



**DYSTONIA
MEDICAL RESEARCH
FOUNDATION
CANADA**

CASE FOR SUPPORT



DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

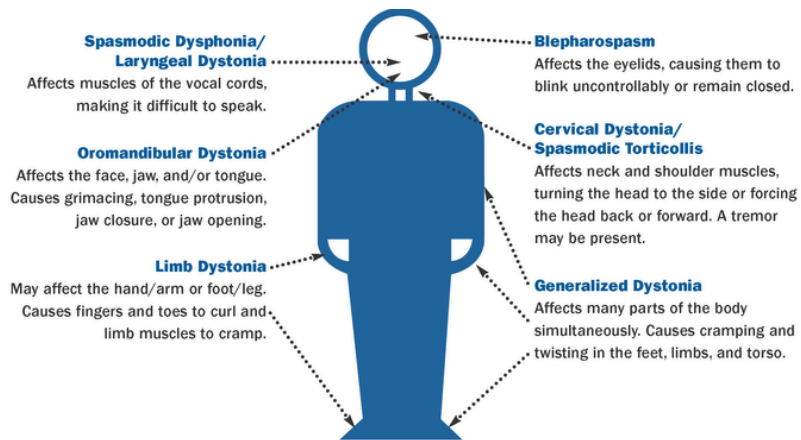
*serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie*

WWW.DYSTONIANCANADA.ORG/CASEFORSUPPORT

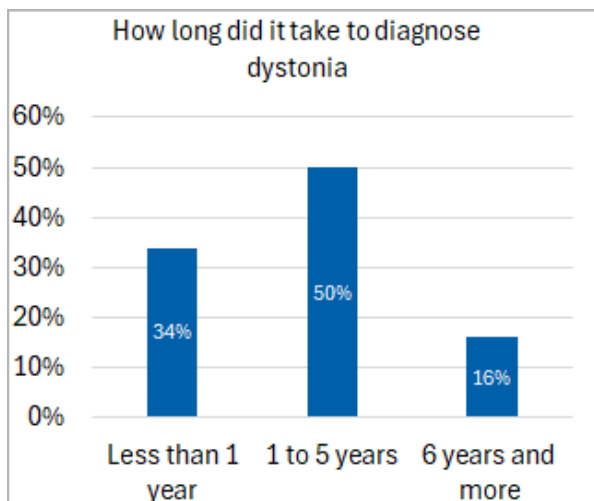
WHAT IS DYSTONIA?

Dystonia is a complex neurological movement disorder that causes involuntary muscle contractions, tremors, and twisting movements. It can affect any part of the body and disrupts daily life with pain, uncertainty, and isolation

Dystonia's complexity often leads to long delays in diagnosis and treatment. Patients typically wait 6 months to 3 years to see a specialist, with some experiencing diagnostic delays of up to 10 years. Even after diagnosis, limited treatment options and access to care can further postpone effective management.



Source: Understanding Dystonia Factsheet by DMRF



Source: DMRF Canada Survey 2019

Watch How Dystonia Affects Lives



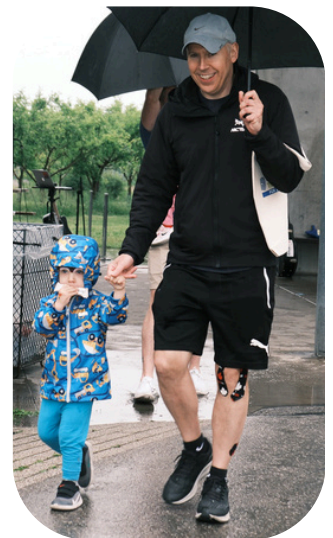
“The worst part of dystonia is the life it steals from you. I was at the height of my career only to have it ripped away from me.”

Astrid Frauscher

These challenges highlight the urgent need for greater support, including accessible mental health resources, specialized care, and ongoing research, to improve patients' quality of life and address the complex impact of dystonia.

Facts About Dystonia

Third most common movement disorder



70% of dystonia patients state that pain is one of the top challenges in living with dystonia



Affects approximately 50,000 people in Canada



32% of the community were incorrectly diagnosed with tremors and mental health disorders prior to receiving a diagnosis of Dystonia



Dystonia can be inherited, acquired, or idiopathic (no known cause)



59% stated that Dystonia has negatively impacted their ability/capacity to work



Men, women and children of all ages and backgrounds are affected

UNHEARD VOICES: THE REALITY OF LIVING WITH DYSTONIA



"Suddenly it seemed like the task that I once saw as achievable was now slipping from my reach." - Sarah Anderson, Manitoba (Generalized Dystonia)



"During my young adulthood, my symptoms worsened, but doctors couldn't figure out what was wrong. For 20 years, I relied on Tylenol to manage daily life, including work and motherhood. Eventually, I could no longer work and had to resign from my job. Without a formal diagnosis, those around me thought I was just neurotic, which led me to stop socializing." - Jennifer Lovell, Winnipeg (Generalized Dystonia)

"These failed attempts saw medical staff call me a drug addict, an alcoholic, and a liar. Even though I was previously diagnosed, they refused to even ask a neurologist to take a look at me." – Jason Young, Nova Scotia (Paroxysmal Dystonia & Dyskinesias)

Direct quotes from dystonia thrivers detailing what it is like to live with dystonia.



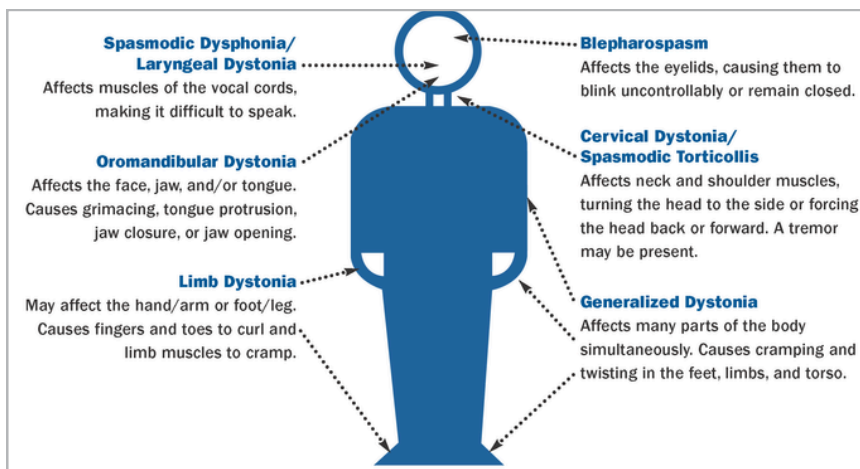
THE ROLE OF DMRF CANADA: SUPPORTING A STRUGGLING COMMUNITY

Dystonia Medical Research Foundation (DMRF) Canada's mission is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well being of affected individuals and families.

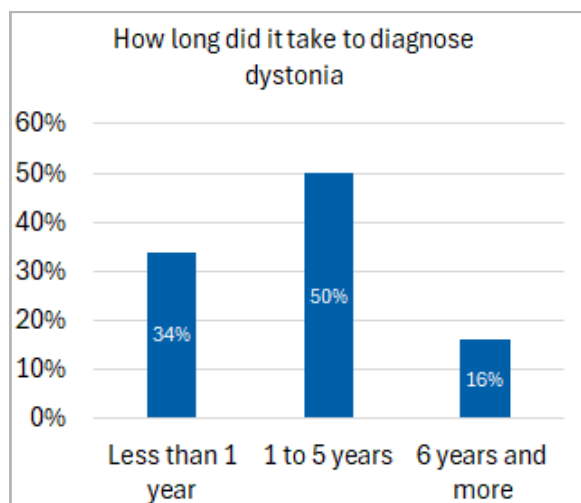
Without the clinical/research investments, support, advocacy, and awareness our organization brings to the community, individuals will continue to struggle, go undiagnosed, and live without hope. DMRF Canada stands as the sole organization in Canada dedicated to serving the dystonia community. Our mission is clear: we relentlessly advocate for their health, offer unwavering support, and strive to educate the world about dystonia.

DYSTONIA: A COMPLEX DISORDER AND THE PATH TO BETTER CARE

Dystonia is characterized by involuntary muscle contractions that can manifest as abnormal movements and body postures resulting in the difficulty of individuals having control over their movements. It can either be caused by genetics, a result of other health conditions such as stroke, physical trauma, or other diseases, or as a side effect of certain medications.



Source: Understanding Dystonia Factsheet by DMRF



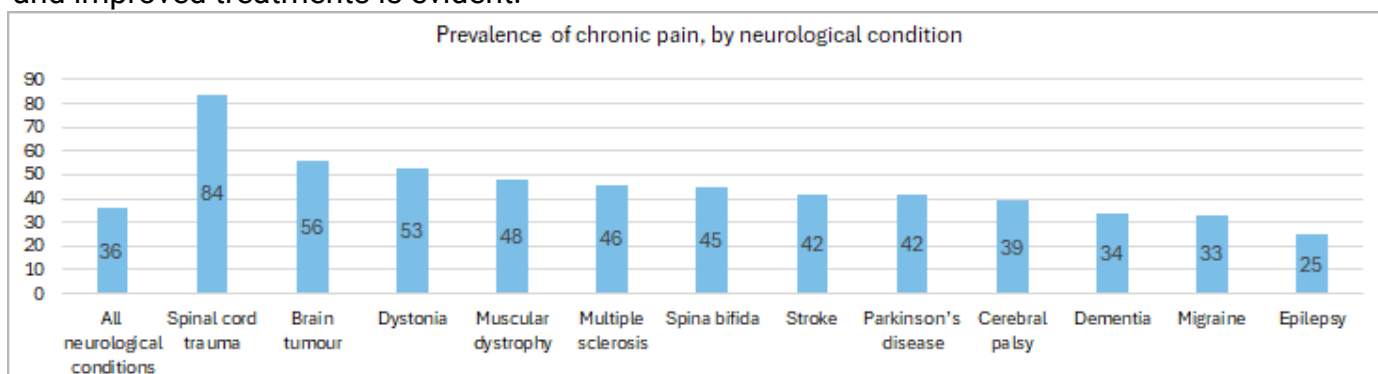
Source: DMRF Canada Survey 2019

While dystonia may be the third most common movement disorder affecting approximately 500,000 people in North America, it is rare due to being inherently diverse or heterogeneous. As explained by Scarduzio and Standaert (2003), every form of dystonia is completely different, including its cause, how it manifests, and the symptoms experienced by affected individuals.

Diversity is just one big concern that flakes the community, the other is the journey to diagnosis. It often takes 1-10 years due to misdiagnosis

and wait times of 6 months to 3 years to see a specialist, as reported by patients and doctors. Even after diagnosis, patients face further delays in starting treatment due to the need for comprehensive assessments and the limited availability of treatment options.

Patients with dystonia endure prolonged periods of pain, uncertainty, and distress, and some live without any effective relief. The pressing need for enhanced clinical care and research into new and improved treatments is evident.



ABOUT THE ORGANIZATION

The Dystonia Medical Research Foundation was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia.

DMRF Canada is a registered non-profit Canadian charity governed by a volunteer Board of Directors, and we now mark 50 years of advancing research, education, and support for the dystonia community. We work in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partner with other like-minded research organizations to fund excellent dystonia research in Canada.

DECADES OF IMPACT

Let's highlight some significant achievements that DMRF Canada has helped drive forward.

45 YEARS AGO	TODAY
Only 200 accounts of dystonia had ever been published	Over 20,000 studies and reviews on dystonia have been published, with more added every day.
Patients were routinely misdiagnosed and treated for psychiatric illness.	Dystonia is defined as a neurological syndrome of involuntary muscle contractions.
The genetics of dystonia were not understood, and no genetic changes were associated with dystonia.	Numerous genes and gene markets associated with dystonia have been identified.
Lack of knowledge prevented the development and dedicated drug treatments of dystonia.	Comprehensive treatment strategies have been widely accepted, and new drugs are being identified.

Over the last 45 years, advancements in basic and clinical research have led to sophisticated genetic studies, insights from neuroimaging technologies, and unprecedented drug discovery efforts. The growing dystonia field led to the launch of the open-access journal 'Dystonia' providing a centralized, go-to publication by and for dystonia investigators.

For over 40 years, DMRF Canada Support Groups have been a lifeline for those affected by dystonia. Since the pandemic, we've expanded our programs and resources to reach remote communities, offering support both in-person and online. Nearly all support resources are now available in English and French. In the past decade, registered patients have increased by 400%, reflecting our growing impact.

Each September, Dystonia Awareness Month continues to break new ground, reaching tens of thousands and raising public awareness. Through nationwide news coverage, municipal participation, landmark illuminations across Canada, and grassroots efforts, we consistently surpass previous milestones, amplifying the impact year after year.

We also collaborate with over 20 organizations to enhance services and address the needs of the dystonia community.

WHY WE NEED YOUR HELP

Too often sidelined, dystonia receives far fewer resources than its true impact warrants. It remains one of the most underrecognized and under-resourced neurological conditions, despite its growing prevalence and increased recognition through improved diagnosis. Dystonia affects more than 30% of people living with Parkinson's disease, according to the [Michael J. Fox Foundation](#). Across isolated and complex forms of dystonia, we estimate that over 50,000 Canadians live with this chronic, disabling condition that profoundly impacts quality of life.

Our vision depends on the strength of our community and partners. As a self-funded charity without government support, every partnership helps sustain vital programs and prevent service cuts. We operate with exceptional efficiency, keeping administrative costs lower than they were a decade ago so that more of every dollar goes directly to research, support, and improved care.

Access to specialized care remains one of the greatest challenges for people living with dystonia. With fewer than 80 neurologists in Canada focused on movement disorders*, tens of thousands face limited access to timely treatment. DMRF Canada is helping address this gap by funding a clinical and research fellowship at SickKids and Toronto Western Hospital, where Dr. Lindsey Vogt is advancing expertise in both pediatric and adult dystonia.

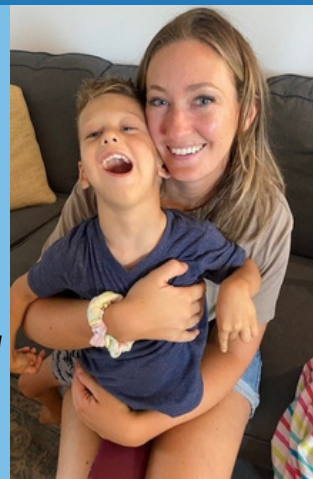
We also invest in advanced medical education to help physicians improve their skills in diagnosing and managing dystonia. These programs ensure that new research discoveries translate into improved care and faster results for patients across Canada.

Your contributions can help ensure that we continue to make a difference in the lives of countless individuals. Together, we can overcome these challenges and strengthen our foundation for a brighter future. Every effort counts and moves us closer to achieving our mission.

*Source: Parkinson Canada, [Explorations into Health System Solutions for Parkinson's in Canada](#).

"With so much time and frustration involved in finding a diagnosis and the ongoing search for treatments that could help, I knew there must be so many others like Fletcher suffering every day from dystonia. Armed with only a diagnosis, my family scrambled to learn more about the disorder that was torturing my son.

During my search, I was relieved to discover DMRF Canada. Knowing there was a community of other parents like me, supporting children like Fletcher, I was immediately motivated to do everything I could to further their mission to support research and a cure." - Ashley, mother of a boy who was diagnosed at 2-years old.



OUR MISSION IN ACTION: HOW YOUR CONTRIBUTION MAKES A DIFFERENCE

RESEARCH

Expansion of our research investments and continued relationships with patients, medical professionals and researchers to help develop the best clinical treatments and promote collaboration within the dystonia community

Invest in Dystonia Research

We are committed to addressing both current needs and long-term goals. By partnering with organizations like the Banting Research Foundation, DMRF USA, and various organizations, we aim to support initiatives that lead to improved dystonia treatments.

Driving Global Research Efforts

We collaborate with the DMRF USA, Global Dystonia Registry, and Dystonia Coalition to gather data, across multiple scientific disciplines. This collaboration facilitates a layered and sophisticated understanding of dystonia.



Knowledge Translation

We prioritize delivering accurate information to assist patients, caregivers, and medical communities. Key findings are shared through bi-annual newsletters in English and French, as well as quarterly E-newsletters for timely updates.

Build Relationships

We are dedicated to supporting Canadian researchers and clinicians. Our initiatives include hosting information sessions to recruit research participants and partnering with various organizations for educational programs, such as the Annual Canadian Movement Disorders meeting and the National Residents' Movement Disorder Course. These efforts aim to cultivate future experts and improve care for those living with dystonia.



SUPPORT

Provide critical support and foster supportive relationships with the dystonia community members by providing effective resources to help all affected

Support

Build a sustainable support network for the dystonia community by maintaining relationships with over 40 volunteers across 32 local areas in nine provinces. Our efforts assist support group leaders, most of whom are dystonia patients, in organizing patient information sessions and facilitating support group activities, including National Virtual Support Meetings and local gatherings.

Empower

Meet the needs of the community by assisting existing and newly diagnosed dystonia patients. Through resources like the Jackson Mooney Patient Education Grant and workshops from partner organizations, we empower individuals to advocate for themselves and take control of their care.



2018 Calgary Dystonia Symposium

AWARENESS & ADVOCACY

Raise awareness and advocate for the needs of the dystonia community now and in the future

Promote Dystonia Awareness

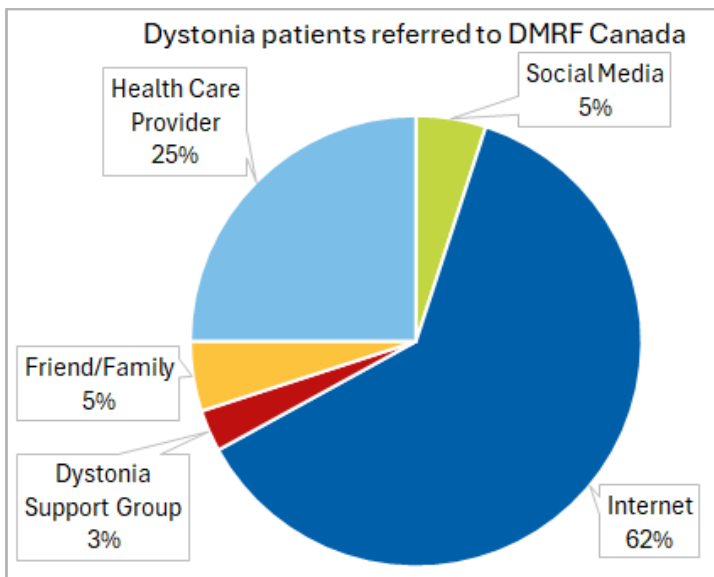
Enhance understanding of dystonia within the general public and medical community through ongoing campaigns, such as illuminating landmarks during awareness month and engaging in public relations initiatives, including media interviews.

Strengthen Advocacy Efforts

Efforts - We are building relationships with key stakeholders and organizations to address policy needs and increase visibility for dystonia. This includes collaboration with initiatives like the National Population Health Study of Neurological Conditions and the Canadian Brain Research Strategy to advocate for brain research investments.

Educate Future Medical Professionals

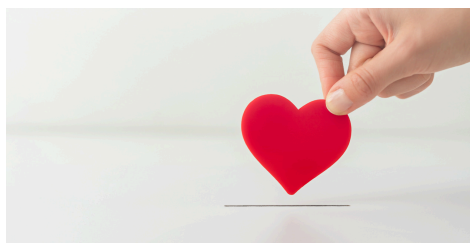
By partnering with educational institutions, we are equipping future medical professionals with insights into the challenges faced by those living with dystonia, fostering a more informed healthcare community.



Source: DMRF Canada 2023

WAYS TO GIVE

One time Gift: Change the future for dystonia patients in Canada with a one-time gift, no matter the size our mission survives because of you.



Monthly Giving: Charity revenues can fluctuate dramatically month to month and year to year. A recurring donation of just \$5/month will ensure a steady source of funding for our multi-year research projects and reduce administrative costs.

Employee Giving : Did you know that your gift to DMRF Canada could be doubled - or even tripled? Many companies have a matching gift program that will double or triple any charitable contributions made by their employees.

Donate – A – Car: You can turn your vehicle into dollars to support Dystonia Medical Research Foundation Canada! Working on our behalf, Donate-a-Car Canada will accept your vehicle for donation - running or not, old or new!

Planned Gifts: By including the DMRF Canada in your will, you help to ensure that dystonia research will be supported until we achieve our mission to find a cure. Your legacy can be a future free from dystonia!

Tiltify: 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.

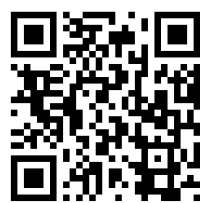
Contact DMRF Canada

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dystoniacanada.org/social-media



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