

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

Fall 2021

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DMRF Co-Founder, Frances Belzberg was recently appointed to the Order of British Columbia.

PLEASE RENEW YOUR MEMBERSHIP

Support the dystonia community with a donation to DMRF Canada.

visit: www.dystoniacanada.org/donate

Thank you for your support.

Foundation Update

Dear Friends,

This year marks the 45th anniversary of the founding of the Dystonia Medical Research Foundation (DMRF). This milestone provides an opportunity to reflect on our accomplishments over the years. Most importantly, the DMRF brought dystonia out of obscurity and into the spotlight of neuroscience and movement disorders research.

Thanks to our generous supporters, we continue to better understand dystonia with every new research discovery. We work to build awareness in our community, to policymakers, institutions, and the general public. Over the past 45 years, DMRF has helped light a path forward for individuals and families facing a diagnosis. No one has to face dystonia in the dark, alone.

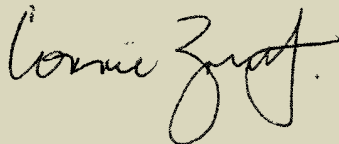
We are proud of the research that we have supported and the community that we have built, but this 45-year milestone is not an occasion we celebrate. We continue to work hard to meet our mission so that one day, we can close our doors for the right reasons: because a cure is discovered, and no person is ever burdened by dystonia.

Thanks to the commitment of generous friends who continue to support our service to the community, we know that day is coming. On behalf of all of us at DMRF Canada, we thank you for your continued trust and faith in our work.


Sincerely,



Connie Zalmanowitz,
Chair, DMRF Canada
Board of Directors

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

Archana Castelino,
National Director

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 with your physician about the procedures and treatments mentioned herein.

Samuel Belzberg 6th International Dystonia Symposium Rescheduled

Due to Covid, the Samuel Belzberg 6th International Dystonia Symposium in Dublin, Ireland has been rescheduled for June 1–3, 2023. The scientific meeting is named for DMRF Co-Founder Samuel Belzberg who sadly passed away in 2018. Co-Chairs are H. A. “Buz” Jinnah, MD, PhD of Emory University School of Medicine and Antonio Pisani, MD, PhD of University of Pavia. The symposium is a joint effort of Dystonia Europe and the DMRF. The program is designed for clinicians and investigators to provide a comprehensive overview of important scientific advances in the field and stimulate discussion within and across disciplines. **The International Dystonia Symposium is the seminal international dystonia meeting for investigators and clinicians, dating back to 1975.**

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Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation (DMRF) Canada is a registered Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRF Canada funds medical research toward a cure, promotes awareness and education, and supports the well-being of affected individuals and families. We work in partnership with the DMRF in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and with other like-minded research organizations to fund excellent dystonia research in Canada.

Board of Directors

Samuel Belzberg
Co-Founder
1928 - 2018

Frances Belzberg
Co-Founder & Honorary Chair

Connie Zalmanowitz
Chair

Pearl E. Schusheim
Secretary/Treasurer

Directors

Dennis Kessler
Casey Kidson
Rosalie Lewis
Catherine Mulkins

DMRF Co-Founder appointed to the Order of British Columbia

DMRF's Co-Founder, Frances Belzberg, was one of sixteen exceptional people appointed to the Order of British Columbia, the province's highest form of recognition, Lt. Gov. Janet Austin, chancellor of the order, has announced.



"Each one of this year's Order of British Columbia recipients has made tremendous contributions to their communities," said Premier John Horgan. "I want to extend my congratulations and honour them for their leadership and dedication as community leaders. We are all truly grateful for your leadership."

This year, 257 British Columbians were nominated. Since its inception, 475 British Columbians have been appointed to the Order of B.C. Members have been appointed from all regions of the province and in numbers generally proportionate to a region's population.

Ms. Belzberg was nominated by the Jewish Federation of Greater Vancouver in recognition of the significant contributions she has made to the neurological subspecialty of movement disorders and the dystonia community.

DMRF Canada is thrilled that Fran's establishment of the DMRF, as well as her continued passion and dedication to raising funds towards a cure for dystonia, have been recognized. "On behalf of the DMRF Canada Board of Directors, we congratulate Fran on this incredible achievement, and we applaud her tireless efforts to help those living with dystonia to live their best lives," said DMRF Canada Chair, Connie Zalmanowitz.

To learn more about the Order of British Columbia and this year's appointments, visit: www.dystoniacanada.org/news/FrancesBelzberg

In Tribute

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

Ines Albarracin Frances Kennedy Donald O'Malley
Stasia Hilder Pearl Mitchell
Elizabeth Ann Jackson Bertha Mosa



Thank You for Your Support

Donations should be sent to:
Dystonia Medical Research Foundation Canada
550 St. Clair Ave West, Suite 209,
Toronto ON, M6C 1A5
www.dystoniacanada.org/donate

Dystonia Research: You Can Have a Global Impact

Dystonia Coalition update:

The Dystonia Coalition is a collaboration of medical researchers and patient advocacy groups that are working to advance the pace of clinical and translational research in dystonia to find better treatments. Principal Investigator H. A. 'Buz' Jinnah, MD, Ph.D., recently provided an update on the activities and accomplishments of the Coalition and the significance of this research for the patient community. A recording of this is now available for viewing at www.dystoniacanada.org/dystonia-coalition.

DMRF Canada updates our website regularly with new research articles.

Visit: www.dystoniacanada.org/latest-dystonia-research-news

You Can Help Shape Dystonia Research - Sign Up Today!

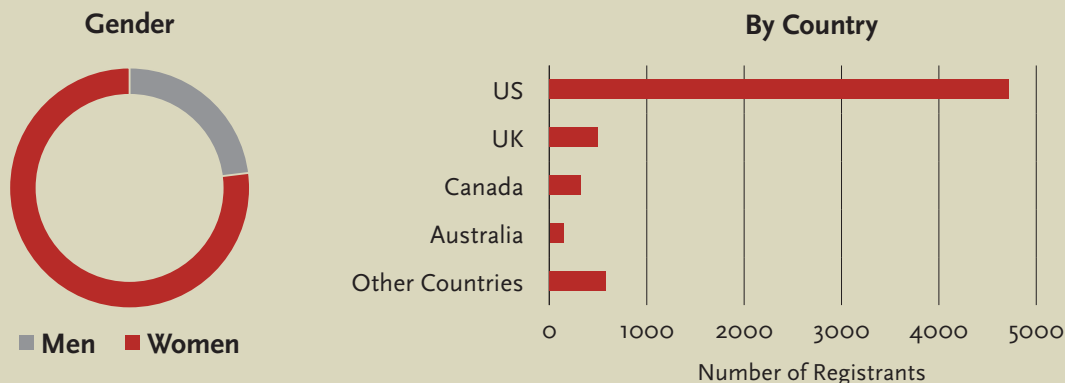
So far only close to **1,000 people** with dystonia in Canada have registered with the Global Dystonia Registry.

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 to learn more and register.



- Launched December 2011 with currently over 6,100 people registered
- Owned and managed by the Patient Advocacy Groups
- Scientific Committee reviews requests
- Voluntary and compliant with all privacy laws
- 90 countries represented with highest percentages in US, UK, Canada and Australia



www.globaldystoniaregistry.org

Research Update: 2021 Grants & Research Fellowships

DMRF Canada is dedicated to advancing research for more treatments and, ultimately, finding a cure for dystonia. Our aim is to support the best and brightest minds in the field, both in Canada and internationally. Working with our sister organization, the DMRF in the US, DMRF Canada supports various research projects. Below are the latest research projects that have been funded by the DMRF.

GRANTS & CONTRACTS

Genetic Modifiers of Penetrance in DYT₁ Dystonia – 2nd Year

David Arkadir, MD, PhD

Hadassah Medical Center and Hebrew University of Jerusalem

Normalizing DYT₁ Cholinergic Neurons by CRISPR Disruption of Mutant TOR1A Allele

Xandra Breakefield, PhD

Massachusetts General Hospital

A Next Generation Sensing Neural Interface Study for Adaptive DBS in Dystonia

Simon Little, MBBS, MRCP, PhD

University of California, San Francisco

The Role of Cholinergic Neurons in Isolated Focal Cervical Dystonia – 2nd Year

Scott Norris, MD

Washington University School of Medicine

Role of Cerebellar Network Excitability and Plasticity in the Pathophysiology of Dystonia

Antonio Pisani, MD

University of Pavia

Targeting the cAMP Pathway in the Striatum to Treat Dystonia

Emmanuel Roze, MD

Paris Bain Institute

Connie and Jim Brown Early Stage Investigator Award Cerebellar Repetitive Transcranial Magnetic Stimulation in Monogenic Myoclonus-Dystonia

Anne Weissbach, MD

University of Lubeck

RESEARCH FELLOWSHIPS

Investigating Abnormal Neurodevelopment in a Novel in vivo Model of Inherited Dystonia

Simon Lowe, PhD

University College London Institute of Neurology

Neural Signals in the Cerebellar Nuclei Gate the Manifestation of Dystonia-like Symptoms

Meike van der Heijden, PhD

Baylor College of Medicine

Non-invasive Neuromodulation to Study Long-term Plasticity Mechanisms in Task-specific Dystonia

Noreen Bukhari-Parlakturk, MD, PhD

Duke University School of Medicine

Immune Mechanisms in Cervical Dystonia

Laura Scorr, MD

Emory University School of Medicine

Please visit:

www.dystonia-foundation.org/research/current-projects/ for details on each project.

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TorsinA Restoration in DYT₁ Dystonia Model Identifies a Critical Therapeutic Window



A protein in the brain called TorsinA is known to cause childhood onset dystonia when it cannot function properly due to genetic changes in the DYT₁/TOR1A gene. This makes TorsinA a possible target for new treatment approaches. Numerous research teams across the world are investigating whether restoring normal TorsinA function could be an effective strategy to reverse or even prevent dystonia.

One of the most notable aspects of DYT₁/TOR1A dystonia is that symptoms typically begin during a very specific age window, approximately 9–12 years of age. Even if a person has the DYT₁/TOR1A gene variant, if they reach age 30 without developing symptoms, they almost never develop dystonia. This suggests there is something about the young developing brain that makes it vulnerable to dysfunctional TorsinA.

William Dauer, MD, Director of the Peter O'Donnell Jr. Brain Institute and Professor of Neurology and Neuroscience at UT Southwestern Medical Center, led a study to specifically test whether TorsinA function is uniquely necessary during a critical neurodevelopmental period, and whether genetic rescue is similarly only possible during a specific period of brain development. To rigorously address these questions, he and his team developed a series of experiments in mice. They found that embryonic suppression of TorsinA caused dystonia-like motor symptoms and observable changes in the brain. By contrast, TorsinA suppression in adult mice caused no apparent abnormalities. Furthermore, the ability to correct the TorsinA dysfunction and reduce dystonia symptoms was only possible during specific periods of brain development. Restoring TorsinA expression in young symptomatic mice reversed the abnormal movements and changes in the brain. By contrast, restoring TorsinA expression in adult mice had no effect. These important findings demonstrate that normal TorsinA function is critical to early brain development and suggest that TorsinA-based therapeutics may need to be targeted early in the course of DYT₁/TOR1A dystonia.

Dr. Dauer is a past DMRF grant recipient and past member of the Medical & Scientific Advisory Council.

Li J, Levin DS, Kim AJ, Pappas SS, Dauer WT. TorsinA restoration in a mouse model identifies a critical therapeutic window for DYT₁ dystonia. *J Clin Invest.* 2021 Mar 15;131(6):e139606.

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DMRF Launches First Scientific Journal Dedicated to Dystonia

The DMRF has partnered with Frontiers Media to launch *Dystonia*, an open access journal. The journal will bring visibility to the growing dystonia field and highlight advancements in science and clinical practice. This is the first scientific journal exclusively dedicated to dystonia and a major milestone for the dystonia scientific community.

Up until this point, dystonia studies have been published in various neurology and neuroscience journals. Since the beginning of 2020 alone, more than 1,600 dystonia papers have been scattered across the medical literature. On average, three new dystonia papers are published every day. *Dystonia* provides a centralized, go-to publication by and for dystonia investigators. It is Gold Open Access, which means the content is available to the medical community and public at no charge to readers.

Manuscripts are being accepted now at frontierspartnerships.org/journals/dystonia. The journal is partially supported by the Joan Miller Young Investigator Fund and Tuft Family Foundation.

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Shelby Newkirk, 2021 Freedom to Move Ambassador and Team Canada swimmer for the 2020 Tokyo Paralympics

“Thank you! Together we accomplished something incredible. We came together as a community, despite our physical challenges, to raise funds and awareness for dystonia. We simply could not have done this without you, and for that, I am so grateful.”

The Power of You:

Raising Awareness and Funds for Dystonia

Once again, the dystonia community has come through to show that we are motivated and mighty! DMRF Canada is pleased to share that once again, you have made a difference in the lives of people living with dystonia by walking, running, biking, and moving for this year’s Freedom to Move event, which took place over the entire month of June.

Close to 200 people came together from 8 provinces across the country to raise close to \$70,000 for dystonia research and support programs.

In addition to raising much-needed funds, this year’s Freedom to Move also provided the opportunity to build awareness of dystonia through social media and community outreach. Special thanks to dystonia advocates Ellis Siliker, Nedeem Bazley, and Debbie Bauer for their work on obtaining press coverage in various publications.

On behalf of DMRF Canada Staff, our Board of Directors, and the 50,000 Canadians who have dystonia, thank you for your incredible dedication to making this year’s event a success!

Visit www.dystoniacanada.org/freedomtomove to view pictures from this year’s event.

With Thanks to Our Top Fundraisers

Special thanks to the following individuals who were our top fundraisers, raising a combined total of over \$20,000.

1. D. Backer of Team Greater Sudbury;
2. M. Guy of Team Greater Sudbury;
3. F. Mazzella of Team Franco’s Dystonia Busters.

*With Thanks to Our Sponsors
for their Generous Support*



Announcing: Jackson Mooney Patient Grant Award Recipients 2021

DMRF Canada is pleased to announce the recipients of the 2021 Jackson Mooney Patient Grant for Dystonia (JMPG). This annual grant, established by Jackson and Jefferson Mooney, aims to provide financial assistance of up to \$5,000.00 for Canadian residents living with dystonia in financial need and committed to enhancing their current situation through furthering their education.

This year, the JMPG Committee opted to provide funding for education to two very worthy candidates:



Emily Ives

“This grant means so much to me and has given me the opportunity to turn my dream of furthering my education into a reality. With the support of the Jackson Mooney Patient Grant, I hope to use my passion to create a more inclusive world.”

Emily Ives was diagnosed with generalized dystonia at the age of 14; however, she began experiencing her dystonia symptoms at the age of 11 when she was misdiagnosed with scoliosis. A grade 12 student living in Saskatoon, SK, Emily has always been passionate about fashion and design. “I have always been creative and loved fashion for as long as I can remember. When I was diagnosed with dystonia, I started putting more time into designing and sewing garments as a positive outlet.”

After Emily graduates high school, she will be attending Ryerson University to obtain a bachelor’s degree in design. Emily intends to build a career around her mission to create a more inclusive and sustainable fashion industry. The JMPG Committee was inspired by Emily’s dedication to her passion for design, despite her diagnosis, and was delighted to be able to help her with her goal.



Laura Fréreau

“I feel so fortunate to have this support from the dystonia community as I begin a new chapter with my graduate research. Thank you to the Mooney family and the Dystonia Medical Research Foundation.”

Laura Fréreau is an Occupational Therapist (OT) living in Montreal, Québec, with her partner and children. She was diagnosed with paroxysmal dystonia after years of experiencing symptoms in her hands while performing certain tasks. Since that time, her symptoms have escalated, and now she has more severe episodes that also affect speech, coordination, and ongoing involuntary twisting movements.

Accepting that she was no longer able to practice as an OT full time, due to the nature of the work worsening her symptoms, Laura decided to pursue doctoral studies in rehabilitation science, researching the role of OT in supporting patients during long diagnostic delays. Laura begins her first course at McGill University in September 2021. The JMPG Committee is pleased to support Laura in this exciting new chapter of her career.

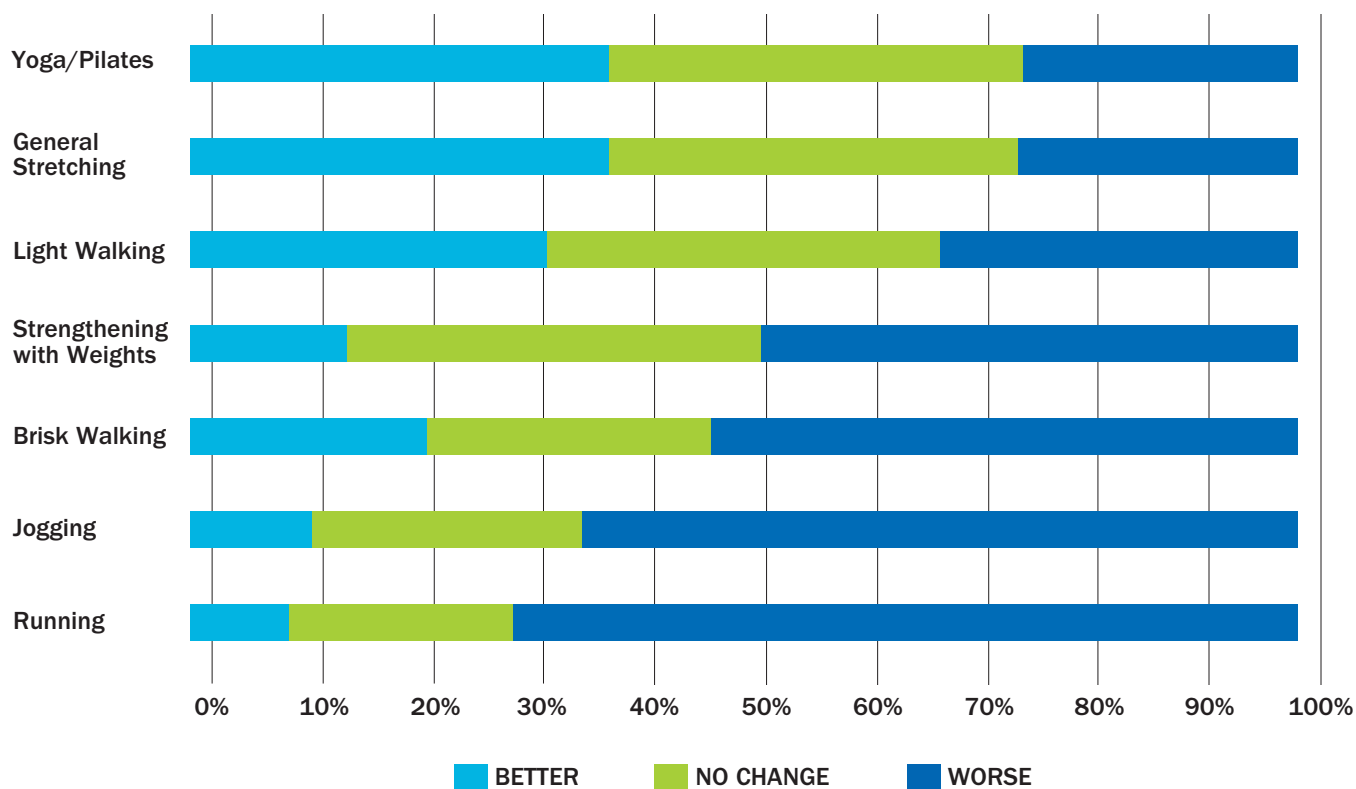
DMRF Canada is grateful to Jefferson and Jackson Mooney and the JMPG Committee for their dedication to supporting this initiative. We also wish to thank those of you in the community who continue to support our mission. **Thanks to your support, we can offer this support to the community and encourage everyone in our network to pursue their best life with dystonia.**

To learn more about the Jackson Mooney Patient Grant, as well as the details for the 2022 grant, visit: www.dystoniacanada.org/dystoniapatientgrant

High Impact Exercise More Likely to Worsen Dystonia

The benefits of exercise and physical activity for neurological disorders is well-known. Individuals with dystonia may experience numerous barriers to healthy levels of exercise, including the fact that physical activity sometimes worsens dystonia symptoms. A team of exercise scientists and physical therapy experts at University of Auckland in New Zealand conducted a survey of 260 dystonia patients about physical activity and barriers to exercise. The survey revealed that lower intensity exercise, such as light walking and general stretching, were among the least aggravating for dystonia symptoms.

This table shows the percentage of survey participants who answered 'better' (bright blue), 'no change' (green), and 'worse' (dark blue) for each activity. Higher impact exercise tended to worsen dystonia, while low impact exercise may be beneficial, or at least not aggravating, for two-thirds of dystonia patients.



McCambridge A, Meiring RM, Bradnam LV (2019) Physical activity, sedentary behavior, and barriers to exercise in people living with dystonia. *Front Neurol* 10:1121

Bradnam, L.V., Meiring, R.M., Boyce, M. et al. Neurorehabilitation in dystonia: a holistic perspective. *J Neural Transm* (2020).

For tips on increasing physical activity visit: www.dystonia-foundation.org/benefits-of-exercise/

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Resources and Support for the Community

More Than Twisting: An In-Depth Look at the Non-Motor Symptoms of Dystonia

“Health professionals are starting to recognize that symptoms like social anxiety, low mood, disrupted sleep, pain, and fatigue can impact the quality of life of people with dystonia just as much as, or sometimes even more than, uncontrollable movements and postures. Recognizing this, however, is just the beginning. It’s time now to start discussing new management plans.” - Dr. Davide Martino.

DMRF Canada is fortunate to work with Dr. Davide Martino, Ph.D. MD, Director of the Movement Disorders Program at the University of Calgary. Dr. Martino has been a dedicated advocate and supporter of the dystonia community for more than a decade.

Over the past few years, Dr. Martino has shared thoughtful insights and research findings on the non-motor symptoms of dystonia at various educational conferences and webinars that included topics such as stress and anxiety, sleep disturbances, and depression.

Dr. Martino continues to support the community by working to advance and encourage a more comprehensive approach to treating dystonia. He is even working on a new research proposal that would aim to bridge gaps in healthcare provisions, building a case for a more integrated model of care for the dystonia community.

As a way to bring the dystonia community up to date on Dr. Martino’s research, DMRF Canada will be offering a new webinar that will focus on the non-motor symptoms of dystonia.

“More than Twisting: An In-Depth Look at the Non-Motor Symptoms of Dystonia” will be presented on November 9, 2021.

This webinar will include a Q&A with the community and will cover important topics, including:

- Data to support the various ways that patients experience the non-motor symptoms of dystonia.
- Details on the most common non-motor symptoms and possible treatment for these symptoms.
- Recommendations for improving quality of life, despite a dystonia diagnosis.

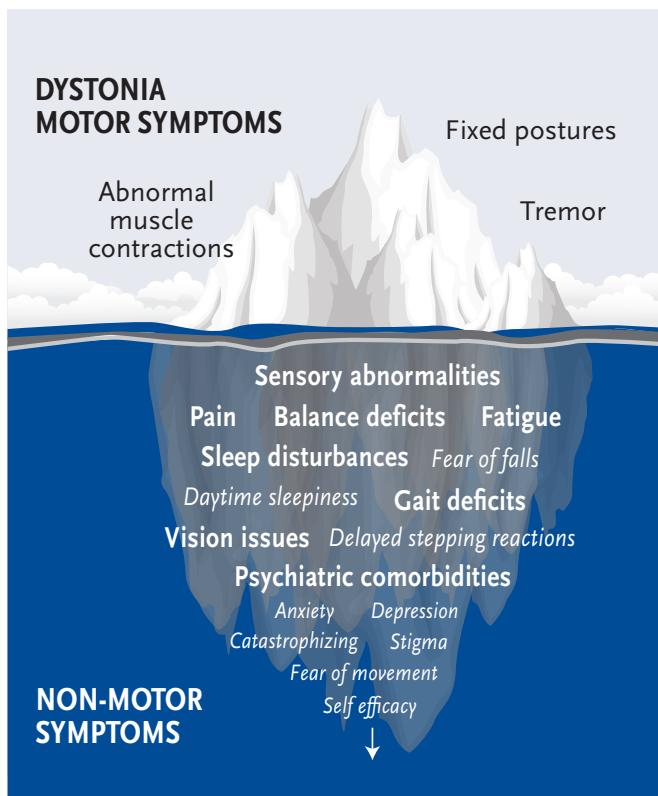


Image adapted from a figure in Bradnam, L.V., Meiring, R.M., Boyce, M. et al. Neurorehabilitation in dystonia: a holistic perspective. *J Neural Transm* (2020).

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To learn more about this significant educational program and for additional information on how you can live well with dystonia.

visit www.dystoniacanada.org/livingwellseries

To participate in a virtual study on pain in adult-onset idiopathic dystonia by Dr. Bruno and Dr. Martino from the University of Calgary.

visit www.dystoniacanada.org/clinical-trials-for-dystonia



Mental Health Resources for Dystonia

Dystonia can be a painful and challenging disorder to live with. Managing the day-to-day challenges can seem overwhelming. To better serve the dystonia community with the resources they need, we've updated our mental health resources page to provide more information on crisis warning signs and the number for the Canada Suicide Prevention Service: 1-833-456-4566. If you, or a loved one, are experiencing a crisis, please do not hesitate to call 911.

For more information, **Visit:** www.dystoniacanada.org/mental-health-resources

New Online Resources

Dystonia Podcast in the Works

“As an athlete with dystonia, I was inspired by those also thriving with dystonia. I want to use this podcast as a way of bringing those with dystonia a little closer together despite being miles apart.”

Dystonia thriver Casey Kidson is at it again. Many of you will be familiar with Casey – she is the Founder of Dyfying Dystonia; and is a proud champion, advocate, and ambassador for living well with dystonia, through fitness and positivity - and someone who is a wonderful source of inspiration for the community.

We are thrilled to share that Casey has a new project – one that will serve to educate, inspire, and empower the community – she will be launching her podcast in mid-September 2021! Entitled; “Dyfy the Storm”, Casey aims to share stories of courage, passion, and athletic endeavours demonstrated by individuals from around the world with dystonia to continue to raise awareness for dystonia and inspire others by showing them that despite some challenges and limitations, anything is possible.

For more details on what Casey has been up to, visit: www.dystoniacanada.org/dyfying-dystonia-series

Dystonia Thrivers Channeling their Creative Pursuits

We are grateful to the many inspiring individuals that have directed their unique life experiences into creative endeavours. There are many in the community who are published authors and professional musicians. To help highlight these individuals and celebrate their achievements, our website now features a catalogue of their work. **Visit** www.dystoniacanada.org/arts

Peer Resource for Musicians

Thank you to the DMRF for creating a private peer support group on Facebook for musicians affected by dystonia. Musicians with Dystonia Support Forum: facebook.com/groups/musiciansdystonia



Dystonia Moves Me – September is Dystonia Awareness Month

It's that time of year again! DMRF Canada is proud to announce that September is Dystonia Awareness Month in Canada and the US. We will be leading dystonia awareness initiatives across Canada throughout the month and beyond.

Greater awareness of dystonia can lead to a faster diagnosis process and more research into the disorder that could lead to a cure.

Here is What You Can Do to Support Our Efforts:

- **Promote Dystonia Awareness Through Social Media:** Post, tweet, message, and promote dystonia awareness using #dystoniamovescanada #dystoniamovesme #dystoniaawareness to your networks.
- **Check Out Local Landmarks:** We're lighting up Canada in blue and white! If you see a local landmark on the list, please take a picture and tag us on social media! **Visit:** www.dystoniacanada.org/dystoniaawarenessmonth for a listing of landmarks and dates.
- **“Do It for Dystonia” this Awareness Month:** Have a birthday coming up or a hobby or particular interest you love doing? It is time to let yourself shine. Through “Do It” you can host your own fundraiser while raising much-needed awareness for dystonia. **Start your campaign today:** www.dystoniacanada.org/doit
- Jennifer Ashton, 2020 Jackson Mooney Patient Grant co-recipient and author, has decided to donate proceeds from her E-book, *People like Frank and Other Stories from the Edge of Normal* to DMRF Canada and Dystonia UK from September 1 - 7.

For a complete listing of awareness activities, **please visit:** www.dystoniacanada.org/dystoniaawarenessmonth

Dystonia Awareness Month

Dystonia
MOVES ME

www.dystoniacanada.org

Dystonie Partage Update

Congratulations to French Montreal (Dystonie Partage) Support Group Leader, Chantale Boivin, for being named a co-recipient of the Neurological Health Charities Canada (NHCC) Change Maker Award 2020. She has been hard at work organizing meetings and information sessions for the French-speaking dystonia community in Quebec. Thank you to Chantale and the volunteers of Dystonie Partage for their support!

Read Chantale's story here: www.dystoniacanada.org/changemakers

This Dystonia Awareness Month, Dystonie Partage and Neuromotrix will offer adapted physical activity sessions in french (virtually) for people living with dystonia. Preference will be given to residents of Quebec! Thanks to Allergan: an AbbVie company, and Merz Therapeutics for their support of this program.

To learn more about these activities, please visit: www.dystoniacanada.org/montreal



Shape the Future of Dystonia Research – Sign Up for the Legacy Society

DMRF Canada established the Legacy Society to acknowledge those who have made a lasting commitment to supporting dystonia research by naming DMRF Canada in their estate plans.

Planned gifts are contributions that are committed in the present but given in the future. Planned gifts may offer a variety of benefits to donors, including flexibility and tax savings. They often enable individuals or families to contribute more generously to DMRF Canada than traditional donations. For example, one of the easiest options is to remember DMRF Canada in a will.

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

Wills and Bequests

Bequests are the simplest of planned gifts. Just one sentence is all that is required to include DMRF Canada in your will.

A bequest is simply a statement in a Will that stipulates a gift to an individual or organization. All donations—including bequest gifts - will enable DMRF Canada to continue to move forward in its mission to find a cure and to serve those affected by this debilitating disorder.

Life Insurance

You can name the DMRF Canada as the primary beneficiary of part or all of

your life insurance policy. Ask your insurance professional to help you make the Foundation your beneficiary.

When making your gift, please note that the legal name of the DMRF Canada is “the Dystonia Medical Research Foundation Canada.”

For more details on estate planning, **please visit:** www.dystoniacanada.org/legacy

DMRF Canada Legacy Society Honours Visionary Donors

A special thank you to long-time DMRF Canada supporters and former Winnipeg Support Group Leaders, Barbara and Brian Crow, for establishing a Trust to support DMRF Canada. Through the Trust, an annual gift will be made to assist with our dystonia support programming and invest towards DMRF Canada’s future service to the dystonia community.

If you would like to join the Legacy Society and receive more information on planned giving options, complete and return the back page in this newsletter, or please get in touch with National Director, Archana Castelino at archanacastelino@dystoniacanada.org



SENSORY TRICKS BY DYSTONIA TYPE

Here are noted examples of sensory tricks, not an exhaustive list.

Cervical Dystonia

- Touching specific parts of the face, cheek, temple, nose, behind the ear, back of the head, back of the neck
- Raising the arm and holding finger near the sensory trick spot without touching face • Visual focus on a specific target, focusing on a stationary object while walking
- Looking in the mirror
- Resting the back of the head or neck
- Resting the back or shoulder
- Bending forward
- Wearing a collar or scarf
- Leaning elbows on armrest
- Yawning

Blepharospasm

- Tight goggles or glasses
- Lundie Loop attachments on glasses
- Touching or pulling on eyelids
- Tape on eyebrows
- Touching specific parts of forehead, nose, side of eyelids, chin
- Pushing back head
- Massaging cheek bones, eyelid, forehead
- Closing the jaw, chewing gum
- Covering the eyes
- Picking teeth
- Wearing a cap or turban

Blepharospasm + Oromandibular Dystonia (Meige Syndrome)

- Talking, singing/ humming
- Pulling on upper eyelid
- Pinching back of neck
- Yawning
- Belching
- Sucking in or blowing air
- Drinking cold beverage

Lower Cranial Dystonia/ Oromandibular Dystonia

- Toothpick in mouth
- Holding object clenched in teeth
- Dental splint
- Touching lip
- Touching lower face
- Touching tongue to top of mouth
- Biting lips
- Swallowing
- Tilting head forward
- Chewing gum
- Sucking, whistling, kissing
- Pen/cigarette/tongue depressor in mouth
- Biting food or plastic between back teeth, dental prosthetic
- Singing, talking
- Thinking about talking
- Playing instrument with larger mouthpieces
- 5 minute ice massage of facial muscles

Laryngeal Dystonia/ Spasmodic Dysphonia

- Smiling
- Grimacing
- Laughing
- Speaking over loud background noise

Focal Hand Dystonia/ Writer's Cramp

- 5 minute hand immersion in cold water
- Adjusting pen grip, writing with closed fist
- Using pens of different sizes
- Writing on chalk board
- Painting
- Touching specific part of 'normal' hand to the dystonic hand

Runner's Dystonia

- Holding hands above head
- Running in clockwise direction
- Mentally imagining running in clockwise direction

Truncal Dystonia/Camptocormia

- Low-slung back pack
- Using walker with wheels
- Pressing back against wall

DYT1 Dystonia

- Piano playing

From Ramos VF, Karp BI, Hallett M. Tricks in dystonia: ordering the complexity. J Neurol Neurosurg Psychiatry. 2014 Sep; 85(9):987-93.

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Bid to Benefit Dystonia Research

Famed Canadian cartoonist, Lynn Johnston, best known for her comic strip series, *For Better or For Worse*, will be auctioning off her artwork with all proceeds benefitting dystonia research and support programs. You can own pieces of art created and signed by this wonderful artist, and dystonia thriver!

Start Date of Auction:

October 4, 2021 - 11:00 am ET

End Date of Auction:

October 10, 2021 - 9:00 pm ET

Visit: www.dystoniacanada.org/auction



Your Network is Our Network

DMRF Canada is a testament to the power of community and connection.

We exist, and our mission survives because of you - reaching out to make connections, raising funds through employee giving programs, corporate match opportunities, connecting our organization to private and public foundations, and leveraging your contacts to help raise awareness of the condition via community publications, national advertisers, and social media. Over the past two years alone, DMRF Canada has received more than \$25,000 in donations because of you generously sharing your network. Thank you. To learn more about employee giving and other ways to support our cause, visit: www.dystoniacanada.org/fundraise



Catherine, DMRF Canada Board Member: *“Leveraging my company’s employee giving program to benefit the dystonia community has made my donation go farther, and it helped to raise awareness of the condition to my broader community. I encourage anyone who is working for a corporation to take a few moments to learn more about what your company will do to support your charitable giving efforts.”*



Tim, former DMRF Canada Board Member: *“I have always been proud to connect my passion for finding a cure for dystonia to my personal and professional networks. Talking about our need for more research in order to find a much-needed cure for dystonia allowed me to open the doors for the foundation that would not have been possible otherwise. I encourage all passionate dystonia community members to consider making introductions to our mission. Expanding the dystonia community network to raise funds for more support and ultimately a cure for dystonia will benefit everyone.”*

Thank You to Our Support Group Leaders and Area Contacts

A special thanks to our area contacts and support group leaders for their tireless efforts over the past 18 months, providing peer-to-peer support while dealing with the challenges of the pandemic themselves.




Our support group network is comprised of dedicated volunteers across the country. Many of our volunteers are people with dystonia or/and their loved ones. They help with general dystonia-related questions, but are not qualified to counsel people regarding medical advice, mental health crises, or urgent medical matters. For help with these concerns, please contact your doctor or licensed health care professional. To connect with a volunteer in your area, visit: www.dystoniacanada.org/support

Yes, I want to support DMRF Canada. Please add your selection below.

Yes, I want to invest in critical dystonia research. Here is my gift of:

\$250 \$150 \$75 \$45 \$ _____

Option 1: I am sending my cheque made payable to the Dystonia Medical Research Foundation Canada.

Option 2: Please charge my credit card:   

Card #:

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Expiry:

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

Yes, I want to join the DMRF Canada Monthly Giving Team.

\$50 a month \$25 a month \$10 a month \$5 a month \$ _____ a month

Please charge my credit card:   

Card #:

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Expiry:

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Please provide an email address: _____

Make online donations at: dystoniacanada.org/donate-now

* Each payment, including the first payment, will be made in the middle of the month.
You can stop your monthly gift at any time by contacting DMRF Canada.

Charitable #12661 6598 RR0001

Cut along dotted line

