

What is the Cause?

The cause of dystonia is not known at this time. Scientists believe dystonia symptoms result from improper signals in the nervous system that cause muscles to contract involuntarily. Researchers and doctors do not yet fully understand the neurological mechanisms that cause this abnormal muscle contraction.

Blepharospasm may be *primary* (meaning that it is the only apparent neurological disorder a person has, with or without a family history), or be brought on by *secondary* causes such as physical trauma.

Primary blepharospasm may develop spontaneously with no known family history or may be inherited. Some people with blepharospasm have family members with dystonia affecting different body areas.

Secondary blepharospasm may occur due to drug exposure, brain injury, or in association with disorders such as parkinsonian syndromes and Wilson's disease.

What Is DMRF Canada?

The Dystonia Medical Research Foundation Canada (DMRFC) is a registered non-profit Canadian charity. DMRFC funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families. DMRF Canada works in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partners with the Canadian Institute of Health Research (CIHR) in funding excellent dystonia research in Canada.

For more information on DMRF Canada or dystonia, contact:

Dystonia Medical Research Foundation Canada

PO BOX 1009 STN TORONTO DOM
TORONTO ON M5K 1P2

Email: info@dystoniacanada.org

Phone: 416.488.6974

Toll Free: 800.361.8061

Charitable Registration Number 12661 6598 RR0001

www.dystoniacanada.org

Special thanks to Aleksandar Videnovic, MD, MSc of Northwestern University, Feinberg School of Medicine for reviewing this publication.

Created and produced by DMRF (United States)

© Dystonia Medical Research Foundation 2010

This brochure was made possible through a generous grant from Ipsen Biopharmaceuticals Canada Inc.



Blepharospasm DYSTONIA OF THE EYES & BROW



What is Blepharospasm?

Blepharospasm is a form of dystonia, a neurological movement disorder. Blepharospasm produces patterned, repetitive muscle contractions in the eyelid and brow muscles. This results in increased blinking and involuntary closing of the eyes. People with blepharospasm have normal vision, but the forced closure of the eyelids or repetitive blinking may interfere with sight. This sight impairment can affect walking, driving, reading, and other everyday activities.

Blepharospasm may be referred to as a “cranial dystonia.” Cranial dystonia is a broad description for any dystonia that affects the face and head.



Are There Different Forms or Varieties?

Blepharospasm is a particular form of dystonia. As described above, blepharospasm may be primary or secondary. Symptoms vary from mild blinking to sustained, forced closure of the eyes.

When blepharospasm occurs with dystonia in the face or jaw (oromandibular dystonia), the term *Meige's syndrome* may be used. In such cases, spasms of the eyelids are accompanied by jaw clenching or mouth opening, grimacing, and/or tongue movements.

What Treatments are Available?

One of the most effective treatments for blepharospasm is regular botulinum neurotoxin injections to the affected muscles. It is unfortunate that a therapy that has improved the lives of countless individuals with blepharospasm and other dystonias cannot shed the term “toxin” from its name. Understandably, this idea of injecting a “toxin” into the body may cause concern.

Botulinum neurotoxin injections have decades of research demonstrating that they are a safe and effective medical therapy. Botulinum neurotoxin has been approved for use in Canada since 1990. Injections for blepharospasm were among the earliest medical uses.

Oral medications—including clonazepam, lorazepam, and trihexyphenidyl—are helpful in some cases.

If botulinum neurotoxin injections and medications are not effective, myectomy surgery in which portions of muscle are removed may also alleviate symptoms in some patients. Botulinum neurotoxin injections may or may not be required following myectomy surgery.

Many individuals find personal tricks and techniques that lessen symptoms. These may include wearing sunglasses (especially oversized wrap or shield styles) to reduce light sensitivity, rubbing the eyelids, speaking, and/or placing the hand to the face.

How is This Likely to Change or Progress Over Time?

Symptoms of blepharospasm may begin with increased blinking due to light sensitivity or a sensation of irritation in the eye. Blepharospasm almost always affects both eyes, but may begin in one eye. Symptoms may progress slowly. Symptoms are typically worsened by stress and may improve after sleep. Some individuals develop sensory tricks to temporarily relieve symptoms such as gently touching the face, rubbing the eyes, or speaking.

How is This Going to Affect My Daily Life?

Living successfully with blepharospasm is possible. The early stages of onset, diagnosis, and seeking effective treatment are often the most challenging. The symptoms may vary from mild to severe, and symptoms often fluctuate from day to day. Individuals must learn to adapt to the changes in vision or reduced vision due to eye closure, and this may require learning new ways to do daily activities.

Individuals living with blepharospasm are strongly encouraged to:

- Seek out the best medical care.
- Educate yourself about dystonia and treatment options.
- Develop a multi-layered support system of support groups, online resources, friends, family, and mental health professionals, if needed.
- Investigate complementary therapies.
- Get active within the dystonia community.

What Kind of Doctor Treats Blepharospasm?

The kind of doctor who is typically qualified to diagnose and treat blepharospasm is a neurologist who specializes in movement disorders. Certain ophthalmologists and neuro-ophthalmologists may also treat blepharospasm.

Diagnosis of blepharospasm is based on information from the affected individual and the physical and neurological examination. At this time, there is no test to confirm diagnosis of blepharospasm, and in most cases assorted laboratory tests are normal.

Blepharospasm should not be confused with conditions such as ptosis, blepharitis, or hemifacial spasm.

What Support is Available?

The Dystonia Medical Research Foundation Canada (www.dystoniacanada.org) can provide educational resources, self-help opportunities, contact with others living with blepharospasm, volunteer opportunities, and connection to the greater dystonia community. The Foundation offers support groups throughout the country and online social forums.