



**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  
d'asservant toutes personnes atteintes de dystonie*

[WWW.DYSTONIANCANADA.ORG/CASEFORSUPPORT](http://WWW.DYSTONIANCANADA.ORG/CASEFORSUPPORT)

# 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.**



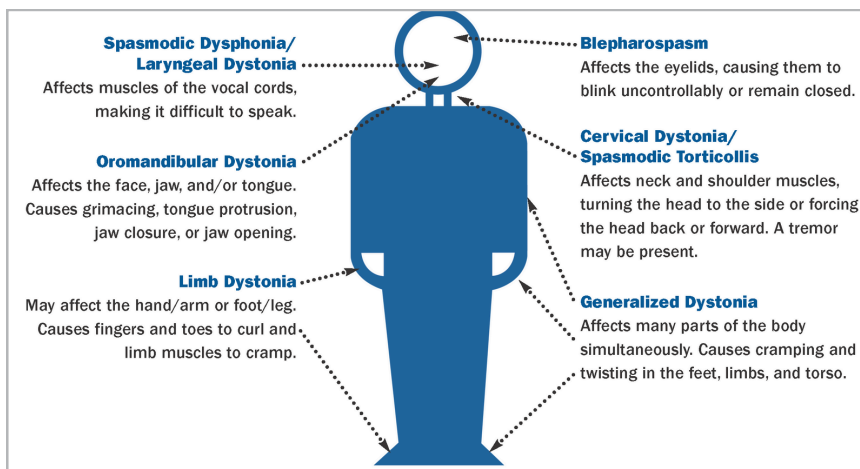
## THE ROLE OF DMRF CANADA: SUPPORTING A STRUGGLING COMMUNITY

*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.*

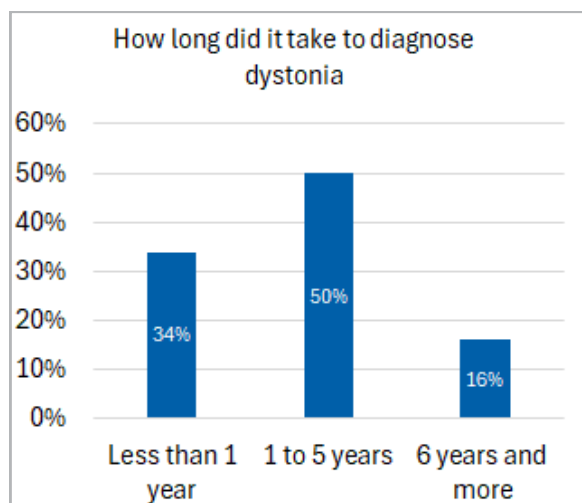
Without the clinical/research investments, support, advocacy, and awareness our organization brings to the community, individuals will continue to struggle, go undiagnosed, and live without hope. DMRF Canada stands as the sole organization in Canada dedicated to serving the dystonia community. Our mission 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

The neurological movement disorder, 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



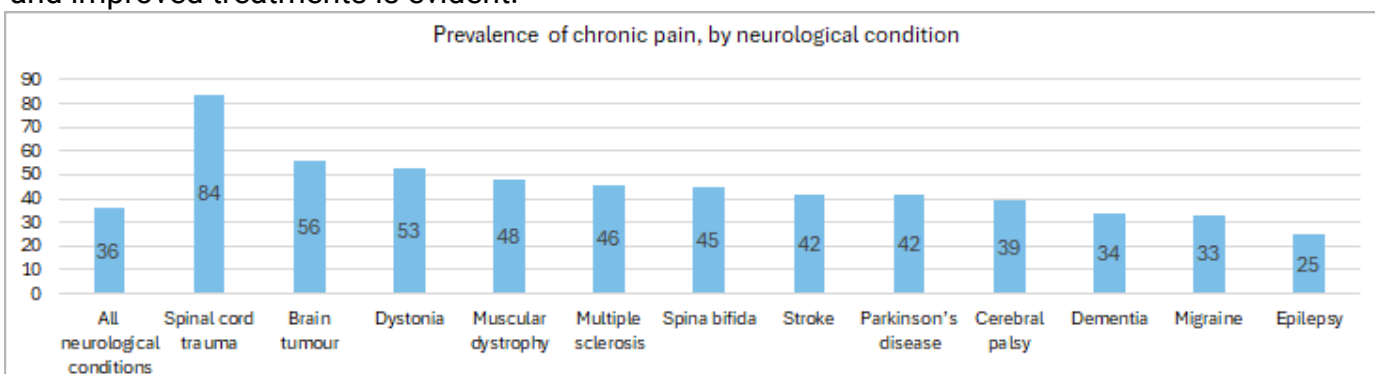
Source: DMRF Canada Survey 2019

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.



Statistics Canada, neurological condition, household population aged 15 or older reporting one neurological condition, Canada exuding territories, 2011/2012. Source: 2011/2012 Survey on Living with Neurological Conditions in Canada.

# 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. Our Board is comprised of key dystonia community stakeholders– people with dystonia and their family members. 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

Our mission's success hinges on the strength of our community. Across Canada, we serve every province with just two full-time and one part-time staff. Volunteers have played a pivotal role in getting us to where we are today, dedicating their time to advancing our cause.

Yet, we now face growing challenges. Demand for our services is rising, but financial support has not kept pace. Community fundraising, volunteer involvement, and donations have all declined, putting our future at risk. Now more than ever, we need your help to sustain and expand our work.

As a self-funded organization, we rely entirely on contributions, fundraising efforts, and partnerships. Without government funding, we must secure resources to cover our operating costs and meet the increasing needs of the people we support. We've been operating with the same administrative budget since 2014, despite rising demands for our services. **Without additional funding, we may face the tough decision of reducing critical services that so many rely on.**

*"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.*



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.

# 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.

**"Mobility is an indispensable gift for most living creatures, everybody has the right to move and be independent. Dystonia and other movement disorders constantly threaten mobility and research still has a lot to do to find better treatments and eventually a cure."**

**DR. ALFONSO FASANO**



### 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

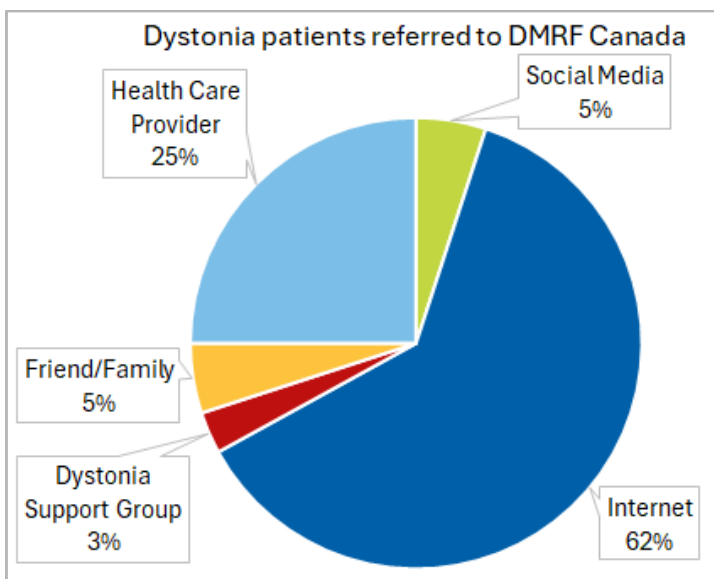
Enhance understanding of dystonia within the general public and medical community through ongoing campaigns, such as illuminating landmarks during awareness month and engaging in public relations initiatives, including media interviews.

### 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

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

**Call:** (416) 488-6974

**Toll Free:** (800) 361-8061

**Email:** [info@dystoniacanada.org](mailto:info@dystoniacanada.org)



## Find us on social media

[dystoniacanada.org/social-media](http://dystoniacanada.org/social-media)



○ IT FOR THE ONES NOT YET DIAGNOSED  
○ IT FOR THE DYSTONIA THRIVERS  
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