



# Dystonia Medical Research Foundation Canada

## *Empowering Patients in Canada*

2020

## ABOUT DMRF CANADA

- Dystonia Medical Research Foundation (DMRF) Canada is a national charitable organization that was established in 1976 by Sam and Fran Belzberg, after their daughter was diagnosed with dystonia.
- The DMRF Canada is dedicated to supporting individuals (and their families) who suffer from dystonia.
- We are a volunteer led organization (with over 30 Group Leaders or Area Contacts), one full time staff, one part-time staff and a variety of interns, and dedicated volunteers.
- We are a national registered charity that is accountable to a Board of Directors.



# DMRF CANADA BOARD OF DIRECTORS

## 2019 - 2020

Fran Belzberg, *Honorary Chair*

Bill Saundercook, Chair, DMRF Canada Board of Directors

Pearl Schusheim, Treasurer and Secretary

Grant Connor, Director

Heather Connor, Director

Dennis Kessler, Director

Rosalie Lewis, Director

Tim Williston, Director

Connie Zalmanowitz, Director



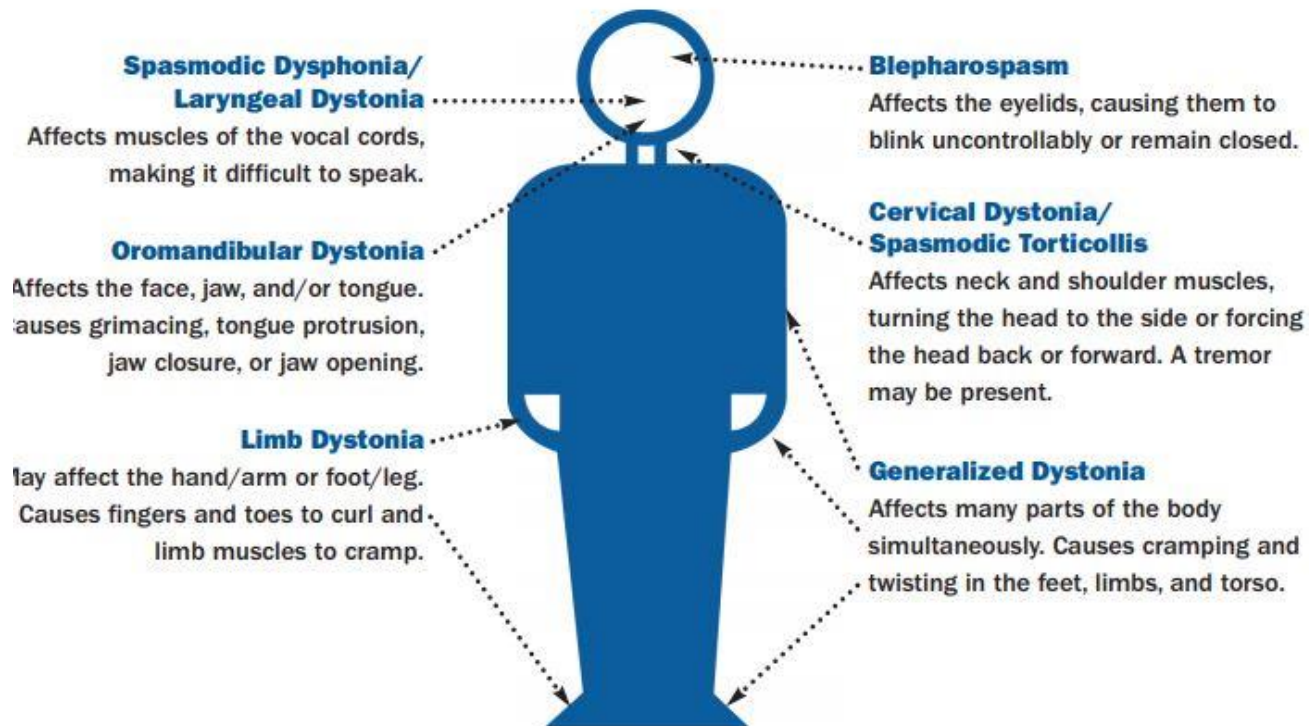
# WHAT IS DYSTONIA?

- Dystonia is a disorder that causes muscles in the body to contract and spasm involuntarily.
- individuals who are affected by dystonia cannot control or predict the movement of their bodies. Dystonia is the third most common movement disorder following essential tremor and Parkinson's disease, affecting approximately 300,000 people in North America.
- Dystonia does not discriminate. Men, women and children of all ages and backgrounds are affected
- Dystonia may be genetic or result from other health conditions such stroke, physical trauma, other diseases, or as a side effect of certain medications
- Although there is not yet a cure for dystonia, treatments are available.



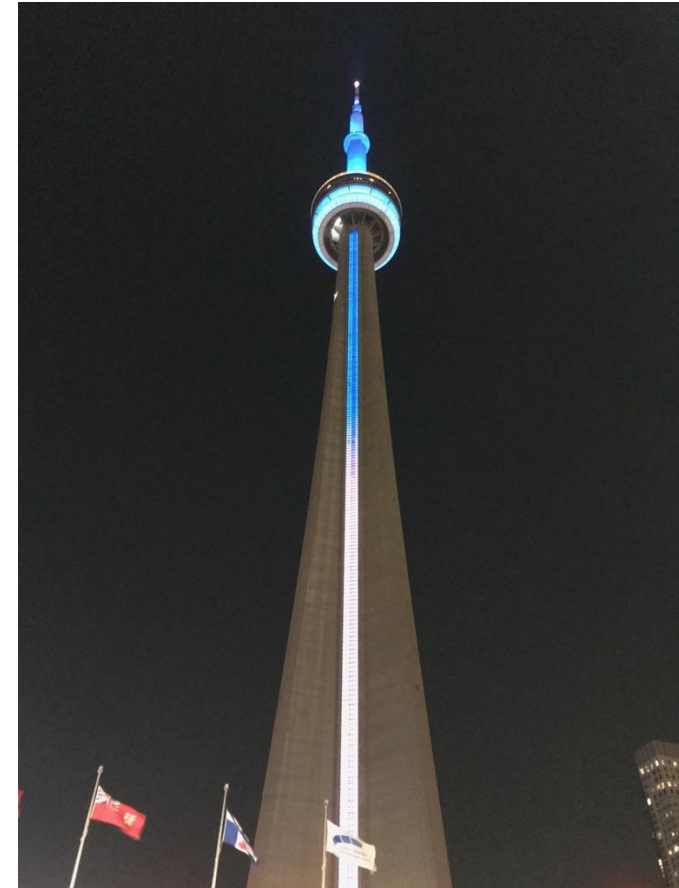
# WHAT IS DYSTONIA?

- Symptoms of dystonia do not appear the same in every patient. Dystonia may affect a specific part of the body or many parts simultaneously.



# ABOUT THE DMRF CANADA

- Our mission 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.



## 2020 VISION: EMPOWER DYSTONIA PATIENTS IN CANADA

- Build awareness of dystonia to the general population and to the front line health care population,
- Build confidence in DMRF Canada within the dystonia community in Canada so that patients know that they have a relevant, credible organization who has their best interests at heart;
- Give patients the education, tools and information they need to be aware of all of their health care options
- Provide ways for patients to act as advocates for the DMRF Canada and dystonia in general.

# OUR PRIORITIES: DYSTONIA RESEARCH FUNDING

- DMRF's globally-focused "Science Portfolio", is the single largest dystonia research program in North America, led by a committee of movement disorder specialists, is focused on contracting with researchers on specific projects, engaging the biotech industry and providing opportunities for the next generation of experts.
  - DMRF Canada contributes to this global fund each year, in an effort to support the best and brightest research out there.
- In 2020, DMRF Canada is once again investing in Canadian research as well, continued funding of the two-year Clinical and Research Fellowship (awarded to Dr. Mario Sousa at Toronto Western General) and partnering with the Banting Research Foundation to award the 2020 Discovery Grant.



# OUR PRIORITIES: DYSTONIA PATIENT CARE AND SUPPORT


Programs to Bring the Community Together, to Educate and Empower – Encourage them to Advocate for Themselves:

- **Support of over 30 Local Support Groups Across the Country:**
  - This includes monthly meetings, or less formal gatherings;
  - Online support via DMRF Canada operated channels (Facebook, Twitter, email and phone as needed).
- **Opportunities for Education and Learning to Empower Patients:**
  - Currently Planning a Montreal Symposium (March 2020)
  - Ongoing Webinars and community events.


# OUR PRIORITIES: EDUCATION AND AWARENESS

- Providing patients with information and opportunities for patient care (dystonia patient protocols based on patient needs).
- Informational Literature (brochures, patient support materials, website, social).
- Awareness events and activities, including Dystonia Awareness Month.



**DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA**  **FONDATION DE RECHERCHE MÉDICALE SUR LA DYSTONIE CANADA**

serving all dystonia affected persons  
servant toutes personnes atteintes de dystonie

**DO YOU SUFFER FROM ANY OF THESE?** 

- Involuntary muscle movements;
- Muscle spasms;
- Uncontrollable body movements ;
- Blinking of your eyes;
- Problems with your speech;
- Twisting or movement of your head and neck;
- Abnormal posture and body positions

**IF SO, YOU SHOULD TALK TO YOUR DOCTOR, AS YOU MAY HAVE DYSTONIA, A NEUROLOGICAL MOVEMENT DISORDER.**

**VISIT: [WWW.DYSTONIACANADA.ORG](http://WWW.DYSTONIACANADA.ORG) TO LEARN MORE.**

**TEL: 1-800-361-8061**  
**EMAIL: [INFO@DYSTONIACANADA.ORG](mailto:INFO@DYSTONIACANADA.ORG)**

**LES DIFFÉRENTS VISAGES DE LA DYSTONIE**

**"JE SUIS AUX PRISES AVEC LA DYSTONIE, MAIS LA DYSTONIE N'A PAS DE PRISE SUR MOI."**

**Jason Y.**

Septembre est le Mois de la sensibilisation à la dystonie.  
Pour plus de détails, consultez: [www.dystoniacanada.org](http://www.dystoniacanada.org)

**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.**

Septembre is Dystonia Awareness Month.  
Visit [www.dystoniacanada.org](http://www.dystoniacanada.org) to learn more.

# 2019 ACCOMPLISHMENTS AND ACTIVITIES

## ■ Research

- Two grants, totalling \$100,000 to Dr. Kiss at the University of Calgary and Dr. Fasano at Toronto Western Hospital.
- A grant in partnership with the Banting Foundation to Dr. Nicholas Strzalkowski at Mount Royal University.
- A two year Clinical and Research Fellowship, valued at \$100,000 to Dr. Mario Sousa at Toronto Western Hospital
- Supported the Dystonia Research Fund in collaboration with the DMRF in the United States

## ■ Awareness

- Dystonia Awareness Video - viewed, passed, and shared over 5,000 times since its launch in September 2019
- Published two newsletters, six e-newsletters
- Over 10,000 dystonia awareness and educational materials distributed in Medical and local communities
- Lit up over **15** major landmarks during Dystonia Awareness month in September

## ■ Patient Support

- Organized a full-day free Dystonia Symposium in Vancouver, as well as Information Sessions in Winnipeg and Kelowna.
- Supported over 60 local support group community events.
- Provided patient support to thousands of patients by phone, mail, email and via social media.
- Awarded dystonia patient (educational) grants to two deserving students.

# A STRONG PARTNERSHIP: WORKING TOGETHER TOWARD A STRONGER COMMUNITY

- **Please consider supporting DMRF Canada.**
  - We would be happy to work with you to determine the most appropriate recognition and benefits based on your commitment.
  - Thank you for your consideration.

Contact: Stefanie Ince, Executive Director, DMRF Canada

[stefanieince@dystoniacanada.org](mailto:stefanieince@dystoniacanada.org)

416.488.6974

THANK YOU FOR  
YOUR SUPPORT!

DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION  
CANADA



FONDATION DE  
RECHERCHE  
MÉDICALE SUR LA  
DYSTONIE  
CANADA

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