

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

Dystonia Awareness Month Is Here! September 2018

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Dear friends,

We're thrilled to present several items that we have come up with to help make this year's Dystonia Awareness Month a success! This year we've worked hard to provide you with many ways to get involved, get the word out, and share your dystonia experience to your networks. These initiatives would not be possible without the generous support of our incredible volunteers, our sponsors and supporters, and you – the dystonia community who does so much to increase awareness and support. Thank you.

DMRF Canada remains focused on doing everything possible to accelerate the availability of improved treatments, greater awareness, and more support for every dystonia patient. Read on to learn what we have in store for Dystonia Awareness Month.....

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Introducing Dystonia Awareness Month 2018 Press Release: The Many Faces of Dystonia

This September, DMRF Canada is launching its campaign; The Many Faces of Dystonia to help raise awareness of the condition, and the



various ways that it can impact individuals who suffer from dystonia. The campaign includes photos of real life patients, as well as details on their personal experience with dystonia, and will be circulated in a variety of social and traditional media channels with an aim to spread awareness of the condition.

The Many Faces of Dystonia campaign was created together with DMRF Canada Volunteers - the Support Group Leaders from over 30 different communities across Canada – all who are battling some form of dystonia.

Please click <u>here</u> to read our full press release and learn more about what we have in store this September.

How can you get involved this September?



Look out for Landmarks Lit Up In Blue and Check Out The Monuments Near You!

This September, we will be lighting up Canada in blue and white in honor of Dystonia Awareness Month. You can click <u>here</u> to find a full calendar of the monuments that will be lit up and when. Make sure you snap a pic of the monuments near you and tag us on social media with the hashtags #dystoniaawareness #dystoniamovesme #dystoniamovescanada to help

spread awareness!

Participate in The Many Faces of Dystonia Campaign

This September, we encourage you to share your story as well as the "Faces of Dystonia" stories that have been so generously shared with us on social media. Tag us and use the hashtags #dystoniaawareness #facesofdystonia #dystoniamovesme #dystoniamovescanada to help raise awarenss about dystonia. Click here to learn all about The Many Faces of Dystonia Campaign.



Join Us At The Montreal Dystonia Symposium!

This September 8th, DMRF Canada, in partnership with Dystonia-Partage will be hosting a French speaking Dystonia Symposium at the Sandman Hotel, Longueuil, QC. Space is limited, so register today to reserve your spot!

REGISTER TODAY: Calgary Dystonia Symposium

This two-day symposium is FREE but space is limited, so make sure you register for your spot while you can! Click here to register today!

Register Now!

There are so many more ways that you can participate in Dystonia Awareness Month and help raise awareness about dystonia this September.

Click <u>here</u> for a full overview of everything that we have going on this month, including how you can participate on social media and become a Dystonia Ambassador!

News in The DMRF Canada Community:

New Dystonia Research Funding Announced

Congratulations Dr. Nomazulu Dlamini!



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

Read our <u>full article</u> to learn more about the award and 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.

2018 Jackson Mooney Dystonia Patient Grant Recipient Announced

Congratulations Sarah Anderson

This summer, DMRF Canada was pleased to announce the selection of Sarah Anderson as the recipient of the Jackson Mooney Dystonia Patient Grant. Sarah is a high school student interested in pursuing her teaching degree. Sarah suffers from generalized dystonia because of oxygen deprivation at birth. When describing her educational goals, Sarah says; "despite the

inevitable challenges living with dystonia presents, I was always that typical child who looked to the future with goals such as eventually having a career. For this reason, academic success has been a major focus for me."

DMRF Canada wishes to thank all applicants, and a special thank you to Jackson Mooney and his brother Jefferson, both who generously came up with the idea for the grant and have committed to funding this on an annual basis.

To learn more about Sarah and the Jackson Mooney Dystonia Patient Grant, click here.

Promise and Progress Science Report

Stay up to date with DMRF Canada's research funding.

Our annual Promise and Progress Science Report provides details about all the recent research and developments being funded by DMRF Canada. Click here to check it out!

DMRF Clinical Fellow Launches "Toxin Club"

Article Subtitle

This August, <u>DMRF Canada Clinical Fellow Karlo Lizarraga launched the "Toxin Club"</u> at Toronto Western Hospital. The Toxin Club will serve as a place for all Movement Disorder Fellows at the hospital to gather, share information, and discuss best practices in Clinical Treatment. These meeting will serve as a fantastic resource for all current Fellows at the hospital, as well as all incoming Fellows at the hospital.

Coming Soon: Get Your Own Dystonia Alert Bracelet!

Wearing a dystonia alert bracelet will provide important information about your condition to medical professionals and loved ones in the event of an emergency situation when you may be unable to communicate. Click here to learn more about when this will be available.



Dystonia Alert

Legacy Society

The DMRF Canada established the Legacy Society to acknowledge those who have made a lasting commitment to supporting dystonia research by naming DMRF in their estate plans. By including the DMRF Canada in your future giving plans, 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.

While the DMRF Canada could not operate without the generous cash donations received every day, there are some gifts for which we are happy to patiently wait.

You can make a commitment of support to the DMRF today that is fulfilled in the future.

To learn more about the DMRF Legacy Society email Stefanie Ince, Executive Director at: stefanieince@dystoniacanada.org

Upcoming Support Group Meetings:

September 5th: Kelowna Awareness/Information Booth.

September 8th: Hamilton Support Group Meeting

September 8th: Winnipeg Support Group Meeting

September 28th: Toronto Support Group Meeting

September 29th: Mississauga Support Group Meeting

Please visit our website at www.dystoniacanada.org