

Dystonia Medical Research Foundation Canada



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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.
- 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.

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 one 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 important research to help patients today; as well as the future by supporting the next generation of treaters and researchers:

- In 2023 we also launched our first multicenter research study – with researchers collaborating from France, and Ontario and British Columbia in Canada. If successfully completed, this project will provide a dynamic system for unbiased diagnosis and clinical evaluation of dystonia.
- In 2022, we launched for the first time a partnership research grant with Canadian organization Rare Diseases: Models & Mechanisms Network (RDMM) to investigate disease pathogenesis by understanding the genetic contributors to this disorder and/or to inform therapeutic strategies.
- For the first time, in 2022, we also collaborated with the Dystonia Coalition (global consortium) to support a research grant focused on diagnostic accuracy for the non-motor symptoms of dystonia.
- We awarded a two-year (2023-2025) Clinical and Research fellowship, supported by Merz Therapeutics, to [Dr. Talyta Grippe](#) at the Toronto Western Hospital Movement

Disorders Centre, whose research is focused on electrophysiological assessment of movement disorders.

- In partnership with the Banting Research Foundation, we support the Discovery Award for innovative health and biomedical research projects by outstanding new investigators at universities and research institutes in Canada. In 2022, we awarded this grant to [Dr. Luka Milosevic](#), for his project focused on physiologically-informed and data-driven methods for advancing neuromodulation therapies in dystonia.
- We awarded a two-year (2021-2023) Clinical and Research fellowship, supported by Merz Therapeutics, to [Dr. JiaRen Chai](#) at the London Movement Disorders Centre, University of Western Ontario, whose research is focused on non-invasive treatments for dystonia.
- We fund the best worldwide research through the DMRF in the United States. Since 1976 this collaboration has funded over 400 grants awarding \$35 million in research funding.

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.

- In 2022, we published **two newsletters, five e-newsletters**, and have supported the community through our **digital and print resources** that have been **accessed over 150,000 times**.
- In September 2022, we celebrated our most successful Dystonia Awareness Month to date, breaking our previously held record for engagement. We connected with over **25,000 people online**. We engaged Canadian businesses and lit up **10 major landmarks** to show solidarity with the dystonia community.
- Throughout June and July 2023, we hosted the largest nation-wide, virtual and in-person fundraiser for dystonia called Freedom To Move: Run, Walk and Wheel for Dystonia. Over 130 participants across Canada registered. Together, we raised over \$50,000 for dystonia research and support programs.

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

- There are approximately 50 Group Leaders and Area Contacts representing over 30 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.
- Since March 2020, specialized virtual programs and support group meetings have been offered both online and in-person. New meeting formats allowed patients to connect with others across Canada.
- Since 2016, we have annually awarded deserving students with dystonia the Jackson Mooney Patient Grant to help them in pursuing their career goals.
- In 2022, we began the revitalization of our support network with the formation of a Support Advisory Group - a group dystonia support volunteers representing the different types of dystonia and geographical regions of Canada.
- In 2023, we welcomed in total 7 new support group co-leaders for Thompson-Okanagan, Greater Vancouver Area, Calgary, and Greater Toronto Area.
- As the challenges and needs vary with each dystonia type, from 2021 we started offering specific dystonia type meetings. We also continue to collaborate with other organizations across the globe to share such support and resources.

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. Thomas noticed troubling symptoms affecting his vocal cords when his band, Thomas Wade and Wayward, was achieving domestic success on the Canadian charts. Their path towards national recognition was fully realized when Thomas Wade and Wayward secured three Juno nominations and seven Canadian Country Music Association awards from 1997 through to '99.

Thomas' success on the national charts was a big leap from his small-town roots in Burford, Ontario. He came from a musical family and was surrounded by diverse musical influences in his childhood. At age four he learned how to play guitar, at the age of six he began performing in front of live audiences and at the age of seven he penned the first of many songs, sitting on his back porch.

He moved towards bigger goals with his family band, Silver Wings, a popular dance band in the Brant County area. By the time he had graduated from Fanshawe College with a degree in music production, he was lead singer of Thomas Wade and Wayward and on tour. He sought more challenges and expanded his skills in music.

Thomas 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, Thomas struggled with vocal difficulties. At first, his ability to sing seemed to slip away gradually, then completely for reasons vocal coaches and doctors couldn't explain. He was forced to struggle through shows, hoping for some kind of a solution. But eventually he had to give up as he was unable to sing at all. It was devastating to lose not only the career he had

built over a lifetime, but integral part of his identity. Then, over the next two years he slowly lost control of his tongue and his jaws severely affecting his speech.

By the time Thomas 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 him know that Oromandibular Dystonia is incurable.

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

In the years between when he noticed difficulties with his voice and an official diagnosis, Thomas turned his attention towards writing and producing, focusing 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, he 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.

Instead, Thomas felt drawn to recapture the love of music that had inspired him to become a singer in the first place, creating an album of music that echoed the sounds that had called him to a life in music - in essence, Thomas says, he decided to “follow the love”. The result was a classic album and a triumphant return with the album, “Blue Country Soul”.

Through hard work, determination, and tremendous effort, Thomas 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 with his first book, a chronicle of his journey through dystonia, called “Singing in my sleep”.

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.

IMAGES and LOGOS

DMRF Canada



Dystonia Strong



Dystonia Moves Me



THE MANY FACES OF DYSTONIA



