### What is Blepharospasm?

Blepharospasm is a form of dystonia, a movement disorder. Blepharospasm causes involuntary muscle contractions in the eyelid and brow muscles. The repetitive muscle contractions may be subtle and result in mild blinking, or more robust and cause sustained, forced closure of the eyes. People with blepharospasm have normal vision, but the forced closure of the eyelids may interfere with sight.

## How do Symptoms Change or Progress Over Time?

Symptoms of blepharospasm may begin with increased blinking, light sensitivity, a sensation of eye irritation or dry eyes, or a foreign body sensation. Blepharospasm almost always affects both eyes, but may begin in one eye. Symptoms are typically worsened by stress and may improve after sleep. Some individuals discover "sensory tricks" which are movements or gestures that temporarily relieve symptoms such as gently touching the face, rubbing the eyes, or speaking.

### What is the Cause?

Experts believe dystonia results from excessive signals arising from the brain that cause muscles to contract inappropriately. However, the exact reason why the brain delivers these excessive signals is not completely understood.

Blepharospasm may result from drug exposure, brain injury, or disorders such as parkinsonian syndromes and Wilson's disease. In many cases, there is no identifiable cause.

#### What is the DMRF?

The Dystonia Medical Research Foundation (DMRF) is a 501(c)3 non-profit organization that has served the dystonia community since 1976. The DMRF funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families.

The DMRF can put you in touch with others with dystonia for networking and support.

## To learn more about dystonia and the DMRF, contact:

## Dystonia Medical Research Foundation

One East Wacker Drive, Suite 1730 Chicago, Illinois 60601-1980

**Phone:** 312-755-0198 **Toll free:** 800-377-DYST (3978)

Email: dystonia@dystonia-foundation.org

**Web:** www.dystonia-foundation.org Connect with the DMRF on Facebook, Twitter, and YouTube

Special thanks to Andres Deik, MD for reviewing the content of this brochure.

# **Blepharospasm** DYSTONIA OF THE ..... EYES & BROW YSTONIA

### **Are There Different Types?**

Blepharospasm may occur in association with dystonia of the face or jaw (oromandibular dystonia) in what is known as *Meige's syndrome*. In such cases, spasms of the eyelids are accompanied by jaw clenching or mouth opening, grimacing, and/or tongue movements.

### **What Treatments are Available?**

The most effective treatment for blepharospasm is regular botulinum neurotoxin injections to the affected muscles. Although a medication with the word "toxin" in it may seem confusing, botulinum neurotoxin injections have decades of research and clinical experience demonstrating that they are safe and the most effective therapy available. Botulinum neurotoxin has been approved for use in the United States since 1989, and has improved the lives of countless individuals with dystonia.

Botulinum neurotoxin injections for blepharospasm typically include multiple injection sites applied around the eyes and brows. The most common side effects from the injections are the development of droopy eyelids or double vision, both of which are temporary. Although injections are administered with an extremely fine needle, ecchymosis ("black eyes") may rarely occur because the delicate tissues surrounding the eyes bruise easily. This typically resolves within days, with minimal treatment such as cold or warm compresses. In experienced hands, botulinum neurotoxin injections have extremely low incidences of side effects.

Oral medications—including clonazepam, lorazepam, and trihexyphenidyl—can be helpful in select cases.

In cases that do not respond to other treatments, myectomy surgery in which portions of muscle are removed may be attempted. However, botulinum toxin injections may still be needed following the surgery, and the procedure's benefits may not be permanent.

Accessories that may lessen symptoms include dark glasses (particularly wrap-around style sun glasses with additional side coverage), frames with FL-41 tinted lenses, or eyelid crutches.

# How is This Going to Affect My Daily Life?

Living well 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.
- Learn 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 type of doctor that is typically trained to diagnose and treat blepharospasm and other dystonias is a neurologist with special training in movement disorders, often called a movement disorder specialist. Neuro-ophthalmologists, ophthalmologists, and other health care providers may also diagnose and treat blepharospasm, depending on their training and experience. Individuals are encouraged to confirm that the health care professionals they consult have specific training and experience in treating blepharospasm.

The diagnosis of blepharospasm relies on the ability of a qualified healthcare professional to recognize the symptoms and rule out other possibilities. Blepzharospasm should not be confused with conditions such as ptosis, blepharitis, or hemifacial spasm.

### What Support is Available?

The Dystonia Medical Research Foundation (DMRF) can provide educational resources, self-help opportunities, contact with others living with blepharospasm, volunteer opportunities, and connection to the greater dystonia community.