

May 2025

Re: Partnership of Freedom to Move: Run, Walk, and Wheel for Dystonia 2025

To whom it may concern,

The Dystonia Medical Research Foundation (DMRF) Canada is a registered national charitable organization, founded in 1976, dedicated to supporting individuals and families affected by **dystonia—a debilitating neurological movement disorder** that affects over **50,000 Canadians**. Our mission is to **advance research, promote awareness and education, and support the well-being of those living with dystonia**.

Dystonia is not only disabling—it is often severely painful. According to [Statistics Canada](#), **53% of individuals with dystonia experience chronic pain**, far exceeding rates for migraine, stroke, multiple sclerosis, and muscular dystrophy, and well **above the 36% average for all neurological conditions**. In the absence of government support, community support is required close critical care gaps and improve the quality of life for thousands.

We invite you to support our **Freedom to Move: Run, Walk, and Wheel for Dystonia** which is more than a fundraiser—it's a national movement rooted in **compassion, inclusion, and empowerment**. Your support will help improve the lives of Canadians living with dystonia while supporting a **sustainably executed, community-driven event**. The campaign will run **virtually across Canada from June 1–30**, with a few **in-person events across Canada**.

In 2024, thanks to dedicated supporters across **seven provinces**, Freedom to Move raised over \$50,000, directly supporting **research, patient education, and support services**. Since its inception, the initiative has raised over **\$1 million** for dystonia-focused programs.

This year, we're proud to **co-host our Toronto event on June 8th with Hydrocephalus Canada**, a registered health charity serving individuals with hydrocephalus and spina bifida. This collaboration allows us to amplify our reach, enhance efficiencies, and unite the voices of communities affected by neurological disorders, while also reducing our environmental footprint by sharing resources, minimizing duplication, and streamlining operations—creating a more sustainable and impactful event for both communities.

We would appreciate any contributions by way of **corporate donations or prize contributions**. If you have any questions, please feel free to reach out to me directly at archanacastelino@dystoniacanada.org.

Thank you for considering this opportunity to support Canadians living with dystonia.

Sincerely,



Archana Castelino
National Director, DMRF Canada

Dystonia Medical Research
Foundation (DMRF) Canada Presents



Your Race, Your Way



Virtually June 1-30th 2025
In person June 8th 2025 at
Downsview Park, Toronto



DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

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



Charitable Registration Number 12661 6598 RR0001

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DMRF Canada Board Member, Casey Kidson-Reid completed her 2024 Virtual Freedom to Move race on the Rocky Mountains in Banff, AB

ABOUT DMRF CANADA

The Dystonia Medical Research Foundation (DMRF) 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 Mission

The mission of DMRF Canada 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.

Our success is driven by the strength of our community. With a small but mighty team of just three full-time staff, we proudly serve every province and community across Canada. Supported by over 50 dedicated volunteers, they are the heartbeat of our mission, tirelessly advancing our cause.



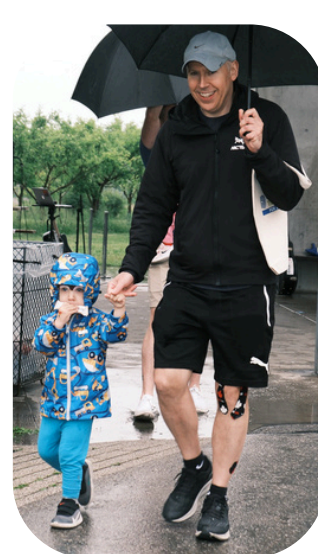
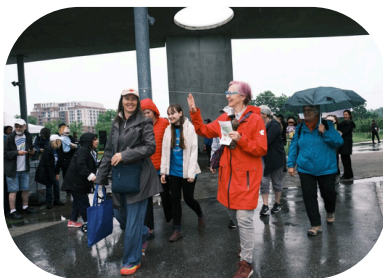
DMRF Co-Founder, Frances Belzberg with 2023 Freedom to Move Ambassador, Jirome De Castro



Board Member, Catherine Mulkins, welcomes the crowd at the 2024 Toronto event.

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



Individuals with dystonia
are more likely to experience anxiety
and depression than the general
population, and at higher rates
than individuals with other
chronic disorders



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



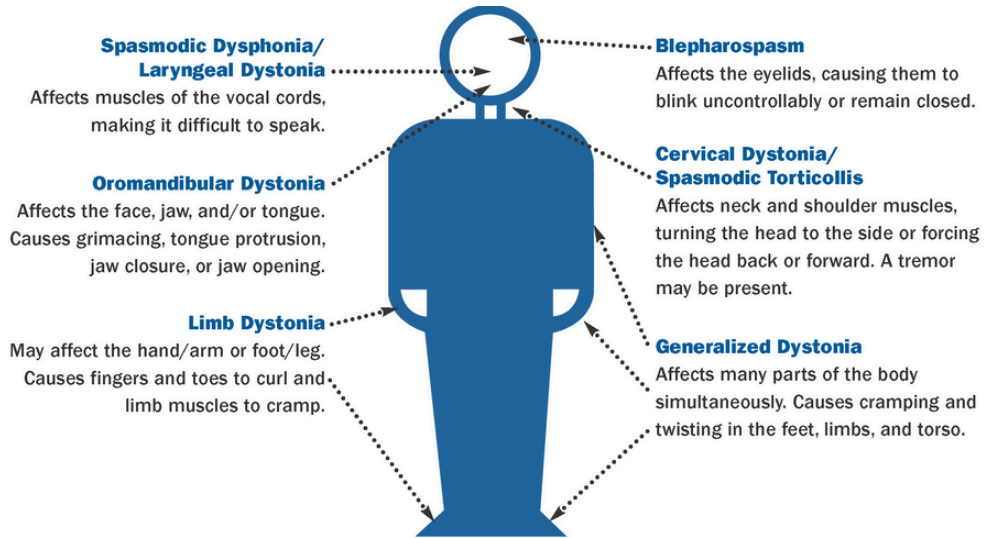
2/3 of survey
respondents waited
1+ year for
diagnosis due to
long wait times or
misdiagnosis



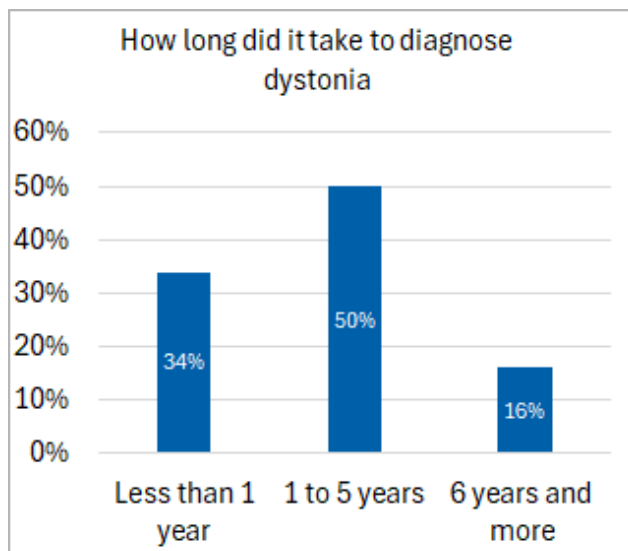
Men, women and
children of all
ages and
backgrounds are
affected

WHAT IS DYSTONIA?

Dystonia is a complex and often painful neurological movement disorder that disrupts lives with repetitive muscle contractions, causing tremor-like movements or twisting into abnormal postures. There are various types of dystonia, each with its own distinct causes and characteristics.



Source: Understanding Dystonia Factsheet by DMRF



Source: DMRF Canada Survey 2019

Dystonia can impact any part of the body. Patients endure chronic pain, uncertainty, and distress, with many finding no effective relief. For those affected, even simple tasks can feel overwhelming with each movement serving as a challenge.

Dystonia's complexity and the long journey to diagnosis are major challenges. Misdiagnosis and wait times of 6 months to 3 years to see a specialist can delay diagnosis by 1 to 10 years. Even after diagnosis, treatment is often delayed due to the need for assessments and limited treatment options.

Our 2017 *Real Patients, Real Answers* Survey found that 41% of dystonia patients experience depression, with 32% citing mental health as their primary challenge—an issue even more pronounced in remote communities with limited access to specialized care.

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.



"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

FREEDOM TO MOVE

Freedom to Move (FTM): Run, Walk and Wheel for Dystonia is the Foundation's flagship community event taking place throughout June 2025. The annual event remains the organization's largest fundraiser and in-person awareness event. Participants will complete a walk, run, or wheel either virtually between June 1st - 30th anywhere in Canada or at our Toronto in-person event site on June 8th at Downsview Park.

Our community's involvement is crucial to the success of Freedom to Move. Having the option to participate virtually encourages people to support the dystonia community and expand their social impact within their networks to help maximize awareness and research funding for dystonia.



WHY WE NEED YOUR HELP

To turn our vision into reality, we need dedicated partners. As a self-funded organization with no government support, we rely on the strength of our remarkable community, including our partners, to cover costs and meet growing demands. Our efficiency has brought our administrative costs back to 2015 levels, but without additional funding, we risk cutting back essential services.

The need for specialized care is urgent. A 2022 Parkinson Canada study reveals that fewer than 80 neurologists in Canada specialize in movement disorders like dystonia. With 50,000 Canadians affected by dystonia—alongside countless others with movement disorders—there is a critical need to invest in training more specialists, reducing wait times, and expanding treatment options. This is not just a call for research funding, but for immediate action to address the care gap.

Partnering with Freedom to Move highlights your commitment to inclusivity and equity. Dystonia affects people of all ages, races, and genders, with varying levels of disability. Your support helps bridge gaps in access to care, advance research, and raise awareness for this diverse community. By supporting Freedom to Move, you champion Diversity, Equity, and Inclusion (DEI) and help build a future where everyone, regardless of background or ability, has the freedom to move. Together, we can build a future where dystonia is no longer an obstacle.

FTM Celebrations & Investing in a Dystonia-Free Future

Over the past 40 years, the dystonia community’s Toronto walk has raised over \$1 million, fueling significant advancements in research and providing essential support for those affected. The event’s greatest impact is that every dollar raised goes directly into services, support, and crucial dystonia research funding. Research is vital as it drives the discovery of better treatments and ultimately a cure, while support services improve the quality of life for those living with the disorder.

In 2024, FTM attracted participants, sponsors, and donors from 31 cities across Canada, raising \$50,000 for critical dystonia research and essential support programs. Beyond the live event, our online presence was equally remarkable, with over 3,000 visitors to our registration site and significant engagement on social media, achieving more than 7,000 impressions.

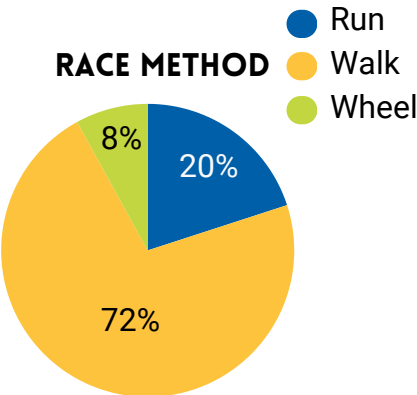
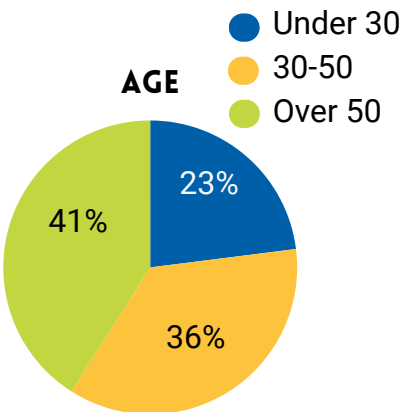
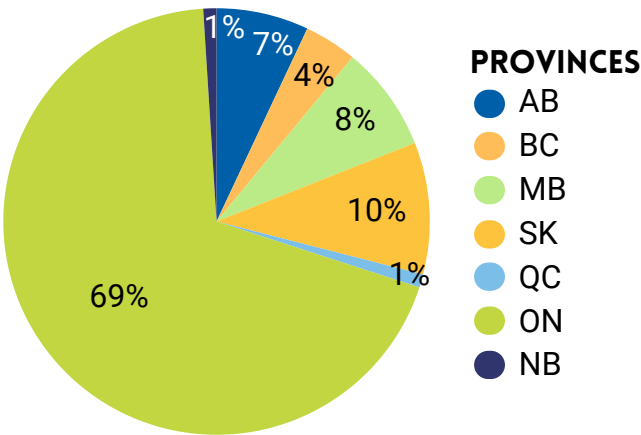


Jirome De Castro, our 2023 Freedom to Move ambassador, was diagnosed with cervical dystonia in 2015. He competes in marathons and triathlons, donating all funds raised towards improving the lives of others with dystonia.

Freedom to Move provides a special opportunity to connect with others in the dystonia community; something that has been deeply important to Jirome ever since his diagnosis.

Our Community

Our participants are a diverse group, with a large contingent of Ontario-based walkers over 50. In addition to our dedicated team, the event is supported by dystonia ambassadors, support group leaders, patients, families, healthcare professionals, and advocates. This committed community helps raise funds and advance the mission of DMRF Canada, offering brands a unique opportunity to connect with a passionate audience.



To find out more on our Freedom to Move 2024 accomplishments, please scan this QR code to watch our recap video!

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THANK YOU FOR CONSIDERING A PARTNERSHIP WITH US. YOUR SUPPORT WILL HELP DRIVE VITAL PROGRESS FOR THOSE AFFECTED BY DYSTONIA.

For further details please contact:
National Director, Archana Castelino
info@dystoniacanada.org | 1-800-361-8061



Contact DMRF Canada

Visit: www.dystoniacanada.org

Call: (416) 488-6974

Toll Free: (800) 361-8061

Email: info@dystoniacanada.org



Find us on social media

dystoniacanada.org/social-media



○ IT FOR THE ONES NOT YET DIAGNOSED
○ IT FOR THE DYSTONIA THRIVERS
○ IT TO RAISE AWARENESS
○ IT TO FIND A CURE!

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

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