the face of a little-known, confusing, and debilitating condition. Brenda's quirky sense of humour makes this candid account of life with dystonia a thought-provoking and an entertaining read.

Brenda was the president of the Edmonton Dystonia Support Group for twelve years and is still involved in raising funds and lending guidance to newly-diagnosed dystonia patients. She wrote A Twisted Fate to raise awareness about dystonia, and she looks forward to the day that medical researchers find a cure for this unwelcome intruder. To order A Twisted Fate go to Amazon.ca

In Tribute – Anita Pearlman

By: Connie Zalmanowitz, Edmonton Support Group, DMRFC Board Member, Daughter

My mom, Anita Pearlman, passed away March 5 of 2014, after a brief illness.



The late Anita and Paul Pearlman with Laurie Zalmanowitz (centre)

She was a young 82, still very much engaged in current events (reading 2 newspapers a day), playing mahjong, participating in yoga and loving social gatherings. With my son and her grandson Laurie living with dystonia, my mother was an active volunteer in the Edmonton Dystonia Support Group. Every year she happily stuffed over 300 envelopes during the mail out of our annual letter campaign and helped stuff them again, when it was time to send receipts. She and my dad helped out with our Walk and Wheel Events back in 1999, 2000, and 2001 helping us raise over $50,000 in three years. When we started having our casinos in 2008, I could always count on her to be a chip runner. She was at our last Annual General Meeting in December 2013. That was one of her last outings.

My mom was always very supportive of the work I did to raise awareness and funds for dystonia. She loved and admired her grandson Laurie and knew that her help would get us just a little closer to finding the answers we all want. She will be missed.

In Memoriam

Our Condolences to the Family and Friends of:

Bert Calvert, Doris Davis, Jean Henderson, William Jago, Judy Johnston, William McLuhan, Anita Pearlman, Donald Steere, Carolyn Leigh Stock, Inge Wirag

A TALE OF TWO SISTERS

Laurie Bell & Penny Patterson

Sisters Penny Patterson and Laurie Bell grew up Dundas Ontario with their parents, another sister and two brothers. Life was normal in this rural family until Penny started exhibiting balance problems 47 years ago around the age of five. Laurie started experiencing earaches and jaw aches in 1989.

Laurie Bell & Penny Patterson

How did you get your diagnosis?

Laurie: Penny recommended I see her neurologist. I made my appointment with her in Sept of 1989.

Penny: Oddly enough, because of balance problems we were directed to an ear specialist. He found nothing wrong with my ears and directed us to a wonderful neurologist in Hamilton, Dr. Daniel Levy. He knew pretty quickly what I had. But to be sure I had to go to Sick Kids hospital for tests and a spinal tap.

What treatments have you been on?

Laurie: I have tried many different drug combos. Many were incompatible with my system, or had little effect on my dystonia. I had denervation surgery, in 1993, in Montreal. This gave me return of some flexion & stopped my migraines. It caused an extreme loss of support on the left side of my neck.

Penny: What haven't I been on? I was one of the first kids to try L-dopa (Now Sinimet) in the pure form at age 8 in Montreal's neurological Hospital. It made me very nauseous, gave me nightmares, hallucinate but it helped. I came home after 6 weeks alone in Montreal hospital a new improved me! I'm thinking age 9. At age 20 I underwent a thalamotomy on the left front quadrant of my brain. The doctors were all set to do the other quadrants but after the first one, I said 'No Way'! (Being wide awake for brain surgery is not fun.) At 26-27 I had a severe decline. My torso was constantly in spasm to the left while my head went into severe retro position. This was the first time dystonia caused me disabling pain that I recall, besides many headaches I had as a kid. I became clinically depressed and was on major drug trials which lead to unhealthy weight-loss. But I got help for my depression, got pain relief from Tylenol #4 and Botox shots that helped tremendously with my retro postured head. First Botox shots were in 1989...I was back!

How are the treatments you are currently on helping you?

Laurie: Gabapentin is a good neuro pain reliever, with no obvious side effects. I am also taking clonazepam & baclofen. Have been taking them for so long, I am no longer really aware of what they do. I would probably notice a change if I went off them. I have decreased my dosages of them both with little change. I include regular physiotherapy and yoga sessions as part of my treatment.

Penny: I take anti-spasm and pain meds mostly for muscle and head-aches and Botox twice a year. I can tell when I've missed or forgotten my Spasm meds. My hands become more uncooperative than they already are and I can tell when Botox is wearing off but have more trouble feeling it kick in.

How has dystonia impacted your life?

Laurie: It is difficult to have to give in to being more dependent on others, especially my husband. (Because he wants to be too helpful) Having to quit work was extremely emotional. It is very difficult to have to move at such a slower pace...in all things. It has shown me the importance of physical activity, as my physiotherapy and yoga programs have been life savers. They have helped me stop needing narcotic pain killers.

Penny: This is a very difficult question to answer. I've had dystonia for as long as I can remember. Mom and Dad didn't let me just sit life out, they were always pushing me to get out there and live life however I could. So I did and still do. I keep myself as physically fit and flexible as I can. But life with dystonia is all I remember. It's not who I am but just something I deal with.

What has being a part of support group meant to you?

Laurie: It has given me an occupation, purpose. It has helped to educate me at a time when we had no internet. It helped me gain a place in a local

dystonia community, with whom I can share much. And help, too. Helping others is a huge aid in maintaining my positive attitude.

Penny: I've been a participant and was the leader for several years. I got the most value as a leader but found that I required more tangible support to lead the group. As a group member, my participation has declined.

How has being sisters helped your journeys?
***Laurie*:** Having Penny to turn to gives me an instant support group. Any advice I need, ranting "I want to do", understanding "I need" is just a phone call away. She also mentored me in a big way when I was first diagnosed...mainly by giving me an example to follow.

Penny: Laurie plays a special part in my life. Laurie has become my sounding board, my crying wall and my voice of reason. I think she has become more understanding of what I went through as a kid and now as an adult. Sharing a common challenge has helped bring us closer together and has also resulted in having a sister that can help and support me in ways that only someone walking the walk can do.

What encouraging words can you share with others?
Laurie: First, educate yourself, find support. Get a handle on your pain, any way you can, then you can begin to rebuild your life in a different direction, if current doors have been closed to you. Try any treatment once, naturopathy, hypnosis, Physiotherapy, yoga, pharmaceuticals...whatever works, stay with it...talk with people who have tried these treatments. Find a way to keep your body moving. This brings fresh blood (oxygen) to spasm sites and will help flush away pain causing toxins. It will help keep tight muscles loose.

Penny: Dystonia doesn't define who you are. Get out there and live the best life you can. To coin a phrase, this is not a dress rehearsal – make the most of what you got!

Freedom to Move for Dystonia Events

Sudbury and District, *Leader Mary Guy*

We all had a good time raising $18,000 with less than 50 people. That is quite an accomplishment and we should all be proud. Half of this came from the tremendous efforts of Dwayne Backer who brought in $9001.25, once again surpassing last year's total. Wal-Mart again contributed $2,000 to match the employee's contributions. Thank you Dwayne for all of your hard work. You are an inspiration to all of us.

Top prize winners for the most pledges obtained were: Dwayne Backer, Richard & Mary Guy, Brianne Cartmill, and Lauraine Blais. Congratulations to all of you! A special thank you to Linda Thompson, for organizing the BBQ, donating the hamburgers and getting a door prize. Thanks to Harry Thompson for delivering the BBQ to the site and getting some amazing door prizes. Thank you Len Shymkiw for barbequing and door prize, Brenda Morris, Barb Zaitz, Lise Depatie and Sue Leroux for keeping track of the walkers and the money that they brought in Thank you all again for your support. You are all special people.

Hamilton Area, *Hamilton Area Co-Leader Rose Gionet*:

FREEDOM TO MOVE 2014, RAISED OVER $7,000.00 Our awesome volunteers made the day go smoothly and we just couldn't have enjoyed it without them namely: the group of young people who helped with refreshment area: Alex Ramsay, Kayla Louden, Samantha Leroux Kelsey Gowans, Violet Griffen and volunteers Lorraine Stevens, Marian Voisin(check-in), Shirley McManus, Tammy Louden (raffle & 50/50 tickets) Ron Ramsay (BBQ) and Wendy Ramsay (kitchen help) Myrtle Gowans, Paul Gowans, Dave Bell, Dave Stevens, Dave Gionet (set-up). I could do this without my husband, Roland who oversaw the setup; announced the draw numbers and prizes, and my co-leader Laurie Bell who always gives 100% of her time and helping hand, plus contributing great prizes. Thanks to : Schneiders (Jerry Pilon); Allergan(Marlynn Fortino) and Giant Tiger, (Myrtle Gowans)for the refreshments. Raffle table gifts were donated by Lynn Johnston cartoonist, *For Better or For Worse*, Molson, Royal Botanical Gardens, Abronne Facial Produces, Shoppers Drug Mart, 3 for 1 Glasses, CE Johnson, Home Hardware, Garden Gallery, Pampered Chef, Vicors Vice Restaurant, Powerhouse Restaurant, Tim Hortons, Raffle gifts: Marian Voisin hand-crocheted blanket and two watercolours by Judy Vansickle .

Golden Triangle District, *Leader Judy Harsch*

Our walk took place on June 1 and it was a beautiful day. We had 7 participants and 5 walkers. We raised $1,385.00

Greater Toronto Area — Chuck's Run/Walk for Dystonia, *Chair, David Jaakkola*

This year's event was spectacular with over 230 participants and 50 volunteers. Chuck's Run/Walk raised $33,000 due to the efforts of our many committed volunteers. In particular: David Jaakkola, Chair, Bill and Paul Saundercook, Honourary Chairs, Alison Cook and Jenny Mulkins, Media Relations, Shirley Lee, GTA Support Group Leader – along with legions of volunteers managing every aspect of the event from Greeters, Table and Tent set up, Course Marshalls, Water Station Attendants, Registration. Thanks to Region of Peel Students, and Loretta Jacques DMRFC, registration, set up, suppliers, permits.

Shirley Lee (GTA Support Leader), Diane Gillespie, Barbara Jaakkola, Stephanie Wong, Wendy Paul

Top fundraisers included David Jaakkola, Alison Cook, Cory Tkachuk, John Mazzella, Sid Paul and Bill Saundercook . Sponsors included, Merz, Dunpar, Daniels Corp, Grenadier and No Frills.

Please Donate – We Need Your Help!

Copy or Clip this form and return in the envelope provided to: **Dystonia Medical Research Foundation Canada, 305-121 Richmond St. West, Toronto, ON M5H 2K1**

❍ **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 $_____**

❍ **I wish to make a monthly donation ❍$50 ❍ $25 ❍ $15**

PAYMENT OPTIONS

❍ **Please charge my credit card: ❍ VISA ❍ MasterCard ❍ American Express**

Name on Card: _____Card Number: _____

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Phone **Email Address**

Charitable Registration Number 12661 6598 RR0001