Dystonia
Medical
Research
Foundation
Canada

Fondation de
Recherche
Médicale sur la
Dystonie
Canada

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

DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

PRESS KIT

Dystonia Awareness Month

DYSTONIA STRONG

Charitable Registration Number 12661 6598 RR0001

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Contents

ABOUT DYSTONIA *2*

- WHAT IS DYSTONIA? 2
- WHAT ARE THE FORMS OF DYSTONIA? 2
- WHAT ARE THE SYMPTOMS OF DYSTONIA? 2

ABOUT THE DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA *3*

OUR MISSION *3*

IMAGES and LOGOS *3*

- DMRF Canada 3
- Dystonia Strong 4
- THE MANY FACES OF DYSTONIA 5

ABOUT DYSTONIA

WHAT IS DYSTONIA?

- Dystonia is a neurological movement disorder that is characterised by involuntary muscle contractions, which force parts of the body into abnormal as well as painful movements or positions.
- It is a condition that knows no age, ethnic or racial boundaries – it can affect young children to older adults of all races and ethnicities.
- We estimate that 50,000 people in Canada have dystonia. Dystonia is the third most common movement disorder following essential tremor and Parkinson's disease.
- Patients with dystonia may experience uncontrollable twisting, repetitive movements or abnormal postures and positions. These can affect any part of the body, including the arms, legs, trunk, face and vocal cords.

WHAT ARE THE FORMS OF DYSTONIA?

- There are over 10 different forms of dystonia. And dozens of diseases and conditions also include dystonia as a major symptom.
- Dystonia can impact one body part (for example the face, neck, hands or feet), or it may be generalized throughout multiple muscle groups.
- Dystonia may be genetic or result from other health conditions such as stroke, physical trauma, other diseases, or as a side effect of certain medications.

WHAT ARE THE SYMPTOMS OF DYSTONIA?

- Those with dystonia will experience muscle contractions, muscle twisting and uncontrollable, involuntary spasms that can be very painful.
- Symptoms of dystonia are usually chronic but may also appear only during "attacks" or episodes.
- It is more than a movement disorder. Besides the movements and postures of dystonia, individuals may experience additional symptoms such as anxiety, depression, persistent pain, and impaired sleep.
- According to Statistics Canada, 53% of individuals with dystonia experience chronic pain, far exceeding rates for migraine, stroke, multiple sclerosis, and muscular dystrophy, and well above the 36% average for all neurological conditions.

For more information about the Dystonia Medical Research Foundation Canada, please visit:
www.dystoniacanada.org

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ABOUT THE DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

- The Dystonia Medical Research Foundation Canada is the only organization that is dedicated to supporting approximately 50,000 patients in Canada that are suffering from dystonia.

- The mission of the Dystonia Medical Research Foundation (DMRF) Canada is threefold:
  - To advance research for more treatments and ultimately a cure for dystonia;
  - To promote awareness and education;
  - To support the needs and well-being of affected individuals and families.

OUR MISSION

Research

Expansion of our research investments and continued relationships with patients, medical professionals and researchers to help develop the best clinical treatments and promote collaboration within the dystonia community.

We strategically invest in research to improve treatments and deepen scientific understanding of dystonia. Through partnerships with national and international organizations like the Banting Research Foundation, DMRF USA, Dystonia Coalition and the Global Dystonia Registry, we fund initiatives that drive innovation across multiple disciplines. Our investment supports not only research collaboration but also the translation of findings into accessible knowledge for patients and healthcare providers. By engaging Canadian researchers and clinicians through educational programs, DMRF Canada ensures sustained growth in national dystonia expertise and care.

Support

Provide critical support and foster supportive relationships with the dystonia community members by providing effective resources to help all affected.

We work with 40+ volunteers across 9 provinces to maintain a sustainable support network. Our efforts assist support group leaders, most of whom are dystonia patients, in organizing patient information sessions and facilitating support group activities, including National Virtual Support Meetings and local gatherings.

Awareness & Advocacy

Raise awareness and advocate for the needs of the dystonia community now and in the future.

We enhance understanding of dystonia within the general public and medical community through ongoing campaigns, such as illuminating landmarks during awareness month and engaging in public relations initiatives, including media interviews. We also partner with educational institutions to inform and equip future medical professionals about the challenges faced by those living with dystonia, fostering a more informed healthcare community.

IMAGES and LOGOS

DMRF Canada

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Dystonia Strong

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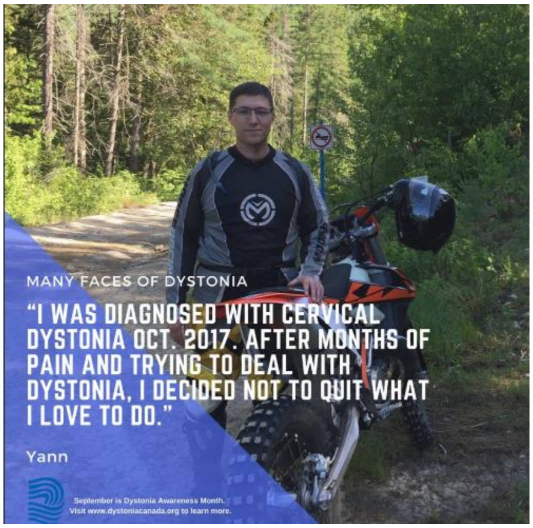
Dystonia Moves Me

Dystonia
MOVES ME
www.dystoniacanada.org

la dystonie
me fait bouger
www.dystoniacanada.org

THE MANY FACES OF DYSTONIA



MANY FACES OF DYSTONIA

"I WAS DIAGNOSED WITH CERVICAL DYSTONIA OCT. 2017. AFTER MONTHS OF PAIN AND TRYING TO DEAL WITH DYSTONIA, I DECIDED NOT TO QUIT WHAT I LOVE TO DO."

Yann

September is Dystonia Awareness Month.
Visit www.dystoniacanada.org to learn more.

MANY FACES OF DYSTONIA

"I HAVE DYSTONIA, BUT DYSTONIA DOES NOT HAVE ME."

Jason Y.

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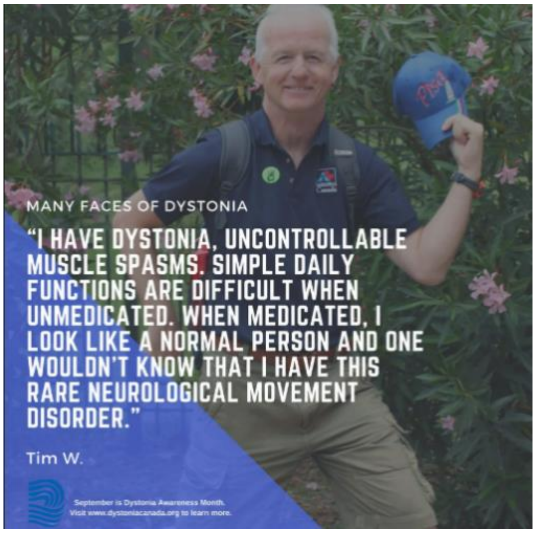

MANY FACES OF DYSTONIA

"I HAVE DYSTONIA, UNCONTROLLABLE MUSCLE SPASMS. SIMPLE DAILY FUNCTIONS ARE DIFFICULT WHEN UNMEDICATED. WHEN MEDICATED, I LOOK LIKE A NORMAL PERSON AND ONE WOULDN'T KNOW THAT I HAVE THIS RARE NEUROLOGICAL MOVEMENT DISORDER."

Tim W.

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MANY FACES OF DYSTONIA

"IT BOTHERS ME AT TIMES WHEN PEOPLE STARE AT ME BECAUSE OF THE TREMORS. I TRY TO KEEP BUSY AND CONVINCE MYSELF SOME PEOPLE HAVE MEDICAL PROBLEMS WORSE THAN I DO."

Phyllis R.

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MANY FACES OF DYSTONIA

"THE GREATEST CHALLENGES I EXPERIENCE WITH DYSTONIA ARE: INDIVIDUALS NOT BELIEVING IN AND/OR TAKING THE DISABILITY SERIOUSLY AND DYSTONIA CAN BE/IS INVISIBLE TO THE EYE."

Jennifer S.

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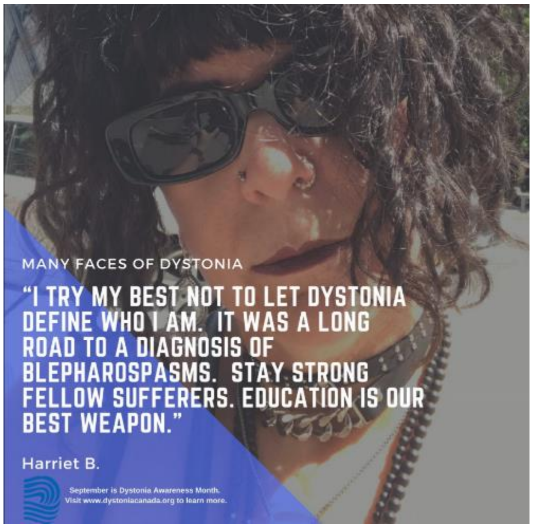

MANY FACES OF DYSTONIA

"I TRY MY BEST NOT TO LET DYSTONIA DEFINE WHO I AM. IT WAS A LONG ROAD TO A DIAGNOSIS OF BLEPHAROSPASMS. STAY STRONG FELLOW SUFFERERS. EDUCATION IS OUR BEST WEAPON."

Harriet B.

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