Support Dystonia Research Today

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Please provide an email address:

_____

◯ **Yes, I want to join the DMRF Canada Monthly Giving Team.** DMRF Canada Monthly Donors create a sustainable financial base for research which helps accelerate the research breakthroughs that patients urgently need.

◯ $50 a month ◯ $25 a month
◯ $20 a month ◯ $10 a month
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OR

◯ **Yes, I want to support the DMRF Canada with a one-time gift.**

◯ $250 ◯ $100 ◯ $50 ◯ $25 ◯ $ _____

Payment method:

OPTION 1: ◯ For monthly giving, I am sending 12 postdated cheques made payable to the Dystonia Medical Research Foundation Canada.

◯ For a one-time gift, I have enclosed my cheque made payable to the Dystonia Medical Research Foundation Canada.

OPTION 2: ◯ Please charge my credit card each month for monthly giving:

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Make online donations at: **dystoniacanada.org/donate-now**
* Each payment, including the first payment, will be made in the middle of the month. You can stop your monthly gift at any time by contacting DMRF Canada.

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The Dystonia Medical Research Foundation (DMRF)

The DMRF Canada is a registered non-profit Canadian charity. 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 works in partnership with the Dystonia Medical Research Foundation in the United States as well as other research funding partners to ensure funding of the best and most relevant dystonia medical research worldwide.

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Innovation for patient care

Contact Us

For more information on dystonia and DMRF Canada, contact us at:

Dystonia Medical Research Foundation Canada

Tel: (416) 488-6974
Toll Free: (800) 361-8061
Fax: (416) 488-5878
Email: info@dystoniacanada.org
Web: www.dystoniacanada.org

Dystonia Medical Research Foundation Canada
Fondation de Recherche Médicale sur la Dystonie Canada
serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

What is Dystonia?

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What is Dystonia?

Dystonia is a disorder that affects the nervous system. Abnormal signaling from the brain causes muscles to tighten and twist involuntarily. These muscle spasms force areas of the body into awkward movements and positions. It may be painful and interfere with daily activities. It is considered a neurological movement disorder.

Dystonia affects over 50,000 in Canada, of all ages and backgrounds. Most common forms affect adults but it can also occur in childhood especially if genetic. To accurately describe a dystonia diagnosis, several specific pieces of information must be accounted for.

For more details and information visit **www.dystoniacanada.org/whatisdystonia** or contact us at **1-800-361-8061** or **info@dystoniacanada.org.**

How many forms of dystonia are there?

There are many forms of dystonia. Dozens of diseases and conditions also include dystonia as a major symptom. Dystonia may affect a single body area (e.g. face, neck, hands, feet) or be generalized throughout multiple muscle groups. Please see inside of brochure for a complete list.

What are the clinical features?

Clinical features are the signs and symptoms of dystonia, which can vary a great deal from patient to patient. These include age at which symptoms began, body distribution, certain qualities about the symptoms, and the presence of other movement disorder symptoms or other neurological features. Doctors use these factors to guide diagnosis and treatment.

What is known about the cause of dystonia?

In many cases, individuals develop dystonia without any obvious cause. However, if a cause can be identified, this may guide treatment. When describing dystonia by the cause, it may be characterized as primary, secondary, or dystonia-plus:

Primary Dystonia

The word primary describes a case in which the dystonia is the only neurological disorder that the person has. Primary dystonias include some genetic forms (such as DYT1 dystonia in which a gene has been identified) and forms for which a cause is not usually found (such as most focal dystonias).

Secondary Dystonia

Secondary dystonias result from apparent outside factors and can be attributed to a specific cause such as exposure to certain medications, trauma, toxins, infections, or stroke.

Spinal cord injury, head, and peripheral injury are also recognized contributors to dystonia. Other examples of secondary dystonias include drug-induced dystonias and dystonias- associated with cerebral palsy, cerebrovascular disease, cerebral infections and post-infectious states, stroke, encephalitis, brain tumor, and toxins.

Dystonia-plus

Sometimes dystonia occurs along with symptoms of other neurological disorders or has a particular quality that resembles another disorder. These forms may be put in a category called dystonia-plus.

How Is dystonia treated?

Because each case of dystonia is unique, treatments must be highly customized to the needs of individuals. Physicians may combine approaches, including the following:

- Botulinum neurotoxin, a biological product, is injected into specific muscles where it acts to relax the muscles and reduce excessive muscle contractions. Botulinum toxin injections are most common for focal dystonia.
- Oral medications: There are many medications that have been shown to improve dystonia.
- No single drug works for every individual, and several trials of medications may be necessary to determine which is most appropriate for you. Working with your physician to determine the drugs best suited for your case may be challenging, but finding the right drug(s) can result in a dramatic improvement in symptoms.
- In severe cases, several surgical techniques including deep brain stimulation (DBS) may be offered.
- Complementary therapies such as daily relaxation and breathing techniques may also be beneficial. It is best to consult your doctor to discuss the best treatment options for your unique circumstances.

Is dystonia life-threatening?

For the overwhelming majority, dystonia does not shorten life expectancy and is not fatal. In severe generalized dystonia that affects many body areas, problems can arise that are secondary to the dystonia and require emergency care. These circumstances can be life-threatening if not treated, for example if breathing or heart function is compromised. However, these instances are quite rare and usually treatable. Dystonia does occur as a symptom of many degenerative disease, some of which do impact mortality, but the dystonia itself does not shorten life span.

Forms of Dystonia

Doctors use these classifications to guide diagnosis and treatment. Forms of dystonia include:

Focal dystonias affect a specific group of muscles or body parts, including:

- **Blepharospasm** affects the muscles of the eyelids and brow.
- **Cervical dystonia** affects the neck and sometimes the shoulders.
- **Oromandibular dystonia** (cranial dystonia) includes forceful contractions of the face, jaw, and/or tongue.
- **Spasmodic dysphonia** (laryngeal dystonia) affects the vocal cords.
- **Hand dystonia** (writer's cramp) affects the fingers, hand, and/or forearm.
- **Lower limb dystonia** affects the leg, foot, and/or toes.

Musicians' dystonias are task-specific dystonias sometimes given this name because constant use of various muscles and movements can contribute to dystonia among musicians related to their performance.

Early-onset generalized dystonia (DYT1 and non-DYT1) is characterized by twisting of the limbs and torso.

Dopa-responsive dystonia refers to a group of dystonias that respond to a medication called levodopa.

Myoclonus dystonia is a hereditary form that includes prominent jerk-like movements called myoclonus.

Paroxysmal dystonias and dyskinesias involve episodic abnormal movements which occur only during attacks.

X-linked dystonia-parkinsonism is a hereditary form of dystonia (also called Lubag disease) that includes symptoms of parkinsonism.

Rapid-onset dystonia-parkinsonism is a hereditary form of dystonia that includes symptoms of parkinsonism.

Secondary dystonias are forms triggered by factors such as trauma, medication exposure and toxins.

- **Trauma:** Dystonia may follow trauma to the head and/or to a specific area of the body.
- **Drug-induced** (Tardive dystonia & dyskinesias): Specific drugs can cause dystonia.
- **Neurological and metabolic disorders:** Dystonia can occur as a symptom of multiple disorders such as stroke and Parkinson's disease.

Psychogenic dystonia is secondary to psychological/ psychiatric causes or an underlying pain syndrome.

How do I explain dystonia to someone else?

Dystonia can be a very difficult thing to explain to others, but it is very important. Having the support of loved ones is a critical part of living well with dystonia. Providing your family and friends with the information included in this brochure may help them understand what dystonia is and how it can be treated. Talking about dystonia is an inherently personal choice, and one only you can make for yourself.

Support is available

You are not alone. Across Canada there are many resources—support groups, movement disorder neurologists, and the DMRF Canada. Contact us and we will help you get connected to the appropriate point of contact. One of the most enriching resources for a patient and for their family members are support groups—this allows individuals to grow in confidence, knowledge, and helps them deal with the difficulties of dystonia while being amongst their peers. Becoming involved in the dystonia community in turn makes you a champion to create change.

Here are some other ways for you to get support and stay connected:

http://www.dystoniacanada.org/findsupport

Follow us on Facebook :
https://www.facebook.com/DMRFC/

Follow us on Reddit:
https://www.reddit.com/r/Dystonia/

Follow us on Twitter:
https://twitter.com/dystonia_canada

◯ **Yes, I want to learn more about joining a local support group.**

Please provide an email address:

_____

For more information visit **www.dystoniacanada.org/support** or contact us at **1-800-361-8061**