

DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION  
CANADA



FONDATION DE  
RECHERCHE  
MÉDICALE SUR LA  
DYSTONIE  
CANADA

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

# Dystonia Canada Report

A Newsletter from  
Dystonia Medical Research  
Foundation Canada

Spring/Summer 2024



The Community Support and Education Network  
Building a Thriving Connected Community in Canada

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## 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

The Dystonia Medical Research Foundation (DMRF) Canada continues to push forward in our efforts to make a difference. Our mission is to advance research for treatments and a cure, to promote awareness and education, and to support the well-being of individuals and families living this dystonia. In the pages of this newsletter, you will see examples of information and activities that support this mission. It is hard to believe all this can come from such a small, but mighty foundation.

Many don't realize just how small we are. Serving every province and territory in Canada, we have a team of two full-time and one part-time staff. We are self-funded, relying on contributions, fundraising efforts and strategic partnerships. We do not receive direct government funding. So how do we set out to accomplish a mission of such magnitude?

The answer is in our volunteers and our community.

We rely on the financial contributions of our members and their communities. We depend on the manpower of volunteers to create fundraising opportunities. We seek the expertise of our support group leaders to make local connections. We need the insight of our members to develop programs that make a difference. We learn from the lived experience of our community to know where to most effectively channel resources. We receive direction and financial oversight from our board members.

Because of these collective efforts of our small staff and army of volunteers, we are able to take our impact far beyond the walls of our office to make a difference Canada-wide and even globally. We couldn't possibly do it without our community.

In order to continue our contributions to cutting-edge research, programming for patients and their families, community education, advocacy and awareness, we look to grow our most valuable resource. We encourage you to champion our cause. Consider growing our reach by inviting your friends, and families to join you in lending a helping hand to support our mission in any way that you can. You can find a list of volunteer opportunities on page 14, with more to come later this year.

We thank you for your continued involvement and support. We couldn't do it without you!

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

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Co-Founder

1928 - 2018

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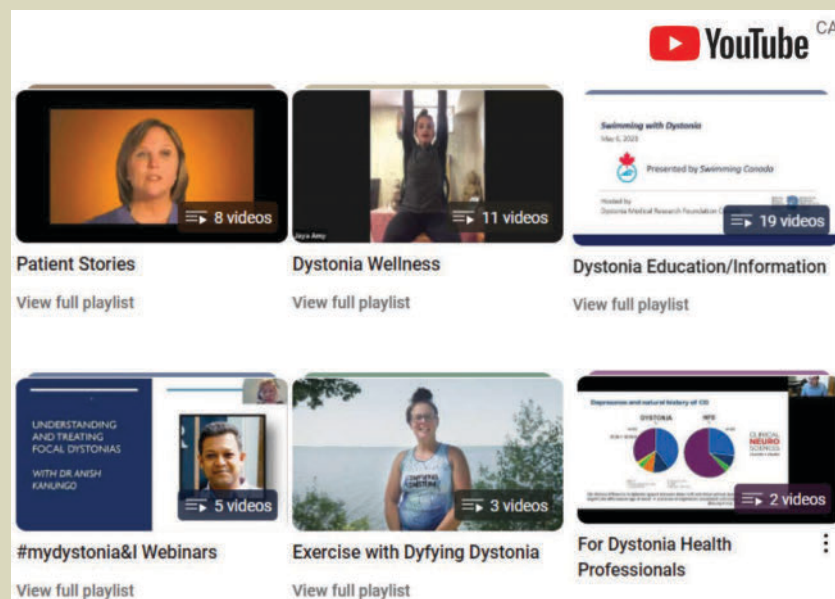
Rosalie Lewis

Catherine Mulkins

## DMRF Canada's YouTube Channel has officially reached 1,000 subscribers!

Thank you to all subscribers. If you haven't visited our channel yet, it is packed with resources to help affected individuals and families navigate life with dystonia. Explore our diverse content and don't miss the Dystonia Awareness Video!

[www.youtube.com/@dystonia\\_canada/playlists](http://www.youtube.com/@dystonia_canada/playlists)



## Dystonia Journal Update

The DMRF's official journal, aptly titled *Dystonia* has now published over 40 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](http://www.frontierspartnerships.org/journals/dystonia)



## In Tribute

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



**Hugh Chapman**

**Carl Johansen**

**Marc Massicotte**

**Lois Jackson**

**Pierre Lalonde**

This Dystonia Canada Report is supported by AbbVie Canada

# Dystonia Research Watch

The DMRF is dedicated to supporting research on all aspects of dystonia to improve treatment and ultimately find a cure. DMRF's scientific leaders keep close tabs on emerging research that may affect the dystonia community. Two research areas have recently gained momentum:

## 1.) Non-motor symptoms of dystonia

A recent DMRF workshop was dedicated to non-motor aspects of dystonia; a summary paper will be published soon in *Dystonia*. Interestingly, another study published in *Parkinsonism and Related Disorders* inquired about the possibility that injected botulinum neurotoxin (BoNT) may also reduce anxiety in patients with cervical dystonia. DMRF promotes and supports interdisciplinary studies of the non-motor symptoms of dystonia.

### **Dystonia is an open access journal**

Dystonia aims to be the leading journal in the field by publishing research results on all basic, clinical, and translational aspects of dystonia. You can freely access the journal at: [frontierspartnerships.org/journals/dystonia](http://frontierspartnerships.org/journals/dystonia)

To assess the severity of motor symptoms, researchers used the Toronto Western Spasmodic Torticollis Rating Scale (TWSTRS), and to assess the levels of anxiety, they used State-Trait Anxiety Inventory (STAI). The STAI scale allows researchers to separate state from trait anxiety. State anxiety is the anxiety a person feels when faced with a threat or frightening situation and will pass when the threat or frightening situation has passed. Trait anxiety appears to be ever-present general tendency to worry, be fearful and perceive events as threatening.

## 2.) Non-invasive neuromodulation as a potential therapy for certain types of dystonia

DMRF issued a call for research proposals that focus on non-invasive brain stimulation therapies, and several projects are ongoing. To those living with dystonia, progress in novel therapies can seem slow and there are many reasons for that. A recent article in DMRF's scientific journal, *Dystonia*, discusses the factors hindering research specifically regarding transcranial magnetic stimulation (TMS).

Here is more detail from two recent studies:

### **Study Explores Botulinum Neurotoxin's Effect on Anxiety in Cervical Dystonia Patients**

It is well documented that as many as 30 to 40% of people with cervical dystonia also experience increased anxiety. In a recent study published in *Parkinsonism and Related Disorders* ([www.elsevier.com/locate/parkreldis](http://www.elsevier.com/locate/parkreldis)), researchers from Rush University, Chicago, report the results of a 12-week prospective, observational study of the effect of botulinum neurotoxin (BoNT) injections on the state of anxiety in 60 people with cervical dystonia (CD). They tested the hypothesis that BoNT has a beneficial effect on anxiety that is independent of its effect on motor severity.

Participants were evaluated at the time of BoNT treatment and six weeks later, the time considered to have the maximum benefit for motor symptoms. These evaluations were conducted via telemedicine. Participants were asked to complete the Generalized Anxiety Disorders-2 item (GAD-2) survey every two weeks using a special app until the conclusion of the twelve-week study. All participants had been treated with botulinum neurotoxin previously for an average of 9.5 years.

Other published studies have been conducted in CD and depression and mood. One study showed that improvement in depression symptoms was correlated with pain lessening, and that mood and CD motor symptom improvements were also positively correlated. The current study assessed BoNT treatment's impact on improving anxiety symptoms independent of the state of motor symptoms.

Investigators concluded that improvement in anxiety is unlikely to be only secondary to the improvement in the motor symptoms of CD. This may indicate a potential direct benefit of BoNT on anxiety. They acknowledged that the mechanism for this is not known, and that more investigation is needed to better understand this relationship.



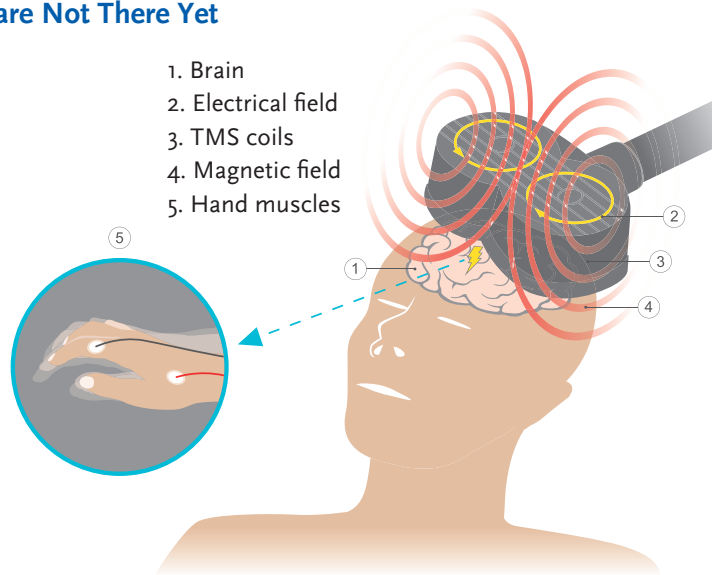
## Transcranial Magnetic Stimulation for Dystonia: Why We are Not There Yet

Transcranial magnetic stimulation (TMS) has emerged as a non-invasive treatment of some brain ailments. Considered noninvasive because it is done without any surgery, this form of brain modulation uses changing magnetic fields to induce an electric current at a specific area of the brain through electromagnetic induction. An electric pulse generator, or stimulator, is connected to a magnetic coil attached to the scalp.

Initially used as a research device, TMS has shown great promise in treating many neurological and psychiatric conditions. However, despite numerous studies, it has not been approved for dystonia. Why is that? A group of researchers from Duke University tried to answer this question in a review article recently published in *Dystonia*, DMRF's scientific journal.

Authors of the review article, *Transcranial magnetic stimulation: the road to clinical therapy for dystonia*, identified four major roadblocks that thwart adoption and approval of TMS for treatment of dystonia. These include limited and inadequately designed clinical trials; insufficient and sketchy evidence that TMS objectively affects behavioral measures; observed variability in response to TMS due to complex technical issues and selection of patients; and difficulties in optimizing TMS parameters to achieve the desired therapeutic effect. The article presents progress

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TMS, not yet approved for dystonia, delivers stimulation to targets in the brain through the skin and skull.

achieved over the last few decades and identifies clear goals for future studies, such as comprehensive identification of reliable behavioral measures for various types of dystonia, precisely testing a range of stimulation parameters, using different modes of stimulation, and applying computational methods and models to optimize TMS efficacy.

Time will tell if these goals can be achieved to further research of TMS as a potential treatment for various types of dystonia.

## Working Group Tackles Classification of Dystonia



A group of leading dystonia researchers from around the world, who have been working to update the 2013 classification of dystonia to reflect learnings of the past ten years, met at University College of London on December 4th and 5th, 2023. Much has been learned about dystonia since this highly-cited article was published and this effort will better help doctors diagnose and treat the movement disorder.

Dystonia Classification Working Group members are shown top row, L to R: RJon Mink (USA), Marina deKoning Tijssen (The Netherlands), Victor Fung (Australia), Joachim Krauss (Germany), Jan Teller (DMRF Poland), Sanjay Pandey (India).

Bottom row, L to R: Christine Klein (Germany), Tony Lang (Canada), Mark Hallett (USA), Alberto Albanese (Italy), Buz Jinnah (USA), Marie Vidailhet (France), Kailash Bhatia (UK). Missing from the photo is Joseph Jankovic (USA).

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We are thrilled to announce that we will once again be hosting our biggest event of the year: **Freedom to Move: Run, Walk, and Wheel for Dystonia in June 2024!**

Each June, Canadians from coast-to-coast unite to raise awareness and critical funds for dystonia. To date, Freedom to Move has raised over \$1 million to fund research, support programs, and advocacy efforts for people living with dystonia.

Join us and thousands of others to complete a walk, run, or wheel either **virtually in your own community** or at our **in-person Toronto event on Sunday, June 2nd at Downsview Park.**

NEW to Toronto this year: we are thrilled to announce that we will be partnering with Hydrocephalus Canada to co-host the

in-person event. Hydrocephalus Canada is a registered neurological health charity dedicated to serving the spina bifida and hydrocephalus communities across Canada. With a shared vision to raise funds and awareness, and to inspire a better future for all, we aim to maximize our impact and administrative efficiencies, while uniting the collective voices of our neurological communities.

### Virtual Event

**When:** June 1 – 30, 2024  
**Location:** Anywhere in Canada  
**Early Bird Pricing:** \$10/Adult;  
 Free for Children

### Toronto In-Person

**When:** June 2nd  
**Where:** Downsview Park  
**Early Bird Pricing:** \$30/Adult;  
 \$10/Child

*Don't Wait,  
 Register Today!*



**Don't Miss the Early Bird Deadline of May 14th - Prices Will Go Up!**

## Sign up, Warm up, Show Up— Start Your Race, Your Way Today:



### Step 1 - Register [www.freedomtomove.org](http://www.freedomtomove.org)

Participants can sign up as an individual, or join forces with friends, family members, or co-workers and register as a team.



### Step 2 - Set a goal

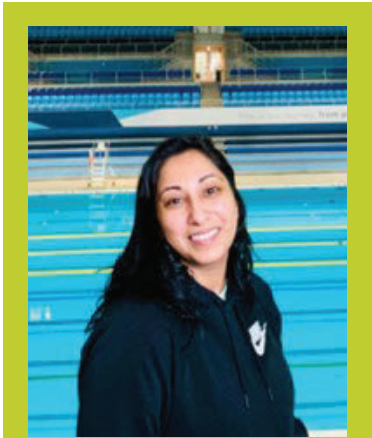
From the amount you'd like to raise – the number of kilometers you will run, walk or wheel - or the number of times you share the event with friends or family – this event gives you the freedom to move the way you want!



### Step 3 - Share!

Once you've registered, remember to share your fundraising page with your network. Encourage others to sign up or support you in your effort to raise funds for dystonia. Remember to use the hashtag #FreedomToMove when you share online.

# Freedom to Move Family Ambassador: Sumbul Zafar and Her Family



*"I am honoured to be this year's Ambassador and I hope you and your friends and family join us. Dystonia is a relatively rare disorder, but there's strength in numbers and our collective impact is mighty. I know when we join together, our community has the ability to change lives."*

Meet Sumbul Zafar: wife, mother of three children, dystonia advocate, competitive Para swimmer, and our 2024 Freedom to Move Ambassador.

Sumbul's journey with swimming can be described as "full circle". Her passion for swimming was ignited in early childhood with her first lesson taking place at age three and joining a competitive swim team at ten.

Shortly after qualifying for the 2014 Fina World Masters in Montréal, Sumbul suffered a stroke, which left residual impacts to the right side of her body. The involuntary muscle spasms and twisting of her body prevented Sumbul from attending the championships and eventually, she was diagnosed with dystonia.

Despite her diagnosis, Sumbul was determined to continue swimming. However, Sumbul was frustrated that she wasn't swimming at the caliber that she had been prior to her stroke, and her confidence was shaken. She attempted to rejoin competitive swimming from 2015 to 2017 but fell short of completing those seasons due to a lack of understanding how to train with dystonia.

It took another child and the pandemic to give Sumbul the time to look inward. She recognized that she had disengaged from the activities she loved and kept her world small to live a less challenging life. She also realized that she was not truly living her life to the fullest.

Returning to swimming with a renewed sense of clarity, Sumbul eagerly trained for the opportunity to compete in the 2023 Fina World Masters in Japan and upon registering for the season discovered the dystonia was an eligible physical impairment to be classified as a Para swimmer. Over the last year, Sumbul has had the opportunity to travel to the USA and France representing Canada on the World Para Swimming Series. Sumbul looks forward to continuing her training

towards her goal of making a World Championship team and looks forward to continuing to represent Canada as a Para Swimmer in the years to come.

When asked how Sumbul balances pursuing her dream of competitive swimming, life with dystonia and her family responsibilities, she credits the power of her support network which includes her three children and her husband, Ryan. "It's important to engage your support network when living with dystonia, as one diagnosis can change so many people's lives. We work together as a team to achieve our goals while respecting each other's boundaries and time" shares Sumbul.

To read more about Sumbul's journey with dystonia, please visit: <https://dystoniacanada.org/sumbulzafar>

You can follow Sumbul on Instagram @the.dystonia.yodha to get tips on preparing for this year's event.

## Your Impact

Help us to raise **\$50,000** for dystonia research and support programs. These much-needed funds could support one year of the DMRF Canada Clinical and Research Fellowship, as well as other important dystonia research studies. We can't support these important projects without you.



# FOCUS ON DYT<sub>1</sub> Dystonia

## A form of hereditary, generalized dystonia

DYT<sub>1</sub> dystonia, also known as early-onset, torsion dystonia, is a severe form of hereditary, generalized dystonia. Generalized dystonia refers to dystonia that is not limited to a single part of the body but affects multiple muscle groups throughout the body.



Generalized dystonia typically affects muscles in the torso and limbs, and sometimes the neck, face, and vocal cords. Patients have difficulty moving their bodies freely and controlling their body movements.

DYT<sub>1</sub> dystonia typically begins around age 10 with the twisting of a foot or arm. Symptoms tend to begin in one body part and progress to involve additional limbs and the torso. Symptoms tend to be less severe the later in life they start and if they start in a hand or arm.

Most cases of early onset torsion dystonia are directly associated with a mutation that affects the DYT<sub>1</sub> gene, which scientists discovered in 1997 with the support of the DMRF. In its normal state, the gene is responsible for providing the body with the genetic instructions to produce a protein called torsinA. The mutated DYT<sub>1</sub> gene results in an abnormal form of torsinA, and this abnormal protein starts a chain reaction of biochemical processes that somehow disrupts the communication between the brain and muscles. This disruption of the nervous system leads to the debilitating physical symptoms of DYT<sub>1</sub> dystonia.

### Symptoms of DYT<sub>1</sub> Dystonia

- Twisted postures, for example in the torso or limbs
- Turning in of the foot or arm
- Muscle spasms, with or without pain
- Unusual walking with bending and twisting of the torso
- Rapid, sometimes rhythmic, jerking movements (often myoclonic jerks)
- Progression of symptoms leading to areas of the body remaining in sustained or fixed postures

DYT<sub>1</sub> dystonia is dominantly inherited, meaning that only one parent needs to have the mutation for a child to inherit the disorder. However, the DYT<sub>1</sub> mutation also exhibits reduced penetrance, which means that not every person who inherits the mutated gene will develop symptoms. Only about 30% of individuals who have the DYT<sub>1</sub> genetic mutation will develop dystonia. Research is ongoing to better understand this phenomenon.

If a person does not manifest symptoms before the age of 28 years, they will usually remain symptom free for life—even if they have the DYT<sub>1</sub> mutation. The DYT<sub>1</sub> mutation is responsible for about 90% of early onset generalized dystonia in individuals of Ashkenazi Jewish ancestry and up to about 50% of early onset generalized dystonia in other ethnicities.

### Treatment

Individuals with dystonia are encouraged to seek treatment from a movement disorder neurologist or child neurologist with special training in movement disorders. A multidisciplinary team of expert medical professionals may be appropriate to tailor treatment to the needs of the patient.



Genetic counselors are trained to help people decide whether getting a genetic test is right for them. They will also help interpret test results and offer counsel on the significance of the results for that family.

—Deborah Raymond, MS, genetic counselor at Mount Sinai Health System, New York City

A movement disorder specialist will develop a treatment plan that is customized to each patient. Most individuals require a combination of therapies. Treatment to lessen dystonia symptoms may include oral medications such as anticholinergics, baclofen, and benzodiazepines combined with botulinum neurotoxin injections, and/or surgical procedures such as deep brain stimulation (DBS). Research suggests that individuals with DYT1 dystonia tend to have the best outcomes from DBS compared to other forms of generalized dystonia.

Genetic testing is available to test for the DYT1 gene mutation. Individuals and families who wish to learn more about genetic testing for DYT1 and other genetic mutations associated with certain dystonias are advised to consult a genetic counselor. (See accompanying article.) “Understanding the genetic implications of DYT1 dystonia can be overwhelming,” said

Deborah Raymond, MS, genetic counselor at Mount Sinai Health System, New York City. “Genetic counselors are trained to help people decide whether getting a genetic test is right for them. They will also help interpret test results and offer counsel on the significance of the results for that family.”

Specific treatment may be needed to prevent loss of motion in the joints and/or curvature of the spine due to the dystonic postures. Complementary therapies to support overall functioning and wellness may include occupational therapy, physical therapy, speech/voice therapy, and other interventions depending on a person’s symptoms. Individuals with childhood onset generalized dystonia may have increased risk for depression, so monitoring and addressing emotional and mental health is often an important part of the treatment strategy.

#### Sources:

Epidemiology of DYT1 dystonia; Joseph Park, AB; Scott M. Damrauer, MD; Aris Baras, MD, MBA; Jeffrey G. Reid, PhD; John D. Overton, PhD; and Pedro Gonzalez-Alegre, MD, PhD; *Neurology: Genetics*, October 2019

The pathophysiological basis of dystonias; Xandra O. Breakefield, Anne J. Blood, Yuqing Li, Mark Hallett, Phyllis I. Hanson, and David G. Standaert; *Nature Reviews | Neuroscience*, March 2008

Deep Brain Stimulation in DYT1 Dystonia: A 10-year Experience; Fedor Panov, MD; Yakov Gologorsky, MD; Grayson Connors, BA; Michele Tagliati, MD; Joan Miravite, RN; Ron L. Alterman, MD; *Neurosurgery*, July 2013

## What is a Genetic Counselor?

The first step for individuals and families who wish to learn more about genetic testing for dystonia is to consult a genetic counselor who is trained to educate families and prospective parents on the likelihood and risks of inherited diseases. Genetic testing is only available for specific forms of dystonia for which a gene mutation has been identified, like DYT1.

A genetic counselor can help individuals and families understand what testing may be appropriate for them. Testing may be suggested for adults and children who exhibit clinical symptoms that resemble the forms of dystonia for which gene tests are available. Adult biological relatives of individuals who have been identified as having a genetic form of dystonia may also be eligible for testing. Genetic testing in children who do not exhibit symptoms is generally not recommended, even if a biological relative tests positive for a dystonia mutation.

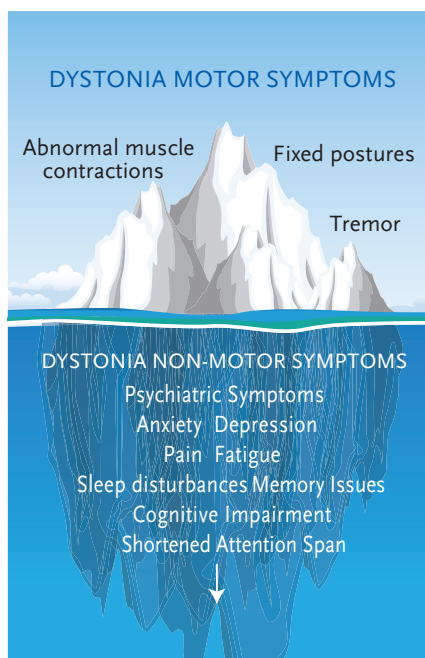
Individuals can locate a genetic counselor by consulting their movement disorder specialist or family doctor. For more information regarding genetics and dystonia, please visit: [www.dystoniacanada.org/about-dystonia/genetics](http://www.dystoniacanada.org/about-dystonia/genetics)

# Not Just In Your Head: Non-Motor Symptoms of Dystonia

Lurking beneath the surface of dystonia are unseen struggles—the non-motor symptoms that can profoundly impact the lives of those affected. These hidden dimensions, including anxiety, depression, sleep disruption, chronic pain, fatigue, and cognitive impairment, can significantly diminish quality of life.

Understanding the non-motor symptoms of dystonia is crucial for improving the quality of life for dystonia patients. These symptoms significantly impact daily living but often go unnoticed or undertreated. A lack of awareness among healthcare professionals and standardized assessment methods leaves many struggling to get the help they need. By shedding light on these non-motor symptoms, we can equip clinicians with the knowledge and tools to effectively diagnose and manage them, leading to better overall care for individuals with dystonia.

The Dystonia Medical Research Foundation hosted a virtual scientific workshop, Non-Motor Symptoms of Dystonia, in March 2023. The program was co-chaired by Kathryn Peall, MD, PhD of Cardiff University in the United Kingdom and Davide Martino, MD, PhD of the University of Calgary in Canada. The meeting brought together experts from across the world to discuss the evidence of non-motor symptoms in dystonia, examine existing assessment and treatment methods, and to collaborate on future progress in the field. This meeting highlighted the DMRF's commitment to this important topic and reinforced the scientific community's dedication to focus research to improve the quality of life for patients. The scientific summary was recently published in *Dystonia*, the DMRF's scientific journal.



The workshop participants opened the meeting by discussing the importance of researching non-motor symptoms. Identifying the non-motor symptoms of dystonia allows for the development of more holistic treatment plans that address not just the physical manifestations of dystonia, but also the emotional and psychological toll it takes. By recognizing the pain, fatigue, and anxiety that often accompany dystonia, healthcare professionals can provide targeted therapies and support systems that go beyond simply managing movement control.

Additionally, investigating non-motor symptoms offers a unique window into the underlying mechanisms of dystonia. These seemingly separate features

may hold clues to the complex neurological processes at play, potentially leading to breakthroughs in diagnosis and even treatment. By studying the interplay between motor and non-motor symptoms, researchers hope to unlock a deeper understanding of the disease, paving the way for more effective interventions.

The workshop looked at this issue from several perspectives, breaking down the non-motor symptoms into different categories. Workshop faculty shared the current research in each topic before providing insight into the future of non-motor research.

## Psychiatric Symptoms

Psychiatric symptoms are the most studied non-motor symptoms of dystonia. Most studies examine the prevalence of anxiety and depression in different types of dystonia patients compared to a control group. Indeed, patients with cervical dystonia, blepharospasm, spasmodic dysphonia, focal hand dystonia, writer's cramp, and musician's dystonia reported more instances of anxiety and depression than the respective control groups.

Why is this the case? Researchers are still working to find an answer. And while some might assume that mental health concerns follow a dystonia diagnosis, some studies have shown the opposite. Indeed, some research has found that psychiatric symptoms

were present in patients before their motor symptoms began. The areas of the brain thought to be related to mental health conditions are also the areas of the brain affected by dystonia, indicating that there may be a link. Further research is needed to further examine this phenomenon.

### **Pain**

The effect of chronic pain on quality of life is well-documented, both with dystonia patients and others. In fact, cervical dystonia patients report chronic pain more frequently than any other non-motor symptom. Researchers are developing new tools to study pain in dystonia further. This includes the development of new rating scales, which allow patients to better assess and define their experience. The scales provide a consistent way to measure feelings of pain, which will allow researchers to compare patient experiences more broadly. While more work needs to be done in this topic, studies have shown that injectable botulinum toxin can help reduce pain.

### **Sleep Disruption and Fatigue**

Studies on the effects of sleep disruption on dystonia patients are very limited. Sleep is critical to a healthy brain—a good night of uninterrupted sleep allows the brain to slow its activity, to reset and repair itself, and to adapt to meet any anticipated needs. Research on the motor symptoms of dystonia has found that brain plasticity, or the ability of the brain to rewire itself in response to certain internal and external influences is intrinsically connected to the disease itself. Researchers believe therefore that the inability to get a good night's rest might exacerbate these symptoms.

Fatigue, or the perception of physical and mental effort, is also understudied in dystonia. Researchers are working to develop sleep studies to better

measure the effects of sleep and fatigue on the disorder.

### **Cognitive Dysfunction**

Executive function, defined as a set of mental skills that include working memory, flexible thinking, and self-control, is the only form of cognitive ability to be consistently studied and disrupted by dystonia. Studies have found patients struggle with sustained attention, complex movement planning and visuospatial working memory, which refers to the ability to recall shapes and colors along with their location and movements. For some DBS patients, cognitive function improves after surgery. For other dystonia patients, more research is needed to best understand this symptom.

### **Pediatric Dystonia**

Little research has been conducted on non-motor symptoms in children with dystonia. Participants in the workshop discussed whether children and young adults should be treated and studied separately than adults, or if using the same tools to study patients from childhood through adulthood would more accurately capture symptoms. In either case, researchers are developing measurements best suited for this patient population.

### **Models of Care**

The meeting ended with a discussion about improving models of care to comprehensively address motor and non-motor symptoms of dystonia. Many dystonia patients visit their doctor on a quarterly basis for brief appointments centered around botulinum toxin injections. The appointments rarely involve the screening, assessment, or management of non-motor symptoms, much to the dissatisfaction of patients. Instead, management of these symptoms often becomes the responsibility of primary care doctors who lack the

specialized knowledge on how these symptoms connect. If movement disorder specialists aren't trained to recognize the significance of non-motor symptoms, they may be missing key indicators of the disease. Additionally, patients may begin to think that their non-motor symptoms are less important than their motor symptoms and fail to report them, creating a cycle that may be difficult to counteract.

Screening for non-motor symptoms in dystonia could be an important first step in better treatment options and more quantitative data to assist further studies. Many other movement disorders have screeners to this end, and the researchers involved in the workshop are interested in developing a similar screener for dystonia patients.

In conclusion, research into the non-motor symptoms of dystonia is not just about alleviating discomfort; it's about unlocking a deeper understanding of the brain and its complexities. By delving into these hidden dimensions, we pave the way for more effective treatments, potentially even prevention for a wider range of neurological conditions. The DMRF's unwavering dedication to this critical research, coupled with their unwavering support for the dystonia community, is a beacon of hope in the ongoing quest to conquer this challenging disorder.

Those interested in reading the complete article in the journal *Dystonia* can find it here:

<https://www.frontierspartnerships.org/articles/10.3389/dyst.2023.11860/full>

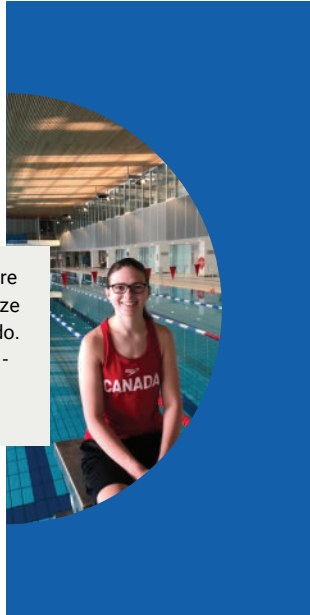
You can request or download a fact sheet on this topic. Visit [www.dystoniacanada.org/dystonia-information-materials](http://www.dystoniacanada.org/dystonia-information-materials)

## Community Education and Impact – Building a Thriving Connected Community

Last Fall, DMRF Canada was proud to announce our newest initiative to strengthen opportunities for individuals with dystonia and their loved ones to learn, connect, and unite with each other – *The Community Support and Education Network*

### Shelby Newkirk

It's important to know where you need help. And to realize what you can and cannot do. It's okay to be sad about it - and then it's okay to move ahead and live your life.



Born out of the unique circumstances of a post-pandemic world and utilizing DMRF Canada's robust network of support groups across the country, the Program connects members of the dystonia community through three impactful initiatives:

- Half-day in-person regional educational events for affected individuals and their loved ones to meet dystonia specialists, discuss the latest research and treatments, and connect with one another.
- Intimate in-person support group meetings that foster community engagement, information exchange, and connection.
- A national virtual patient education and support session to ensure that individuals with dystonia can connect with others regardless of location or mobility.

Critical to the Program's success is sponsoring partner AbbVie Corporation's generous support at the Diamond level, and Ipsen Canada's support at the Gold level, which ensures the opportunity for the dystonia community to connect and learn from healthcare professionals and each other.

With meetings already underway, the Program's impact is already being felt by the dystonia community. Here's a look at some of the events that have taken place over the past few months:

### Greater Vancouver Area – September 30th, 2023

Rounding off "Dystonia Awareness Month", our Greater Vancouver Support Group hosted a day of dystonia wellness education and community connection featuring informative and inspiring presentations from neurologist, Dr. Anish Kanungo and physiotherapist, Sally-Anne Stelling. Many thanks to Group Leaders Luisa Hudniuk and Robin Krantz for their terrific efforts in bringing this event together. We would also like to extend a special thank you to DMRF Canada co-founder Frances Belzberg for joining us. Frances has been an active board member for over 45 years, and it was an honour to have her in attendance.

*"I left very hopeful. The movement disorder specialist was so knowledgeable and very approachable. His dedication to this disorder gives people like me hope."*  
- Attendee





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

During “Brain Awareness Week”, DMRF Canada was proud to host a webinar discussing recent research and insights on dystonia and the quality of life with specialist guest speaker, Dr. Davide Martino Ph.D. MD, Director of the Movement Disorders Program at the University of Calgary. We were delighted to have representation from our dystonia support groups bringing the much needed lived experience perspective to the conversation. A virtual support session followed the webinar allowing the dystonia community across the country to connect and bond over shared experiences.

*Special Thanks to Our Diamond Sponsor*

abbvie

## Upcoming Meetings – Save the Date



### Neurologic Music Therapy – Weekly on Thursdays Via Zoom

Neurologic Music Therapy (NMT) is the evidence-based practice that makes use of standardized musical exercises that can be applied to areas of functioning including cognition, motor skills & communication. These sessions use music-based movement and singing interventions that are endorsed by the World Federation for Neurologic Rehabilitation, to help you reduce tension and improve your quality of life in a fun and supportive environment.

Free NMT classes are offered to the dystonia community by student music therapists at the University of Toronto's Faculty of Music.

Please visit: [www.dystoniacanada.org/events/NMT](http://www.dystoniacanada.org/events/NMT) to learn more and register.

### Winnipeg, MB – Monthly Hybrid Support Meetings

The Winnipeg Support Group will be hosting monthly hybrid meetings this spring. This means you can join the meeting in-person and connect face-to-face at the St. Mary Magdalene Church OR from the comfort of your own home through Zoom. Meetings will be held on April 21, May 19th, and June 21st from 1:00 to 3:00 PM CT.



Please visit: [www.dystoniacanada.org/upcoming-events/winnipeg](http://www.dystoniacanada.org/upcoming-events/winnipeg) for full details.

### Regional Education Sessions with Dystonia Experts

Stay tuned for more information on regional half-day education events taking place this fall.

**Winnipeg, MB** - October 19th, 2024 at the Deer Lodge Centre with Movement Disorder Specialist, Dr. Doug Hobson.

**Edmonton, AB** - To be determined.

We have plans for more in-person meetings to take place throughout the year, so please make sure you are signed up for our email list to receive the latest notifications and news – we don't want you to miss out on an event close to you!

Please visit: [www.dystoniacanada.org/signup](http://www.dystoniacanada.org/signup) or scan the QR code



DMRF Canada frequently updates our list of upcoming events on our website here: [www.dystoniacanada.org/upcoming-events](http://www.dystoniacanada.org/upcoming-events) or scan the QR Code.

If you'd like to connect with a volunteer in your area, please visit: [www.dystoniacanada.org/support](http://www.dystoniacanada.org/support)

## Living with Dystonia: Online Resource Update



Dystonia is more than just a movement disorder. Individuals diagnosed with dystonia commonly experience symptoms that affect more than how the body moves. Living well with dystonia often requires addressing more than the physical movement symptoms.

Recognizing this need, DMRF Canada has updated our online resource bank to include more tools for managing your physical and emotional well being courtesy of the Mood Disorders Society of Canada. Please visit: [www.dystoniacanada.org/living-with-dystonia](http://www.dystoniacanada.org/living-with-dystonia)

## Calling All Volunteers – Make a Difference in your Own Community

One of the most impactful ways DMRF Canada provides support is through our Support Group Network. With 40+ groups across Canada, these groups serve as a lifeline and provide opportunities for people with dystonia and their families to connect and thrive in the community. We are looking for new Support Group Leaders to volunteer in the following communities:

- Victoria, BC (New leader)
- Calgary, AB (3 volunteers required - Co-leader, Secretary and Treasurer)
- Fredericton, NB (Co-leader)
- Hamilton, ON (New leader)
- Toronto, ON (New leader)



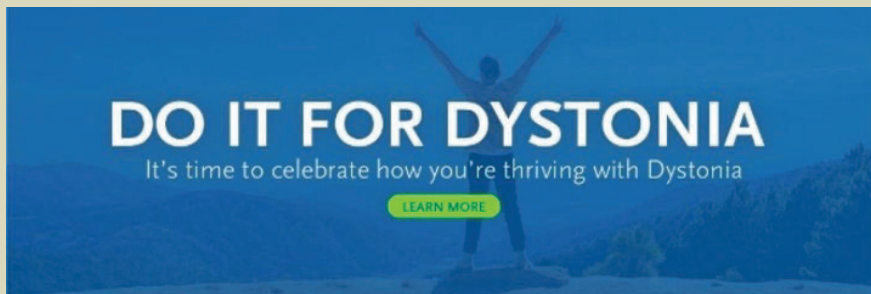
Volunteers can take on different roles or tasks within the group.

To read more about the Support Group Leader role, responsibilities and eligibility please visit: [www.dystoniacanada.org/volunteer](http://www.dystoniacanada.org/volunteer) or scan the QR Code below. If you are not interested in leading a group, but you would still like to volunteer your time, please let us know.

Email [info@dystoniacanada.org](mailto:info@dystoniacanada.org) with your contact information and the community you'd like to volunteer in.



## How will you *Do It for Dystonia* in 2024?



Get started today, visit: [www.dystoniacanada.org/doit](http://www.dystoniacanada.org/doit)

Congratulations to our top “Do It” fundraising campaign for 2023 “Tour du Mont Blanc pour la Dystonie” hosted through Facebook. For tips on how you can fundraise through Facebook, please visit:

[www.dystoniacanada.org/facebookfundraising](http://www.dystoniacanada.org/facebookfundraising)

Through “Do It”, you can raise funds for critical dystonia research and support programs when you want and the way you want.

Honour a loved one or celebrate a special day. Make it a team effort or go it alone. If you have a special talent or hobby, make that part of your “Do It” campaign.

## Patients Needed for Dystonia Research Study in Toronto:

Dr. Talyta Grippe at the 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. This study involves 1 study visit that is 4 hours long. To collect the study's data, the researchers are using a noninvasive brain stimulation technique called transcranial magnetic stimulation (TMS) and electrical stimulation.

On May 16 at 2 pm Eastern Time, DMRF Canada will facilitate a live presentation with Dr. Grippe to answer questions for those interested in participating in this study. For more details and to register, please visit – [www.dystoniacanada.org/study-Grippe](http://www.dystoniacanada.org/study-Grippe).

We appreciate the dystonia community's participation to assist dystonia research efforts.

*This study is part of the 2023 – 2025 DMRF Canada Clinical and Research Fellowship (Supported by Merz Therapeutics) granted to Dr. Talyta Grippe.*

## 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.



## Supporting Young Investigators Moves Dystonia Research

The Dystonia Medical Research Foundation has long been a proponent of supporting young investigators through its fellowship programs for both researchers and clinicians. Supporting young investigators through mentorship and funding not only paves the way for new discoveries and dystonia treatments but also builds the dystonia scientific community. Simply put, the more investigators we get involved in dystonia research correlates to more, faster, and better discovery.



L to R: William Dauer, MD; Lauren Miterko, PhD; and Samuel Pappas, PhD of University of Texas Southwestern Medical Center, Dallas.

There has been much progress in our understanding of dystonia since the DMRF was founded in 1976. Discovery of the DYT1 gene, a better understanding of the TorsinA protein's role in dystonia, and the use of botulinum neurotoxin therapy (BoNT) and deep brain stimulation (DBS) treatments for dystonia are just a few scientific advances that have occurred. However, too many unanswered questions still exist. Scientific research is the only way to resolve these questions and unravel the mysteries of this complex movement disorder that will lead to a cure for dystonia.

Scientific discovery takes time, requires the combined efforts of many, and thrives on new, fresh ideas...three areas where young investigators are critical. To get perspective on how supporting young investigators advances science, DMRF spoke with William Dauer, MD, professor of neurology and neuroscience and director of the Peter O'Donnell Jr. Brain Institute at UT Southwestern Medical Center, Dallas.

Dauer is a past member of the DMRF Scientific and Medical Advisory Board and was the first recipient of the DMRF's prestigious Stanley Fahn Award, which is given to young investigators who conduct groundbreaking dystonia research with the hope of finding better treatments. The DMRF established this award in honor of Stanley Fahn, MD, who has made visionary and lasting contributions to the field of dystonia and is a lifetime member of the Board of Directors.

### **Early support influences career choice**

Dauer remembers his own early days as a young investigator at Columbia University's Department of Neurology where he worked under Fahn, then the director of the Division of Movement Disorders.

"I did my movement disorder fellowship there, and the Dystonia Medical Research Foundation had a long-standing relationship with the movement disorder groups," Dauer says. "Stan Fahn, Susan Bressman, Paul Green...these people were all my mentors. They were always present at meetings and in this community."

**"This is a community. We're on a mission together. We're supporting and challenging each other, and it is really exciting as a scientist."**

**—William Dauer, MD**

In 1997, Dauer was a fellow when investigators discovered the gene for DYT1 dystonia. "That changed my whole life, being witness to that discovery. Dystonia is what I've worked on for my entire career. It was a big deal and DMRF was there," Dauer says. "I can still remember being in the room across the hall, hearing Susan Bressman jump up and down when they discovered the gene for DYT1 dystonia."

Dauer says he had developed an interest in dystonia from his clinical work but could have chosen a career in more well-known neurological disorders, like Parkinson's disease. The scientific network and community around dystonia research drew him to the field where he's now been focused for decades.

### **A community on a mission**

This feeling of community came from the families affected by dystonia who led the DMRF then and many of whom are still involved today. "They understood at a very high level the importance of the science, bringing in new ideas, and developing fundamental understanding before being able to test interventions that potentially impact their own child. That's unusual and is really important to the mission of the DMRF," he says.

The DMRF also fosters new ideas by hosting meetings focused on certain aspects of dystonia that need critical attention, bringing young and seasoned scientists together from around the world who may not normally connect, and by continuing to fund projects that show promise.

"It's beyond the money. Yes, the money is obviously important, but it goes way beyond the money," Dauer says. "This is a community. We're on a mission together. We're supporting and challenging each other, and it is really exciting as a scientist."

### **Planting seeds of commitment**

Funding investigators early in their careers can plant seeds of gratitude that grow into dedicated careers in dystonia and a desire to give back as mentors themselves.



The timing and environment at Columbia became the ideal mix for Dauer when he applied for his first DMRF fellowship. The DYT<sub>1</sub> mutation had just been discovered, and he mentored under Rene Hen, PhD, who was an early adapter of using genetically modified mice. Dauer was awarded a DMRF fellowship to pursue research on mice with the DYT<sub>1</sub> dystonia mutation.

“I can’t overstate how important those initial years of funding and community support from the DMRF were,” Dauer says.

### Continuing the cycle of mentorship

Mahlon DeLong, MD, world-renowned neurologist who specialized in dystonia and other neurological movement disorders, was DMRF’s scientific director when Dauer was awarded his first DMRF fellowship.

“That was phenomenally important to know that people, like Mahlon DeLong, who I had great respect for were interested in my work and valued it,” Dauer says. “He’s a giant in the field. And being able to talk with him and bounce ideas off him was incredibly important.”

Valuing his own mentee experience, Dauer has since helped mentor other young investigators who have been awarded DMRF fellowships and have gone on to specialize in dystonia or related research in their own labs.

“These are the fruits of that DMRF community and their initial support of young investigators. Being part of this community amplifies what’s going to be important to solve the problems of dystonia and what needs to be researched next,” he says.

### Investing in the future

These are difficult problems that will take longer than one investigator’s lifetime to solve. “It takes a large, robust energetic community and young trainees. Trainees come with fresh eyes. They don’t come with preconceptions, and they’re the ones who ask ‘why?’,” Dauer says. “Young scientists are critical to the health and vitality of the community. They’re critical for the future growth and discoveries to be made by the community.”

Supporting young investigators creates on-ramps into dystonia research, expanding the field and leading to new ideas. An investigator may not consider dystonia at first but might be interested

in the nuclear envelope or the stress response of neurons, for example. “They might come across some dystonia literature that addresses these topics. If DMRF can support them early in their research, they can study these things in the context of dystonia,” Dauer says.

Young investigators bring new scientific ideas and a fresh perspective to the understanding of dystonia that builds upon what we already know.

“New ideas are so important to an intellectual community.” Dauer says. “When you get investigators doing high quality work, interesting and innovative things, and taking chances—especially when they’re young—it creates fuel for more established scientists in the field. That intellectual energy is what really drives science forward.”

Apart from supporting young investigators globally, DMRF Canada also supports young Canadian investigators through the DMRF Canada Clinical and Research Fellowship as well as our partnership grant with the Banting Research Foundation in Canada. To learn more about how we support research, visit [www.dystoniacanada.org/research](http://www.dystoniacanada.org/research)

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# Mental Health Support May Be as Close as Your Computer

Living with dystonia presents unique physical and emotional challenges. For many, finding the right mental health support can make a significant difference in improving their quality of life.

Fortunately, the digital age has made it easier than ever to access online therapy suitable for the needs of individuals with dystonia. However, it is important to know exactly what you want, need, and expect before you begin. Additionally, many new online services are emerging, and critically assessing the benefits of these services is key.

There are many benefits to online mental health treatment. Meeting with therapists virtually means that you can have a therapy session from the comfort of your home. This is especially valuable for those with mobility issues, transportation issues, or those who live in rural areas. In addition, many online platforms include messaging with a therapist—something that might be beneficial to many in the dystonia community.

To get the most out of your online therapy experience, there are important steps to take. You may want to talk with your physician or a trusted friend or family member as you begin this process.

## Assess your needs:

Reflect on your emotional well-being and identify the specific challenges you'd like to address. Are you looking for a neutral third-party to help identify coping strategies to reduce stress? Do you need help navigating the changes in your life brought on by your dystonia? Identifying your goals can help as you begin the search for the right mental health provider for you.



## Research and explore:

Look for therapists who specialize in chronic conditions and ideally have experience with movement disorder patients. Many providers have experience in chronic conditions and chronic pain and can use that expertise to help guide you. DMRF Canada has an informational packet for mental health providers that will help familiarize them with dystonia as they prepare for your session. This can be found on our website at [www.dystoniacanada.org/mental-health-professionals-canada](http://www.dystoniacanada.org/mental-health-professionals-canada)

Utilize online therapy directories, search engines, or mental health platforms to find potential therapists. DMRF Canada has a resource library with materials to help you make informed decisions. In recent years, many online mental health companies have emerged—make sure you do your research to verify if these will be a good fit for you. Questions to ask may include: Do they take your insurance, or are they subscription services? What level of experience do the therapists have—are they students or have they been practicing for some time? Are you able to pick a provider, or are they assigned to you?

## Verify licensing and security:

Ensure that your chosen therapist is licensed to practice in your province or territory. Licensing is meant to protect both you and the mental health provider. Licensed mental health providers have received the proper, graduate-level training to help patients. This training includes supervised

clinical experience and that they've passed provincial and national licensing exams. Making sure that you are talking with a provider licensed in your province is critical—many provinces have online directories to check if your provider has the necessary qualifications.

In addition, make sure the platform you are using is secure. Therapy works when patients have a private space to share deeply personal experiences and emotions. If you're using video appointments, make sure the feed is secure. Like telehealth appointments with a physician, the system should be encrypted and Personal Information Protection and Electronic Documents Act (PIPEDA)-compliant. This also goes for messaging with a therapist. Secure portals are essential and should be able to verify your identity and that of your provider.

### **Discuss compatibility:**

Finding a therapist can take time—not every provider is a good fit for every patient. Many providers offer free initial consultations, which allows you the opportunity to assess their approach and personality. Don't be discouraged if the first person you talk to isn't right for you—it can take time to find the right fit, and finding the right person is important. Building a strong rapport with your therapist is essential for effective online therapy, so take the time to find someone you're comfortable sharing your concerns with.

### **Navigate financial considerations:**

Online therapy is often more affordable and accessible, but it's crucial to explore payment options. Contact your insurance provider to inquire about coverage for online therapy. Some online providers do not accept insurance and instead operate as a subscription service. This might be right for some patients, but not for all. It's worth checking with your insurance provider to see if they cover teletherapy appointments and what costs they'll cover.

Research companies or providers may offer competitive fees or sliding-scale payment options for out-of-pocket costs. Many of the companies that do not accept insurance do offer sliding-scale payment options or financial assistance.

### **Seek additional support and resources:**

Therapy may not be necessary for everyone. Mental health is an ongoing journey, and support beyond therapy can make a significant difference.

Online therapy can be a powerful tool to help navigate the complexities of dystonia and provide the support and guidance you need to live your best life. By assessing your needs, researching qualified therapists, addressing financial considerations, and seeking additional support, you can embark on a journey toward emotional well-being and resilience.

## **Explore Dystonia Support Groups and Coping Strategies**

Sharing your experiences and insights while learning from others in similar situations can be tremendously beneficial. In addition, speaking about these issues can help reduce the stigma around both mental health and dystonia. Join online support groups or communities specifically tailored for dystonia patients.

### **Online Support Groups:**

DMRF Canada has many local support groups that can provide a sympathetic and understanding ear. In addition, the DMRF USA has online Facebook groups to provide community support. It is important to remember that support groups are not professional mental health services, but rather groups of people who are also living with dystonia and can empathize, provide practical coping strategies, and provide peer support. Information about these offerings can be found online.

If you'd like to connect with a volunteer or group, please visit:

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

### **Coping Strategies:**

Explore coping mechanisms to manage the emotional impact of dystonia. Incorporate mindfulness, relaxation techniques, and self-care into your routine. Breathing exercises, working on your hobbies, or being in nature can provide significant stress reduction in your life. Similarly, building a support system with your friends, family, and community can be extremely beneficial.



# How to Talk with Your Doctor About Dystonia

A dystonia diagnosis can be life changing. To get the best outcome from your treatment, you should be actively involved in the development and management of your care plan.



Research has shown that people who have strong partnerships with their healthcare providers do better both physically and emotionally. Central to developing a strong partnership is good communication with your doctor, which sounds simple but has its challenges. The time limitations of medical appointments, stress brought on by waiting for answers, and simply not knowing what questions to ask are a few examples. In addition, identifying a doctor who shares your communication style—who you are in sync with—contributes a great deal to effective communication.

To achieve effective communication, some planning is necessary and starts with finding the provider that is a good fit for you. It is important that you feel comfortable talking with your doctor about how you feel, how your treatment is going, and about your questions, concerns, and expectations from your

treatment plan. Don't be afraid to recognize that the doctor you are currently working with may not meet your needs. Always remember that the No. 1 expert on your dystonia is you.

## Preparing for your appointment

- 1. Questions:** Make a list of the questions you want your doctor to answer. It is easy to forget what questions you have when you are waiting for your appointment. Having a list will help you focus on the most important questions and help your doctor respond to them.
- 2. Bring another person if you can:** If possible, bring someone with you to take notes and retain the information that is shared. A family member or good friend will also be there to assist and support you.
- 3. Medications:** Bring a list of your medications to the appointment. It is important for your doctor to know all the medications you are taking, including dietary supplements.
- 4. Learn about dystonia:** Inform yourself about dystonia and the treatment options available. Stay informed about what is happening in dystonia treatment, so you can talk with your doctor about whether a change in your treatment plan will benefit you.

## During your appointment

During your appointment, share your list of questions with your doctor. Be mindful of their time limitations and try to ensure your most important questions get addressed by letting your doctor know your most pressing questions first. Don't be surprised if it is recommended that you make another appointment just to speak with your doctor about all your questions. You can also ask if you can speak with the nurse regarding your questions.



### Some practical steps to consider:

- Repeat the answers back to your doctor to make sure you got them right. Take notes and ask if you can record the responses to your questions if you are not able to have someone with you.
- If the responses are not clear or if you still do not understand, ask your doctor to explain it more simply or perhaps to show you a diagram to better explain.
- If your doctor uses an online patient portal to communicate with you and you need help in understanding how to use the portal, ask if there is someone in the office who can assist you in learning how to use the portal.

### Questions Patients Commonly Ask Healthcare Providers

- ▶ What form of dystonia do I have?
- ▶ How will my dystonia affect my day-to-day life?
- ▶ Is my dystonia genetic? Should I be genetically tested? Should my children be tested?
- ▶ Can I expect my dystonia to get worse? Will it spread?
- ▶ What are my treatment options and what do you recommend?
- ▶ What can I expect from my treatment? When will it start to work? How do I know if it is not working?
- ▶ What are the potential side effects?
- ▶ What is the cost of the proposed treatment?
- ▶ What is the brand and generic names of the drugs being prescribed?
- ▶ If you have pain, ask how your pain will be treated.
- ▶ What is the best way to reach you with questions?

Having your questions answered and your concerns addressed can help reduce the stress and anxiety of living with dystonia. Being an equal partner in your healthcare and having productive conversations with your doctor can make a big difference in getting the most of your treatment.

For more helpful information and resources like this, visit [www.dystoniacanada.org/living-with-dystonia](http://www.dystoniacanada.org/living-with-dystonia)

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## Make it Monthly - Join DMRF Canada's Monthly Giving Team

It would be impossible to sustain DMRF Canada's vital research programs and community outreach without our Monthly Giving Team. The generous support from our monthly donors touches every aspect of the DMRF Canada's activities from events to the free resources and education programs for individuals living with dystonia and their families.

Joining the Monthly Giving Team is an opportunity to have a consistent and meaningful impact on dystonia research, support the programs you love, and bolster awareness efforts. Even just \$5 a month makes a significant difference, and the impact of your gift is felt throughout the dystonia community.

To learn more about how you can join this special group of supporters and make a lasting difference in the fight against dystonia, visit the link below or scan the QR code above. Your contributions sustain the critical work being done by DMRF Canada, and your dedication is deeply appreciated.

Learn more about monthly giving:  
<https://dystoniacanada.org/why-i-give-monthly>

# Advancing Together through Collaboration

## 2nd Annual Canadian Movement Disorders Meeting



DMRF Canada was honored to take part in the 2nd Annual Canadian Movement Disorders Meeting held in Toronto, Ontario, on Saturday, November 25, 2023. This gathering, hosted by Parkinson Canada and the Canadian Movement Disorders Society, brought together a diverse array of professionals, including researchers, movement disorder specialists, neurologists, resident physicians, and scientists.

The event served as a platform for experts to showcase advancements in the field of movement disorders. Engaging panel discussions, notably one centered on healthcare, emphasized the critical importance of ensuring access to care for individuals with movement disorders. The importance and need for establishing a public database where physicians could contribute diagnostic statistics, potentially offering researchers invaluable aggregate data for surveillance of movement disorders, were highlighted.

Advocacy was emphasized in discussions, underlining the significance of raising awareness among policymakers about the needs of those affected by movement disorders. This underscored the essential role of community members and organizations in amplifying voices and incorporating the input of people with lived experience.

Throughout the two days, countless new connections were made. The conference concluded with a sense of shared purpose and a unified commitment to advancing our understanding and treatment of movement disorders.

We extend our heartfelt gratitude to the organizers, Parkinson Canada, and the Canadian Movement Disorders Society, and eagerly anticipate future collaborative endeavors aimed at furthering progress in this field.

*Adapted with permission from Parkinson Canada: Insights from the 2nd Annual Canadian Movement Disorders Meeting*

## Unlocking Insights and Collaboration

In December 2023, DMRF Canada was invited to a meeting of Canadian patient associations facilitated by global biopharmaceutical company, AbbVie Canada. This gathering provided an invaluable opportunity for organizations like DMRF Canada to engage with likeminded organizations including March of Dimes Canada, and Mood Disorders Society of Canada, to exchange knowledge, and delve into the successes and challenges encountered in their work. The exchange of ideas and best practices during the meeting offered DMRF Canada a new perspective on various approaches to advocacy, education, and patient support. Learning from the successes and challenges of other organizations provided valuable lessons that can be applied to advance research, raise awareness, and advocate for policies that prioritize the needs of the dystonia community.



*Image Credit: AbbVie Canada*

One of the most promising aspects of the meeting was the opportunity for collaboration. By forging partnerships with other patient associations, DMRF Canada can leverage collective knowledge and resources to drive positive change for individuals living with dystonia in Canada. We are enthusiastic about using the insights gleaned and the prospects of effective collaborations to facilitate improved care and support for the dystonia community in Canada.

# Brain Awareness Week Canada

During International Brain Awareness Week in March 2024, DMRF Canada proudly stood alongside the Canadian Brain Research Strategy (CBRS) and its partners to champion the awareness for brain research.

This important week provided a platform for the dystonia community to raise its voice, advocating for increased focus and investment in understanding the complexities of the brain. In a CBRS article published in the Globe and Mail on March 11, the urgent need for dedicated funding for brain health, as emphasized by the World Health Organization, was highlighted. It underscored that such funding should be a priority at all levels of governance—be it intergovernmental, national, or regional—and that it should be both driven and supported by governments.

DMRF Canada is collaborating with CBRS to tackle not only the critical aspects of preventing and treating brain conditions but also to craft a comprehensive national strategy aimed at fortifying the brain research landscape. See below the organizations united by the CBRS that are contributing to developing this comprehensive national plan.

We are building on past years' efforts in which DMRF Canada alongside 15 other organizations submitted briefs for the Standing Committee on Science and Research (SRSR). Our collective voice speaks volumes as we advocate for prioritizing brain health and investing in the research that will shape a healthier future for all. Together, we strive to create a more robust ecosystem for brain research in Canada.

Learn more about CBRS and our advocacy work here [www.dystoniacanada.org/advocacy](http://www.dystoniacanada.org/advocacy)



## A National Research Strategy for Brain and Mental Health Brought to You by



Image Credit: Canadian Brain Research Strategy

## New Way to Raise Funds for Dystonia

Are you a Twitch streamer? Know someone with a large audience on TikTok or YouTube? Thanks to Tiltify, you can harness the power of your profile and raise funds for DMRF Canada! Tiltify provides an easy-to-use platform for you to start fundraising in just a few easy clicks.

Visit: <https://tiltify.com/dmrfcanada> to get started.

## 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.

**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**

