

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

## First Ever Dystonia Symposium Takes place in Calgary, Alberta September 15<sup>th</sup> & 16<sup>th</sup>, 2018 One way to honour Dystonia Awareness Month.

**CALGARY, AB – August 15, 2018 –** The Dystonia Medical Research Foundation (DMRF) Canada is pleased to announce that September is dystonia awareness month in Canada. As one of the many initiatives taking place, DMRF Canada will be hosting the first ever two-day Dystonia Symposium for dystonia patients and their loved ones in Calgary, AB on September 15<sup>th</sup> & 16th.

Dystonia is the third most common movement disorder behind Essential Tremor and Parkinson's Disease, it 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**.

On September 15<sup>th</sup> and 16<sup>th</sup>, DMRF Canada is expecting up to 200 people living with dystonia, caregivers, family members, doctors and volunteers to attend the first ever Dystonia Symposium dedicated to educating, empowering and supporting dystonia patients from all over Canada. "We're thrilled to be hosting this symposium here in Calgary", said Calgary Support Group Leader and dystonia patient, Astrid Frauscher. "We're used to nobody recognizing the disorder or knowing anything about it. Having so many people from the dystonia community together is going to be very special". The symposium boasts several educational sessions from movement disorder specialists, a functional neurosurgeon, dystonia patient advocate and blogger **Tom Seaman, a meditation expert**, as well as educations sessions on adjunctive therapies, pain management, and more.

"The University of Calgary Department of Clinical Neurosciences is happy to be supporting this event and we are pleased to be able to provide the information, tools, and knowledge that patients and their caregivers need to live their best life with this condition", said Dr. Davide Martino, Director of the Movement Disorder Program, University of Calgary.

"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, which is what makes this symposium and Dystonia Awareness Month so important to our community"

The event is free for all participants, thanks to the generous support of all three neurotoxin companies which treat the condition: Allergan Canada, Ipsen Pharma, and Merz Canada.

DMRF Canada has several initiatives planned for September 2018, 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 or dystonia awareness month, visit: <a href="www.dystoniacanada.org">www.dystoniacanada.org</a>. To register for the symposium, email: <a href="mailto:info@dystoniacanada.org">info@dystoniacanada.org</a>.

## 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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For more information, please contact: Stefanie Ince, DMRF Canada, stefanieince@dystoniacanada.org (you should add your phone number as well)