

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR
DYSTONIE
CANADA

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

Moving Forward E-Newsletter

June

Dear Friends,

The warm weather is here and that means its walk, run, and wheel weather! Our thanks to all of you who participated and supported our various walk, run and wheel events over the past few months. Thanks to you, we've raised approximately \$80,000 in these events this year! Our thanks to the volunteers, participants, Group leaders, and sponsors who helped to make these events such a success.

And though summer is just arriving, September is right around the corner! Click here for details on how you can support Dystonia Awareness Month this coming September. Remember every act to raise awareness of dystonia helps! As always, thanks for your support,

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Chuck's Run 2018 Was A Success!

Chucks Run, Walk, and Wheel for Dystonia 2018 was a huge success this year, raising over \$10,000 to support critical dystonia research. We want to thank all of our participants and sponsors making this event possible. Special thanks to Chuck's Run 2018 Ambassador, Casey Kidson, for championing our cause and this event.

Check out our photos from the event on [Facebook](#).



September is Dystonia Awareness Month!

Help Us to Raise Awareness for Dystonia

Join the Dystonia Medical Research Foundation (DMRF) Canada to create awareness through the "Dystonia Moves Me Campaign," taking place during the month of September. You can be one of the thousands of volunteers throughout Canada and the U.S. whose goal is to increase dystonia awareness and reach out to those who are undiagnosed.



Click [here](#) to find out how you can get involved in September 2018.

Calgary Dystonia Symposium - 50% Sold Out

Register today!

Join DMRF Canada for a FREE, two-day symposium in Calgary!

When: September 15 from 9:00 – 4:30 pm and September 16 from 9:00 – 1:00 pm

Where: Best Western Village Park Inn, 1804 Crowchild Trail NW – Calgary, AB

The symposium will feature a range of special guests, speakers, and sessions, including a keynote presentation by Tom Seaman! Click [here](#) to learn more about this exciting event, and to see the symposium's full schedule (subject to change).

New Recipient of the 2018 Banting Research Foundation Discovery Award





DMRF Canada, in partnership with The Banting Research Foundation, is pleased to announce our support of Dr. Nomazulu Dlamini, MD PhD. Neurology, from Hospital for Sick Children, as the recipient of the 2018 Banting Research Foundation Discovery Award.

Dr. Dlamini's research project, entitled: *Neural network reorganization and maladaptive plasticity in dystonia post childhood basal ganglia stroke: a developmental model for the investigation of the neurobiological substrate of dystonia*, was one of nine grants this year, out of 47 applications.

Dr. Dlamini's grant application states that this research will "*improve understanding of 'when it occurs, where it occurs, and in whom it occurs', potentially providing paradigm shifting opportunities for the development of future mechanism and individual targeted therapies to impact the lives of children, adults, and their communities.*"

We can't wait to see what discoveries this research will yield. You can read the full funding announcement [here](#). Stay tuned for more updates on Dr. Dlamini's research in the coming months.

Are you a caregiver or parent, supporting a loved one with dystonia?

Remember that as a caregiver, your health and well-being are as important as those of your loved one. [Click here](#) for a list of tools, resources and materials to help parents, as well as their children and teens living with dystonia.

If you're a caregiver taking care of a loved one with dystonia, [click here](#) for a number of resources that can help you to cope.

DMRF Canada support groups are open to caregivers, parents and anyone whose lives are impacted by dystonia. If you are caring for a family member or friend with dystonia, take care of yourself as well. Get help from family, friends and professionals. If you are in a family setting, divide up responsibilities and schedules in ways that spread the load, don't overburden, and provide a sense of teamwork. [Click here](#) to find out more about support groups near you.



Vancouver Scotiabank Charity Challenge

We are thrilled to be joining the Greater Vancouver Area Dystonia Support Group and others from the dystonia community once again.

Employee Giving for Dystonia

Many organizations have an *employee giving program*, where you can designate a gift to a charity of choice. Some corporations will match *your charitable donation*. Often all you need to do is ask. Simply contact your Human Resources department for information on your organization's program, and express your support for them to inform DMRF Canada of the donation. Provide your name and address. Every little bit helps.

Thanks for your support.

again at this year's 5K Scotiabank Charity Challenge taking place on June 24, 2018.

Registration for the 5K Walk is now sold out - BUT you can still support the cause! Here's How:

1. Come Out to Stanley Park to cheer on the individuals that are walking. Email info@dystoniacanada.org if you'd like to stay informed of where the group will be meeting ahead of time. We'll be providing signage and flyers so you can still help to raise awareness of dystonia even if you can't walk.
2. In lieu of registering we are asking you to show support to the Greater Vancouver Area Support Group by making a tax receiptable donation. You can do so by clicking here.

If you have any questions or problems please reach out to Stefanie Ince, Executive Director at stefanieince@dystoniacanada.org

If You Live in Alberta, Have Your Say

Alberta's doctors, through the Alberta Medical Association, have established **albertapatients** to start a dialogue about health care in our province. Our goal is to identify and examine the health care issues that matter most to you. Click [here](#) to provide your input!

Living Well with Dystonia

Resources for living with dystonia.

There is no single strategy for living well with dystonia. DMRF Canada has compiled some suggestions from healthcare professionals, individuals with dystonia, and support leaders.

You can read our suggestions for living well with dystonia by clicking [here](#). Please work with your doctor to create a plan that works well for your unique circumstances.



BBQ Lunch Meeting With Dystonia Community

Join the Toronto Support group for a BBQ Meeting featuring live music and a review of a recent presentation by Dr. Cresswell. A ticket is \$7 per person, and will include food, and drinks!

When: Saturday, June 23, 2018:

Where: 32 Kern Rd, North York, ON, M

If you have any questions please contact at dmrfctoronto@gmail.com. We look forward to seeing you there!

Twisted Talk

A new English-speaking support group in Montreal!

If you are an English-speaking dystonia patient living in Montreal, there is a new support group just for you! Click [here](#) to join Twisted Talk on Facebook and stay up to date with all the talk in Montreal!

Monthly Giving Plan

Join the Monthly Giving Team for \$10 a month!

It is important for small organizations such as DMRF Canada have a steady and predictable revenue base with which to fund ground-breaking research on dystonia. Monthly giving is one way to support critical dystonia research programs, and services throughout the year.

Click [here](#) to read monthly donor testimonials and to join the Monthly Giving Team today!

Clinical Trials for Cervical Focal Dystonia

We need your help!

Participate in a clinical research trial to advance dystonia research!



Symposium Sur La Dystonie

Quand: 8 September 2018 9H a 16H30

Où: Hotel Sandman, Longueuil

Inscription Obligatoire

Participants: 25\$

Professionnels: 50\$

Publicité Symposium 8 sept 2018

Programme Symposium

Clinical Trial on DBS for Focal Hand Dystonia: Click [here](#) to learn more about you can participate in the study.

Clinical Trial for Cervical Dystonia: clinical research study being conducted at Toronto Western Hospital to test a new Cervical Dystonia. Click [here](#) to learn how you can participate.

Upcoming Support Group Meetings For June-July 2018

There is a ton of support out there for individuals living with Dystonia. Find a local support meeting near you:

June 23rd: Calgary Support Group Meeting. Click [here](#) to learn more.

June 23rd: Toronto Support Group Meeting. Don't miss out on this BBQ Lunch Meeting Dystonia Community! Click [here](#) for more details.

June 25th: Free Yoga Class for the Dystonia Community in Edmonton. Click [here](#) to learn more.

July 14th: Hamilton Support Group Meeting. Click [here](#) for more details.

July 21st: Toronto Support Group Meeting. Click [here](#) to learn more.

Stay up to date with all upcoming DMRF Canada events on our [website](#). You can find a full DMRF Canada local support groups [here](#). If you can't find a support group near you, check [list of online support groups!](#)

Quick Links

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