

# Dystonia Canada Report

DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION  
CANADA



FONDATION DE  
RECHERCHE  
MÉDICALE SUR LA  
DYSTONIE  
CANADA

*serving all dystonia-affected persons  
déservant toutes personnes atteintes de dystonie*

A Newsletter of the Dystonia Medical Research Foundation Canada

Winter 2013/14



## Calgary Chapter Presentation

Feng Luo, PhD, Zelma Kiss MD PhD FRCSC, Marg Roy, Chapter President, Yarema Bezchlibnyk, MD PhD

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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**



DMRF Canada eagerly looks forward to the year ahead, to more advancements in dystonia research, to more individuals, organizations and medical professionals becoming aware of dystonia, and, to working with governments to advocate on behalf of people affected by dystonia

Looking back, we take pride in knowing that our outreach to physicians has shortened the average timeline for diagnosis and broadly improved patient care.

We continue to provide help to families at a time when they need it the most – when they first receive the diagnosis of dystonia. We work with a nation-wide network of volunteers who help these people access the resources that they require through one-on-one conversations, support groups, information meetings, awareness events and information on movement disorder neurologists in their province.

Since the beginning, we have been committed to the belief that the best service we can provide the dystonia community is to work every day toward finding a cure. We are nearing a tipping point. Earlier this year, our research partner DMRF celebrated the groundbreaking discovery and identification of a new dystonia gene called GNAL, which impacts both child-hood onset and adult-onset dystonia and provides another important piece of the puzzle in understanding the disorder.

Research advancements like these, fueled by DMRF Canada research investments are finally bringing new treatments for dystonia within the reach of those who are so desperately waiting for them.

The challenge of funding progressive projects for dystonia continues and the number of newly diagnosed who contact DMRF Canada continues to grow. We cannot do this alone.

Our heartfelt thanks goes to all of our donors, supporters and most of all to our volunteers, who help make our research and out-reach efforts possible.

Sincerely,

A handwritten signature in blue ink that reads "Diane Gillespie". The signature is fluid and cursive.

Diane Gillespie, Executive Director

## DMRF Canada Announces Appointment of William (Bill) Saundercook to its Board of Directors.



It is with great pleasure that the DMRF Canada Board of Directors welcomes Bill Saundercook as a member of the Board. The Saundercook family have been long time leaders in the Toronto dystonia community. Bill's brother Chuck Saundercook the second youngest of nine Saundercook siblings died from complications of generalized dystonia at the age of 16 in 1978. Over the years, Bill has been a tireless supporter of dystonia awareness and research through hosting fundraising swimathons in the family's small backyard pool to leading the annual Chuck's Run/Walk in High Park as Honourary Co-Chair alongside his brother Paul.

Professionally Mr. Saundercook has been a teacher with the Dufferin - Peel Catholic School Board; Toronto City Councillor High Park for 25 years and held positions in Council of Deputy Mayor, Budget Chief and many others. Bill currently is Senior Vice President of Forum Research in Toronto.



*David Jaakkola and Bill Saundercook at Chuck's Run*

### *In Memory*

**ELIZABETH (BETTY) CATHERINE SAUNDERCOOK** Passed away peacefully on Wednesday, November 27, 2013 in her 80th year at her home with her children and grandchildren at her side. Betty valued family, friends, faith and a positive outlook. Her influence lives on in all of those she touched by her presence.

Betty had a long history with DMRF Canada. Through her dedication to raising dystonia awareness and raising money for dystonia research Betty has left an enduring legacy. She founded the Toronto DMRF Chapter after her son Chuck died from complications of dystonia in 1978. Mrs. Saundercook was an inspirational fixture at the DMRF Canada Toronto Freedom to Move event each June. In 2012 the Event was renamed "Chuck's Run".



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### *In Memoriam*

***Our Condolences to the Family and Friends of:***

*Betty Eby, Don Eby, Robert Barr, Irene Bouffard, Shawn Burke, Violet Burt, Terry Cholack, Frances Conacher, Lloyd Conliffe, Paul Corbeil, Barbara Hawkins, Blair Mitchell, James Morris, Dwayne Wharram*

# What is Dystonia?

## DMRF Partners with Expert Clinicians to Update Dystonia Definition and Classification

1984 marked a milestone in dystonia research: the DMRF (United States) convened a committee of movement disorder experts to provide the medical community with a definition of dystonia and classification system for the many forms.

Until the late 1970s, dystonia was widely unrecognized or misunderstood as an obscure psychiatric phenomenon. But a small group of neurologists insisted dystonia was being mis-characterized and patients were not receiving proper care.

The 1984 definition and classification secured dystonia's designation as a neurological movement disorder and quickly became the accepted clinical description for several decades to come.

Since that time, researchers have learned so much about dystonia that even the language used to discuss the disorder needed an update. In 2010 Alberto Albanese, MD of National Neurological Institute, Carlo Besta (Italy) began encouraging members of the movement disorders community that the time was right to act, spearheading the effort by asking the DMRF to consider supporting a meeting of experts to review the definition and classification devised in 1984.

### Article at a Glance:

- The definition and classification of dystonia will continue to evolve as the research progresses.
- The word "dystonia" may indicate a specific movement symptom or a collection of neurological disorders in which dystonia symptoms occur.
- A consensus paper drafted by experts simplifies the classification by grouping dystonias by clinical features and by cause.
- Terms like "primary" and "secondary" dystonias have caused confusion, and are being replaced by more accurate descriptions.
- Vague categories like "early onset" and "late onset" are replaced by more specific age designations.

The DMRF provided initial support and helped form a committee of experts to address this matter, eventually partnering with the Dystonia Coalition and the European Dystonia Cooperation in Science and Technology (COST) Action. After preliminary discussions, the process began in 2011 and the committee met opportunistically several times in conjunction with international meetings.

A consensus paper was published this year in *Movement Disorders*.<sup>1</sup> The paper describes the conclusions of an international panel of

investigators with years of experience in the field. The updated definition and classification describe dystonia more accurately and provide an improved framework for the medical community to guide diagnosis, diagnostic testing, treatment, and research.

What does this mean for individuals and families in the dystonia community? The consensus paper integrates some of the latest dystonia research and may influence how your doctor describes dystonia.

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<sup>1</sup> Albanese, A., Bhatia, K., Bressman, S. B., DeLong, M. R., Fahn, S., Fung, V. S.C., Hallett, M., Jankovic, J., Jinnah, H. A., Klein, C., Lang, A. E., Mink, J. W., and Teller, J. K. (2013), *Phenomenology and classification of dystonia: A consensus update. Mov. Disord., 28: 863–873. doi: 10.1002/mds.25475*

## Defining Dystonia: A Moving Target

Ever since the first description of dystonia in the late 19<sup>th</sup> century, there has been ongoing debate about the classification and descriptions of the various forms. The definition and classification will continue to evolve as researchers learn more about dystonia. Dystonia represents a complex group of syndromes. The term dystonia may indicate a specific kind of involuntary movement—i.e. a symptom—or any number of neurological disorders in which dystonias occur.

It is important to have a classification system that guides diagnosis and also identifies dystonias by the cause, if known, to guide future research and treatment. This makes it challenging to develop a single system that serves both purposes.

Instead of classifying dystonia along three major points of reference (cause, age at onset, body distribution) the consensus paper proposes a simplified scheme that classifies dystonia along just two: *clinical features* and *cause*.

## Clinical Features: What are the Signs & Symptoms?

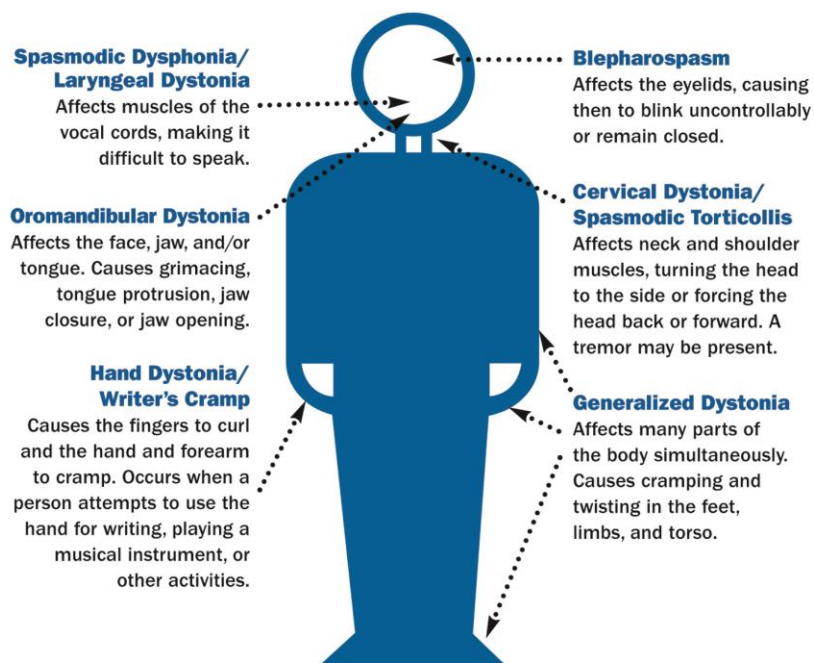
Clinical features are the signs and symptoms of dystonia. These include age at onset, body distribution, certain qualities about the symptoms, the presence of other movement disorders, and other neurological features. Doctors use these factors to guide diagnosis and treatment.

Age at onset for dystonia has traditionally been categorized as late onset (adult onset) and early onset (childhood onset). In order to keep the classification more consistent with stages of human development, the following categories seem more helpful:

- Infancy (birth to 2 years)
- Childhood (3-12 years)
- Adolescence (13-20 years)
- Early adulthood (21-40 years)
- Late adulthood (40+ years)

Definitions for describing body distribution remain largely unchanged in the new classification:

- Focal dystonia: Only one body region is affected. Examples include blepharospasm, oromandibular dystonia, cervical dystonia, laryngeal dystonia/spasmodic dysphonia, and writer's cramp.
- Segmental dystonia: Two or more adjacent body regions are affected. For example, cranial dystonia: blepharospasm plus lower face, jaw, and/or tongue involvement.
- Multifocal dystonia: Two non-adjacent body areas or more (adjacent or not) body regions affected. For example, cranial dystonia plus writer's cramp.
- Generalized dystonia: The trunk and at least two other body areas affected. Generalized forms with leg involvement are distinguished from those without leg involvement.
- Hemidystonia: More body regions restricted to one side of the body are affected.



Dystonia may occur in isolation or in combination with additional movement disorder symptoms such as myoclonus or parkinsonism. The diagram above describes several common manifestations of dystonia.

Daily changes of the symptoms—also referred to as temporal pattern—also guide diagnosis and treatment. The disease course can be static (meaning the symptoms are stable) or progressive (meaning the symptoms change or spread over time). The variability of symptoms may be grouped into four patterns:

- Persistent: Dystonia that is fairly consistent throughout the day.
- Action-specific: Dystonia that occurs only during a particular activity or task.
- Diurnal fluctuations: Dystonia that fluctuates during the day, often in recognizable patterns in relation to sleep and waking.
- Paroxysmal: Sudden episodes of dystonia usually induced by a trigger.

Dystonia can occur in isolation or in combination with other movement disorders. The term “primary” was introduced to define cases in which dystonia is the only present neurological disorder (with or without dystonic tremor). Cases previously referred to as “primary” or “pure” dystonia are now more accurately described as *isolated dystonia*, where dystonia is the only movement symptom with the exception of tremor.

Cases previously identified as “dystonia-plus” or “heredodegenerative” are now more precisely classified as *combined dystonia*: in these cases dystonia is combined with other movement symptoms such as myoclonus or parkinsonism.

The presence or absence of other neurological or medical conditions remains a critical component for classifying dystonia, for both clinical and research purposes; certain forms of dystonia are closely associated with other clinical characteristics that should be considered in the treatment process.

### **Cause: What Do We Know About Why Symptoms Occurred?**

Characterizing dystonia by what is known about the cause—also called *etiology*—is ever-evolving as researchers continue to explore the biological mechanisms that lead to symptoms. Knowing the causes of dystonia will guide more specific treatment and possibly prevention.

The consensus paper recommends considering dystonias in terms of *inherited* or *acquired* forms. Inherited dystonias are those with a proven genetic origin, for example mutations in the DYT-designated genes such as DYT1, DYT5, or DYT11. Acquired dystonias are due to a known specific life event or series of events, for example birth injury, drug exposure, brain injury, infection, and other factors. Psychogenic or functional dystonias are considered acquired dystonias, though this in an area that remains in debate even among experts.

However, there are many cases of dystonia that are *idiopathic*, meaning that there is no identifiable cause. This includes cases with or without a family history. There are families with multiple members who are affected by dystonia—suggesting an obvious genetic component—but no specific gene is known to be the culprit. Many of the focal dystonias that occur in adulthood fall under this category. As more genes are identified, certain idiopathic forms may be reclassified as inherited.

### **What’s in a Name?**

The updated clinical definition and classification of dystonia are significant because they demonstrate how far the research has progressed over the last 30 years. The field of dystonia has matured to the extent that it outgrew even the language used to discuss it. The authors of the consensus paper offer a simplified, more accurate system for doctors to diagnose and treat dystonia, and for investigators to guide further research. The DMRF is proud to have played a role in this important research milestone.

## Mindfulness-based Stress Reduction - a program to assist coping with stress and chronic illness



Toronto Support Group member Stephen Liu has found great comfort and relief in managing his dystonia symptoms through Mindfulness-based stress reduction (MBSSR). This program is offered in many hospitals, clinics and through private practitioners across Canada. In some provinces the program may be covered by the provincial health care plan, with a doctor's referral.

Mindfulness-based stress reduction is a behavioral meditation program modeled on the program developed by Dr. Jon Kabat-Zinn at the Stress Reduction Clinic at the University of Massachusetts Medical Center. MBSR is an approach to self-care

that can assist in managing stress, pain and illness. The practice of meditation is used to help people learn to focus awareness on body sensations, thoughts, and emotions in a nonjudgmental way. Through this practice, a person is given the opportunity to explore their inner world of mind/body, recognize and mobilize their inner psychological resources and take better care of the self.

## Dystonia Research in Calgary - Hosted by Calgary Chapter

The Calgary Chapter headed by President Marg Roy hosted an awareness/information session on November 2 at the Carriage House Hotel in Calgary. Over 40 people were in attendance, including DMRF Canada's Executive Director, Diane Gillespie. The keynote speaker was Zelma Kiss MD PhD FRCSC, Associate Professor, Clinical Neurosciences, Director Therapeutic Brain Stimulation & Research Laboratory, Hotchkiss Brain Institute, University of Calgary. Also contributing were Feng Luo, PhD, Post-doctoral research associate and Yarema Bezchlibnyk, MD PhD, Resident in Neurosurgery and Post-doctoral research associate.

The individual presentations offered a diverse overview of dystonia, causes, and treatments – in particular Deep Brain Stimulation (DBS). Marg Roy, chapter president commented, "The presentation was an excellent explanation of DBS and the amazing effects it can have on the lives of patients with severe dystonic symptoms. When nothing else seems to handle the pain and postures, DBS can usually restore so much of normal life to the dystonia sufferer as we have seen in our own group. Great to see the ongoing research this team is providing. It was most heartening to see so many new faces amongst our regular supporters."



The next general Calgary Chapter meeting will be held on Saturday May 10, 10:00 a.m. at the Carriage House Hotel, Windsor A Room, Calgary. The keynote speaker will be Tamara Pringsheim, MD, Assistant Professor, Department of Clinical Neurosciences, Psychiatry, Pediatrics and Community Health Sciences, University of Calgary. Dr. Pringsheim will present a special paper on the prevalence of dystonia and a presentation of types of and treatments for dystonia.

## Hamilton Area Dystonia Support Group Update

Our first meeting, after a summer break, was on Sept. 14. We do not often have speakers, but on that day, Thomas Wade, Canadian Country singer & songwriter came to talk to us about his own journey with dystonia and how hypnosis has helped him and others with dystonia.

Thomas was leader of the group **Thomas Wade & Wayward**, who released their debut album in 1996. The album produced seven singles on the Canadian Country Music chart, including the Top 10's "Zero to Sixty" and "She's Getting Serious." Between 1997 and 1998 Thomas Wade and Wayward received seven CCMA awards. The group was also nominated for three Juno Awards for Best Country Group or Duo in 1997, 1998 and 1999.



Wade launched a solo career in 2000 when he signed to Shoreline Records and released his debut album, *Lucky 13*. Five singles were released from the album, including the Top 10 "Running Away with You." Following the release of a career retrospective in 2001, *So Far*, Wade was diagnosed with oromandibular dystonia. While he was forced to end his recording career, he has continued his career as a songwriter. Celine Dion included one of Wade's songs, "Come to Me," on her 2004 album *Miracle*.

When Wade was diagnosed at Toronto Western Hospital in 2006 his symptoms were extreme. By 2010 he had worked with movement disorder specialists, but with no satisfaction. So, he began working with holistic healers and found much relief with hypnosis and relaxation techniques. He is once again able to play live shows and record his own songs and is in studio with his new group "River Deep" (featuring Colin Amey and Denise Wade). Currently a documentary is in production about his career and his battle with dystonia.

"I have been working with Liona Boyd to help her heal from Focal Dystonia using hypnosis, and the principles of Neuro-Plasticity that I used to heal myself. As well, I have worked with someone with respiratory Dystonia and Blepharospasm with very good results. Basically just to qualify, I actually can't claim to heal anything, as a Hypnotist...it is against the rules of the National Guild of Hypnotists." says Wade.

**The Third Annual Local music night for dystonia was held On October 19**, was held in Dunnville, Ont. at Flyer's Bakery & Café with \$360 being raised. It was a third annual local music night for dystonia. Several local musicians came to play a couple of tunes each. Some were originals, some were covers and many folks came to enjoy.

### Upcoming Hamilton Area Dates:

**Support Group Meetings:** April 12, September 14, November 8, December 13, St. Peter's Hospital, 10:30 a.m. Coffee, tea & cookies are provided

**Freedom to Move Walkathon –Saturday June 14, 2014, 10 a.m. Battlefield Park Pavilion  
77 King St. W., Stoney Creek, ON**

## Dr. Douglas Hobson presents to Winnipeg Support Group



Dr. D. Hobson, Director of The Movement Disorder Clinic at Deer Lodge Centre in Winnipeg presented to the Winnipeg Support Group. The group sent Dr. Hobson questions provided by the members prior to the meeting. Here are just two of the questions and corresponding answers:

1. There seems to be little if any awareness among general practitioners and other health providers, dentists, ophthalmologists, etc. about dystonia. What is being done to overcome this? *"This is an ongoing problem across the country. My peers and I provide continuing medical education regularly, when asked, to physicians out in practice and during their training, but there is no way to ensure the message reaches the majority of treating physicians particularly in some specialties that may not come out for our sessions. It is difficult to reach doctors through refresher and upgrading presentations if they do not attend. A recent study showed that it takes an average of three years after symptoms start for a person with dystonia to be accurately diagnosed in the Prairie Provinces. The average in Canada was longer."*
2. Are there any new developments coming from the discovery of genes linked to dystonia, or research into use of stem cells, etc.? *"This research in the genetics of dystonia is making steady progress. This eventually will lead to a better understanding of the underlying cause and with this new treatment options will be discovered. As is typical of medical research in many areas, the amount of available funding is the main limitation to moving faster in the process. I am not aware of any advances in stem cell research specific to dystonia."*

Dr. Hobson also presented an overview of the new dystonia clinical classification of dystonia being introduced in Canada.

The Winnipeg 'Dystonia Flapjack Fundraising and Awareness Breakfast' tickets are available. Saturday April 26 from 8 -10 a.m. at Applebee's Restaurant, 2025 Pembina Hwy. Tickets are \$ 10 each for a delicious pancakes, bacon, juice and coffee breakfast with \$7 from each ticket sold, going to the support group. There are 150 tickets. Please call Brian Crow (204-255-2633) for tickets.

**Upcoming Support meetings are: 1 p.m., Mar. 8, Apr. 12, May 10 and Jun. 14, St. Boniface Hospital, Room AF002**

## Greater Toronto Area Support Group

On October 21, the new GTA Support Group had its first combined Meeting. Shirley Lee, GTA Support Group Leader hosted and Diane Gillespie, DMRFC Executive Director led the group in a networking session and a presentation on DMRF Canada, its services, research funding, support groups and current advocacy initiatives. She stressed the importance for people with dystonia to use support systems and find ways to reduce stress. Ms. Gillespie encouraged everyone to look at ways that they can contribute to fundraising – as it is the key to more dystonia research and support.



**GTA Support Meetings: Greater Toronto Area – Last Friday each month – General Meeting April 26, 32 Kern Road, Toronto, Elaine Markowitz presenter, Mindfulness-based Stress Reduction.**

## Chuck's Run/Walk – 10:00 a.m., Sunday June 1, High Park, Toronto

### More Support Group Dates - Contact your local leader for information

**Golden Triangle** –March 2, April 6, May 4 –Freedom to Move Walk- 1:30 p.m. Sunday June 1, Victoria Park, Kitchener, ON

**Sudbury** –Freedom to Move Walk – 9:30 a.m., Sunday June 8, Howard Armstrong Recreation Centre, Hanmer, ON.

**Saskatoon**— Second Saturday of the month with no meetings in June, July, August, & September

**Ottawa** – Morning of every second Tuesday of the month (informal coffee get-together)

### DMRF Canada is recruiting group leaders in these areas:

- Vancouver • Vancouver Island • Ottawa • Montreal • Mississauga
- Etobicoke • Scarborough • Peterborough • Barre • North Bay • Halifax

Please contact Diane Gillespie 1-800-361-8061 if you are interested in joining or volunteering.

## Volunteer Chapter/Support Group Leaders and Area Contacts

<b>BC</b>	Anne	Skomedal	Kelowna Support Group Leader	250.763.7739	<a href="mailto:rskomedal@shaw.ca">rskomedal@shaw.ca</a>	
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	Cindy	McKay	Kelowna Area Contact		<a href="mailto:cansoda@shaw.ca">cansoda@shaw.ca</a>	
	Arlene	Czop	Chilliwack Area Contact	604.824.9849	<a href="mailto:raczop@shaw.ca">raczop@shaw.ca</a>	
	Grant	Kaiser	Vernon/Salmon Arm Area Contact	250.542.8509	<a href="mailto:cgkaiser@shaw.ca">cgkaiser@shaw.ca</a>	
<b>AB</b>	Margaret	Roy	Calgary President/Support Group Leader	403.271.4438	<a href="mailto:roymg@telusplanet.net">roymg@telusplanet.net</a>	
	Brenda	Lewis	Edmonton Support Group Leader	780.915.4294	<a href="mailto:bklewis@telus.net">bklewis@telus.net</a>	
	Joanne	Alford	Edmonton Area Contact	780.752.8605	<a href="mailto:dystoniasupport@shaw.ca">dystoniasupport@shaw.ca</a>	
<b>SK</b>	Diane	Haugen	Saskatoon Support Group Leader	306.477.0577	<a href="mailto:dystonia@sasktel.net">dystonia@sasktel.net</a>	
<b>MB</b>	Barbara	Crow	Manitoba Area Contact	204.255.2633	<a href="mailto:bcrow@mymts.net">bcrow@mymts.net</a>	
<b>ON</b>	Monica	McCool	Cornwall Area Contact	613.936.1356		
	Judy	Harsch	Golden Triangle Support Group Leader Kitchener/Waterloo/Guelph	519.767.9721	<a href="mailto:jjmarie@rogers.com">jjmarie@rogers.com</a>	
	Laurie	Bell	Hamilton Area Support Group Co-Leader	905.774.4111	<a href="mailto:landbell@shaw.ca">landbell@shaw.ca</a>	
	Rose	Gionet	Hamilton Area Support Group Co-Leader	905.575.3534	<a href="mailto:rgionet@shaw.ca">rgionet@shaw.ca</a>	
	Margaret	Ebdon	Kingston Area Contact	613.345.2115	<a href="mailto:Marge1002@gmail.com">Marge1002@gmail.com</a>	
	Jane	Soules	Kingston Area Contact	613.498.1472	<a href="mailto:soules1@sympatico.ca">soules1@sympatico.ca</a>	
	Michelle	Goodhue	London Area Contact	519.455.7457	<a href="mailto:bgood137@sympatico.ca">bgood137@sympatico.ca</a>	
	Bruce	Goodhue	London Area Contact	519.455.7457	<a href="mailto:bgood137@sympatico.ca">bgood137@sympatico.ca</a>	
	John	Heney	Ottawa Area Contact	613.224.6888	<a href="mailto:jjheney@netrover.com">jjheney@netrover.com</a>	
	Brian	Hall	Greater Toronto Area(GTA) Contact - Oshawa		<a href="mailto:bdh333@gmail.com">bdh333@gmail.com</a>	
	Shirley	Lee	GTA Co-Leader	416.441.2232	<a href="mailto:leeshirley0@gmail.com">leeshirley0@gmail.com</a>	
	Mary	Guy	Sudbury Support Group Leader	705.524.0606	<a href="mailto:maryguy@bellnet.ca">maryguy@bellnet.ca</a>	
	Tracy	Henry	Chatham-Kent, Sarnia-Lambton Support Group Leader	519.354.6833	<a href="mailto:tracyhenry1224@yahoo.ca">tracyhenry1224@yahoo.ca</a>	
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	<b>NB</b>	Edna	Jordan	Fredericton Area Contact	506.453.0708	
Tim		Williston	Fredericton Area Contact	506.457.2388	<a href="mailto:tim.williston@hotmail.com">tim.williston@hotmail.com</a>	
<b>NS</b>	Shirley	Sharkey	Moncton Support Group	506.204.2722	<a href="mailto:j.s.sharkey@rogers.com">j.s.sharkey@rogers.com</a>	
	Marcellin	Chiasson	Port Hawkesbury Area Contact	902.625.1811	<a href="mailto:marcellin.chiasson@ns.sympatico.ca">marcellin.chiasson@ns.sympatico.ca</a>	

### Join a Support Group

Dystonia often impacts every aspect of a person's life, and learning to live with dystonia can be a profound adjustment. Many people with dystonia describe the process of diagnosis and everyday coping as riding a rollercoaster with dramatic ups and downs. Despite the challenges of living with the disorder, members of the dystonia community are resilient, inspiring people. People with dystonia and their family and friends are benefitting from being a part of the dystonia community through their local support groups across Canada.

**DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA**  
**STATEMENT OF FINANCIAL POSITION**  
**YEAR ENDED DECEMBER 31, 2012 and 2011**

<b>ASSETS</b>	<b>2012</b>	<b>2011</b>
<b>Current Assets</b>		
Cash	375,634	248,649
Guaranteed investment certificates	100,349	200,000
Amounts receivable	7,376	10,764
Prepaid expenses	1,858	1,882
	<b>485,217</b>	<b>461,295</b>
<b>LIABILITIES &amp; NET ASSETS</b>		
<b>Current Liabilities</b>		
Accounts payable & accrued liabilities	8,004	35,141
Deferred Revenue	1,620	3,500
<b>Net Assets</b>		
Unrestricted	475,593	422,654
	<b>485,217</b>	<b>461,295</b>

**STATEMENT OF OPERATIONS & NET ASSETS**

**REVENUE**

Donations/Grants/Fundraising	544,811	381,429
Interest	1,607	3,693
	<b>546,418</b>	<b>385,122</b>

**EXPENSES**

Research grants & activities	267,000	256,920
Awareness, Education & Services	102,319	111,613
Fundraising	59,853	48,323
Administrative and professional costs	53,629	39,450
Advocacy	9,467	8,635
Governance	1,211	1,192
	<b>493,479</b>	<b>466,133</b>
<b>EXCESS of revenues over expenses</b>	52,939	(81,011)
<b>NET ASSETS, beginning of year</b>	422,654	503,665
<b>NET ASSETS, end of year</b>	<b>475,593</b>	<b>422,654</b>

# In Recognition

The Dystonia Medical Research Foundation thanks its many supporters, donors, sponsors and benefactors in 2012. 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.

## \$100,000 and up

Bel-Fran Charitable Foundation

## \$50,000 to \$99,999

Edmonton Support Group  
Estate of Cathryn Sweetnam

## \$25,000 to \$49,999

Canterbury Coffee Corporation  
DMRF Toronto Chapter  
(inparticipation with DMRFC Chuck's Run/Walk)

## \$10,000 to \$24,999

Lohn Foundation  
The Medtronic Foundation

## \$5,000 to \$9,999

Allergan Canada Inc.  
Deans Knight Capital Management Ltd.  
Murray Dunlop  
Hamilton Area Support Group  
Lutsky Families  
The Alvin and Mona Libin Fdn.

## \$2,500 to \$4,999

Calgary Chapter - DMRFC  
CIBC Children's Foundation  
Deloitte and Touche Foundation  
Diamond Foundation  
Theresa Furey  
Manitoba Support Group  
Wedgewood Hotel and Spa

## \$1,000 to \$2,499

Lil Faider  
Golden Triangle Support Group  
Green Shield Canada  
Murray and Tracy Henry  
Bob and Lily Lee  
MacDonald Development Corp.  
Bert Maron

Brian Mullen  
Daniels Oakmount Corporation  
PDA Architects  
Audrey Saliba  
Pearl Schusheim  
Sgt. Rick McDonald Mem Fund  
The Dianne and Irving Kipnes Foundation  
The Pekarsky Family Foundation  
Daniel and Connie Zalmanowitz  
Barry Zalmanowitz and June Ross

## \$500 to \$999

Atlas Copco, Global Strategic Customers  
Jennifer Barnett  
Darko Vranich-Vrancor Group  
Detour Gold Corporation  
Dine Alone Records Inc.  
Goldie Feldman  
Julius Gaudio  
Chris Greco  
Menashe and Riva Grinshpan  
Karen Hancin  
Aubrey Hannah  
Karen Hoar  
Monty and Eileen Kobrin  
James and Marilyn Luffman  
Eleanor McChesney  
Myguy Management Services Ltd.  
Richard Guy Professional Corp.  
Evan Roberts  
Sonamguy Inc.  
Stikeman Elliott  
Cheryl Thompson  
Hal Zalmanowitz  
John Zilli

## \$250 to \$499

Robert Abells  
Atlas Copco, Lively ON  
Frtitz Becker  
David and Laurie Bell  
Alyssa Boyd

Lou and Nancy Canton  
Janet Cauthers  
Joey Cecchini  
Earl Consky  
Richard and Sheron Currey  
John Di Costanzo  
Shirley Farquharson  
Lloyd and Yvonne Frazer  
JM and Deborah Ghent  
Greg Saari Merchandising Ltd.  
Herman and Faye Sarkowsky Charitable Foundation  
John and Marjorie Hines  
Jody House  
Intact Foundation  
Doug and Sherry Julien  
Steve and Lorraine Landau  
Leon and Jennifer Lenchner  
Lynn Johnston Productions Inc.  
Sean Mahoney  
Terry and Linda McBride  
Heather McCallum  
Helen McCuaig  
Melcor Developments Ltd.  
Douglas and Joanne Menard  
Catherine Mulkins  
Stephen and Denise Rogow  
Bill Saundercook  
Geoff Taber  
Grant Vogel and Lomore Alima  
Alanna Walters  
Christine Woodhouse  
Lauren Woods  
Jana Zalmanowitz

## \$100 to \$249

Melanie Aitken  
Mal Albaum and Maxine Bass  
Bernice Alford  
Michael Ambrosio  
Keith Anderson  
Gary and Joanne Appelt  
APS-Antian Professional Services  
Brenda Arseneau

Shirley Avery  
Elizabeth Baker  
Lance and Karen Balch  
Justin Barney  
Debbie Bauer  
Bay Street Video  
BBT Machining Inc.  
Bijoux Village  
Lise Bisnaire  
Raymonde Bisnaire  
Brenda Blakey  
David Bookhalter  
Angus Botterell  
Ghislain Boudreau  
Wayne Brassem  
Sydney Broer and Audrey Shecter  
Anne Brown  
Mark and Mary Burke  
Stephen Callahan  
Doris Carr  
Ken Cartmill  
Clyde Chafe  
Margaret Chambers  
Fraser Chapman  
Hugh Chapman  
Oscar Chiarotto  
Kyra Clarkson  
David and Susan Colvin  
Conoco Phillips Canada  
Ben and Ruth Coppens  
Jon Cote  
Laurine Cowie  
Elizabeth Coyne-Dubeau  
Andrea Crosthwaite  
Ron Csillag and Debbie Berlach  
Arlene Czop  
Sami and Mary Bess Dabliz  
Christian Dano  
Robert and Kathy David  
Colin Davies  
John de Valence  
David and Trudy Deacon  
Giovanni Delevadova  
Florival and Anne Marie Desousa  
Maria and Delores Di Costanzo  
Frank Di Costanzo  
Joseph and Elsie DiCiccio  
Gisele Dillon  
Kelly Dip  
David Douglas  
Paul Doyle  
Robert and Carol Dyck  
Peter Edmunds  
Peggy Epan

Richard Epstein & Rosemary  
Greisman  
Errol Raff Professional Corporation  
Greg and Catherine Farnell  
Bunny Ferguson  
John Ferrante  
Dewayne and Doreen Ford  
Robert Ford  
Mike Fraser  
Fulton United Church Women  
Fleurette Gallen  
Roland and Rose Gionet  
Mort and Elaine Goldbach  
Doug and Carol Gordon  
George Gowans  
Myrtle Gowans  
Jim and Ann Gowans  
Paul and Sheila Greenwood  
Alynn Grover  
Larry and Adelle Gusse  
Ernie Gutstein  
Adam Guy  
Mary Guy  
Sean Haggerty  
Mark Hammerschlag  
Barbara Hampe  
Norman and Roberta Hanson  
Judy Harsch  
Brian Heller and Bev Kupfert  
Nick Hertz  
Stuart Hicks  
Stu and Mary Higdon  
Sharon Hollohan  
Deborah Horowitz  
Margo Howard  
Eileen Hudson  
Scott Hudson  
Wendy Huseman  
William Hutchison  
Jean Hutton  
William and Shirley Jago  
Michael James  
Myron and Janice Jespersen  
Florence Johnson  
David Jonas  
Carl and Mavis Jonsson  
Juniper Networks' Company  
Matching Gifts  
Chester Kajdas  
Gregory Kasparian  
Jeremiah Katz  
Walter Kealy  
Keith Tankel Professional Corporation  
Ross Kennedy

Karen King  
Bernard and Anna Kleinberg  
Judith Klugerman  
Helen Ku  
Allain Labelle  
Lajoie Bros. Contracting Ltd.  
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Jordanna Lipson  
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Elizabeth Lloyd  
Enza Lucivero  
Barbara MacAulay  
Karen Mack  
Eric and Sharon Macklin  
Ruth Malitz  
Sharon Marcus  
Mike and Heather Marshall  
Ginette Martel-Gauthier  
Mirella Martire  
Frank Martire  
Maria Martire  
Marianne Martyn  
Seana Massey  
Nicholas Mattison  
John and Marisa Mazzella  
Joyce McGeachy  
Craig McGuffin  
Billy and Crystal McIntosh  
Walter and Marcia McCall  
Sharon McKinley  
Hazel McVicar  
Bryan and Joan Melick  
Claude and Lucile Milette  
Arliss Miller  
Josh and Michelle Miller  
Edna Mills  
James Moddle  
Bob and Joan Moir  
Franco Montano  
Gilles Montsion  
Mary Jane Mossman  
Jenny Mulkins  
Christine Mulkins  
Anne Marie O'Brien  
Kim Olnier  
John and Shirley O'Neil  
OT Grand Consulting Ltd.  
Sylvie Ouellet  
Reeva Parker  
Sid Paul  
Steven and Conni Pataki  
Tom Patterson  
Robert Paul  
Anita Pearlman

Dorothy Pearsall  
Stuart Peikes  
Ted Perioris  
Morris and Sarah Perlis  
Elaine Perry  
Wayne Pertman  
Asher and Sharon Pertman  
A. Petras  
Michael Pierson  
Steve Pocrnic  
Kent and Cindy Rapley  
Carolyn Readman  
Diane Reil  
Robert Richards  
Anna Richter  
Dan and Mona Rosenberg  
Allen Rudolph  
Mary Rukavina  
Evelyn Russell  
Ray Rutman  
Daniel Sacke  
Diane Sandler  
Elizabeth Saundercook  
Paul Saundercook  
Joseph and Nancy Saundercook  
Julia Sax  
Norman Schayer  
Sara Schiff  
Eric and Elexis Schloss

Stephan Schuler  
SCM Insurance Services/ClaimsPro  
Inc.  
Scotiabank, 57 Durham St. Sudbury  
Lorraine Scott  
Hart Sernick  
Shirley Sharkey  
Jack Sharp  
Howard and Reeva Shein  
Kayla Shoctor  
Marshall and Debby Shoctor  
Leonard Shymkiw  
Mary Smiley  
Edward and Linda Smith  
Howie and Debbie Sniderman  
Lorne Sorge  
South Cayuga United Church Women  
South Saskatchewan Community  
Foundation (Lyn Goldman)  
Michael Spaziani  
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STC Construction Group Inc.  
Don Steele  
Shawn and Donna Steggles  
Sharon E. Stevens  
Marilyn Stewart  
Mark and Lorraine Stillman  
Mark Stoneburgh  
Norma Stoneburgh

The Church of St. John The Evangelist  
Jerry and Anne Tollinsky  
Joanne Tucker  
Turco Persian Rug Company  
Connie Vandelloo  
David and Heather Vickar  
Ronald Vipond  
Joanne Volden  
Isabelle Waddell  
Tom and Audrey Wakeling  
Gitta Wallen  
Gavin Ward  
Marvin Waxman  
Joe and Faigie Weinstock  
Edward and Barbara Welch  
Dwight Wenham  
William West  
Jean Whistler  
Ron Wickman  
Ronald Wild  
Roberta Wilson  
Yaffa and Shelly Wise  
Norman Witten  
Joseph Wohlgelernter  
Tony and Christine Wyergangs  
Gerald Wyler  
Mary Yannakis  
Leo Zalmanowitz and Diane Vimy

### **DMRF-Funded Researchers Discover Possible New Clue in Cervical Dystonia**

A DMRF U.S. - funded study that was recently published in the medical journal *Movement Disorders* adds another clue to the genetic basis for cervical dystonia. The results, while preliminary, point to the possibility that problems in sodium channels in neurons may contribute to cervical dystonia. Sodium channels play a role in how neurons conduct electrical signals.

These findings are consistent with existing theories that implicate dysfunction of a sodium channel as a feasible contributor to dystonia. Prior studies have pointed to additional protein channels as having a role in specific manifestations of dystonia—for example recently identified mutations in ANO3-DYT23 leading to cranial-cervical dystonia.

The authors recommend that additional study is needed to confirm their findings and make the data publicly available to encourage further analysis.

