



The Mysterious Disorder Impacting 50,000 Canadians

The Many Faces of Dystonia

September is Dystonia Awareness Month.

TORONTO, ON – August 30, 2018 – The Dystonia Medical Research Foundation (DMRF) Canada is pleased to announce that September is dystonia awareness month in Canada.

Dystonia, the third most common movement disorder behind Essential Tremor and Parkinson's Disease, is a relatively unknown neurological disorder that is characterized by persistent or sporadic muscle contractions, causing abnormal repetitive movements or postures, at times resembling a tremor. Depending on the severity of the condition, patients are faced with varying degrees of disability or pain. Dystonia affects an estimated 50,000 people in Canada.

"Dystonia is a rare disorder with many different forms and varying treatment options, so building a general understanding of dystonia has been a challenge," says Stefanie Ince, executive director, DMRF Canada "There is still no known cure and only limited treatments are available. We struggle with a general lack of awareness, not only within the general population, but also within the medical community."

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.

"Some of us suffer from terrible neck twist (Cervical Dystonia), while others may experience ongoing tremors in arms and hands (Myoclonus Dystonia), causing shakes or jerking motions. Dystonia can also impact, lower limbs, and even your eyelids, causing them to stay shut for periods at a time." said Joanne Alford, Support Group Leader in Edmonton, AB. "It can be very difficult for patients because there is a lack of understanding – not only within the public but also from the medical community itself. By putting our faces and experiences forward, our goal is to educate people on what dystonia is and the devastating ways that it can affect individuals.

DMRF Canada has several initiatives planned for September 2018 – including two separate Dystonia Symposium Events – one in Calgary, AB and one in Montreal, QB. In addition, they are working with the medical community, volunteers and dystonia patients from across the country to encourage grassroots campaigns, social media messaging, and to raise awareness.

To learn more about dystonia, the campaign or dystonia awareness month, visit:

www.dystoniacanada.org.

About the Dystonia Medical Research Foundation (DMRF) Canada

The Dystonia Medical Research Foundation was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia. The mission of the 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. DMRF Canada is a registered non-profit Canadian charity governed by a volunteer Board of Directors.

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