

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  
Dystonia Medical Research  
Foundation Canada

Fall/Winter 2024

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Working Together to Transform the Lives of the  
Dystonia Community

## PLEASE RENEW YOUR MEMBERSHIP FOR 2024

*Support the dystonia community with a donation to DMRF Canada.*

**visit: [www.dystoniacanada.org/donate](http://www.dystoniacanada.org/donate)**

*Thank you for your support.*

# Foundation Update

We're excited about this season's update as it highlights one of the most effective elements of our community – collaboration. As a small number of voices, partnering with others helps the DMRF Canada amplify our efforts. The nature of dystonia means we support a relatively small, yet diverse population. For this reason, we remain deeply committed to exploring and advancing research across the spectrum of dystonia to develop more effective treatments and interventions. Collaboration makes this monumental effort possible!

In the following pages you'll see instances of how collaboration is the key to our success. For example, this year's partnership with Hydrocephalus Canada to co-host the Freedom to Move Toronto fundraising event helped share the workload while also amplifying our voice (page 4). We also partnered with the University of Toronto, welcoming two medical students from the Temerty Faculty of Medicine to improve community awareness and program access (page 11). In addition, partnerships with the Banting Research Foundation (page 10) and corporate sponsorships are crucial to further our commitment to awareness and research.

Collaboration with these organizations would not be possible without the dedication of our community and members. On these pages, you will also find tools and opportunities to make your awareness and fundraising efforts even stronger through our dystonia awareness month media campaign (page 15) and our new support flyer (attached).

Thanks to our dedicated volunteers and efficient operations, our administrative costs are now lower than they were in 2014. This allows us to direct more donations into impactful initiatives and programs.

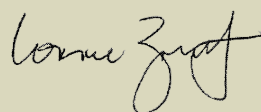
**While our community is dedicated to giving both time and money, we acknowledge that we are too small to do it alone! To further our impact, we ask that you think creatively to help us expand our reach, by tapping into your own network.** See "Your Network is Our Network" (page 19) for how you can make this possible.

We thank our community for being vocal about their needs and generous with their resources. You are truly a vital part of our journey and the reason we continue to do what we do, making meaningful strides toward a better future for those affected by dystonia.

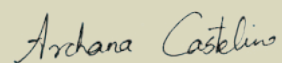
Sincerely,



Connie Zalmanowitz,  
Chair, DMRF Canada,  
Board of Directors

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

Archana Castelino,  
National Director,  
DMRF Canada

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 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. 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.

### Board of Directors

Samuel Belzberg

Co-Founder

1928 - 2018

Frances Belzberg

Co-Founder & Honorary Chair

Connie Zalmanowitz  
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Pearl E. Schusheim  
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Dennis Kessler

Casey Kidson

Rosalie Lewis

Catherine Mulkins

## 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](http://www.globaldystoniaregistry.org) to learn more and register.



## Participate in Dystonia Research Studies in Toronto

Dr. Susan Fox and her team at Toronto Western Hospital are conducting two Dystonia Coalition Projects on dystonia. The main study and the related Patient Centered Outcome (PCO) app project are designed to work together to advance the understanding and treatment of dystonia. Please visit:

[www.dystoniacanada.org/Dystonia\\_Coalition\\_Projects](http://www.dystoniacanada.org/Dystonia_Coalition_Projects)

Dr. Talyta Grippe at Toronto Western Hospital is recruiting for a study that aims to understand how the interactions across different areas of the brain of a dystonia patient differ from those without dystonia.

For more information, please visit: [www.dystoniacanada.org/study-Grippe](http://www.dystoniacanada.org/study-Grippe)



## In Tribute

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

Jeannine Marie Helene Lonneberg  
Noreen May Williston

*This Dystonia Canada Report is supported by*

abbvie



# Uniting Across Canada for a Cure



Throughout the month of June, the dystonia community across Canada united once again for our largest fundraising event of the year, *Freedom to Move: Run, Walk and Wheel for Dystonia*. This year's event drew in over 110 participants. Thanks to the efforts of all participants, donors, and sponsors, the event raised \$50,000 for critical dystonia research and essential support programs!

Visit: [www.dystoniacanada.org/freedomtomove](http://www.dystoniacanada.org/freedomtomove) to watch our event wrap up video.



## Freedom to Move Toronto – June 2 at Downsview Park

Despite the rainy weather, our Toronto community came out in full force to run, walk, and wheel for dystonia. For the first time, we were joined by Hydrocephalus Canada, a fellow neurological health charity that serves the hydrocephalus and spina bifida communities in Canada, to co-host the event. With a shared vision to raise funds and awareness, and to inspire a better future for all, both charities were able to maximize their administrative efficiencies while amplifying the collective voice of our neurological communities. Special thank you

to DMRF Canada Board Member, Catherine Mulkins and her team for their unwavering support of the event. Special thanks to all volunteers for their excellent help throughout the event!



DMRF Canada National Director, Archana Castelino with Dr. Grippe at the Toronto event

We were honoured to have Dr. Talyta Grippe from Toronto Western Hospital and Krembil Research join us at this year's event. Dr. Grippe is the recipient of the 2023 – 2025 DMRF Canada Clinical and Research Fellowship Supported by Merz Therapeutics. Funds raised at events like Freedom to Move directly support the training of the next generations of movement disorder specialists like Dr. Grippe. Dr. Grippe is actively recruiting dystonia patients in her research study in Toronto. Further details and how to participate for Dr. Grippe's study can be found on page 3.



Photo Credit: Steve Kean

## Freedom to Move Virtual - June 1st to June 30th

In addition to our in-person Toronto event, our virtual event drew in dystonia thrivers from all across Canada. From northern Ontario to the prairies and even the Rocky Mountains, participants completed a run, walk, or wheel course, any length, anywhere – indoors or outdoors, and had the entire month of June to do it! Thank you to all that participated.



Casey Kidson

### Virtual Highlights

- Kingston, ON Group Leader and DMRF Canada Board Member, Casey Kidson kicked off her Freedom to Move challenge in Banff, AB surrounded by the picturesque Rocky Mountains.
- A new Freedom to Move record for distance completed over the month of June was set by Regina Group Leader, Judy Dove as she walked over 175 km.
- Our Winnipeg Group gathered on June 23rd to complete their walk together at St. Vital Park in Winnipeg. Thank you to the Group Leader, Jennifer Lovell, for organizing the outing. To read more about Jennifer, her journey with dystonia, and upcoming events in the Winnipeg area, please turn to pages 13 and 14.

## Congratulations and Thank You to Our Top 3 National Fundraisers

1. Mary Guy of Team Greater Sudbury
2. Franco Mazzella of Team Franco's Dystonia Busters
3. Cheryl Cline of Team The Shakers

A very special thank you to our Family Ambassador Sumbul Zafar and her family for their incredible efforts throughout this year's event!

Freedom to Move  
Family Ambassador 2024  
**Sumbul Zafar**

"Dystonia is a relatively rare disorder, but there's strength in numbers and our collective impact is mighty."

@the.dystonia.yodha



## Thank you to our Sponsors and Partners



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Functional dystonia is one of the most misunderstood forms of dystonia. Some of the misconceptions about functional dystonia stem from the stigma around its psychiatric aspects and the history of misguided diagnosis of dystonia in general.

To gain a better understanding about functional dystonia and unravel some of the myths around the disorder, DMRF spoke with Mark Hallett, M.D. retired Chief of Medical Neurology at the National Institute of Neurological Disorders and Stroke and a founder of the Functional Neurological Disorder Society. Dr. Hallett is also one of the leading dystonia researchers who is part of the Dystonia Classification Working Group, which is updating the classification of all forms of dystonia in order to help doctors diagnose and better treat the disorder.

### What is Functional Dystonia?

“To derive a good definition of functional dystonia, we must first understand the hierarchy of functional disorders,” Hallett said.

Functional neurological disorders, the broad category, can manifest as almost any type of neurological symptom that is genuinely experienced and distressing, characterized by variability in the same task and across tasks. “Variability in performance is to say that there is dysfunction in the nervous system, which leads to variable manifestations of an abnormality over time,” Hallett said. “There are times when the patient can function normally, but other times there is dysfunction.”

With functional movement disorders, the neurological symptoms display as movement disorders, such as tremor, myoclonus, gait disorders, tics, and dystonia.

“The term genuinely refers to the fact that the symptom is involuntary. It’s not something that someone brings on themselves. It is real, a genuine symptom,” he said. In functional dystonia, there is abnormal, unintended movement or positioning of the body due to the nervous system not

### Possible Indicators of Functional Dystonia

- Sudden symptom onset
- Symptoms are varying and unpredictable over time
- Symptoms contradict hallmark features of other neurological disorders
- Symptoms lessen with distraction
- Spontaneous remissions and relapse
- Psychiatric symptoms
- Exposure to psychological stressors

working properly. Functional dystonia most often causes symptoms in the face, neck, shoulders, torso, and/or limbs.

### What Causes Functional Movement Disorders?

Many researchers believe functional movement disorders such as functional dystonia occur due to an underlying vulnerability in the brain combined with an external trigger, though the mechanism is not yet fully understood.

“The limbic system is the brain’s emotional network,” Hallett said. “There’s a fair amount of evidence that there is an overactivity of that network in the brain, which is an underlying predisposing factor. Then, other

factors come into play which trigger this predisposition into an abnormal sickness belief.”

Triggers could be excessive stress or other factors, but the person has a predisposition in the brain that manifests as a movement disorder.

“Something would trigger the abnormal sickness belief that would drive the manifestations. We don’t understand it completely,” he said.

### How Does Functional Dystonia Differ From Other Forms?

Diagnosing functional dystonia can be difficult and should be left to movement disorder neurologists and psychiatrists with experience in diverse neurological diseases.

“There has always been confusion in the area of dystonia between functional and other causes of dystonia,” Hallett said. “In fact, when I began my own neurological career,



all of the focal dystonias were presumed functional. They were called psychogenic or conversion disorders then. We no longer use those terms.”

The main difference in the nature of functional dystonia versus other types is that patients with functional dystonia are capable of normal function, but the brain isn’t allowing it.

“In the case of dystonia, DYT1 for example, the brain doesn’t appear to be capable of normal function,” Dr. Hallett said. “In the case of functional dystonia, the brain is capable of normal function. It’s just that the brain isn’t functioning normally at that time.”

### **What are Possible Indicators of Functional Dystonia?**

Neurologists still have difficulty in differentiating functional dystonia and other types of dystonia. The symptoms can look the same in that they are characterized by abnormal movements and postures. The differences are subtle, but some clinical indicators point to functional dystonia.

“Nothing is ever 100%, but some types of abnormal posturing turn out to be more likely functional. One type of situation is when the dystonia comes on very suddenly because most dystonias come on gradually,” Dr. Hallett said.

Another indicator might be when the dystonia is fixed, like a clenched fist that never changes. “There are other types of dystonia that will cause that, but clinicians should consider functional in these cases,” he said. “Another one we were just talking about at our clinical rounds is a pulling of the mouth in one direction. I don’t know why that tends to be more likely functional, but it can be.”

Another indicator can be the disappearance of the movement with distraction. “If someone has an abnormal posture and their attention is distracted, and the dystonia and that abnormal posture go away, that would be more likely to be functional,” he said.

### **How Do You Treat Functional Dystonia?**

There are two main approaches for treatment of functional dystonia: physical therapy and psychotherapy with cognitive behavioral therapy being the most common.

Physical therapy when done properly acts to show the patients that they are capable of normal function. “In some

patients physical therapy works very well and very quickly because by using physical therapy, it is possible to change the sickness belief,” Dr. Hallett said.

Psychotherapy can potentially help to calm down the over-activity of the limbic system that is leading to the abnormal sickness belief. “In terms of functional dystonia versus other types of dystonia, the treatment is quite different,” he said.

### **How Common are Functional Movement Disorders?**

Because of the difficulty diagnosing functional disorders, it is hard to quantify how many suffer from functional movement disorders including functional dystonia. But, functional movement disorders represent up to 25% of patients treated in movement disorder clinics.

It is very common for patients to have different movement disorders at the same time, which is the case for both functional and other causes of dystonia.

“There was a recent large study series of more than 4,000 patients, and the most common movement disorder was called mixed, which is different types in the same patient,” Hallett said.

The most common individual functional movement disorder is tremor, but dystonia is probably the second most common, Hallett says.

### **Quelling the Misconceptions of Functional Dystonia**

Functional dystonia is a real disorder that mimics other forms of dystonia and can be disabling and painful. Patients are not making up symptoms and can suffer for years with the movement disorder.

“I tell patients, ‘you have dystonia.’ In some patients it is caused by genetics or other causes, sometimes unknown. But, this is caused by a functional mechanism,” Dr. Hallett said

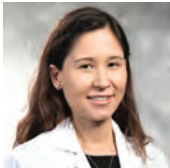
The good news for patients with functional dystonia is that their condition is treatable since it is due to dysfunction of the nervous system, not neurological damage or disease. “A functional disorder is imminently treatable if you can make the right diagnosis and you get into the right therapeutic program. Once you get past the stigma of the psychiatric feature, that should be good news,” Hallett said.

# 2024 Research Grants and Fellowships

## 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 research aimed at expanding the knowledge of the genetic, molecular, physiologic and pathologic basis of dystonia. The new 2024 grants are:

**Noreen Bukhari-Parlakturk, MD, PhD**



***Accelerating Personalized TMS Therapy for Focal Hand Dystonia***  
Duke University,

Durham, North Carolina

Dr. Bukhari-Parlakturk will explore the effectiveness of transcranial magnetic stimulation (TMS) as a non-invasive treatment for dystonia. She will test the clinical effectiveness of this treatment on patients with focal hand dystonia and hopes to leverage her findings into a phase III clinical trial.

*"The reason I was very interested in working in dystonia is because I realized there are very few effective treatments for our patients."*  
~Bukhari-Parlakturk

**Meike van der Heijden, PhD**



***Relationship between cerebellar Purkinje and nuclei cell spike signals in dystonia***

Virginia Tech University,  
Roanoke, Virginia

Dr. van der Heijden seeks to further explore the neural mechanisms in the cerebellum that cause dystonia. By using mouse models to examine two different cell types found in the cerebellum, she hopes to uncover how changes in brain signals can cause dystonia.

*"Every drop in the bucket makes a big wave [in dystonia research] and I want to be a part of that wave."*  
~van der Heijden

**Katja Lohmann, PhD & Laura Scorr, MD**  
***Role of the immune system in dystonia***



University of Luebeck  
Luebeck, Germany  
Emory University,  
Atlanta, Georgia



Drs. Lohmann and Scorr are combining their extensive scientific resources and expertise to explore a less studied aspect of dystonia: the immune

system function. They believe this study will lead to better diagnosis and treatment of dystonia.

*"This has the potential to be an ongoing, exciting, international collaboration that will benefit patients in both Europe and the US."* ~Scorr

*"It's really nice to know so many patients are behind us as we do this kind of research."* ~Lohmann

**Christian Schlieker, PhD**



***Systematic identification of cellular networks underlying dystonia***

Yale University,

New Haven, Connecticut

Dr. Schlieker intends to identify the genetic networks involved in DYT-TO RIA dystonia. The study will explore disease-causing gene networks that could become novel drug targets.

*"Since [becoming involved with the DMRF] I've been connected to the dystonia community; it's been a rewarding experience for me as a researcher to have that direct contact with patients and their families."*

~Schlieker

## 2ND YEAR GRANTS

**Daniel Corp, PhD\***

***Neuroanatomical Isolation of Networks in Dystonia through Analysis of Causal Brain Lesions***  
Deakin University, Victoria, Australia

**Jean-Francois Nankoo, PhD\***

***Theta Burst Transcranial Focused Ultrasound as a Novel Treatment for Cervical Dystonia***  
University Health Network,  
Toronto, Canada

**Christian Schlieker, PhD\***

***Developing High-Throughput Assays to Enable Drug Development for DYT1 Dystonia***  
Yale University, New Haven, Connecticut

*For more details about 2nd Year funding projects, please visit the Fall 2023 DMRF Canada newsletter on our website: [dystoniacanada.org/newsletters](https://dystoniacanada.org/newsletters)*

The DMRF's official journal, aptly titled *Dystonia* has now published over 50 articles and provides open access premier research on all basic, clinical, and translational aspects of the different forms of dystonia. To stay up to date on the latest developments, please visit:  
[www.frontierspartnerships.org/journals/dystonia](https://www.frontierspartnerships.org/journals/dystonia)



## RESEARCH FELLOWSHIPS

Postdoctoral fellowship awards recognize and support outstanding young scientists who have earned a doctoral degree and have embarked on a period of mentored research. With the DMRF, we are supporting postdoctoral fellows who are working to fundamentally improve our understanding of brain dysfunction and molecular mechanisms underlying dystonia.

### Abigail Wilson, PhD

#### **An In Vivo Drug Repurposing Screen to Identify Novel Treatments for DYT-TOR1A Dystonia**

University College London,  
London, United Kingdom

Dr. Wilson aims to find new drug treatments for patients with DYT-TOR1A dystonia. Using fly models with the same genetic mutation, she will test medications used for other disorders to see if they positively impact the dystonia symptoms. She hopes this will facilitate further therapeutic options for dystonia patients.

*"I want to work in dystonia because there's so much we don't know about this disease and therapeutic options are really limited."*

~Wilson

### Wilson Lucia Feldmann, MD

#### **Naturalistic neurophysiology for DBS therapy improvement in dystonia**

Charité Hospital, Berlin, Germany

Dr. Feldmann will explore the effectiveness of deep brain stimulation by using a sensing-enabled neurostimulator to record brain electrical activity in dystonia. This study could lead to the development of personalized therapy for dystonia.

*"What we want to find with this research is how these biomarkers behave in the everyday lives of patients." ~Feldmann*

### Filipa Franca de Barros, PhD

#### **(2nd Year\*) The Role of Basal Ganglia Pathways Engaged in Skilled Forelimb Movement in a Mouse Model of DYT1 Dystonia**

Champalimaud

Foundation,

Lisbon, Portugal

### Linda Kim, PhD (2nd Year\*)

#### **Spike-Triggered Adaptive Closed-Loop Cerebellar Deep Brain Stimulation for Dystonia**

Baylor University, Houston,

Texas

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## NHCC Embraces New Advocacy Strategy for National Data on Neurological Conditions

DMRF Canada, a member of Neurological Health Charities Canada (NHCC), is excited to announce a renewed advocacy focus on a National Population Health Study of Neurological Conditions. This initiative aims to prioritize knowledge and comprehensive health data on the incidence, prevalence, and impacts of neurological conditions, building on the success of the previous study from 2009 to 2013. Recognizing the evolving landscape of neurological health, NHCC plans to involve individuals with lived experiences from the start.

The previous study, Canada's first-ever population health study of neurological conditions, provided invaluable insights and informed policy and investment decisions through its report, Mapping Connections. This report is still in use by the Public Health Agency of Canada and Health Canada.

We are at a pivotal moment where improved understanding of neurological health can significantly impact healthcare planning and support for Canadians. NHCC proposes to collaborate with the federal government to develop a renewed survey.

We seek allies in government, elected MPs, influential leaders within the public and charitable sectors, and other stakeholders to strengthen our position and improve the well-being of those affected. If you can help, please contact us at [info@dystoniacanada.org](mailto:info@dystoniacanada.org).

To read NHCC's Submission to the Federal Finance Committee's 2025 Pre-Budget Consultation, visit [dystoniacanada.org/advocacy](https://dystoniacanada.org/advocacy).



## Available Now! Samuel Belzberg 6th International Dystonia Symposium Summary for the Dystonia Community



DMRF Co-Founder and Honorary Chair, Frances Belzberg opened the Symposium with an important reminder for researchers: *People are waiting. People, like my daughter, are waiting for scientific breakthroughs and answers. So, let's get to it!*

The Samuel Belzberg 6th International Dystonia Symposium, held in Dublin, Ireland last year, brought together top dystonia researchers from 32 countries, including 68 faculty members and nearly 350 attendees, all striving for a deeper understanding of dystonia and how to treat those affected. The summary presents the latest dystonia science, covering an overview of:

- Current Knowledge
- New Thinking and Research Findings
- Topics of Debate
- Questions for Future Exploration



To read the summary in full, please visit: [www.dystoniacanada.org/news/ids6-summary](http://www.dystoniacanada.org/news/ids6-summary)

Thank you to the Dystonia Medical Research Foundation (USA) for allowing us to share this summary.

## Fostering the Next Generation of Dystonia Researchers: Updates from our 2022 Dystonia Discovery Award Recipient, Professor Luka Milosevic



In partnership with the Banting Research Foundation, DMRF Canada was proud to present Professor Luka Milosevic the Dystonia Discovery Award in 2022. Professor Milosevic's study *Interrogating basal ganglia circuit function in Parkinson's disease and dystonia* focused on comparing the activity of neurons in a specific part of the basal ganglia called the globus pallidus internus (GPI) in people with Parkinson's and dystonia. Professor Milosevic and his team also investigated the adaptability of these neurons over shorter and longer periods of time.

As presented in Professor Milosevic's lay summary, the study's findings support the idea that GPI neurons function differently in Parkinson's and dystonia, with Parkinson's showing more inhibited GPI activity and dystonia showing less. These differences in neuron activity and plasticity might explain the distinct symptoms of these disorders and could influence treatment strategies like deep brain stimulation. Understanding these differences at the cellular level helps explain the unique characteristics of Parkinson's and dystonia. This knowledge can lead to more targeted treatments for each disorder.

### 3rd Annual Canadian Movement Disorders Meeting

From November 8 to 9, 2024, DMRF Canada will be attending the 3rd annual Canadian Movement Disorders Meeting organized by Parkinson's Canada and the Canadian Movement Disorders Society in Toronto, ON. The meeting gathers clinicians, researchers, movement disorder specialists, neurologists, resident physicians, and scientists nationwide to discuss recent advancements in research and care for movement disorders, like dystonia. Stay tuned for updates from this meeting.

# Community Education and Impact

## Warm Welcome to our New Support Network Volunteers

One of the most impactful ways DMRF Canada provides support is through our Support Group Network. In our Spring 2024 Newsletter, DMRF Canada put out a call to grow our most valuable resource: our support group network volunteers. We are pleased to welcome our new volunteers in Calgary AB - Carol, Libby, and Cynthia.



We are still looking for new Support Group Leaders to volunteer in the following communities:

- Victoria, BC (New leader)
- Fredericton, NB (Co-leader)
- Hamilton, ON (Co-leader)
- Toronto, ON (Co-leader)



To read more about roles, responsibilities and eligibility please visit: [www.dystoniacanada.org/volunteer](http://www.dystoniacanada.org/volunteer) or scan the QR Code. If you are not interested in leading a group, but you would still like to volunteer, please email us [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

## Making Meaningful Impact: A Transformative Volunteer Experience for Medical Students

In the fall of 2023, DMRF Canada welcomed two medical school students, Christian Singh and Janice Tai, from the Temerty Faculty of Medicine at the University of Toronto, to volunteer with the Foundation over the course of nine months. During their time with the Foundation, the students refined our digital resources, ensuring they are more accessible for the people living with dystonia and their loved ones and completed an assessment of queries received from the community to identify support needs.



*"Collaborating with DMRF Canada as medical students was an eye-opening experience. Initially, we did not know what to expect from a placement at a medical research foundation. However, as we learned more about the amazing resources and individualized support the Foundation provides to people from many walks of life across Canada, we gained a clearer understanding of how meaningful this work is. It allowed us to gain invaluable insights into the diverse challenges faced by dystonia patients across Canada," said Christian and Janice.*

On behalf of DMRF Canada, we thank the UofT Temerty Faculty of Medicine, Health in Community (HC) team and the students.

## Online Resource Update Now Available

DMRF Canada recently updated our support page to make it easier for you to find proper support in your own community or virtually. Please visit: [www.dystoniacanada.org/support](http://www.dystoniacanada.org/support) to connect with a volunteer based on geographic location, dystonia type or find a dystonia treater in your local area.



As highly requested by the dystonia community, DMRF Canada has been building a physiotherapy resource bank. Please visit: [www.dystoniacanada.org/physiotherapy-and-dystonia](http://www.dystoniacanada.org/physiotherapy-and-dystonia) to see what supports are available in your community or scan the QR Code. If you are treated by a physiotherapist and they are not listed, please encourage them to email us: [info@dystoniacanada.org](mailto:info@dystoniacanada.org) to be added.

# Community Education and Impact (Continued)

## Catching Up with our 2022 Jackson Mooney Patient Education Grant Awardees, Julie and Astrid

In 2022, the Committee awarded the Grant to two deserving candidates, Julie Emied from Toronto, ON and Astrid Frauscher from Calgary, AB. DMRF Canada recently caught up with Julie and Astrid to see how the Grant has impacted their lives.



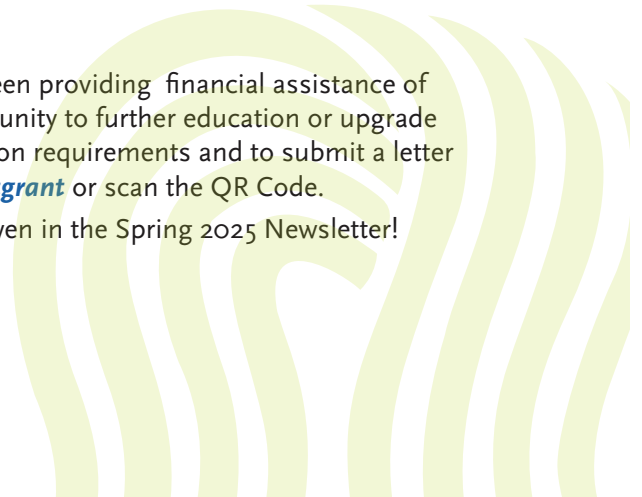
**Julie:** My life has truly blossomed since receiving the Grant. I am currently in my third year of my degree in Social Work and my minor in Disability Studies at Toronto Metropolitan University (TMU). Before receiving the Grant, I was taking 2 courses per semester. With Grant's support, I increased my course load to 3 per semester, and I am on track to graduate in 2025. I am very active in the TMU community, I am involved in various activities and committees that help improve accessibility at the University. I also sit on the Deep Brain Stimulation Advanced Therapies Committee at Toronto Western Hospital, and I am on the Board for Citizens with Disabilities- Ontario board. If you asked me 5 years ago "where do you see yourself in 5 years?" I would not have anticipated what an impactful life I am living. A few years ago, I did not envision myself pursuing a degree after graduating from college. Now, I am confident to say I see myself working towards a master's degree in social work after graduation.

**Astrid:** The Jackson Mooney Patient Education Grant has put the words "I can" back into my vocabulary. Before being diagnosed with cervical dystonia, I worked for 25 years in the Alberta oil and gas industry. With great disappointment, I had to resign from my position and go on disability leave as I was unable to complete my work because my dystonia caused my head to lie on my shoulder. Since receiving the Grant, I have completed my diploma in Child and Youth Support Work and have become a therapeutic foster mother to my 14-year-old foster son in addition to raising my own 13-year-old biological child. The worst part of dystonia is the life it steals from you. I was at the height of my career only to have it ripped away from me. My world was black, I was depressed, never having anything to do because I was unable to. I have now found a place where I can give back and feel worthy again.



Since 2017, the Jackson Mooney Patient Education Grant has been providing financial assistance of up to \$5,000 for individuals with dystonia, providing the opportunity to further education or upgrade skills to pursue new career goals. To learn more about application requirements and to submit a letter of intent, please visit: [www.dystoniacanada.org/dystoniapatientgrant](http://www.dystoniacanada.org/dystoniapatientgrant) or scan the QR Code.

Stay tuned for an update from our 2023 Awardee, Amanda Loewen in the Spring 2025 Newsletter!





# Community Education and Impact (Continued)

## Dystonia and Quality of Life Webinar + Virtual National Support Group Meeting – March 16th, 2024

During “Brain Awareness Week”, DMRF Canada was honoured to host a webinar with specialist guest speaker, Dr. Davide Martino Ph.D. MD, Director of the Movement Disorders Program at the University of Calgary. Dr. Martino provided an insightful lay summary of recent research developments and current trends within the movement disorder field. Following his presentation, Dr. Martino provided a Q & A session moderated by DMRF Canada which then flowed into a virtual support session allowing the dystonia community across the country to connect and bond over shared experiences.

This virtual education session was highly valued by attendees, with Dr. Martino’s informative Q & A session and the exploration into how the non-motor symptoms of dystonia can profoundly affect one’s quality of life being the highlight of many participants’ experiences. Thank you to all that attended.

*“Learning sessions like these are valuable, and provide information I can share with my family and friends to help them better understand my condition.”*  
- Attendee

*Special Thanks to Our Diamond Sponsor*



## Connect In-Person or Virtually Through Our Upcoming Meetings

### Dystonie-partage (Montreal) September 28, 2024

Our French speaking support group, Dystonie-partage, will be hosting a hybrid support meeting from 1:15 PM to 3:30 PM Eastern Time in-person at the Holiday Inn Montreal Longueuil or virtually via Zoom. The meeting will focus on how physiotherapy can be an effective treatment to help manage dystonia symptoms with guest speaker, Benoit Labbé, physiotherapist. Thank you to our sponsors, AbbVie and Ipsen for their generous support of this meeting.



For further details, please visit: [www.dystoniacanada.org/events/dystonie-partage-montreal-reunion-28-septembre-2024](http://www.dystoniacanada.org/events/dystonie-partage-montreal-reunion-28-septembre-2024)

### Winnipeg Symposium, October 19th, 2024

The Winnipeg Support Group will be hosting a free education and support session at Deer Lodge Centre from 1:00 PM to 4:30 PM Central Time. Featured speakers include Dr. Douglas Hobson, Director of the University of Manitoba Movement Disorder Program and Jenell Chorney, a therapist specializing in counseling for chronic diseases/disorders and healthcare issues. Make sure to secure your spot by October 18th. Special thanks to our sponsors Abbvie (Diamond Level) and Ipsen (Gold Level).



Register now at: [www.dystoniacanada.org/events/winnipeg-dystonia-meeting-october-19-2024](http://www.dystoniacanada.org/events/winnipeg-dystonia-meeting-october-19-2024) or scan the QR code.



### National Virtual Support Group Meetings This Fall

Join dystonia support meetings from the comfort of your own home through our virtual sessions taking place on September 21st and November 16th from 1:00 PM to 3:00 PM Central Time. Please check your corresponding time zone. These meetings provide an opportunity to connect with dystonia thrivers across Canada. Special thank you to our Winnipeg Group Leader, Jennifer, for hosting these meetings.



For a full listing of upcoming events, please visit: [www.dystoniacanada.org/upcoming-events](http://www.dystoniacanada.org/upcoming-events) or scan the QR Code.

## Jennifer's Journey to Diagnosis

*"You may not see it but there's a war going on inside my body."*

– Jennifer Lovell, Winnipeg, MB

Jennifer Lovell is our Winnipeg Support Group Leader and a courageous member of the dystonia community. Jennifer's journey with dystonia has been filled with challenges, but it is also a testament to her resilience and determination to advocate for better awareness and treatment of dystonia.

### Going Back to the Beginning

Since I was a child, generalized dystonia has been lingering in the background. At age three, my family noticed signs of stiffness, spasms, and cramping in my legs, but it was ignored as they assumed I would grow out of it. Through my teens and into young adulthood, my symptoms became more pronounced, but doctors weren't sure what was wrong with me. I sought help from a pain clinic to help alleviate the extreme discomfort I was experiencing but the treatments didn't work because it was dystonia causing the pain. I was forced to self-medicate using Tylenol to get through school, motherhood, and work for more than 20 years.

### What Dystonia Took from Me

At age 35, I was working a demanding job at the Faculty of Medicine at the University of Manitoba. I was still able to move fairly well, but it was incredibly difficult to sit still at my computer. Ultimately, I could no longer work and had to resign. My social life was also greatly affected. With no formal diagnosis, people close to me suspected that I was just neurotic, so I stopped going out and socializing.

A little over a decade passed, and I was getting progressively worse. I visited a neurologist who recommended a movement disorder specialist for my condition. I was annoyed with the suggestion of seeing yet another specialist and rolled my eyes. At my appointment with the new specialist, he took one look at me and could see I had dystonia. I was mad and bewildered when I left the office. The word "dystonia" echoed in my mind, and I thought, well, 'what is dystonia?' I researched my symptoms as soon as I got



home, and based on what I was reading, it finally felt that I knew what had been happening to me. I was happy about putting a name to what I was experiencing.

### Finding Hope with a Diagnosis

During a follow-up visit with my neurologist, I asked him why I wasn't diagnosed sooner. ***Where did I go wrong? I had visited doctor after doctor, specialist after specialist, and I would leave angry because no one seemed to understand my problem. He said that it wasn't my fault, and that people just don't know about dystonia.***

From there, I told everyone I could about my journey to a diagnosis. I felt it was my duty to warn others, so they didn't have the same outcome. While searching for more people with dystonia, I looked up DMRF Canada's Winnipeg Dystonia Support Group, joined, and eventually became the Group's Leader.

As a Leader, I host regular support meetings and connect one-on-one with other people living with dystonia. Despite the strides we've made in raising awareness of dystonia in the medical community and the public, I still hear very similar stories to my own, and I want to fight to change this.

Together, I know we can transform lives. Let's fight to ensure that people with dystonia aren't waiting 44 years like I did for a correct diagnosis and treatment.

To read Jennifer's full story, please visit:  
[www.dystoniacanada.org/jenniferlovell](http://www.dystoniacanada.org/jenniferlovell)

# September is Dystonia Awareness Month

September marks **Dystonia Awareness Month**. DMRF Canada is proudly partnering with AbbVie Canada on a national PR campaign to define cervical dystonia impact across Canada.

Through this initiative, we are sharing powerful stories of Canadians living with cervical dystonia and their care partners as well as perspectives from medical professionals in the media. Our goal is to increase understanding and awareness of cervical dystonia amongst the broader public and to share accurate educational resources about cervical dystonia to help empower affected individuals to make informed decisions about their health. Please keep an eye out for stories in your local media and visit: [www.dystoniacanada.org/cervical-dystonia-pr2024](http://www.dystoniacanada.org/cervical-dystonia-pr2024) for a full list of postings.

## Amplifying our Collective Voice to Raise Awareness

As the only Canadian charity dedicated to serving the dystonia community, raising awareness about dystonia is an integral part of DMRF Canada's 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.

Throughout the month of September, unite with other dystonia thrivers across the country and help raise awareness about dystonia. Here are a few ways you can make an impact:

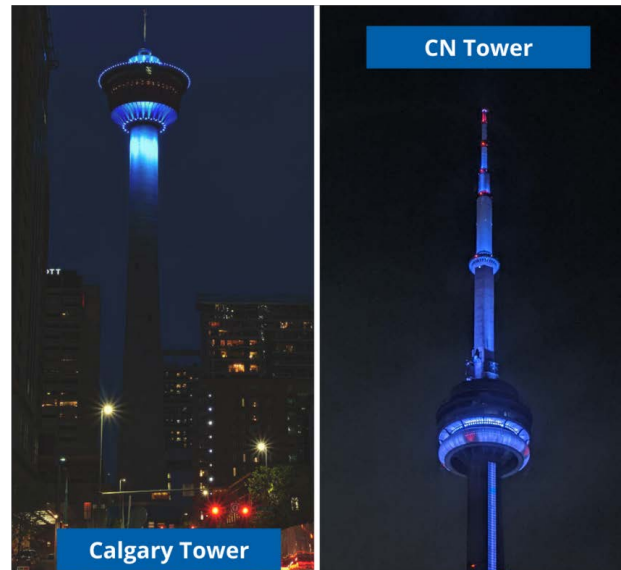
**Wear Blue for Change:** Show solidarity by wearing blue throughout September. Spark conversations and make a bold statement. Share pictures online and remember to use hashtag **#dystoniaawareness** and tag **@dmrfcanada** to increase your engagement.

**Landmarks lighting up in Dystonia Blue:** If you see one, please take a picture and tag DMRF Canada on social media. Make sure to tag your local politicians as well to help spread the message. Visit: [www.dystoniacanada.org/september-dystonia-awareness-month-o](http://www.dystoniacanada.org/september-dystonia-awareness-month-o)

**Spread Awareness Online:** Harness the power of the global community through social media and post important facts about dystonia on your accounts. Remember to use **#dystoniastrong** and **#dystoniaawareness** when sharing.

**Connect with Local Media:** Reach out to your local media using our Press Kit and request a feature about Dystonia Awareness Month or share your journey with dystonia. No one can tell your story better than yourself and awareness month is an apt time to share.

**Become a Dystonia Awareness Ambassador:** Help increase awareness of dystonia in your local community and distribute dystonia informational materials. Visit: [www.dystoniacanada.org/become-dystonia-awareness-ambassador](http://www.dystoniacanada.org/become-dystonia-awareness-ambassador)



For further details and a complete list of activities, please visit: [www.dystoniacanada.org/dystoniaawarenessmonth](http://www.dystoniacanada.org/dystoniaawarenessmonth)



# FOCUS ON Laryngeal Dystonia

Laryngeal dystonia (also known as spasmodic dysphonia) is a disorder that affects voice muscles in the larynx (voice box), resulting in difficulty speaking. It is a type of dystonia, or movement disorder, which results in involuntary muscle contractions of muscles controlling the vocal cords during attempts to speak.

Depending on which laryngeal muscles are involved, abnormal muscle contractions may result in the voice sounding raspy and strangled with patterned “breaks” or interruptions, or breathy and whispery. It may take added effort to speak, but the voice may improve when whispering, laughing, or singing. Some people experience shaking of the voice when talking. Symptoms may vary during the day, become aggravated by certain speaking tasks—such as talking on the phone—or increase during stressful situations. Symptoms may improve after sleeping or after consuming alcohol. Most cases of laryngeal dystonia (LD) develop in adults. Although LD may appear at any time during adulthood (and even in adolescence), symptoms most commonly start in people between 40–50 years old. Laryngeal dystonia is diagnosed more frequently in women than men.

Dr. Scott Norris, Washington University School of Medicine, St. Louis, who is a former clinical fellow and current member of the DMRF Medical and Scientific Advisory Council (MSAC), says laryngeal dystonia is considered “relatively rare.” “However, determining a true number for those affected remains quite challenging given our suspicion that laryngeal dystonia is likely under recognized and commonly misdiagnosed,” Norris says. “A recent analysis of all available epidemiological data indicates that laryngeal dystonia represents the least common reported form of idiopathic dystonia, where dystonia affecting muscles of the neck, eyes, hand is more common.”

There are a few different types of laryngeal dystonia:

**Adductor laryngeal dystonia:** This form is the most common. The muscles that bring the vocal cords together contract involuntarily and excessively during speech. This causes a tight, strangled-sounding voice quality, often with abrupt starting and stopping of the voice resulting in “breaks” or an interrupted speech pattern.

## Symptoms of Laryngeal Dystonia

- Voice sounds raspy and strangled, breathy and whispery, or shaky and trembling.
- It may take added effort to speak.
- Abrupt starting and stopping of the voice can result in a broken speech pattern.
- Laryngeal dystonia symptoms may come and go.

**Abductor laryngeal dystonia:** In this form, the muscles that separate the vocal cords contract involuntarily, causing them to be held apart, and resulting in a breathy, whispering voice.

**Adductor breathing laryngeal dystonia:** Also called respiratory dystonia, this rare condition affects the muscles that bring the vocal cords together. However, instead of contracting during speech (like in adductor laryngeal dystonia described above), the muscles do so during breathing. These spasms create noisy and labored breathing. Individuals may also experience trouble swallowing

due to difficulty breathing while eating.

**A combination of the above:** Some individuals have symptoms that resemble more than one classification of laryngeal dystonia. Others may have a voice tremor and/or tremor affecting adjacent areas.

Researchers are investigating possible triggers of laryngeal dystonia. Several genes that predispose patients to LD have been identified, and about 12% of individuals with LD have a positive family history.

Injury to the larynx or neck area may trigger laryngeal dystonia. Infection or inflammation may also have a role in precipitating this disease although this remains unclear. Experts believe LD results from abnormal brain signals that cause the vocal cord muscles to contract inappropriately. However, why the brain delivers these excessive signals is not completely understood.

## Diagnosis

Diagnosis of laryngeal dystonia typically requires a comprehensive evaluation by a physician with expertise in voice



disorders. This might include a neurologist or ear nose and throat (ENT or otolaryngologist) specialist. Sometimes a speech language pathologist assists with diagnosis.

Patients are frequently referred to these specialists by their primary medical doctor or a speech therapist. The specialist will take a detailed medical history and conduct a physical examination, including a thorough assessment of the patient's voice to identify characteristic features of laryngeal dystonia and establish the potential cause of voice abnormalities. To visualize the voice box, an examination called laryngoscopy might be performed. This procedure allows the healthcare provider to visualize the vocal cords during speech using a camera to assess for characteristic features of laryngeal dystonia.

Individuals with laryngeal dystonia may learn compensatory habits, or tricks, to make speaking easier. For example, someone with adductor laryngeal dystonia that has a very strained, choked-sounding voice may find that symptoms are reduced by whispering. The whispering voice may initially sound like the less common, abductor form because of how the individual is trying to control the symptoms. Humming before speaking or breathing techniques may also be helpful.

### **Treatment**

Therapeutic decisions should be discussed between patient and providers to meet individual patient needs. However, botulinum neurotoxin (BNT) injections, which are typically performed by an otolaryngologist or neurologist, remain the mainstay of effective treatments for LD. BNT, a biological product, is injected directly into the affected muscles in the throat, relaxing the muscles and reducing excessive muscle contraction. After a short period of time, typically several months, the nerve endings regenerate, the muscle gradually regains strength and muscle contractions or "spasms" return.

BNT generally lasts an average of three months, but the duration of benefit can vary. It may require several injections to establish the optimal individualized dose because each person is different.

Speech/voice therapy is often incorporated into the treatment plan, especially before and after botulinum neurotoxin injections. Voice therapy does not typically affect the abnormal muscle spasms but can address the fatigue associated with the added effort required to speak. Techniques that focus

on controlling and using the breath to make the most of the voice may be helpful in some cases.

Oral medications may also be tried but are rarely as effective as injections and are not without side effects. In cases that don't respond well to available treatments, a surgical procedure called selective laryngeal adduction denervation and reinnervation (SLAD/R) may be an option for those with adductor laryngeal dystonia. Botulinum neurotoxin injections may still be needed following the surgery, and the procedure's benefits may not be permanent.

### **Living with LD**

Patients describe many challenges that relate to living with LD. Many express frustrations regarding time from voice symptom onset to diagnosis. The disorder itself contributes to difficulty communicating due to disruptions in speech, which can be frustrating and create challenges communicating at home, work, and elsewhere. Coping with a chronic voice disorder can be associated with the development of feelings of anxiety, depression, and frustration.

Finally, many individuals struggle with the associated stigma of having a voice disorder and the challenge of describing their voice disorder to others around them who inquire. LD may be associated with social withdrawal, isolation and avoidance behaviors (avoiding social situations or minimizing verbal communication).

### **Emerging Treatment Strategies**

Botulinum toxin injections remain the current cornerstone of LD treatment. Botulinum toxin applications have evolved into more individualized treatment strategies (i.e. dosing based on severity of symptoms, prior response, and impact on patient's quality of life). There are now advancements in techniques to improve precise targeting of botulinum toxin (EMG, ultrasound, direct visualization of the vocal cords) that improves outcomes with fewer side effects.

"In general, there is increasing knowledge of laryngeal dystonia across healthcare providers as well as increasing collaborative care models that involve neurologists, ENT specialists and speech therapists," Norris says. There is ongoing research to investigate the cause of laryngeal dystonia and new medications, neuromodulation, and potential surgical treatment options. As our understanding of the condition deepens, further innovations in treatment strategies are likely to emerge.

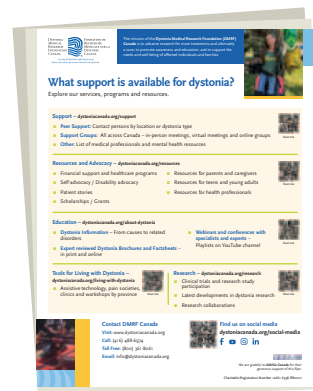
# New Dystonia Resources Flyer: Helping People Connect with Essential Resources

DMRF Canada is excited to announce the launch of a new flyer designed to support individuals living with dystonia. This initiative was inspired by many who have recently discovered our resources after years of managing the condition in isolation.

Dystonia can be challenging to navigate without proper support and information. Despite its impact, many people remain unaware of the support available. This flyer serves as a vital tool in spreading awareness, directing patients to important information about dystonia, available services and programs, and how to connect with our community for support and guidance.

We encourage you to help us amplify this message by distributing the flyer in your local community. You can pin it at your local GP clinic or pharmacy to ensure that it reaches those who may benefit from it. Thank you for helping us extend our reach and provide crucial support to those in need.

With thanks to AbbVie Canada for their generous support of this initiative. 



Pin me at your local clinic.

# Volunteer Opportunity at Bingo World and Gaming - Richmond Hill

Attention Greater Toronto Area Residents! DMRF Canada is excited to announce a fundraising opportunity through Bingo World and Gaming Richmond Hill. In exchange for volunteers' time, DMRF Canada will receive a portion of the money raised from the Bingo events. With two successful sessions already taken place on July 10th and August 23rd, we are off to a great start.

## Volunteering Details

- **Shift Duration:** Each volunteer shift will last 2.5 hours.
- **Funds Raised:** Each event will generate approximately \$3,000 for dystonia research and support programs.
- **Commitment:** We are seeking volunteers who can participate every two months for at least six months.
- **Requirements:** You do not need to have dystonia to volunteer. Volunteers should be able to walk or stand for their 2.5-hour shift and be capable of tucking in chairs.



For more information or to volunteer, please email us at [info@dystoniacanada.org](mailto:info@dystoniacanada.org) or call (800) 361-8061.

# Dystonia and Cerebral Palsy

Dystonia, a common condition in individuals with cerebral palsy (CP), will be discussed at the 78th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPD).

As part of this event, a Community Forum will be held on October 26, specifically catering to those affected by dystonia and CP, as well as their parents and caregivers. There will be a dedicated one-hour session introducing the new AACPD dystonia care pathway.

To learn more, visit

[www.dystoniacanada.org/dystonia-CP](http://www.dystoniacanada.org/dystonia-CP)



## Your Network is our Network

The strength of our mission lies in the power of our community. In recent years, we have faced significant challenges. The need for support has greatly increased, while financial support has declined. Economic factors impacting most charities have affected us as well, and we have sadly lost some of our most generous donors and supporters who raised funds for our cause until their last breath.



We are experiencing a decline in community fundraising, volunteers, and donations. This is why we need your help to sustain and increase our impact through partnerships with organizations that can provide sponsorships, grants, and donations. Even if you don't have close connections, the organization you work for might have a program to support charities.

### How You Can Help

- **Corporate Sponsorships and Grants:** If you have connections to companies or foundations that may be interested in supporting our cause, please introduce us. Many organizations are eager to support charitable initiatives through sponsorships, grants, and donations.
- **Employee Giving Programs:** Many organizations offer matching gift programs that can double or even triple your donation. To learn more about Employee Giving Programs, please visit: [www.dystoniacanada.org/employee-giving-program](http://www.dystoniacanada.org/employee-giving-program)
- **Spread the Word and Donor Referrals:** Help us raise awareness by leveraging your contacts. Share our mission with your network through community publications, national advertisers, and social media.

Your involvement can make a true difference. For further information, please visit: [www.dystoniacanada.org/connectdmrhc](http://www.dystoniacanada.org/connectdmrhc)



## Legacy Giving: Leave a Gift that Lives On

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.

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

For more details on estate planning, please visit: [www.dystoniacanada.org/legacy](http://www.dystoniacanada.org/legacy)

## Have Your Gift Go Further by Donating Securities and Mutual funds

One of the most efficient ways to donate to DMRF Canada is through a donation of securities or mutual fund shares. With a donation of securities or mutual funds, capital gains tax does not apply, allowing you to give more and avoid paying capital gains taxes. By donating shares directly, you get a larger tax credit and give more to the cause you care about.\*



For more information, please email National Director, Archana Castelino [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

\* The information above is not intended as legal, financial or other professional advice. A professional advisor should be consulted regarding your specific situation.

## 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.*

Your support matters. We exist, and our mission survives because of you. There are various ways to support DMRF Canada to have your impact felt today and ensure a brighter tomorrow for the 50,000 Canadians living with dystonia.

ADDRESS BOX

### Become a Member of the Monthly Giving Team Join our Monthly Giving Team and Provide Year-Round Support

“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 make a one time gift to invest in critical dystonia research. Here is my gift of:

\$250    \$150    \$75    \$45    \$ \_\_\_\_\_

I am sending my cheque made payable to the Dystonia Medical Research Foundation Canada.

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

Please provide an email address: \_\_\_\_\_

**Please note:** DMRF Canada has removed mailed in credit card information as a payment method to help safeguard donor information. You can still make a credit card donation or sign up to be a member of our Monthly Giving Team by visiting our website [www.dystoniacanada.org/donateonline](http://www.dystoniacanada.org/donateonline) or scan the QR Code. You can also call our office at 1.800.361.8061. **Charitable #12661 6598 RR0001**



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