

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 from the
Dystonia Medical Research
Foundation Canada

Fall 2015

Renewal Notice

By supporting DMRF Canada with a minimum donation of \$40.00 annually you will continue to receive the latest news and information about dystonia. Renew today and you will receive:

- Two issues of the Dystonia Canada Report sent to you each year;
- Ongoing special notices of DMRF Canada events and activities in your community;
- A tax receipt for your gift.

How to support DMRF Canada:

1. Go to **www.dystoniacanada.org** and select "Donate Now"
2. Use the enclosed donation envelope, and return the form on the back of this newsletter
3. Call DMRF Canada at **1-800-361-8061** or **416-488-6974**

Thank you for your support!

Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation (DMRF) Canada is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRF Canada 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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Foundation Update

Dear Friends,

Since I joined Dystonia Medical Research Foundation (DMRF) Canada a few months ago, I have been warmly welcomed by our supporters, partners and volunteers. Thanks to all of you for taking the time to share your stories, thoughts and experiences with dystonia. It has been inspiring to hear about the great successes that our organization has achieved so far.

Coming into an organization and being 'new' provides a great insight about how an organization works. I have been struck by how passionate our group is. Thank you to the donors who place their trust in DMRF Canada and who allow us to carry out the important work that we do. Thank you to the many volunteers who have dedicated their time, passion and support in any number of areas – from helping and supporting individuals who have just been diagnosed with dystonia, to organizing event and corresponding with other individuals who are suffering from dystonia, your dedication is appreciated.

I am well aware that there is still so much more to be done, and I am confident that if we continue

to work towards the same goal we will succeed.

Sincerely,



Stefanie Ince
Executive Director
stefanieince@dystoniacanada.org

P.S. DMRF Canada is looking for new volunteers in a number of communities across Canada – particularly in the following cities: Calgary, London, Ottawa, Montreal and Halifax. If you are interested in learning more about how to become a volunteer please get in touch with me directly!



Canadian donations should be sent to:

Dystonia Medical Research Foundation Canada

121 Richmond St. W. Suite 305

Toronto, ON M5H 2K1

Contact us at 416-488-6974 or Toll Free: 1-800-361-8061

Email: info@dystoniacanada.org

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

2015 Chuck's 5 Km Run/Walk Breaks Fundraising Records

Bill Saundercook, Chair

The 4th annual Chuck's Run was a great success, with over 200 participants and over 60 volunteers. This year's event broke all fundraising records, raising almost \$46,000. This was due, in large part to a very dedicated fundraising team. The top fundraisers this year included: Sid Paul, Hermann Michlits, Catherine Mulkins, Franco Mazzella, Shirley Lee, Julie Marzinotto and John Mazzella. At the event, we were honored to recognize the 2015 Chuck's 5 Km Run/Walk Ambassador, Samantha (Sam) Michlits. You can read Sam's story on page 2.

A very special thanks to the many dedicated volunteers managing all aspects of the event, including: Alison Cook, Terry Jacques, Shirley Lee, Steve McKenzie, Jenny Mulkins, Ruel Ramirez, Paul Saundercook, Kelly Yerxa and the TELUS team. As well, I would like to make special mention of David Jaakkola, who has been a vital and important champion of the Toronto Freedom to Move Walk/Run since the beginning. David's leadership has been instrumental in our continued success. We would also like to thank our corporate partners: Merz for their sponsorship of \$5,000.00, as well as the Grenadier Group for their continued support.

We are looking forward to an even more successful event next year. If you are interested in getting involved in next year's event, please email info@dystoniacanada.org as planning for next year's event will begin shortly.



In 2012 the DMRF Canada annual Freedom to Move for Dystonia Walk / Run was named 'Chuck's Run for Dystonia' after Charles (Chuck) Saundercook who was diagnosed in 1972 with generalized dystonia at the age of 12. In 1978 Chuck became one of the first Canadians to receive deep brain stimulation. He improved with the procedure but developed pneumonia and in his weakened state, died at age 15. In his final chapter, Chuck donated his body and brain to help others in furthering dystonia research. Since then the entire Saundercook family have been steadfast supporters of dystonia awareness and research.

Consider Hosting Your Own Event:

Do you have an idea for your own event? It's fun and we can help you make it easy to do. Consider: Golf Tournament, Dinner Party, Car Wash, Musical Gather/Comedy Festival, Group Walk, Bowling Tournament, or anything else! Contact us for information on event fundraising: info@dystoniacanada.org, 1-800-361-8061 or: 416-488-6974

Samantha Michlits – DMRFC Special Ambassador

Debbie Michlits, Mother of Samantha

Twenty-four year old Samantha Michlits felt an uncomfortable tug in her left arm that began in 2007, when she was sixteen. Not wanting to alarm her parents, Debbie and Bruno, Samantha didn't mention the unusual feeling until one day when her mother noticed something was amiss. Thus began their journey towards diagnosis.

Initially Samantha was misdiagnosed twice at the Movement Disorder Clinic at Toronto Western Hospital. The first time as Complex Tic Disorder and then again as Somatoform Disorder. Something just didn't sit right with Samantha's parents who continued to press on looking for a better explanation. Fortunately Samantha's mom has a friend in the medical system that recommended Samantha meet with Dr. David Crisp, a neurologist in the Oshawa area. Dr. Crisp did a lot of work with Samantha and was also not satisfied with the diagnosis. He then pushed for Samantha to be seen by Dr. Tony Lang. It was Dr. Lang who finally diagnosed Samantha with Generalized Dystonia in 2013. Generalized Dystonia affects multiple areas of the body and in Samantha's case it affects her left arm, neck and torso.

Samantha takes numerous medications which together provide some relief from the constant and uncomfortable movement she experiences but doesn't eliminate her pain entirely. There are many unwanted side effects to the medications so it becomes a trade-off between side effects and relief of the movement. Samantha has explored DBS surgery but has ruled that out for the time being. Recently, Samantha began Neuroplastic Training with Dr. Joaquin Farias and has found the therapy to be very helpful and she continues to improve.

In 2014, Samantha graduated with High Distinction from the University of Toronto with a degree in Conservation Biology and this September she will begin a Master's degree in Environmental Science. Samantha is also active in the DMRF Canada GTA Support Group.



Connect with Others in your Community:

Visit www.dystoniacanada.org/support for a list of DMRF Canada Support Groups available throughout the country.

Visit us on Facebook:
<https://www.facebook.com/DMRFC>

IN TRIBUTE



Bruce Goodhue

DMRF Canada and the London Ontario Support Group are deeply sorry to announce the passing of Bruce Goodhue, Group Leader for the London Ontario Support Group.

Bruce was an incredible person and constant champion of dystonia support and awareness in support of his wife, Michelle. Together, Bruce and Michelle lead the DMRF Canada Support Group in London, Bruce worked tirelessly to keep the group together for over ten years. Bruce was a loving, devoted husband. We are all so lucky to have had a chance to meet him and work with him - and we are all so saddened to hear of his passing.

Our heartfelt thank you to Bruce for his constant support and dedication to the DMRF Canada. He will be truly missed.

DMRF Canada extends our condolences and gratefully acknowledges the generous gifts received in memory of the following:

**Helen Fisher
Janet Fox
Susan Pope**

DMRF & Cure Dystonia Now Announce Collaboration to Investigate Possible New Treatment*

Medication May Lessen Dystonia with Fewer Side Effects than Existing Drugs

The DMRF and Cure Dystonia Now (CDN) are collaborating to co-support a research investigation that may one day lead to a new dystonia drug. The medications most frequently prescribed to treat this debilitating disorder are ironically those with some of the highest incidence of intolerable side effects, which limit their use. A team of American and European investigators is exploring whether a drug called AZD1446, a.k.a. TC-6683, could potentially provide relief for dystonia patients without the unintended effects frequently caused by existing pharmacological therapies.

The investigation is led by David Standaert, MD, PhD, Professor and Neurology Chair at University of Alabama and includes Antonio Pisani, MD, PhD, Associate Professor of Neurology at University of Rome Tor Vergata and DMRF Stanley Fahn Awardee.

Art Kessler, President of the DMRF, explains: "This project addresses two important issues for the dystonia community: We need additional treatment options and we need to find new ways to offer treatment with minimal side effects. This project provides an important opportunity to investigate a possible new medication for dystonia while pursuing a better quality of life for patients." Kessler developed an especially debilitating childhood onset form of dystonia at age eight and knows firsthand the challenges inherent in treatment.

Marc Miller, Director and Co-President of CDN states, "Our priority is to work with the brightest and most motivated doctors and scientists, and our goal is

to discover new treatments. This project is an exciting opportunity to do both." Two generations of the Miller family are affected by dystonia.

Dystonia treatment typically requires a combination of approaches including oral medications, botulinum neurotoxin injections, surgical interventions, and supportive therapies such as physical therapy. In some people, a class of drugs called anticholinergics may replace or compound the physical symptoms with equally disabling cognitive effects such as drowsiness, hallucinations, and memory difficulties. Striking a balance between controlling the dystonia and preserving the ability to function in daily life is a challenge for physicians and patients alike.

Dystonia results from improper signals in the nervous system that instruct muscles to contract excessively. Experts do not yet fully understand the neurological mechanism that causes the abnormal muscle contractions, but the origins appear to stem from an imbalance of neurotransmitters in the brain and changes in brain cell synapses. Standaert and team are using a genetically engineered mouse with abnormal neuronal signaling to examine whether AZD1446 can correct the abnormal signaling and restore the balance of neurotransmitters. In separate studies, the drug has been examined for use in treating attention deficit/hyperactivity disorder and Alzheimer's disease.

ARTICLE AT A GLANCE

- DMRF and Cure Dystonia Now are collaborating to co-support a research investigation that may lead to a new dystonia drug.
- Investigators are exploring whether AZD1446 could potentially provide relief for dystonia with fewer side effects than existing medications.
- The drug has been examined for treating attention deficit/hyperactivity disorder and Alzheimer's disease.

Are you interested in funding research like this?

Consider investing in the Dystonia Medical Research Foundation Canada. Visit: www.dystoniacanada.org/ donate or see the back page of this newsletter to make your donation).

Freedom to Move

DMRFC is deeply grateful for our grassroots volunteers who work year round to promote dystonia awareness and fundraise for medical research. Every effort and every volunteer makes a difference.



Dystonia Support Group Hamilton Area, Rose Gionet, Group Co-Leader

This year marked the 20th year for the walk and it was a great success.

We had 65 participants at the walk, including 13 volunteers. Special thanks goes out to Marian Voisin (check-in and raffle prizes draw), Shirley McManus (50/50 tickets), Wendy Gionet (kitchen) Ron Ramsay (barbeque), Lianna Ramsay, Tammy Loudon (raffle tickets), Kayla Loudon, Lorraine Stevens (check-in), Dave Stevens (setup), Paul Gowans (refreshment tickets), Roland & Dave Gionet (setup).

We were able to raise \$5,456.00 with donations, raffles, 50/50 plus refreshments. Special thanks to Jerry Pilon, for getting hotdogs donated from Schneider's, refreshments from Marlynn Fortino from Allergan, Flo Johnson donated the hot dog buns and Myrtle Gowans the condiments, chips from myself. My husband Roland is always a great help from collecting the pledges to helping with setup and doing the draws. A heartfelt thanks to all those involved. It would be very difficult to run this event without the help and hard work of all of the volunteers.



Dystonia Support Group for Golden Triangle Area, Judy Harsch, Group Leader

The Golden Triangle walk was held on June 14, 2015 and it was pouring rain so it was originally cancelled. Fortunately, the rain stopped in Kitchener and Penny Patterson, Brian Mullen, Paul and Jackie Strub and Bob Kaufman went over to Victoria Park and did the walk.

We raised \$1,585.00, which is pretty good considering our small group. For anyone who has dystonia and who would like to meet with others in their community, please feel free to get in touch with us. For more details on how to get involved or upcoming meetings or events please visit www.dystoniacanada.org/goldentriangle.



Dystonia Support Group of Sudbury and District, Mary Guy, Support Group Leader

We really pulled up our socks this year for our dystonia walk on Sunday, June 8th, despite the rainy day. Thanks to the generosity of those that sponsored our walkers we raised a total of \$20,802. More people attended and those that couldn't sent in their pledge money and did their walk in their community. I was especially pleased that my four adult children Jennifer, Allison and Adam from Southern Ontario and Mary Bess from Sudbury attended along with grandchildren, Paige, Adelaide (who won the children's door prize), Dahlia, Adam, Cohen and Miles.

The star of the walk of course was Dwayne Backer. Dwayne again outdid himself. Every year he tries to raise more money than the year before and every year he succeeds. This year he raised \$9,871. He did all this with an injured neck and the confines of his dystonia. Even though he is retired from Walmart he was able to canvass his former associates and get a matching grant from Walmart for a total of \$3,436. Thank you Walmart. Dwayne continues to amaze us all. He is such an inspiration!

Prizes were donated from DMRF Canada to the top fundraisers: Dwayne Backer, Mary and Richard Guy, Karin Hancin from Timmins, Jocelyne Robert from Sturgeon Falls and Coco Lariviere. Special thanks goes to Linda Thompson for once again organizing the BBQ, Len Shymkiw for his barbequing skills, our experienced desk crew of Brenda Morris, Barb Zaitz, Lise Depatie and Sue Leroux and all the merchants who donated food and door prizes.

If anyone is interested in walking with us in 2016 please give me a call at 705-524-0606. We would be happy to have you join in the festivities.

My Dystonia Story

Robin Kranz, DMRFC Vancouver Support Group Co-Leader

In May of 2002 I was diagnosed with focal dystonia. The neurologist identified it as Cranial or Meige's syndrome and I, like everyone else I knew, including my doctor asked, "What is this? I've never heard of this before." The neurologist informed my husband and me that he had good news and bad news: the good news was that he knew what I had. The bad news was that I would have it forever. There was no cure and controlling the symptoms was the goal. I remember walking outside of the clinic and feeling weak in my knees. No cure? How could that be?

Journey to diagnosis

During the previous year and a half I had visited the optometrist three times complaining of issues with my vision. I was constantly tilting my head back so that I could read the computer screen or anything else that I needed to view. I thought there was a problem with my vision or my glasses. The optometrist couldn't find anything wrong and I continued to struggle - rubbing my eyes and getting a sore neck from trying to see. At the time, I was working as department head for a college program that had a significant distance education component to it: reading was not optional. I had just celebrated my forty eighth birthday and had also just completed a Master's degree. I was happy in my life and moving forward in a busy and productive way.

In the fall of 2001 I got sick; something that was unusual for me, although, over the previous few months I was not feeling up to my usual energetic self. I ended up in bed for a week with what I thought was the flu. I have not been able to work since.

My eyes were shut. I couldn't keep my eyes open. My head was bobbing up and down and side to side. I was biting my tongue and my cheeks. My jaw was clenching and my breathing was shallow. My voice was also affected. I steadily got worse. I ended up in emergency with panic attacks related to my breathing. I believed I wasn't able to breathe even though I logically knew that I could. I wasn't able to drive, watch T.V. or read. My life, as I knew it, was over. The doctor referred me to a local

neurologist who sent me for the normal tests and x-rays and eventually to the UBC clinic to confirm what he thought I had. It was a relief when I finally was diagnosed, but really, it was just the beginning...

Learning I wasn't alone

For the next ten years my symptoms were managed with a mixture of Botulinum toxin and anti-depressants. I also tried naturopaths, massage therapy, acupuncture, diet and exercise. I went to a psychiatrist once who asked me why I thought I didn't want to see. I guess he thought that my eyes were shut due to an emotional response or a need or desire to not see.

I always asked my neurologist when I saw him for the Botox shots every three months if there was a cure. He always responded with No – , adding that there would probably never be a cure as dystonia was not "sexy" enough for funding and resources.

I researched what I could, and I tried anything that I came across that I thought might help. I attended Blepharospasm group meetings which were helpful in encouraging me to explore relief options and trying to learn more about dystonia. Most importantly – these meetings were helpful in reassuring me that I was not the only person who had Blepharospasm. It was 12 years before I saw someone else with cranial dystonia and that person was on T.V.

Being alone, without others to talk to about my dystonia was detrimental to me. I felt as if I was in a box that I could not get out of. I developed a strong claustrophobic response to elevators, stairways and even going downhill. I became dependent on others for most of my life needs. I still wake up at night with a breathing panic.



Thank goodness for the support of my family; in particular my husband and sons and a few close friends. Today I am in remission. My dystonia is present but some of my symptoms have lessened. Reading is still difficult and I bite my cheeks and tongue occasionally. I still receive Botox shots every three months for Blepharospasm but not in my large jaw muscles or around my nose.

We moved to the coast and I was able to do more walking and activities on my own. My husband and I helped look after our grandchildren. I recognize that dystonia is individual and each person has their own story and struggle. By co-facilitating the DMRFC Vancouver Support Group I hope that I can do a small part in supporting others as we learn from each other.

I want to encourage more information and understanding of dystonia.

Robin, along with Jackson Mooney, is the Co-Leader for the DMRFC Vancouver Support Group. Find out about other support groups available in your area by visiting: www.dystoniacanada.org/support

Do you want to share your dystonia story?

Email: info@dystoniacanada.org and your story could be featured in an upcoming newsletter.

Stay in Touch!

Sign up for DMRFC's e-mails for the latest updates and announcements: www.dystoniacanada.org/newsletter.

Like us on Facebook. Visit: www.facebook.com/DMRFC

A Fly in the Ointment*

Research Reality Check with Chief Scientific Officer Jan Teller

It is not easy to catch a fruit fly. Scientists recently discovered that fruit flies react to threats as if they were fighter jets, elegantly using aerodynamic forces to perfection. So when you find one hovering around your kitchen, do not chase; it is pointless! Other scientists, probably less impressed with their flying abilities but captivated by their genetics and short life cycle, use fruit flies to study dystonia. Two recent scientific papers, published virtually simultaneously, provide unusually detailed insights into torsinA and the inner workings of the fly brain.

In the first paper, a research team from South Korea, led by Dr. Young Ho Koh and helped by Canadian and US scientists, explored the role of abnormal torsinA in how neurons respond to stress. The researchers show that mutant torsinA is essentially toxic to the fly brain cells and induces a stress response that causes excessive accumulation of cell proteins that are misshaped, damaged, and not fully functional. Abnormal torsinA causes an increase in another protein identified by the team, which helps the neurons compensate for the harmful effects. As a result, flies that carry the human mutant torsinA have a shorter lifespan and accumulate different proteins in their brains. Here, a little fly has become a tiny model of dystonia that can be studied at the brain level to help researchers reconcile the conflicting results obtained in other cell and animal models.

The second paper comes from a group well-known to our readers. In fact, this work was supported in part by DMRF. A team of investigators from Harvard and the University of Alabama led by Dr. Naoto Ito capitalized on the fact that fruit flies, unlike humans, have only one torsin-related gene. If this gene is removed, the insects cannot move normally. There is also a substantial drop in brain dopamine levels and reduction in the activity of a key enzyme in the dopamine pathway. The fly's movement problems can be rescued by feeding the larvae dopamine. In the current study, the team showed that if you insert the human DYT1 mutant of torsinA into the fly, this also inhibits locomotion in larvae and adult flies as well as decreases levels



of the enzyme. Furthermore, when both normal and mutated torsinA were present, there was a similar reduction in the movement and enzyme activities. This seems to support the hypothesis that mutated torsinA interferes with the activity of normal, 'healthy' torsinA.

These studies are remarkable because they are clarifying the role of a known dystonia-causing protein and providing a superb model system to test molecular and cellular hypotheses. This is critical for developing new treatment strategies. The studies reinforce the value of the fly as a dystonia model while rodents and other models have recently attracted a great deal of attention. So, please, think twice before trying to swat a fruit fly—his cousins in the lab are busy helping us solve the mysteries of dystonia.

DMRFC is proud to partner with the Dystonia Medical Research Foundation (DMRF) to fund critical dystonia research.



Not Just Any Body: Living Well with Dystonia*

Dystonia is a movement disorder that impacts the physical body, and it can also affect emotional and psychological health. Living well with dystonia includes treating the physical symptoms, protecting emotional and psychological well-being, and accommodating your unique treatment needs as an individual.

There is no single strategy for living well with dystonia that works for everyone. The following suggestions have been compiled from individuals with dystonia, support leaders, and healthcare professionals.

Seek Out Expert Healthcare Providers

It often takes a team of experienced professionals to diagnose and treat dystonia. This may include a movement disorder neurologist, physical therapist, psychiatrist, psychotherapist/counselor, and others.

Actively Participate in Your Treatment

Learn about dystonia. Make informed choices about your care with the input of your medical team.

Develop a Multi-Layered Support System

Seek out supportive family and friends, local dystonia support groups, online support groups, community events, and self-help resources. Enlist the help of a psychotherapist or counselor to help navigate concerns and vulnerabilities.

Listen to Your Body

Respect and honor your individual need for sleep, rest, nutrition, exercise, relaxation, and time/scheduling.



Cautiously Explore Complementary Therapies

Talk to your doctor about non-traditional therapies that interest you. Different complementary approaches may work for different people, but keep in mind that numerous practitioners and outfits falsely claim to have a unique ability to treat dystonia.



Exercise

The benefits of exercise can be profound. Consider working with a physical therapist to develop an exercise plan that works for you.

Seek Help When You Need It

If you need assistance, reach out and be specific about what you are having trouble with. Accept help when offered—and without guilt.

Treat Depression & Anxiety

Depression and anxiety can dramatically impact quality of life and the severity of motor symptoms. Consider being evaluated for depression and/or anxiety and, if symptoms are present, seek treatment.



Be Mindful of Stress

Regular stress reduction and relaxation practices can have a positive impact on symptoms and overall well-being.



Take Care of Your Relationships

Resist the temptation to isolate from other people. If family or love relationships are strained, consider enlisting the help of a therapist to bring you closer to those you care about.



Remain as Active and Social as Possible

It may be physically and/or mentally demanding to go certain places or complete specific tasks. Plan ahead, pace yourself, and rest when needed.

Embrace Awkward Social Situations

Your symptoms may flare at extremely inopportune times. Strangers may occasionally misinterpret your body language. Be forgiving with yourself in these moments.



Do Things You Enjoy

It can be easy to let pleasurable activities and fun fall by the way side. Create space in your routine for activities and experiences that invigorate you and keep you going.

Contact the DMRFC for Assistance

We can be reached at info@dystoniacanada.org or 1 (800) 361-8061. Visit us on Facebook: www.facebook.com/DMRFC

Special thanks to Steven Frucht, MD and Pichet Termasarasab, MD for reviewing the content of this article.

*Reprinted with permission from DMRF Dystonia Dialogue, Summer 2015, Vol 38, No. 2.

Join the DMRF Canada Legacy Society

Leaving a Legacy of Caring

The DMRF Canada Legacy Society was created to recognize those who have made a lifetime commitment in the battle against dystonia. Please let us know if you are considering making a bequest to the DMRF Canada in your will or would like to discuss any of the planned giving options below. You can check the box on the following page for more information, or contact Stefanie Ince at 1-800-361-8061 or stefanieince@dystoniacanada.org.

Wills and Bequests

Bequest gifts are the simplest of planned gifts. A bequest is simply a statement in a will that stipulates a gift to an individual or organization--for example, the Dystonia Medical Research Foundation (DMRF) Canada. All donations-- including bequest gifts - will enable the DMRF Canada to continue to move forward in its mission to find a cure and to serve those affected by this debilitating disorder. When making your gift, please note that the legal name of the DMRF Canada is "the Dystonia Medical Research Foundation Canada."

The general bequest is probably the most popular type of bequest and is usually stated as a designated dollar amount. (Example: I leave to the Dystonia Medical Research Foundation Canada (DMRF Canada) located in Toronto, Ontario, Canada, the sum of \$50,000.)

A specific bequest may designate a particular item to be donated. (Example: I leave to the Dystonia Medical Research Foundation Canada (DMRF Canada), located in Toronto, Ontario, Canada 2000 shares of XYZ stock.) Or, I leave to the Dystonia Medical Research Foundation Canada (DMRF Canada), located in Toronto, Ontario, Canada my savings account #23456 at (name of your bank).

A residual bequest is used to give all -- or a portion of -- one's estate after specific and general bequests are distributed. (Example: [after specifying any items or amounts to other beneficiaries] I give the rest, residue and remainder of my estate to the Dystonia Medical Research Foundation Canada (DMRF Canada), located in Toronto, Ontario, Canada.)

A percentage bequest allows the amount to be distributed to the DMRF Canada to grow over the years as the estate grows. (Example: [after specifying any items or amounts to other beneficiaries] I give to the Dystonia Medical Research Foundation Canada (DMRF Canada), located in Toronto, Ontario, Canada, 50% of the rest, residue and remainder of my estate.)

A contingent bequest is one that will take effect only if the primary intention cannot be met or if a beneficiary predeceases the donor. (Example: In the event that _____ predeceases me, I direct that the Dystonia Medical Research Foundation Canada (DMRF Canada), located in Toronto, Ontario, Canada, receive his/her designated bequest.)

Life Insurance Gift

You can name the DMRF Canada as the primary beneficiary of part or all of your life insurance policy. Ask your insurance professional to help you make the Foundation your beneficiary.

Please contact Executive Director Stefanie Ince at stefanieince@dystoniacanada.org or 1-800-361-8061 to discuss your options.

DMRF Canada

121 Richmond Street West,
Suite 305
Toronto, ON M5H 2K1




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Yes, I want to continue to support the DMRF Canada

- ☐ **Yes, I want to learn more about how to include DMRF Canada in my Will.**
- ☐ **Yes, I want to join the DMRF Canada Monthly Giving Team.** Monthly giving offers you a way to support our programs and services throughout the year. Join a group of dedicated individuals, who are committed to long-term improvements in the lives of individuals suffering from dystonia.

☐ \$50 a month ☐ \$25 a month ☐ \$20 a month ☐ \$10 a month ☐ \$ _____ a month

Option 1: ☐ I am sending 12 postdated cheques made payable to the Dystonia Medical Research Foundation Canada.

Option 2: ☐ Please charge my credit card each month: ☐  ☐  ☐ 

Card #:

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Expiry:




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OR

- ☐ **Yes, I want to support dystonia research by making a one-time donation**

☐ \$250 ☐ \$100 ☐ \$50 ☐ \$25 ☐ \$ _____

Option 1: ☐ I have enclosed my cheque made payable to the Dystonia Medical Research Foundation Canada.

Option 2: ☐ Please charge my credit card: ☐  ☐  ☐ 

Card #:

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Expiry:

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Please provide an email address: _____

Make online donations at: dystoniacanada.org/donate-now

* Each payment, including the first payment, will be made in the middle of the month.
You can stop your monthly gift at any time by contacting DMRF Canada.

Charitable #12661 6598 RR00001

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