

Dystonia Medical Research Foundation Canada



Contents

ABOUT DYSTONIA	2
WHAT IS DYSTONIA?	2
WHAT ARE THE FORMS OF DYSTONIA?	2
WHAT ARE THE SYMPTOMS OF DYSTONIA?	2
WHAT ARE THE BIGGEST CHALLENGES FOR DYSTONIA PATIENTS?	3
WHAT ARE THE DIFFERENT TYPES OF DYSTONIA?	3
WHAT ARE THE TREATMENTS FOR DYSTONIA?	4
ABOUT THE DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA.....	5
INVESTING IN RESEARCH INTO BETTER TREATMENTS AND A CURE FOR DYSTONIA:	5
EDUCATION AND AWARENESS:.....	6
SUPPORT THE NEEDS AND WELL-BEING OF AFFECTED INDIVIDUALS AND FAMILIES	6
FOR PLACEMENT IN COMMUNITY PAPERS (permission required)	8
Story of an individual with dystonia	8
PROMOTIONAL BLURB	10
FOR DYSTONIA MEDICAL RESEARCH FOUNDATION LOCAL SUPPORT GROUP.....	10
30 Second Radio Spot.....	11
LOGOS	12
DMRF Canada	12
Dystonia Moves Me.....	12

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 many 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.

(Continued)

WHAT ARE THE BIGGEST CHALLENGES FOR DYSTONIA PATIENTS?

- The Dystonia Medical Research Foundation Canada conducted a survey to answer this very question ([see *Real Patients, Real Answers, published in 2017*](#)). We analysed the results and found there are several challenges including:
 - **The time it takes for a patient to receive a proper diagnosis**, due to low awareness in general and even within the medical community. In many cases it takes years for someone who is suffering from dystonia to be properly diagnosed.
 - In fact, a recent survey conducted in 2019 indicated that for 63% of dystonia patients, it took more than one year to receive a proper diagnosis. Of those patients, 45% took over four years to receive a diagnosis and 16% took over ten years.
 - This is due to low awareness of the condition, as well as the fact that there are a limited number of physicians who are familiar and well versed with dystonia.
 - **In addition, individuals who have dystonia continue to report difficulty in finding physicians trained in movement disorders**, particularly in more remote communities. In many cases they may have to wait months, or even years before an appointment to get treated.
- In the survey, we specifically asked the question, what is the biggest challenge you experience with your dystonia? The answers were very similar: depression, social anxiety, dealing with pain, having to give up their old life, having to quit work because of their dystonia, mobility.

WHAT ARE THE DIFFERENT TYPES OF DYSTONIA?

- Physicians have developed a system to classify dystonia to help guide the treatment process:
 - The term primary dystonia is used to describe a case in which the dystonia is the predominant symptom, and the person is not affected by other neurological conditions.
 - Secondary dystonia refers to dystonia that is associated with a known outside factor or condition (such as trauma, drug exposure, stroke, cerebral palsy, and others).

WHAT ARE THE TREATMENTS FOR DYSTONIA?

- There is no cure for dystonia, but treatments are available. Most therapies are symptomatic, attempting to cover up or release the dystonia spasms; therefore, there is no single treatment program appropriate for every case.
- Treatments available include: drug therapy, botulinum toxin injections, surgery and complementary therapies.
- Botulinum Neurotoxin Therapy can be a very good therapy for focal dystonia, but it is masking the symptoms rather than curing the dystonia. Patients would have to continue to go into see a specialist for injections.
- In most cases, the type of doctor who is typically trained to diagnose and treat dystonia is a movement disorder neurologist. The most important step in treating dystonia is working with a doctor who is trained to treat dystonia.

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 WORK

INVESTING IN RESEARCH INTO BETTER TREATMENTS AND A CURE FOR DYSTONIA:

The Dystonia Medical Research Foundation Canada works in partnership with the Dystonia Medical Research Foundation based in the United States to ensure funding of the best and most relevant dystonia medical research worldwide, as well as with other like-minded organizations based in Canada.

We continue to invest in supporting new individuals into the Movement Disorder Field:

- In 2021, we awarded the two-year Clinical and Research fellowship, supported by Merz Therapeutics, to Dr. JiaRen Chai at the London Movement Disorders Centre, University of Western Ontario. In 2019, this fellowship was expanded to include a research component. We previously awarded this fellowship, valued at \$100,000, to Dr. Mario Sousa at Toronto Western Hospital.
- In partnership with The Banting Foundation, we supported the 2019 Discovery Award for Early Investigators and provided a grant to Dr. Nicholas Strzalkowski at Mount Royal University to support his research in muscle sensory feedback in dystonia.
- We support the DMRF in the United States to fund the best worldwide research. Since 1976 this collaboration has funded over 400 grants awarding \$35 million in research funding.
- We published a special 40+ Years of Research Achievements Report, *courtesy DMRF*, providing an overview of the key successes that DMRF has achieved since its inception.

We support research that will help patients today:

- We launched the DMRF Canada ‘Better Clinical Treatments Grant’ with an objective to help patients have a better quality of life. In 2019, we committed to funding **two** one-year research grants taking place in Movement Disorder Centres in Canada throughout 2020 - Dr. Kiss at the University of Calgary and Dr. Fasano at Toronto Western Hospital for a total research investment of \$100, 000.
- Read more about Dr. Fasano and Dr. Kiss research focusing on Better Clinical Treatments for Dystonia at: <https://dystoniacanada.org/research-changes-lives>

EDUCATION AND AWARENESS:

- DMRF Canada works with volunteers, medical professionals (neurologists, movement disorder clinics), and the media to raise awareness of dystonia in a variety of ways.
- We publish two newsletters and four e-newsletters annually, ongoing online updates through social media, media relations activities, and annual Symposium events.
- In 2020 and 2021, we designed specialized virtual programs, webinars, and web-based materials to empower, educate, and support patients and caregivers supporting over 6,000 individuals.
- In September 2020, we celebrated our most successful Dystonia Awareness Month to date, breaking our previously held record for engagement. We connected with over 15,000 people online and lit up 30 major landmarks across Canada to show solidarity with the dystonia community.
- In June 2021, we hosted the largest nation-wide, virtual fundraiser for dystonia called *Freedom To Move: Run, Walk and Wheel for Dystonia*. Close to 200 participants across 8 provinces and 54 cities registered. Together, we raised over \$65,000 for dystonia research and support programs.

SUPPORT THE NEEDS AND WELL-BEING OF AFFECTED INDIVIDUALS AND FAMILIES:

- There are approximately 40 Group Leaders and Area Contacts representing over 20 areas across the country. The purpose of these groups is to provide support, guidance and options to those individuals (and their families) who suffer from dystonia.
- In 2019, we supported over 70 local support group community events taking place in communities all over the country. activities at local community meetings, hospitals throughout the country. Since March 2020, all of our support group meetings have been

conducted online, and in place of in-person events, we have hosted expert-led webinars.

- We've engaged and connected with more than 150 Movement Disorder Specialists and connected some of them with patients who are struggling in these times and unable to access medical help as readily as they may have prior to the pandemic.
- Since 2016, we have annually awarded deserving students with dystonia the Jackson Mooney Patient Grant to help them in pursuing their career goals.

If you or someone you know is struggling with dystonia – or if you are looking for more information, contact the Dystonia Medical Research Foundation Canada at:

www.dystoniacanada.org or 1-800-361-8061.

FOR PLACEMENT IN COMMUNITY PAPERS (permission required)

Story of an individual with dystonia

My Life with Dystonia: Thomas Wade, Canadian country music artist and Juno nominee.

50,000 patients in Canada suffer from dystonia, a neurological movement disorder that affects the nervous system. Abnormal signalling from the brain causes muscles to tighten and twist involuntarily. There are several forms of dystonia, and dystonia may be a symptom of many diseases and conditions.

Thomas Wade was already the successful lead vocalist of an award-winning country-music band, an accomplished songwriter, and emerging solo artist when he was diagnosed with Oromandibular **Dystonia**, a neurological disorder that affects speech. Wade noticed troubling symptoms affecting his vocal cords when his band, Wayward's End, was achieving domestic success on the Canadian charts. Their path towards national recognition was fully realized when Wayward's End secured three Juno nominations and seven CCM Awards.

Wade's success on the national charts was a big leap from his small-town roots in Burford, Ontario. Wade came from a musical family and was surrounded by musical influences in his childhood. At age seven he learned how to play guitar at age and taught himself how to write songs at age ten. He moved towards bigger goals when he became the lead singer of his family's band Silver Wings. By the time he had graduated from Fanshaw College with a degree in music, he was lead singer of Wayward's End and on tour. He sought more challenges and expanded his skills in music. Wade and his band looked towards the international market when nation-wide fame became a reality. At this point, however, his vocal cords had started to fail him, but he didn't know why. Despite acquiring a vast skill set in music, his voice was the critical element in helping him to launch his successful career in music.

For years, Wade struggled with vocal difficulties. At first, he had difficulty uttering words. He could not understand why he was losing his voice. His ability to sing also started to diminish. His limited capacity forced him to cancel shows when entertaining a crowd with his voice was no longer possible. As Wade found himself unable to sing at all and entertain crowds, Wade grappled with losing an integral part of his identity. By the time Wade received an official diagnosis that could help him understand what was affecting his voice, he could no longer speak. Along with an official diagnosis, doctors let Wade know that Oromandibular Dystonia is incurable.

When confronted with the possibility that he might never speak or sing again, Wade made a crucial decision in his life: to learn as much he could about the brain. Wade wanted to defeat his dystonia rather than let it rule him. Wade learned about neuroplasticity, a ground-breaking technique that enables the brain to reorganize itself. Wade even formulated his own exercises, using the principles of neuroplasticity to recover his speech and voice. By 2011, five years after his official diagnosis, Wade was able to sing again.

Despite being able to recover his singing voice through neuroplasticity, Wade decided to take his musical career in a different direction. He realized he didn't want to go back to doing what he did before. In the years between when he noticed difficulties with his voice and an official diagnosis, Wade turned his attention towards writing and producing. He focused on what could be done with the gifts he still had rather than direct his efforts towards what was out of his control. During these years, he wrote for other artists, developing a successful writing career. Once he had gained the use of voice again, Wade decided that he wanted to approach music with a new sense of discovery and appreciation rather than chase the next upward trajectory in his career. Wade had decided to divert his attention from trying to recapture his relevance in the music industry. Instead, Wade sought inspiration from other artists and decided to concentrate on creating the music he had always enjoyed and hoped to make.

Through hard work, determination, and tremendous effort, Wade has continued to pursue music with a different vision of where he'd like to take his writing and singing. From where he now stands in music and in life, he hopes to share his story with others.

The Dystonia Medical Research Foundation (DMRF) Canada is the only organization that is dedicated to supporting the dystonia community in Canada. If you or someone you know is struggling with dystonia, you're not alone. Please visit www.dystoniacanada.org to find out about resources, research, and support.



“Dystonia in even one finger can end a musician’s career. How many musicians have simply disappeared because of Dystonia. More than you know. I was one of them.” - Thomas Wade.

More Photos of Thomas Available upon Request.

PROMOTIONAL BLURB

FOR DYSTONIA MEDICAL RESEARCH FOUNDATION LOCAL SUPPORT GROUP

Dystonia is a neurological movement disorder characterized by involuntary muscle contractions, which force certain parts of the body into abnormal, sometimes painful movements or postures.

Dystonia can affect any part of the body including the arms and legs, trunk, neck, eyelids, face or vocal cords.

It is the third most common movement disorder after Parkinson's disease and Tremor, affecting more than 300,000 people in North America.

Dystonia does not discriminate – affecting all races and ethnic groups.

IF YOU HAVE DYSTONIA YOU ARE NOT ALONE

Join Us!

The (name of) Dystonia Support Group Is Here to Help You

Email: @ or Call

(include local name)

30 Second Radio Spot

Dystonia is a neurological movement disorder impacting over 50,000 people in Canada.

The Dystonia Medical Research Foundation was created over 40 years ago to fund better treatments, and ultimately a cure, and to provide education and support to dystonia patients and their families across Canada.

If you think you have dystonia or you're looking to support, visit [dystoniacanada dot org](http://dystoniacanada.org) to learn about the treatments and supports available to you.

LOGOS

DMRF Canada

**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 Moves Me

