

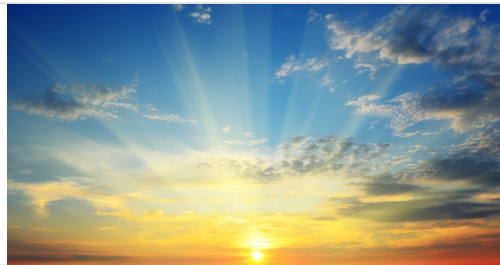
DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

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

DMRF Canada: Summer 2021 Newsletter



Quick Links

[Our Website](#)
[Donate Now](#)
[Contact Us](#)
[Email Us](#)

Table of Contents

[Facebook Fundraising](#)
[DMRF Canada E-Store](#)
[Clinical Research Trials Seeking Participants](#)
[Freedom to Move: Run, Walk and Wheel for Dystonia](#)
[Do It For Dystonia Campaign](#)
[Boccia Equipment Giveaway - Sign Up Today](#)
[Your Network is Our Network](#)
[Save the Date: Dystonia Awareness Month](#)
[Recordings of Previously Held Webinars](#)
[Online Resources & Upcoming Support Group Meetings](#)

Clinical Research Trials Seeking Virtual Participants

A new study from the University of Calgary on pain in adult-onset idiopathic dystonia is looking for participants to join a **virtual** research study. Individuals with adult-onset idiopathic dystonia with or without pain are invited to join, regardless of where you live in Canada. [Click here](#) to learn how you can participate.

Facebook Fundraising



Did you know that you can fundraise for DMRF Canada using Facebook? You can set up a page on your own Facebook account, and the donations will be sent to DMRF Canada.

Get started today by following these simple steps [here](#).



Freedom to Move: Run, Walk and Wheel for Dystonia

In memory of Chuck Saundercook

With close to 200 participants, across 8 provinces in 54 cities, we are happy to report that ***Freedom to Move: Run, Walk and Wheel*** for dystonia was a success.

We raised over \$65,000 and remain committed to raising the outstanding funds needed for research and support programs that impact the lives of the estimated 50,000 Canadians living with dystonia.

Thank you to everyone who supported the largest fundraiser for dystonia research across Canada!

DMRF Canada E-Store



You can help protect yourself and raise awareness of dystonia. Click [here](#) to find out how you can order dystonia merchandise.



Do It for Dystonia - Free Fundraising Opportunity!

Do It for Dystonia, provides many opportunities to fundraise and increase dystonia awareness in creative ways! Do you have a hobby or special interest you love doing? It's time to let yourself shine. Have a birthday coming up and want to make a difference? In lieu of gifts, encourage your network to make a donation.

Click here to learn more about the campaign.

If you need inspiration, see how Jenn will be 'DO-ing IT' in September for the dystonia community below.

FROM SEPTEMBER 1ST-7TH, 2021
PROCEEDS FROM THE SALE OF JENN ASHTON'S EBOOK:
PEOPLE LIKE FRANK AND OTHER STORIES
FROM THE EDGE OF NORMAL
WILL BE DONATED TO DYSTONIA CHARITIES IN CANADA AND THE UK!

- 1 Between September 1st to 7th 2021 go to Amazon.ca or Amazon.co.uk
- 2 Buy the **ebook** version of **People like Frank and Other Stories from the Edge of Normal**
- 3 Download immediately
- 4 Enjoy!

Logos: TIDEWATER PRESS, amazon, DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA, FONDATION DE RECHERCHE MEDICALE POUR LA DYSTONIE CANADA, Dystonia UK

Jennifer Ashton, a 2020 Jackson Mooney Patient Grant recipient will be donating proceeds from the sale of her e-book, **People Like Frank**, to dystonia charities in Canada and the United Kingdom.

When: September 1st - 7th 2021

A special thanks to Jennifer for her support!

Boccia Equipment Giveaway - Sign Up Today

Boccia is a Paralympic sport that can be played by anyone, with or without a disability. Originally designed for people with severe cerebral palsy, it is now enjoyed by players with a wide variety of disabilities.

Boccia Canada will be giving 80 sets to children, youth and adults with disabilities. Recipients will also be connected with trained virtual boccia coaches so that you can make the most of your set.

The registration deadline is **August 15, 2021**. To request a free kit, **click here** to fill out a form. For more information, visit **<https://bocciacanada.ca/>**



Thanks to Boccia Canada for sharing this opportunity with the dystonia community.

Your Network is Our Network

We exist and our mission survives because of you! This includes 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, **DMRF Canada has received more than \$25,000 in donations because of you generously sharing your network.**



If you have any connections to either public or private foundations, or corporations who you think would be interested in supporting our mission, kindly email Archana at archanacastelino@dystoniacanada.org.

To learn more about employee giving, and other ways to support our cause, [click here](#).

Save the Date: Dystonia Awareness Month

September 2021

September is Dystonia Awareness Month. Throughout the month, there are a number of ways to get involved - you can share our [awareness video](#), or reach out to local politicians to raise awareness for dystonia using our [press kit](#).

Keep an eye out for monuments across Canada that will be illuminated blue in support of Dystonia Awareness Month!



Stay tuned for more updates on our website:
<https://dystoniacanada.org/dystoniaawarenessmonth>

Recordings of Previously Held Webinars

- Update on Dystonia Coalition with guest speaker H.A. 'Buz' Jinnah, MD, PhD, courtesy of DMRF
- Deep Brain Stimulation from the Patient Perspective, courtesy of DMRF
- DBS for Dystonia: Technical Aspects, Possibilities and Limitations - By Dystonia Europe
- Writer's Cramp: Assessment and Rehabilitation Management - By Dystonia Europe

Online Resources & Support Groups

DMRF Canada is proud to connect patients with support groups around the country. Click [here](#) to find a support group in your area.



Have you been having difficulty staying connected with others around you? Do you feel that you have trouble communicating how you feel, especially during this time of social distancing? We have an extensive list of [online resources and support groups](#) to help you cope.

Upcoming Support Group Meetings

Neurologic Music Therapy - ONLINE - July 30, 2021

Toronto (GTA) Virtual Support Group Meeting – August 19, 2021

Neurologic Music Therapy - ONLINE - August 27, 2021

Toronto (GTA) Virtual Support Group Meeting – September 16, 2021

Neurologic Music Therapy - ONLINE - September 24, 2021