

## Patient Handouts



# Blepharospasm

## What is blepharospasm?

Blepharo means "eyelid." Spasm means "uncontrolled muscle contraction". The term blepharospasm ['blef-a-ro-spaz-m] can be applied to any abnormal blinking or eyelid tic or twitch resulting from any cause, ranging from dry eyes to Tourette's syndrome to tardive dyskinesia. The blepharospasm referred to here is officially called benign essential blepharospasm (BEB) to distinguish it from the less serious secondary blinking disorders. "Benign" indicates the condition is not life threatening, and "essential" is a medical term meaning "of unknown cause". It is both a cranial and a focal dystonia. Cranial refers to the head and focal indicates confinement to one part. The word dystonia describes abnormal involuntary sustained muscle contractions and spasms. Patients with blepharospasm have normal eyes. The visual disturbance is due solely to the forced closure of the eyelids.

Blepharospasm should not be confused with:

- Ptosis - drooping of the eyelids caused by weakness or paralysis of a levator muscle of the upper eyelid
- Blepharitis - an inflammatory condition of the lids due to infection or allergies
- Hemifacial spasm - a non-dystonic condition involving various muscles on one side of the face, often including the eyelid, and caused by irritation of the facial nerve. The muscle contractions are more rapid and transient than those of blepharospasm, and the condition is always confined to one side.

## How does blepharospasm begin?

Blepharospasm usually begins gradually with excessive blinking and/or eye irritation. In the early stages it may only occur with specific precipitating stressors, such as bright lights, fatigue, and emotional tension. As the condition progresses, it occurs frequently during the day. The spasms disappear in sleep, and some people find that after a good night's sleep, the spasms don't appear for several hours after waking. Concentrating on a specific task may reduce the frequency of the spasms. As the condition progresses, the spasms may intensify so that when they occur, the patient is functionally blind; and the eyelids may remain forcefully closed for several hours at a time.

## What causes blepharospasm?

Blepharospasm is thought to be due to abnormal functioning of the basal ganglia which are situated at the base of the brain. The basal ganglia play a role in all coordinated movements. We still do not know what goes wrong in the basal ganglia. It may be there is a disturbance of various "messenger" chemicals involved in transmitting information from one nerve cell to another. In most people blepharospasm develops spontaneously with no known precipitating factor. However, it has been observed that the signs and symptoms of [dry eye](#) frequently precede and/or occur concomitantly with blepharospasm. It has been suggested that dry eye may trigger the onset of blepharospasm in susceptible persons. Infrequently, it may be a familial disease with more than one family member affected. Blepharospasm can occur with dystonia affecting the mouth and/or jaw (oromandibular dystonia, Meige syndrome). In such cases, spasms of the eyelids are accompanied by jaw clenching or mouth opening, grimacing, and tongue protrusion. Blepharospasm can be induced by drugs, such as those used to treat Parkinson's disease. When it is due to antiparkinsonian drugs, reducing the dose alleviates the problem.

## What are the current forms of therapy?

**Botulinum toxin injections.** Botulinum toxin is an approved treatment for blepharospasm and hemifacial spasm in the United States and Canada. This is a toxin produced by the bacteria *Clostridium botulinum*. It weakens the muscles by blocking nerve impulses transmitted from the nerve endings of the muscles. When it is used to treat blepharospasm, minute doses of botulinum toxin are injected intramuscularly into several sites above and below the eyes. The sites of the injection will vary slightly from patient to patient and according to physician preference. They are usually given on the eyelid, the brow, and the muscles under the lower lid. The injections are carried out with a very fine needle. Benefits begin in 1 - 14 days after the treatment and last for an average of three to four months. Long-term follow-up studies have shown it to be a very safe and effective treatment, with up to 90 percent of patients obtaining almost complete relief of their blepharospasm. Side effects include drooping of the eyelid (ptosis), blurred vision, and double vision (diplopia). Tearing may occur. All are transient and recover spontaneously. Providing the dose is kept small and the injections carried out at a minimum of three-month intervals, repeated treatments remain effective over a long period of time.

Patients and physicians should familiarize themselves with the most current Contraindications, Warnings, Precautions and Adverse Effects on the product inserts and the manufacturers' sites. One point particularly worth noting is that botulinum toxin may be contraindicated for patients with any type of condition that causes muscle weakness.

**Oral medications.** Given the marked benefit of botulinum injections, the use of oral medications for the treatment of blepharospasm and other cranial dystonias has garnered little interest from clinical researchers over the past 15 years. Most pharmacological treatments for neurological and other medical disorders can be characterized as symptomatic. However, there is growing interest in developing medications to prevent disease onset and slow disease progression.

Evaluating the effects of medications in individual patients must be tempered by consideration of drug-drug interactions, drug dosage, etiology of blepharospasm (primary versus secondary), the occurrence of spontaneous remissions, and duration of treatment. Moreover, it is likely that blepharospasm is biologically/genetically heterogeneous. Consequently, what works for one patient may not work for another! Overall, however, a significant fraction of patients with blepharospasm and/or other forms of cranial dystonia will benefit from trihexyphenidyl, clonazepam, or baclofen.

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**Surgery.** Before surgery is recommended, patients are advised to try safe, potentially efficacious, nonsurgical therapy such as botulinum toxin injections. Functionally impaired patients with blepharospasm who have not tolerated or responded well to medication or botulinum toxin are candidates for surgical therapy. At present, protractor myectomy (removal of some or all of the muscles responsible for eyelid closure ) has proven to be the most effective surgical treatment for blepharospasm. Current experience has found that myectomy has improved visual disability in 75-80% of cases of blepharospasm.

**Supportive forms of treatment.** Stress makes all movement disorders, including blepharospasm, worse. Some patients may benefit from a course of stress management from an occupational therapist. Patients learn their own coping techniques, which they share with others at support group meetings. Dark glasses are the commonest aid. They fulfill two functions. They reduce the intensity of sunlight, which bothers many people with blepharospasm, and they hide the eyes from curious onlookers. Unless

the patient is receiving treatment that is effective, he/she is at risk for becoming socially isolated. This fear of sustained spasms occurring while driving, crossing the road, socializing, walking, or taking part in some sporting activity, etc. becomes overwhelming, and the patient stays at home in familiar, safe surroundings. Support from family and friends is important. Thousands of persons are experiencing the same symptoms. The [Benign Essential Blepharospasm Research Foundation](#) has support groups throughout the U.S. and one in Canada. Sharing experiences at support group meetings will reassure a patient and his/her family. Up-to-date treatments and medical advances are also presented at support group meetings and an annual conference. The [Dystonia Medical Research Foundation](#) has support groups throughout the U.S and Canada for persons with all types of dystonia - not just blepharospasm.

The Benign Essential Blepharospasm Research Foundation was established by a Blepharospasm-Meige patient, Mattie Lou Koster. The Foundation was granted its charter in 1981. Its purpose is *"...to undertake, promote, develop and carry on the search for the cause and a cure for benign essential blepharospasm and other related disorders and infirmities of the facial musculature..."*

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Benign Essential Blepharospasm Research Foundation. Botulinum Toxin for Treatment of Blepharospasm. Available at: <http://www.blepharospasm.org/botulinum.html>. Accessed February 4, 2009.

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