



# NANOS

# Patient

# Brochure

# Blepharospasm

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## Benign Essential Blepharospasm (BEB)

Blepharospasm describes any forceful or frequent blinking, which at times can be a normal reaction to very bright lights, eye drops that burn, a foreign body irritating the eye, or dry eyes. Benign Essential Blepharospasm (BEB) is a specific disorder which occurs when the eyelids display this forceful and frequent blinking without an obvious environmental cause. BEB affects about 10 out of every 100,000 people. It affects more women than men, and it tends to occur in middle age. "Benign" indicates that the condition is not life threatening, and "essential" means that it occurs on its own without an obvious cause.

In BEB, symptoms usually develop over a few years then stabilize. Many patients find the symptoms very bothersome. As the condition progresses, spasms occur more frequently during the day and can interfere with the patient's ability to do ordinary tasks such as driving, reading, shopping, and walking. The eyelids may remain forcefully closed for seconds, minutes, or even hours. The spasms do not occur in sleep, and some people find that after a good night sleep, the spasms do not recur for several hours. Many patients develop sensory tricks such as gum chewing, whistling, humming, or singing that enable them to keep their eyes open in order to drive or read. BEB often worsens with bright lights, fatigue, stress, or movement (such as driving). The diagnosis of BEB may be missed or delayed for years while doctors look for other causes of excessive blinking, such as dry eyes.

Many patients with BEB also have dry eyes so artificial tear drops may provide some relief. Specially tinted lenses (called FL-41 lenses) can help to alleviate some of the light sensitivity. The most effective therapy for BEB is botulinum toxin injection into the muscles around the eyes.



Untreated BEB



Botox Injection Sites



After Botox Treatment

## Meige Syndrome

Patients with BEB have spasms of the eyelids. Some patients will also have spasms and other involuntary movements of the rest of the face and neck. These movements can include lip pursing, chin thrusting, and grimacing. When these parts of the face and neck are involved it is called "Meige Syndrome" or oromandibular dystonia. This, too, is treated with botulinum toxin.

## Botulinum Toxin

Therapeutic botulinum toxin is the most effective treatment for BEB and many similar disorders. A drop of the medicine is injected under the skin at affected sites on both sides of the face. The injections take effect over the next few days, relaxing and weakening the little muscles just underneath the skin, preventing spasms. Most neuro-ophthalmologists and some neurologists perform botulinum toxin injections. The injections are performed in the doctor's office and usually take 10-15 minutes. The effect wears off in about 3 months, after which the injections must be repeated. Most patients have no side effects from the injections, however, some experience minor bruising at the injection sites, temporary eyelid drooping, or double vision. There are several different types of botulinum toxin, which are marketed under the trade names Botox®, Xeomin®, Dysport®, and Myobloc®. Often, which type of botulinum toxin is used depends on your doctor's preference.

## Apraxia of Eyelid Opening

Apraxia of eyelid opening (AEO) is a condition in which the patient has difficulty opening the eyelids. AEO is commonly associated with BEB. A patient with BEB and AEO will typically have difficulty re-opening the eyes after a spasm forces them closed. Patients with AEO might elevate their brows or even use their fingers to open their eyelids. Just as BEB reflects a problem in the part of the brain responsible for closing the eyelids, AEO is caused by a problem with the part of the brain responsible for opening the eyelids. Botulinum toxin may not be completely successful in treating AEO.

## **Frequently Asked Questions**

*Can I catch botulism from the botulinum toxin shots?*

No. Botulinum toxin is injected under the skin and does not affect the rest of the body. The small amount of botulinum toxin injected is a fraction of the dose that causes botulism.

*Do the shots hurt?*

Botulinum toxin is injected through a very tiny needle to avoid pain. Most patients report only mild discomfort lasting seconds.

*Are there medications that can be taken by mouth for BEB?*

Oral medications have been used for BEB, but they are only helpful in about 15% of patients. In addition, their effect is often short lasting and associated with side effects.

*Is there a cure for BEB?*

No, there is currently no cure for BEB.

*What other resources may be available for patients with BEB?*

For further information on support groups for patients with facial spasms, you may visit the Benign Essential Blepharospasm Research Foundation (BEBRF) website at <http://www.blepharospasm.org>.