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BEBRF Founder

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dir-s@blepharospasm.org

For further information, contact:

BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION

P. O. Box 12468 • Beaumont, TX 77726-2468, USA
(409) 832-0788 • Fax (409) 832-0890
E-Mail: bebrf@blepharospasm.org
WEBSITE: <http://www.blepharospasm.org/>

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BENIGN ESSENTIAL BLEPHAROSPASM



QUESTIONS AND ANSWERS

Cranial Dystonia

• **Blepharospasm**
Eyelid muscle spasms

• **Oromandibular Dystonia**
Meige
Lower facial and jaw spasms

QUESTIONS AND ANSWERS

- Q** What are the early symptoms of benign essential blepharospasm?
- A**
- Dry eyes
 - Light sensitivity
 - Occasional increased blinking, winking or squinting
 - First symptoms are often noticed when driving
- Q** How do the symptoms of benign essential blepharospasm or oromandibular dystonia (Meige) progress?
- A**
- Increased blinking, squinting, or forced eyelid closure
 - Eyelids clamp shut and eyebrows pull down
 - Symptoms may become so severe that the patient becomes functionally blind
 - May develop lower facial problems such as grimacing of the mouth
 - May develop breathing problems
- Q** What type of doctor treats blepharospasm?
- A** Neurologists, neuro-ophthalmologists, ophthalmologists and oculoplastic surgeons. However, look for one that treats blepharospasm and has experience injecting botulinum toxin.
- Q** What treatments are available for benign essential blepharospasm?
- A**
- Botulinum toxin injections
 - Medical (drug) treatment
 - Surgery (myectomy)
- Q** What is botulinum toxin?
- A** Botulinum toxin is currently the treatment of choice for blepharospasm. When injected into muscles, it temporarily weakens them. It is approved for use in over 60 countries. Blepharospasm patients in the U.S. are currently injected with the following FDA approved botulinum toxins:

See table in next column

Botulinum Toxin	Type
Botox ® (onabotulinumtoxinA)	A
Xeomin ® (incobotulinumtoxinA)	A
Dysport ® (abobotulinumtoxinA)	A
Myobloc ® (rimabotulinumtoxinB)	B

- Q** What is the procedure for a botulinum toxin treatment and what results should I expect?
- A** Using a very fine needle, several injections of botulinum toxin are made around the eyes directly into muscles that are contracting excessively. Positive effects of the treatment for blepharospasm are often seen within about 3 days of botulinum toxin treatment and the maximum effect is often achieved 2-3 weeks after injection. Results from one treatment can last up to 3 months.
- Q** Will botulinum toxin injections make it possible for me to perform activities as before the onset of blepharospasm/Meige?
- A** It's hard to say. The severity of blepharospasm and the response to botulinum toxin treatment is not the same for everyone.
- Q** Is a botulinum toxin treatment painful?
- A** There can be momentary pain during each injection. Some are bothered by the pain more than others. EMLA cream (a prescription topical anesthetic) can be placed on the area approximately 1-1/2 hours prior to injection and may be helpful. A cold compress (or a bag of frozen peas) applied to the injection site before the injections may also be helpful.
- Q** What is the usual botulinum toxin dosage?
- A** There is not a standard dose as each patient is different, the types of dystonia vary, and botulinum toxin comes in various forms. Most physicians start injecting with a low dosage to avoid possible side effects, increasing it as needed. If the first set of injections is not satisfactory, the physician should be notified so that he/she can personalize the treatments to suit the individual patient.

Q What are the possible side effects of botulinum toxin treatment?

- A**
- Temporary drooping of the eyelids (ptosis) may partially obscure vision
 - Eye irritation, dry eyes, tearing, or light sensitivity
 - Occasional blurry or double vision
 - Side effects are usually mild and short in duration

Q What should I do if I'm not getting good results from my botulinum toxin treatment?

- A** Discuss it with your injecting physician. A change of sites or dosage may be needed. If he/she is not willing to work with you, or if after several attempts at solving the issues, you're still not satisfied, you may need to go to a different physician.

Q Is there anything I can do to make the botulinum toxin treatment more effective?

- A** Keep a diary with the following information:
- When injected
 - Number of units
 - When it kicked in
 - Side effects
 - How long it lasted

Communicate honestly with your doctor.

Q What are some reasons for having unsuccessful results from botulinum toxin injections?

- A**
- Incorrect reconstitution of the toxin by the injector
 - Insufficient dosage
 - Injection site selection
 - Injection technique
 - Apraxia of eyelid opening (inability to keep eyelid open in absence of spasms)

Q Can I develop antibodies from botulinum toxin injections?

- A** As a rule, patients who receive treatment only for blepharospasm do not develop antibodies.

Q Is botulinum toxin treatment covered by Medicare and medical insurance?

A Injections should be covered (to some extent) by Medicare and private insurance. Through their Patient Assistance Programs, Allergan (BOTOX®/ onabotulinumtoxinA), Merz Pharmaceuticals, LLC (Xeomin®/ incobotulinumtoxinA), and Solstice Neurosciences (Myobloc®/ rimabotulinumtoxinB) are dedicated to supporting patients who are subject to financial hardships. Some of the Patient Assistance Programs do not apply to patients on Medicare. For information, contact:

Allergan (BOTOX®/ onabotulinumtoxinA) Botox Patient Assistance Program (uninsured and underinsured)

- Phone: 1-800-442-6869 from 9am to 8pm (ET), Monday thru Friday
- Online: <http://www.botoxreimbursement.us>

Merz Pharmaceuticals, LLC (Xeomin®/ incobotulinumtoxinA) Patient Assistance Program (uninsured) and Patient Co-Pay Program (co-pay assistance)

- Phone: 1-888-493-6646 from 8 am to 8 pm (ET), Monday thru Friday
- Online for Patient Co-Pay Program only: <http://www.xeomin.com>

Solstice Neurosciences (Myobloc®/ rimabotulinumtoxinB) Patient Reimbursement Program (financial hardship)

- Phone: 1-888-461-2255, 9am to 6pm (ET), Monday thru Friday
- Online: <http://www.myobloc-reimbursement.com>

Q Do any drugs help benign essential blepharospasm?

A Drugs used to treat benign essential blepharospasm require a prescription and physician supervision. It requires trial and error to find a drug that helps. Some of these drugs may have severe side effects, may lose effectiveness over time, and may be addictive. When stopping these drugs, under a doctor's supervision, they must be tapered off and not stopped abruptly.

Q What are the names of drugs that may help benign essential blepharospasm?

A The following drugs are helpful to some when used in conjunction with injections. This is not a complete list.

Generic Name	Brand Name	Drug Type
Clonazepam	Klonopin	Antiepileptic
Lorazepam	Ativan	Anxiolytic
Diazepam	Valium	Anxiolytic
Trihexiphenadyl	Artane	Anticholinergic
Baclofen	Lioresal	Antispastic
Carbamazepine	Tegretol	Anticonvulsant
Diphenhydramine	Benadryl	Antihistamine

BEBRF does not advocate any particular drug treatment option; therefore, it is strongly suggested that patients do not change medications without first consulting with their physician.

Q Are there drugs that may make blepharospasm worse?

A There are some drugs belonging to a class called "dopamine receptor blocking agents" (DRBAs) that may aggravate blepharospasm and lower facial and jaw spasms.

Q Will my insurance company pay for myectomy surgery?

A Before proceeding with this treatment option, check with your insurance company to be sure that they will pay for it. If not covered by insurance, the full out-of-pocket cost for a myectomy may be surprisingly high and may vary from facility to facility.

Q What are some things you can do to relieve the symptoms of benign essential blepharospasm?

- A**
- Wear sunglasses (type that wrap around to cut wind and glare)
 - Wear a hat with a brim
 - Sit facing away from windows
 - Wear tinted lenses
 - Place warm or cold compresses on the eyes
 - Use sensory tricks (talk, sing or hum, touch temple or forehead)
 - Concentrate on a hobby or non-stressful activity

Q Can benign essential blepharospasm be inherited?

- A**
- A gene for blepharospasm has NOT been identified.
 - 5% of patients with blepharospasm have family members that have facial movement disorders (95% don't).
 - It is possible that there may be some "predisposition" for blepharospasm that can be inherited, but it has not been identified.

Q Is it possible for someone with benign essential blepharospasm to have a spontaneous remission?

A Complete remissions have been reported but they are rare. Sometimes temporary remission occurs.

Q Is benign essential blepharospasm a psychiatric disorder?

A No! It is a neurological disorder. It is sometimes misdiagnosed as a psychiatric disorder.

Q What can I do to help relieve dry eye symptoms?

A It may take some experimenting to find out what works for you.

- Artificial tears
- Moisturizing gels or ointments
- Warm or cold compresses on the eyes
- Fish oil or flaxseed oil supplements
- A humidifier
- Dr. Soparkar's video under "Dry Eyes and Blepharospasm" at <http://www.blepharospasm.org>

Q I need to apply for disability. What should I do?

A BEBRF has a packet of material available at no charge for those patients who are considering filing for Disability under the Social Security Act. This packet does not include disability application forms. These forms may be obtained directly from Social Security or filled out online at www.socialsecurity.gov/disabilityonline