

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

*serving all dystonia-affected persons
d'esservant toutes personnes atteintes de dystonie*

Dystonia Canada Report

A Newsletter from
Dystonia Medical Research
Foundation Canada

Fall/Winter 2022

**DYSTONIA
STRONG**

SEPTEMBER IS DYSTONIA AWARENESS MONTH

**LA
FORCE
DE LA
DYSTONIE**

IN THIS ISSUE

- 1 Three Dystonia Research Grants Awarded in Canada
- 2 New Community Events and Resources
- 3 Emotional Wellness Toolkit
- 4 Tips for Raising Awareness of Dystonia

PLEASE RENEW YOUR MEMBERSHIP

Support the dystonia community with a donation to DMRF Canada.

visit: www.dystoniacanada.org/donate

Thank you for your support.

Foundation Update

The pandemic impacted our lives in many ways, and for many impacted by dystonia, it added to their existing struggles.

Over the last few years, we have seen an increased need for mental health resources and support in navigating unique challenges.

Working in partnership with our dedicated volunteers, and collaborating with our supporters and other like-minded organizations, we were able to adapt and support the community when they needed us most.

We have emerged stronger for it, and we are proud of what we have been able to do as a community.

As we gradually resume in-person activities, we are pleased to share some exciting updates:

- A return to in-person support meetings for the first time since the pandemic in Ottawa, Winnipeg, and Calgary, while continuing to offer virtual gatherings so that anyone can participate, regardless of location.
- Thanks to two casino fundraising efforts of our groups in Calgary and Edmonton, Alberta, we are funding new research projects in Canada, accelerating the development of treatments to improve the lives of those living with dystonia. Please refer to page 7 for further details.
- With the help of more than 160 supporters across Canada, we hosted another successful virtual Freedom To Move: Run, Walk and Wheel for Dystonia event, raising close to \$70,000.

We are delighted to see the dystonia community emerge from the last few years stronger together. And this September, during Dystonia Awareness Month, we celebrate the resiliency of our community.

However, as we continue to hear the struggles of the community - from children to seniors, and individuals to families, from those newly diagnosed to those living with dystonia their entire lives - we know there's still work we need do, while we continue our pursuit of finding a cure.

We don't know what the future will bring in navigating the future waves of the pandemic, but we want you to know we are committed to being there for our patients, families, doctors, and researchers. We continue to look for new avenues of financial support which enables us to fund all aspects of our mission.

As always, we thank you for your dedicated, ongoing support of our mission and look forward to keeping you informed of our progress.



Connie Zalmanowitz,
Chair, DMRF Canada
Board of Directors

A handwritten signature in black ink that reads "Connie Zalmanowitz".



Archana Castelino,
National Director

A handwritten signature in black ink that reads "Archana Castelino".

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 your physician about the procedures mentioned herein.

Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation (DMRF) Canada is a registered 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. We work in partnership with the DMRF in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and with other like-minded research organizations to fund excellent dystonia research in Canada.

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The DMRF Virtual Dystonia Educational Symposium

In late 2021, the DMRF hosted Virtual Dystonia Educational Symposium with a panel of experts. Due to time limitations, some audience questions were not answered live. To read the responses to the questions and watch a recording, please visit:
www.dystoniacanada.org/DMRFvirtualsymposium2021

2022 Jackson Mooney Patient Grant Winners Announced - Astrid Frauscher (Calgary, AB) and Julie Emied (Toronto, ON)

On behalf of the dystonia community, DMRF Canada wishes to thank Jefferson and Jackson Mooney, and we wish Astrid and Julie the very best with the next step in their career path.

Announcing: The 2023 Jackson Mooney Patient Grant application is now open. Deadline to submit is April 30, 2023

You Can Help Shape Dystonia Research - Sign Up Today!

The goal of the Global Dystonia Registry is to support future dystonia studies, including clinical and research trials, through the collection of data on persons affected by dystonia. Although the focal dystonias have many different manifestations, most experts believe they share a common pathogenesis or mechanism that causes the disorder. The common causes may be a similar gene defect, similar lifetime experiences, or both. Collecting information from different patient populations may help us identify the common features that they may share.

Visit: www.globaldystoniaregistry.org to learn more and register.



In Tribute

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

David Bell

Ruth Garson

Marguerite Levesque

Jean Macdonald

Johnathan Roberge

Bella Shore

Joan Snyder

Cookie Rutman

Wayne Young

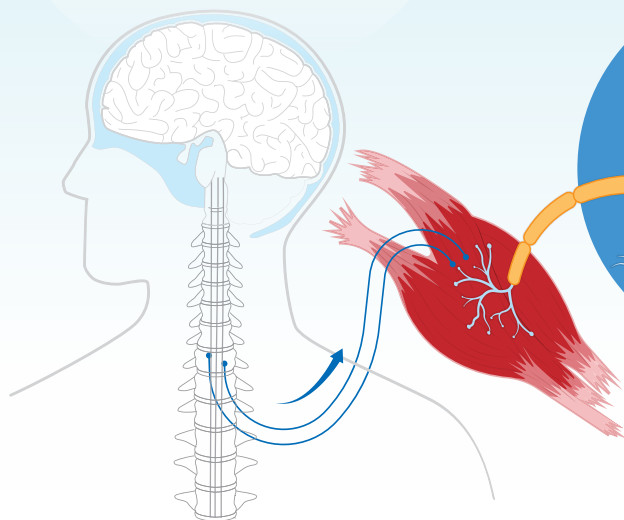


Thank You for Your Support

Donations should be sent to:
Dystonia Medical Research Foundation Canada
550 St. Clair Ave West, Suite 209,
Toronto ON, M6C 1A5
www.dystoniacanada.org/donate

MAKING THE CONNECTION

Untangling Complex Neural Networks is Central to Understanding Dystonia



Excessive muscle contractions are a hallmark sign of dystonia, but the muscles are not the source of the problem. The muscles are responding to abnormal signals from the brain to flex or relax, which cause the dystonic movements and postures.

Research shows that the origins of dystonia lie in the complex pathways and networks of neurons that carry signals from one part of the brain to another.

There are an estimated 86 billion neurons in the human brain, making roughly 100 trillion connections. Neural pathways convey the information and instructions necessary for the brain to function. If there is a problem anywhere along a pathway, the communication between brain structures in that network breaks down. When areas of the brain responsible for movement cannot communicate properly, movement disorders such as dystonia can occur.

Researchers from around the world are painstakingly working to identify the neural pathways and networks implicated in dystonia and pin-point dysfunction within these complex connections. Once the problem areas are identified, researchers can strategize effective treatment approaches.

In late 2021, over three days, dystonia experts from across the world met for a virtual workshop, “Defining the Role of Brain Networks in the Pathophysiology and Treatment of Dystonia.”

The meeting’s distinguished Scientific Co-Chairs, Drs. Mark Hallett of National Institute of Neurological Disorders & Stroke, David Peterson of University of California, San Diego, and Kristina Simonyan of Harvard Medical School led an

intensive program to review what is known about the neural networks involved in dystonia, discuss emerging research, and identify research gaps. A manuscript from the meeting is planned for publication in the DMRF’s new scientific journal, *Dystonia*.

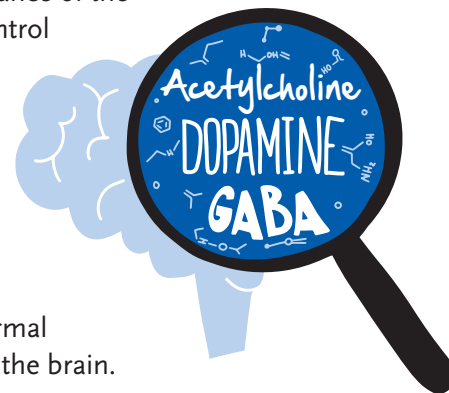
Although the exact mechanisms underlying the origins of dystonia are not fully understood, several contributing neurological problems have been identified. These help explain what goes wrong in the dystonia brain.

Losing Balance: Neurotransmitters

A neurotransmitter is a chemical generated by one neuron to transmit an electrical signal to another Acetylcholine neuron. Some neurotransmitters stimulate neuron activity while others suppress activity, similar to how the gas and brake pedals in a car control acceleration and deceleration.

Dystonia creates an imbalance of the neurotransmitters that control brain activity related to moving the body.

When neurotransmitter levels are not balanced, movement disorders occur. Many oral medications used to treat dystonia act to restore normal neurotransmitter levels in the brain.

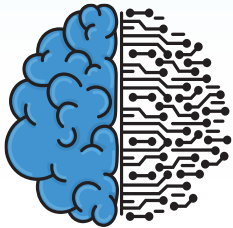


Missing the Connection: Abnormal Neuron Firing



When signals between neurons are compromised by unbalanced neurotransmitters, this disrupts normal firing patterns. Neurons may have trouble initiating or receiving signals. This results in a loss of connectivity in the brain, which disrupts motor pathways. Researchers are investigating whether this altered connectivity in dystonia is specific to certain brain regions or possibly more widespread beyond brain functions specific to movement.

Forever Learning: Neuroplasticity



Plasticity, or neuroplasticity, is the brain's capacity to change over time. The developing brain organizes itself and assigns brain functions to various regions. New neurons can be generated, creating new connections. Neuroplasticity explains how we learn, remember, and adapt behavior. Neuroplasticity likely plays a key role in the development of dystonia- the brain's ability to re-organize and adapt is impaired. The brain loses its internal equilibrium. This opens the door for movements that were once mastered to be 're-learned' incorrectly. The more the nervous system 'practices' activating abnormal movements, the more difficult they are to unlearn. This explains why the benefits of therapeutic deep brain stimulation (DBS) occur over weeks and months: the brain is gradually re-learning how to organize and coordinate normal movement patterns.

Overdoing It: Surround Inhibition



A hallmark sign of dystonia is that the brain activates more muscles than needed to complete a movement task. For example, an individual with focal hand dystonia may pick up a pen to write and experience excessive muscle contractions in the hand and fingers, plus an overflow of involuntary movements in the arm and shoulder. The brain loses the ability to suppress activation of muscles that are not needed to complete a voluntary movement. By contrast, when the normal brain is planning and coordinating movements, it activates the muscles required for a task while inhibiting the surrounding muscles not needed for the task.

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Targeting Brain Pathways in Treatment

A number of existing treatments and investigational therapies act to reduce dystonia symptoms by rebalancing brain activity.

- Deep brain stimulation
- Non-invasive neuromodulation techniques such as repetitive transcranial magnetic stimulation (rTMS) and transcranial direct current stimulation (tDCS)
- Neurorehabilitation/physical therapy
- Medications

Botulinum Helps Balance Brains & Brawn

Even though therapeutic botulinum neurotoxin is injected into muscle and does not enter the brain, this therapy indirectly helps restore balance to neural pathways. While the primary effect of injections is that they reduce muscle contractions, an added benefit is that the relaxed muscles change the sensory information sent back to the brain. This helps balance the motor system in a positive way.

Towards a Brighter Future: Freedom to Move is Making Strides to Improve Lives



Our Ambassador and Team Captain of Conquering Dystonia, Ellis Silliker applauded the efforts of the community this year sharing that, "being a part of this initiative is very special as it gives me a chance to take part in such a meaningful cause that gives back. It's heart-warming to know there are so many people who not only understand the need for more research into dystonia but have taken action to improve the lives of people living with the disorder."

Once again, the dystonia community across Canada united for one common purpose: to raise funds for a future without dystonia. This year's Freedom to Move online national event saw close to 170 participants from 33 cities running, walking, wheeling - and even swimming - to their finish line during the month of June. Thanks to the efforts of all the participants, donors and sponsors, the event raised close to \$70,000 for research and support programs.

A special thank you to DMRF Co-Founder, Fran Belzberg for generously matching donations, dollar for dollar, up to \$10,000! And we were thrilled to present "Team Manitoba" with our inaugural Best Team Spirit Award for their great use of blue and green during their "Walk in the Park" event.

Visit www.dystoniacanada.org/freedomtomove to view our event wrap up video.

Thanks to Our Top Fundraisers

1. Mary Guy of Team Greater Sudbury;
2. Oliver Jaakkola of Team Jaakkola;
3. Franco Mazzella of Team Franco's Dystonia Busters.

A Heartfelt Thanks to Our Top Fundraiser, Mary Guy

Long-time DMRF Canada Sudbury and District Support Group Leader, Mary Guy has led a life of service through her work as an educator, volunteer, and community advocate.

Mary was diagnosed with dystonia in 1995, and since that time she has played a key role in the leadership of the DMRF Canada Sudbury and District Support Group. Whether at her local event in Sudbury or at the national, virtual event, Mary's active, consistent participation in Freedom to Move has contributed to our success year after year. On behalf of DMRF Canada and the dystonia community, we would like to thank Mary for her dedicated support.

*With Thanks to Our Sponsors
for their Generous Support*



Supporting Critical Dystonia Research Here in Canada

DMRF Canada Funds Early Investigator in Partnership with Banting Research Foundation

DMRF Canada is pleased to announce our support of 2022-2023 Banting Research Foundation Discovery Award recipient Luka Milosevic, who was selected for his project; Physiologically-informed and data-driven methods for advancing neuromodulation therapies in dystonia.

Professor Milosevic is a Scientist with a focus on Clinical and Computational Neuroscience at the Krembil Brain Institute, University Health Network and Assistant Professor at the Institute of Biomedical Engineering, University of Toronto.

Professor Milosevic and his team are focused on developing diagnostic models to identify brain biomarkers associated with dystonia and will be using these signals to design new forms of Deep Brain Stimulation (DBS) with a goal to identify better treatment for individuals living with dystonia.

Professor Milosevic's work on brain disorders, combined with the rapidly growing field of neurotechnology, impacts new devices to alter brain activity and new therapies that can be applied to restore neurocircuit function in various disorders, including dystonia.

As current implementation of DBS therapy involves delivery stimulation 24 hours per day, physiologically informed DBS would instead deliver stimulation only when necessary, based on brain signals associated with disease symptoms, thereby reducing side effects and improving quality of life.

For more details on this project and other recent research news, **please visit** www.dystoniacanada.org/latest-dystonia-research-news



"I am delighted to receive this award and to be able to advance our knowledge of the neural substrates underlying dystonia and to progress the field of neuromodulation therapies for those diagnosed"
- Luka Milosevic, PhD

DMRF Canada Awards New Genetic Dystonia Research Grant



Paul Marcogliese, PhD, Assistant Professor, Biochemistry & Medical Genetics, Rady College of Medicine at the University of Manitoba

DMRF Canada is pleased to partner with Canadian organization Rare Diseases: Models & Mechanisms Network (RDMM) to fund a new research grant with lead investigator Paul Marcogliese, PhD, Assistant Professor, Biochemistry & Medical Genetics, Rady College of Medicine at the University of Manitoba.

Dr. Marcogliese and his team are focused on investigating a mutation in IRF2BPL - a little-known gene that is the cause of a severe neuroregressive disorder in children where approximately 50% of cases present with dystonia.

Having spent his doctoral studies

investigating rare forms of neurological diseases, and better understanding the behaviour brain pathology of parkinsonian mice, and using fruit flies to help uncover IRF2BPL as a new human disease gene, Dr. Marcogliese is now focused on determining how the loss of the gene IRF2BPL causes neuronal dysfunction in patients.

Dr. Marcogliese's lab is hoping that the characterization of the Irf2bpl mouse model will shed insight into a rare and devastating disorder in children but also inform on the molecular underpinnings of dystonia in humans. Stay tuned for updates on this exciting research.

A Mid-Year Update from DMRF Canada Clinical and Research Fellow, Dr. Chai

The dystonia community had the chance to hear more about what Dr. JiaRen Chai, DMRF Canada Clinical and Research Fellow, has been up to since his Fellowship began in July 2021. JiaRen Chai, MD, London Movement Disorders Centre at the University of Western Ontario, provided an overview of his work to date in an exclusive DMRF Canada hosted webinar earlier this spring.

Dr. Chai shared highlights from his Clinical and Research Fellowship experience, including the fact that he is honing his skills as a clinician through ongoing exposure to a variety of patients with different forms of dystonia, from cervical to musician's - as well as patients with DBS systems embedded. As a clinician, he has received specialized training for administering botulinum neurotoxin injections, which is a critical skill, and particularly important given the need for this treatment across Canada.

Dr. Chai is integrating his clinical work into a research project that focuses on Transcranial pulsed current stimulation (tPCS), a form of non-invasive Transcranial brain stimulation. This intervention involves a small device that emits a low current through the skull. Currently in the recruiting phase, Dr. Chai will study patients whose dystonic symptoms return earlier than the 3-months timeframe, which is the standard for receiving botulinum neurotoxin injections. For those patients whose dystonic symptoms return at the 8-week mark, Dr. Chai is interested in testing how tPCS, applied for just 20 minutes to his test group – could reduce dystonic symptoms. Similar studies are being conducted at the London Movement Disorders Centre for other conditions, including Huntington's and Parkinson's disease, with promising results.

His end goal is to share the results in the form of a publication in a peer-reviewed journal. If there is a positive result, Dr. Chai expects it could inspire additional, larger studies. Stay tuned for additional updates on this research pilot expected later next year.

We are grateful for Merz Therapeutics' support of this critical program to expand education and training opportunities for the next generation of movement disorder specialists for the treatment of dystonia in Canada.

Dystonia Coalition Award

DMRF Canada, along with Merz Therapeutics, is pleased to partially support the 2022 Dystonia Coalition Pilot Projects Program Award, **"Moodscreen for Cervical Dystonia: A Diagnostic Accuracy Study of Depression and Anxiety"** with lead investigator, *Davide Martino, MD, PhD, of the University of Calgary.*

The goal of the 2022 *Dystonia Coalition Pilot Projects Program* is to foster the most promising clinical and translational studies of direct relevance to dystonia.

This study aims to improve care for individuals with dystonia by identifying the most useful methods to screen individuals for co-occurring depression and anxiety.

This is the first research partnership with the Dystonia Coalition, which is a collaboration of medical researchers and patient advocacy groups focusing on

accelerating clinical research in the field. The Dystonia Coalition is sponsored by the National Institute of Neurological Disorders and Stroke (NINDS), the Office of Rare Diseases Research (ORDR) in the National Center for Advancing Translational Sciences (NCATS) in the United States, as well as several patient advocacy groups.

We thank Merz Therapeutics for their support of this award and look forward to providing updates in the future.

**Thanks to Merz Therapeutics for
their support of these grants**



THERAPEUTICS

Better outcomes for more patients.

Emotional Wellness Toolkit

How you feel can affect your ability to carry out everyday activities, your relationships, and your overall physical and mental health. How you react to your experiences and feelings can change over time. Emotional wellness is the ability to successfully handle life's stresses and adapt to change and difficult times. Below are some tips for protecting and improving emotional health.

LOOK FOR THE POSITIVE

People who are emotionally well have fewer negative emotions and can bounce back from difficulties faster. Another sign of emotional wellness is being able to hold onto positive emotions longer and appreciate good times.

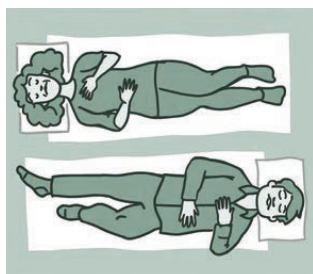


To develop a more positive mindset:

- Remember your good deeds.
- Forgive yourself.
- Practice gratitude. Being thankful stirs up positive emotions.
- Spend time with your friends.
- Explore your beliefs about the meaning and purpose of life.
- Develop healthy physical habits.

MANAGE STRESS

Living with dystonia can be stressful, even under the best of circumstances. Stress can give you a rush of energy when it is needed most. But if stress lasts a long time - a condition known as chronic stress - staying on high alert can become harmful rather than helpful. Learning healthy ways to cope with stress can also boost resilience.



To help manage your stress:

- Get enough sleep.
- Build a social support network.
- Show compassion for yourself.
- Ask for help.
- Exercise regularly.
- Set priorities.
- Try relaxation methods.

GET QUALITY SLEEP

Dystonia can make it difficult to sleep. Sometimes, to fit everything we need to do in a day, we often sacrifice sleep. But sleep affects both mental and physical health. It is vital to your well-being. Sleep helps you think more clearly, have quicker reflexes, and improves focus. Take steps to make sure you regularly get a good night's sleep.



To get better quality sleep:

- Go to bed and get up each day at the same time.
- Sleep in a dark, quiet place.
- Exercise daily.
- Limit the use of electronics before bed.
- Relax before bedtime.
- Avoid alcohol before bedtime and stimulants like caffeine or nicotine.
- Talk to your doctor if you have ongoing sleep problems.

BE MINDFUL

The concept of mindfulness is simple. This practice is about being aware of what is happening in the present moment - noticing all that is going on inside and all that is happening around you. It means not living your life on autopilot. Becoming a more mindful person takes time and practice. Here are some tips to help you get started.



To be more mindful:

- Take moments throughout the day to pause and notice the sights and sounds around you.
- Take deep breaths in through your nose to a slow count of 4, hold for 1 second, and then exhale through the mouth to a slow count of 5. Repeat often.
- Practice mindful eating. Be aware of each bite and feel when you are full.
- Be aware of your body. Do a mental scan from the top of your head to the bottom of your toes, bringing your attention to how each body part feels.
- Seek out mindfulness resources to help improve your practice.

COPE WITH LOSS

Loss can include a death, divorce, or any circumstance in which your world changes - including the lifestyle and ability changes often caused by dystonia. There is no right or wrong way to grieve. Although loss can feel overwhelming, it is possible to move through the grieving process. Learn healthy ways to help you through difficult times.



To help cope with loss:

- Take care of yourself.
- Share your feelings with a caring friend or family member.
- Try not to make any major changes right away after a painful loss.
- Join a DMRF Canada Support Group.
- Consider professional mental health support.
- Talk to your doctor if you are having trouble with everyday activities.
- Be patient. Grief takes time.

STRENGTHEN SOCIAL CONNECTIONS

Social connections help protect health and lengthen life. Scientists are finding that our links to other people can have powerful effects on our health—both emotionally and physically. Whether with romantic partners, family, friends, neighbors, or others, social connections can influence our biology and well-being.



To build a healthy support system:

- Share good habits with family and friends, such as exercise or wellness activities.
- Ask for help from others—especially if you are also coping with dystonia.
- Join a group focused on a favorite hobby, such as reading, hiking, or painting.
- Take a class to learn something new.
- Experience different places and meet new people.
- Join a DMRF Canada support group.
- Volunteer for things you care about in your community, including a community group, school, library, or place of worship.

Living your best life with dystonia requires a commitment to taking care of yourself. DMRF Canada is here to support you in your journey. Visit: www.dystoniacanada.org/resources for additional tips and tools for living well with dystonia.

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New Consensus Guidelines for Botulinum Neurotoxin Therapy for Dystonia & Spasticity



Botulinum neurotoxin (BNT) therapy is one of the most common treatments to reduce dystonia symptoms. BNT therapy involves injecting appropriate doses of BNT into the appropriate selection of muscles. Both the muscles to be treated and the specific doses determine the dosing regimen for an individual patient. Developing the unique dosing scheme for each individual patient requires considerable experience on the part of the physician, making BNT therapy both a skill and an art. Dosing tables are available for physicians to provide a range of optimal doses for each target muscle.

An international working group of movement disorder experts recently published new and improved dosing tables for physicians with the goal of making BNT therapy more effective for patients. For the first time the dosing tables are based on statistical evaluation of real-life data from a large BNT clinic. "So far dosing tables have only been reporting dose ranges coming out of group discussions. Usually, they covered enormous ranges making them virtually useless for practical considerations," explained Dirk Dressler, MD, PhD,

first author of the study and Head of the Movement Disorders Section in the Department of Neurology, Hannover Medical School in Germany. "We give typical doses for each target muscle, we give variability, and we give limits so that the

[physician] has all the information to decide the best target muscle dose." The statistical analysis was based on treatment data from 1,831 BNT injections in 36 different target muscles in 420 dystonia patients plus 1,593 BNT injections in 31 different target muscles in 240 spasticity patients. The investigators differentiated between dosing for dystonia and spasticity, which existing dosing tables do not offer. "We are extremely grateful to our panel of 26 world class experts in BNT therapy from all over the world. We are confident that this publication will be the key source for planning and dosing BNT therapy in dystonia and spasticity for the years to come," said Dr. Dressler.

Dressler D, Altavista MC, Altenmueller E, et al. Consensus guidelines for botulinum toxin therapy: general algorithms and dosing tables for dystonia and spasticity. J Neural Transm (Vienna). 2021;128(3):321-335.

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Finding the Light after My Dystonia Diagnosis - Jackson Mooney



"I have now resumed many previously abandoned activities – including riding a new road bike, playing tennis, golf and, after a four-year absence, driving a car."

Until my dystonia diagnosis in 2005, there had been very few situations in my life which I could not manage, accept, or correct. Although I had some history of situational depression and anxiety, typically within a few months, the symptoms I was experiencing would subside. However, my ability to cope would be significantly altered following my cervical dystonia diagnosis.

In the first few years after my diagnosis, my dystonia was largely neutralized by botulinum neurotoxin injections. Although not a "progressive disease" in the true

sense, it did progress with both increased pain and more intense head turning that was outside of my control.

My greatest difficulty soon became my self-consciousness about my worsening physical symptoms. My head and neck became increasingly crooked, both turning and tilting to the left while causing a rise in my right shoulder, and a frequent tremor in my head.

It seemed the higher my level of stress, the worse my dystonia became.

Continued on page 12

My situation continued to worsen until 2013 when I decided to undergo deep brain stimulation (DBS) surgery. Following the completion of significant testing to ensure I met the criteria for being a good candidate, my surgery was scheduled for early 2014. I was convinced that that would “fix” things and I would return to the life that I had before my diagnosis.

Unfortunately, I did not experience any of the relief that I had been seeking. In fact, my “new” normal now included new physical impairments - my handwriting became illegible, and I struggled to get in and out of bed. My balance became quite impaired.

I also noticed changes in my mood that would come on quickly – at times I would feel quite flat and then would switch quickly to being anxious. I became aware that I also experienced claustrophobia.

While my physical and emotional symptoms continued to worsen, no assistance was offered with respect to counselling, physiotherapy, exercise, or other interventions.

I had always been a very active individual partaking in regular exercise and sports, all of which was now beyond my capacity. In the past, exercise was something that had always helped my mood and it was now out of reach. Now, I could barely do more than shuffle somewhere around half my normal speed.

I was highly conscious of the fact that my lovely partner had suddenly shifted to being my caregiver. I was fearful if our relationship would

survive this dilemma. Of course, this only added to the anxiety and depression. My sleep took a terrible turn for the worse, and it frequently took me two to three hours of tossing and turning before I fell asleep. For this reason, we slept in separate rooms. I truly felt as though I was caught up in a helpless situation; one in which I felt powerless in knowing what to do to change it for the better.

Fighting back against the darkness of dystonia

By June 2014, I had attempted to find help through the use of an antidepressant. Though, it did not provide any relief. I tried to connect with another dystonia patient for some comfort, but we were unable to come together.

My partner located a therapist who offered both biofeedback and psychotherapy. Although the biofeedback would not work due to my DBS, the counselling provided me with some improvement in mood.

During this time, I also reached out to DMRF Canada, which led to a phone call with a kindred spirit; Robin Krantz, who also suffered from dystonia. I found just talking to someone whom I could relate to was a life-altering, and much needed, experience. Without any hesitation, Robin and I decided to form a Vancouver and area support group for people with dystonia.

Finally, I was prescribed a different antidepressant which really helped me. Following this, I began to exercise again – this time with a group of Parkinson’s disease patients three

times a week. This gradual return to exercise eventually led to a modest amount of bicycle riding, which greatly improved my mood.

Although the DBS surgery did originally worsen my situation, I realize now that if I had not chosen surgery, I would have continued to accept the reduction in my ability to participate in the physical activities I had loved in the past. I have now resumed many previously abandoned activities – including riding a new road bike, playing tennis, golf, and, after a six-year absence, driving a car. Being physically able to participate in these activities again, has been such an incredible lift to my spirits. I seldom use the DBS now.

The most significant improvement for me was when I joined the B.C. Brain Wellness Program in Vancouver. I now participate in various exercise programs, including yoga and mindfulness, six to seven times per week. Most recently, my doctor has begun cutting back the units of botulinum neurotoxin injections I require as well as spacing out my appointments as my dystonia symptoms have waned.

With the support of my family, many positive interventions have been achieved, through trial and error, starting with counselling.

My journey with dystonia has had many dark days. But I never gave up. I have continued to improve my quality of life, and through that - have begun to find the light and increasingly saying ‘yes’ to life.

DMRF Canada thanks Jackson for courageously sharing his story with the community. A reminder that all patients must speak with their movement disorder specialist prior to engaging in any course of treatment for dystonia.

To read the journey of others with different forms of dystonia, visit www.dystoniacanada.org/patient-stories

Research Update: 2022 Grants

DMRF Canada is dedicated to advancing research for more treatments and, ultimately, finding a cure for dystonia. Our aim is to support the best and brightest minds in the field, both in Canada and internationally. Working with our sister organization, the DMRF in the US, DMRF Canada supports various research projects.

Below are the latest research projects that have been funded by the DMRF.

New in 2022:

GABA Abnormalities and Stability in Cervical Dystonia

Brian Berman, MD

Virginia Commonwealth University

Quick Summary: The goal of this study is to understand the underlying brain changes in cervical dystonia and the role the neurotransmitter GABA plays in the disorder.

Protein Kinase R Dysfunction in Dystonia

Stephanie Moon, PhD

University of Michigan, Ann Arbor

Quick Summary: The goal of this research project is to understand how changes in Protein Kinase R cause dystonia and possibly identify new drug targets.

Molecular Mechanisms of Dysmyelination in Dystonia

Dhananjay Yellajoshyula, PhD

Case Western University

Quick Summary: White matter abnormalities in the brain contribute to dystonia, and this investigation will explore how a specific gene variant may lead to such abnormalities.

2nd Year Funding

Normalizing DYT1 Cholinergic Neurons by CRISPR Disruption of Mutant TOR1A Allele- 2nd Year

Xandra Breakefield, PhD

Massachusetts General Hospital

Quick Summary: This project seeks to investigate the development of gene therapy for dystonia.

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Summer 2022.Vol 45, No.2*

A Next Generation Sensing Neural Interface Study for Adaptive DBS in Dystonia

Simon Little, MBBS, MRCP, PhD

University of California, San Francisco

Quick Summary: Investigators are examining unique brain activity patterns found in dystonia patients treated with deep brain stimulation.

Role of Cerebellar Network Excitability and Plasticity in the Pathophysiology of Dystonia

Antonio Pisani, MD

University of Pavia

Quick Summary: This project seeks to advance understanding of the underlying neurology of dystonia by focusing on two specific types of inherited dystonia.

Targeting the cAMP Pathway in the Striatum to Treat Dystonia

Emmanuel Roze, MD

Paris Brain Institute

Quick Summary: This project investigates how disruptions in neuron signaling in the striatum lead to dystonia.



Community Education and Impact

New and Improved Support Resources

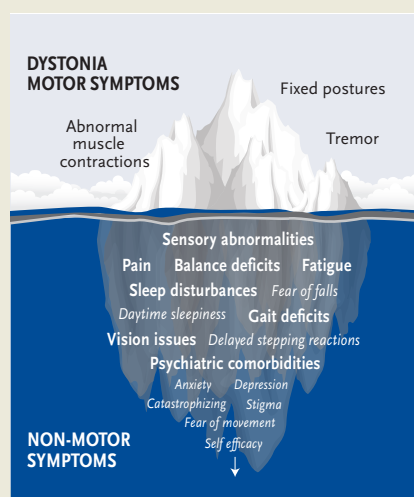
We are excited to announce that a refreshed version of our website www.dystoniacanada.org will be available in September. In addition to an improved user interface complete with enhanced accessibility features, we have also updated and reorganized our information to make it easier for users to find the resources they need.



Additionally, based on feedback, we have re-developed our Support Group Network resources to better equip our leaders with the tools they require to help meet the changing needs of support across Canada.

Our thanks to Allergan: An AbbVie Company for their critical support of these initiatives.

More Than a Movement Disorder: Managing the Non-Motor Symptoms of Dystonia



Dystonia is more than just a movement disorder. Non-motor symptoms are a significant burden and can be as disabling-or even more disabling - as the involuntary movements and postures characteristic of dystonia. Dr. Davide Martino of the University of Calgary has long championed that to live well with dystonia, it is as necessary to treat the non-motor symptoms as it is the motor symptoms. Dr. Martino has recorded a presentation for patients as well as for health professionals about the treatment of the non-motor symptoms. **To watch a recording of the presentation or to share it with your healthcare provider, please visit:** www.dystoniacanada.org/livingwellseries

Taking an active role in managing your mental health and well-being is also an important component to living well with dystonia. Recognizing the need for more mental health resources and tools for the community, DMRF Canada, in partnership with Hydrocephalus Canada,

hosted “From Awareness to Empowerment: Navigating Mental Health with a Neurological Condition” presented by registered Psychotherapist Kristen Drozda. **To watch a recording of this webinar, please visit:** www.dystoniacanada.org/dystonia-information-sessions

Dyfy the Storm Podcast

The brainchild of dystonia thriver and advocate, Casey Kidson’s podcast Dyfy the Storm creates a safe place for dystonia thrivers to share their inspiring stories. Recently, Casey hosted an episode with leaders of the DMRF and DMRF Canada to talk about the many accomplishments of the foundations and highlight the challenges faced today. **To listen to the episode, please visit:** www.anchor.fm/dyfyngdystonia



Thank You to Our Support Group Leaders

DMRF Canada is incredibly grateful to our wonderful network of volunteers, including our dedicated and passionate support group leaders. This summer, we hosted our annual support group leaders conference and met virtually with leaders across the country to discuss our plans to revitalize our support network. Stay tuned, we have big plans in the works to improve support services for people with dystonia.

Stay Connected and Engaged

The DMRF Canada Support Group Network is here for you. Our groups have continued to hold meetings virtually and in-person - creating an opportunity for people to connect over their shared experiences.

See what our Support Groups have been up to, and explore our list for upcoming meetings:



June 18, 2022

Winnipeg, MB – Our Winnipeg Group hosted their Freedom to Move “Walk in the Park” event in Assiniboine Park. Members came together to complete their race and help raise awareness about dystonia.

July 11, 2022

Ottawa, ON – Our Ottawa Support Group hosted their “Welcome Back Lunch” for members to reconnect after a long two-year break due to the pandemic.

July 17, 2022

National Virtual Support Group – Recognizing that not everyone can meet in-person, DMRF Canada has continued to offer virtual meetings over Zoom. Thanks to our volunteer, John for hosting and moderating this session.

Upcoming Meetings

September 10, 2022

Calgary, AB – Our Calgary Support Group will be hosting a “Welcome Back Picnic.” This will mark the first time in two years the group has gotten together in-person. All are welcome!

Visit: www.dystoniacanada.org/calgary for more details

September 24, 2022

Montreal, QC – Our French-speaking support group, Dystonie-Partage, will be hosting a conference with guest speakers Dr. Sylvain Chouinard and registered psychotherapist, Isabelle Fontaine.

Please visit: www.dystoniacanada.org/montreal

Thanks to Allergan: An AbbVie Company and Merz Therapeutics for their support

Neurologic Music Therapy

Since Fall 2020, the Faculty of Music at the University of Toronto has been graciously offering Neurologic Music Therapy (NMT) classes for the dystonia community over Zoom. These sessions use music-based movement and singing interventions to help reduce tension and improve quality of life in a fun and supportive environment. Led by Dr. Corene Thaut and passionate PhD and MA students in the Music and Health Science programs at the University of Toronto, the group recently recorded a presentation highlighting the benefits of the program. **To watch the recording, learn more about NMT, and to sign-up visit:** www.dystoniacanada.org/events/NMT



Celebrating the Strength and Resilience of the Dystonia Community this September

We are thrilled to announce that September is Dystonia Awareness month. Promoting public awareness of dystonia is one of the most important aspects of our mission. In addition to improving society's recognition and understanding of dystonia, increased awareness directly impacts our ability to fundraise for research and identify people and families who need our help.

There's strength in numbers and we all can play a part in promoting awareness. Here's how you can help us remain Dystonia Strong.



Become a Dystonia Awareness Ambassador –To help maximize awareness efforts throughout the month, we are encouraging members to distribute dystonia informational materials in their communities.



Spread Awareness on Social Media Get the word out and help increase awareness of dystonia by sharing important facts on your social media pages. Remember to use the hashtags [#dystoniastrong](#) [#dystoniaawareness](#) when you post.



Check out Local Landmarks – Across Canada prominent monuments will be lit up in blue and white in support of the dystonia community. Please take a photo and tag DMRF Canada on social media. Don't forget to tag your local government officials and local media to increase awareness! Visit our awareness month page for the calendar of monuments to be lit up.



Proudly Display Your Dystonia Branded Merchandise – New for this year, show your support by purchasing a Dystonia Strong yard flag or a DMRF Canada water bottle. Limited supply available.



Bid to Benefit Dystonia Research – Famed Canadian cartoonist and dystonia advocate, Lynn Johnston will once again be auctioning her artwork to benefit dystonia research and support programs. Running from September 20 to September 30, don't miss out on the chance to own signed artwork by this talented artist, storyteller, and dystonia thriver.

For further details and a complete list of activities, please visit: www.dystoniacanada.org/dystoniaawarenessmonth



The Power of Dystonia Awareness

Our Awareness Committee Member and Support Group Leader from Cape Breton, Jason Young, knows of the importance of increasing awareness of dystonia all too well. Inspired from the challenges he faced following his diagnosis of Paroxysmal Non-Kinesigenic Dyskinesia and a desire to improve the experience for others, Jason has made it his mission to raise awareness about dystonia in Nova Scotia. To read more about Jason's journey, please visit: www.dystoniacanada.org/jason's-story



Last year, Jason raised awareness about dystonia in several different ways. From partnering with local businesses, obtaining media coverage, requesting local monuments to light up in dystonia blue, and even asking local politicians to publicly support dystonia awareness month, Jason left no stone unturned.

This year, we approached Jason to get his top tips on raising awareness about dystonia during September.

Start Raising Awareness Today

- 1. Check out DMRF Canada's Awareness Activities List.** They have developed various easy-to-use templates for you to customize and begin your awareness campaign.
- 2. Share your dystonia story.** There's a purpose to sharing your story - even if it seems challenging at first. Sharing creates an opportunity to connect, provide hope to others on a similar path, and it honours the journey that brought you to where you are now.
- 3. The power of collaboration and networking.** Reaching out to even one person can make a difference and could put you in contact with many others. After I reached out to local politicians in my area, they connected me with local business owners eager to help raise awareness about dystonia.
- 4. Say thank you.** After connecting with key stakeholders, including politicians or media contacts, always follow up with a thank you – even if they are unable to honour your request. They may be able to help in the future or point you to someone else who can.

To read more of Jason's tips and suggestions for approaching businesses, local politicians, and media, please visit: www.dystoniacanada.org/jasonstips

25th Anniversary of the Discovery of the TOR1A/DYT1 Gene

Certain moments in dystonia research are flashpoints for accelerating progress. One such flashpoint was the discovery of the TOR1A/DYT1 gene by DMRF-funded investigators in 1997.

2022 marks the 25th anniversary of the announcement from Xandra Breakefield, PhD, Laurie Ozelius, PhD, and their collaborators that they identified a gene variant for early-onset torsion dystonia, a debilitating childhood form of dystonia. Identifying the TOR1A/DYT1 gene was not an overnight accomplishment. Investigators worked for years to locate affected families, collect blood and bio samples, and use the limited technology available to hunt the gene.

This gene identification resulted in a target for new dystonia therapies, testing to aid diagnosis and identify gene carriers, more predictable success from deep brain stimulation, reproductive medicine options to protect future generations of affected families from developing TOR1A/DYT1 dystonia, new investigators joining the dystonia field, and an explosion of data about the biological mechanisms underlying all types of dystonia.

This was made possible thanks to your support and the efforts and support of our partners in the research community.

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Research Bits

There have been a record number of dystonia clinical studies published in recent years. Here are just a few interesting examples.

Investigating Remission

There are occasional reports of dystonia symptoms going into remission. Given the research and prognosis implications of this, investigators did a systematic review of reports of remission in the medical literature. They reviewed data from 2,551 cases with reports predominantly from individuals with cervical dystonia or blepharospasm/Meige syndrome. Complete remission was reported in 12% and partial remission for 4% of cases. Remission rates were higher in cervical dystonia (15%) than in blepharospasm/Meige (6%). Remission occurred on average 4.5 years after onset of symptoms. However, the majority of patients (64%) experienced a return of symptoms. The data suggested that patients with remission were significantly younger at symptom onset than patients without remission. The investigators called for additional study into this important phenomenon.

Mainka T, Erro R, Rothwell J, Kühn AA, Bhatia KP, Ganos C. Remission in dystonia - Systematic review of the literature and meta-analysis. Parkinsonism Relat Disord. 2019 Sep;66:9-15.

Deep Dive into Oromandibular Dystonia

In a study partially supported by DMRF, an international team of investigators embarked on the most comprehensive examination of the clinical features of oromandibular dystonia (OMD) with the purpose of reducing misdiagnosis. The symptoms of OMD include varying combinations of abnormal jaw, tongue, or lower face movements. OMD is particularly disabling because it often interferes with eating and speaking and can cause severe discomfort. Isolated OMD is estimated to account for only 3–5% of all dystonias. Of the 2,020 cases of OMD reviewed, typical age at onset was in the 50s, and 70% of patients were female. The muscles of the lower face were most commonly affected, followed by jaw, and sometimes tongue. OMD more commonly appeared as part of segmental dystonia, rather than occurring as a focal dystonia or within generalized dystonia. Social anxiety and depression were prominent. Botulinum neurotoxin injections improved symptom severity by more than 50% in approximately 80% of patients.

Scorr LM, Factor SA, Parra SP, Kaye R, Paniello RC, Norris SA, Perlmutter JS, Bäumer T, Usnich T, Berman BD, Mailly M, Roze E, Vidailhet M, Jankovic J, LeDoux MS, Barbano R, Chang FCF, Fung VSC, Pirio Richardson S, Blitzer A, Jinnah HA. Oromandibular Dystonia: A Clinical Examination of 2,020 Cases. Front Neurol. 2021 Sep 16;12:700714.

Survey of Musicians Reveal 2%+ Affected by Dystonia

A team of researchers in Brazil set out to evaluate the clinical characteristics and frequency of task-specific dystonia in musicians and to promote awareness of the condition among musicians across the country. They visited orchestras and music schools to deliver lectures on musician's dystonia and invite musicians to complete a questionnaire. They visited 51 orchestras and music schools in 19 Brazilian cities, collecting over 2,200 questionnaires. Of those, 72 individuals with suspicion of dystonia were video recorded and evaluated for motor impairment. Forty-nine individuals (2%+) were diagnosed with dystonia. This is in range with rates reported in previous studies from various countries. The instruments most associated with task-specific dystonia were acoustic guitar (37%) and brass instruments (31%). They concluded that Brazilian musicians with dystonia tend to be male, classical music professionals, around 30 years of age, with arms, hands, or oromandibular muscles most often affected. The research team stressed the career-altering impact of dystonia in musicians and called for greater awareness among musicians, music instructors, and health professionals.

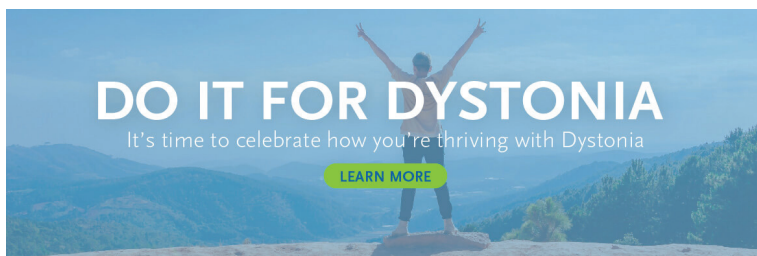
Moura RC, de Carvalho Aguiar PM, Bortz G, Ferraz HB. Clinical and Epidemiological Correlates of Task-Specific Dystonia in a Large Cohort of Brazilian Music Players. Front Neurol. 2017 Mar 6;8:73.

"Musicians with Dystonia Support Forum" is a private Facebook group available for musicians affected by task-specific focal dystonia. Visit the group at: facebook.com/groups/musiciansdystonia

Reprinted with permission from DMRF Dystonia Dialogue Spring 2022.Vol 45, No.1

Join Do It for Dystonia to Help Find a Cure Today

Through *Do It for Dystonia* you can help raise funds for critical dystonia research and support programs when you want and the way you want. From birthday fundraisers to hosting spin class, Do It provides the opportunity for you to tap into your creativity and help make a difference in the lives of the 50,000 Canadians living with dystonia. Join other dystonia thrivers across Canada by raising funds for a future without dystonia.



Our top fundraiser will be featured in the Spring 2023 Newsletter.

To start your campaign today, please visit: www.dystoniacanada.org/doit

Help Shape the Future of Dystonia Research Sign up for the Legacy Society

DMRF Canada established the Legacy Society to recognize those who have made a lifetime commitment in the battle against dystonia by naming DMRF Canada in their estate plans. Through the Legacy Society, you can make a commitment of support today to ensure the continuation of dystonia research in the future. For more details on estate planning, please visit: www.dystoniacanada.org/legacy

Options Include:

- Wills and Bequests
- Life Income Gifts: Charitable Trusts and Gift Annuities
- Qualified Retirement Plans
- Real Estate

Advocacy Updates

As a contributing member of Neurological Health Charities Canada (NHCC), DMRF Canada has participated in various discussions to advocate for improved care, research investments and better resources and access for those impacted by neurological disorders. Here are some of the topics we continue to advocate for:



- Providing input on improving existing federal healthcare policies to include those who have an episodic disability because of their neurological condition.
- Supporting the Canadian Brain Research Strategy (CBRS) - developed by Canadian neuroscience leaders - by providing input from people with lived experience with neurological disorders.
- Providing input to scientific research groups looking to create integrated care systems in Canada to meet the complex care needs of patients and families.
- Pressing for key actions aligned with the vision of a National Neurological Strategy for Canada, with the adoption of the Intersectoral Global Action Plan at the Seventy-fifth World Health Assembly.

To learn more about these advocacy initiatives, visit www.dystoniacanada.org/advocacy

DMRF Canada Needs Your Help - *Please Give Generously*

Each discovery builds toward the next – all leading to the ultimate goal of a cure for dystonia.

Become a Member of the Monthly Giving Team

“My husband and I become monthly donors for many reasons. I have had dystonia since 1993 and my daughter was diagnosed with dystonia about 10 years ago. At my age, I don’t have to remember to donate (not that my spasms would ever let me forget) but hopefully by donating monthly, ongoing research will help future generations fight this disorder.” - Tracy, DMRF Canada Monthly Donor

For a charity like DMRF Canada, revenues often fluctuate dramatically from month to month, and year to year making it challenging to plan multi-year research projects. A monthly donation of just \$5/month will ensure a steady source of funding while reducing administrative costs.

Yes, I want to support DMRF Canada. Please add your selection below.

☐ Yes, I want to join the DMRF Canada Monthly Giving Team.

☐ \$50 a month ☐ \$25 a month ☐ \$10 a month ☐ \$5 a month ☐ \$ _____ a month

☐ Please charge my credit card: ☐  ☐  ☐ 

Card #:

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Expiry:

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☐ Yes, I want to make a one time gift to invest in critical dystonia research. Here is my gift of:

☐ \$250 ☐ \$150 ☐ \$75 ☐ \$45 ☐ \$ _____

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

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

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☐ Yes, I want to join DMRF Canada’s Legacy Society.

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 RR0001

Cut along dotted line

