

**Benign Essential
Blepharospasm,
Meige, and other
related disorders**



**Information for Patients,
Families, Friends, and Doctors**

BENIGN ESSENTIAL **BLEPHAROSPASM** RESEARCH FOUNDATION

The purpose of BEBRF 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...”* (Mattie Lou Koster, Founder)

The Foundation is the only organization solely dedicated to finding the cause and a cure for blepharospasm and Meige (oromandibular dystonia). It is a volunteer non-profit organization that relies entirely on public and private charitable contributions. *It is not endowed or supported by federal or local governments.**

FOREWORD

Although benign essential blepharospasm (BEB) was first described in a North American medical journal in 1895, only in recent years have physicians begun to recognize it as a physical (as distinct from psychological) disorder. It is often misdiagnosed because of a relative lack of awareness among physicians. Neurologists, neuro-ophthalmologists, and ophthalmologists are the exceptions. A number of doctors are dedicated to the fight against BEB/Meige and other related disorders, and they assist the Foundation in promoting awareness, thereby enabling other doctors to recognize and identify the symptoms more easily.

We understand that individual patients will want their personal questions answered by their doctors. However, this booklet was written to empower patients by offering them information and help to cope with BEB, Meige (oromandibular dystonia) and hemifacial spasm. Although BEB and Meige (oromandibular dystonia) cannot be cured at this time, there are effective treatments that reduce the symptoms and permit sufferers to maximize their productivity.

***BEBRF is an Exempt Organization under Section 501 (c) 3
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RESEARCH FOUNDATION**

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WHAT IS BENIGN ESSENTIAL BLEPHAROSPASM (BEB)?

Blepharospasm, a form of focal* dystonia, is a chronic, unremitting, bilateral (both eyes), forcible closure of the eyelids. It is a variably progressive neurologic dysfunction in the motor control center of the brain. It is due to involuntary muscle contractions caused by misfiring of neurons within the central nervous system and involves the fifth and seventh cranial nerves.

WHAT DOES BEB MEAN?

Benign means not fatal.

Essential, in medical terms, means of unknown cause.

Blepharo is derived from a Greek word meaning eyelid.

Spasm means involuntary, forceful contraction of muscles.

Little is known about the cause of BEB and related disorders at this time. On this basis, “essential” blepharospasm seems to be as appropriate as any other designation so far proposed. Essential blepharospasm is an involuntary spasmodic blinking or squinting that is not due to a primary eye disorder.

WHAT IS MEIGE SYNDROME? (oromandibular dystonia)

Meige is also a form of dystonia of unknown cause. It is referred to as cranial dystonia and oromandibular dystonia. There is a difference of opinion among physicians on whether Meige is an extension of BEB or a separate syndrome.

Meige may involve muscle spasms around the eyes, lower face, mouth, tongue, throat, neck and sometimes the respiratory system, any one of which may affect the voice.

* for other focal dystonia definitions, see Glossary on page 16

WHAT ARE THE SYMPTOMS OF BEB?

In the beginning a patient may feel that his/her problem is merely an annoying "habit" and may fail to seek immediate medical attention. Early symptoms of BEB may be occasional increased winking, blinking or squinting of both eyes, or simply an increasing difficulty in keeping the eyes open.

Light sensitivity (photophobia) and dry eye seem to be symptoms with most blepharospasm patients.

If the condition progresses, eyelid spasms become increasingly frequent until they are unremitting. Both eyelids may clamp shut and the eyebrows pull down. All cases do not have the same symptoms.

This condition is usually progressive in the sense that the periods of spasms may become more frequent and the periods of relaxation shorter. However, in some cases, the patient's spasms reach a plateau and remain at that level with no further progression.

WHO GETS BEB/MEIGE?

The most common starting age for symptoms is in the forties to sixties, though a few patients have been diagnosed in their twenties, and some in their seventies. About two or three women are affected to every one man. Estimates of incidence vary from 1 in 10,000 to 1 in 25,000.

IS BEB/MEIGE HEREDITARY?

There is no proven scientific data available on this important topic at this time. However, there are some families in which more than one person has BEB/Meige or other forms of dystonia. This suggests that there is at least a genetic predisposition in some families.

WHAT ARE THE EFFECTS OF BEB/MEIGE?

The spasms may increase in frequency and duration until a patient becomes functionally blind. Facial spasms may become more severe, interfering with speech or eating. The ability to drive, read and watch television, or perform other necessary daily activities can become increasingly difficult.

HOW IS BEB/MEIGE DIAGNOSED?

There is no specific test at this time for diagnosing BEB, Meige and related disorders. When seeking diagnosis from a knowledgeable physician, the physician will take the patient's history and make a determination based on his/her experience. Dr. Giovanni DeFazio at the University of Bari in Bari, Italy and Dr. David Peterson of the University of California San Diego are currently working on the development of a new clinical rating scale that will be used worldwide to help in the diagnosis and measurement of severity of patients with blepharospasm.

BEB/MEIGE — WHAT CAN BE DONE ABOUT IT?

While it is true that there is no known cure at this time for BEB and Meige, there is hope. Treatment aimed at relieving the symptoms of the disorder may be effective. The overall goal of treatment is to help the patient maintain a useful and satisfying lifestyle and help both the patient and the family cope with the disorder and the possible limitations it imposes.

The Benign Essential Blepharospasm Research Foundation (BEBRF) provides encouragement to patients through educational materials and direct personal contact. Through a web of District Directors, State Coordinators, Area Representatives and Support Groups, patients are directed to medical centers where these conditions are treated. Also, the Foundation provides a central clearing house for the distribution of printed informational material, CDs and DVDs relating to blepharospasm, Meige and hemifacial spasm as needed by patients and physicians. An Internet Web site provides up-to-the-minute information, links to other related sites and a bulletin board, which serves as an international support group. A quarterly newsletter is sent to thousands of patients and medical professionals; BEBRF support group meetings are held each year in different geographical areas. BEBRF raises funds through public and private contributions for the research necessary to find the cause and a cure for blepharospasm and Meige.

HOW IS BEB/MEIGE TREATED?

The Foundation does not endorse any drugs or surgical procedures. We simply report the current modes of treatment.

Neurological Approach: This approach has been limited primarily to drug therapy. Use of such drugs as trihexyphenidyl (Artane), clonazepam (Klonopin), baclofen (Lioresal), lorazepam (Ativan) and others have been reported with limited success. Occasionally, short lived responses are seen. However, some of these drugs may cause severe side effects. The efforts of neurological investigators give hope to sufferers of BEB/Meige and related disorders.

Botulinum Toxin Injections: This is currently the treatment of choice for BEB. Small amounts of botulinum toxin are injected into the muscles around the eyes. The injections temporarily weaken the muscles so that forced closure is more difficult. The effect of the injections wears off in weeks or months and repeated injections may be required. BOTOX®* and Xeomin®* (Botulinum toxin A) were approved by the FDA for the treatment of blepharospasm. Many people have been successfully treated for years with this approach. Dysport®*

(botulinum toxin A) and Myobloc® (botulinum toxin B) were approved by FDA for the treatment of cervical dystonia, however they may be used off label to treat BEB/Meige. Botulinum toxins may be contraindicated for patients with conditions that cause muscle weakness.

Surgical Approach: The following surgical procedures are used with variations:

Myectomy: The most commonly used surgical procedure is a “myectomy” whereby some, or all, of the squeezing muscles around the eyes are removed. This approach is reserved for patients who have failed with both drug therapy and botulinum toxin.

Modified or Partial Myectomy: This surgery is less drastic and your physician may recommend this as an alternate procedure. Botulinum toxin injections may still be needed after a partial or modified myectomy.

Investigational Treatment: Deep brain stimulation (DBS): A surgical treatment involving the implantation of a medical device called a brain pacemaker, which sends electrical impulses to specific parts of the brain.

Acetyl Hexapeptide-8 (AH-8), which is the active ingredient in a number of cosmetic creams used to treat wrinkles, is being studied to see if it can extend the life of botulinum toxin injections.

Other Treatments include bio-feedback, acupuncture, hypnosis, relaxation techniques, chiropractic, and nutritional therapy. No proven scientific data is available on these treatments.

* for the generic names of botulinum toxins, see page 16

WHAT IS APRAXIA OF EYELID OPENING?

Apraxia of eyelid opening associated with blepharospasm is the most common cause for failure or minimal improvements with botulinum toxin. These patients have difficulty opening their eyelids even after the spasms of the eyelids have been reduced by botulinum toxin. They use their brows, forehead, neck and face to try to help open the eyelids. After eyelid spasms, a time lag is required before the eyelids will open and the eyelids may again droop closed without obvious spasm.

HOW IS APRAXIA OF EYELID OPENING TREATED?

Myectomy and ptosis repair are the treatments that can provide significant relief for apraxia of lid opening. Botulinum toxin cannot be injected in the central portion of the upper eyelid without inducing ptosis (droopy eyelids). If the orbicularis muscle (squeezing muscle of the eyelid) still has even minimal function in the upper eyelid then the levator muscle (elevating muscle of the eyelid) cannot contract and elevate the eyelid. Removing the upper eyelid orbicularis muscle (myectomy) and tightening the tendon of the levator muscle (ptosis repair) greatly help most of these patients. Frontalis suspension or

frontalis sling (placing a sling from the eyelid to the brow muscle to help raise the eyelid with brow elevation) is a last resort and is only required in approximately 10% of patients with blepharospasm and apraxia of lid opening.

WHAT IS HEMIFACIAL SPASM?

Hemifacial spasm is not a form of dystonia. Hemifacial spasm is a unilateral (one side of the face), involuntary contraction of the facial musculature. It usually begins with a twitching around one eye. At this stage, it can be, and very often is, misdiagnosed as benign essential blepharospasm. The twitching and contraction of the facial muscles slowly progresses and advances down the face to include the musculature of the cheek, the mouth, and the neck. Rarely is the musculature above the eyebrow involved. In atypical hemifacial spasm, the onset of spasm starts in or around the mouth/lip area rather than in the eye area. In most instances, it is curable through surgery.

WHAT CAUSES HEMIFACIAL SPASM?

Hemifacial spasm is believed to be caused by a small arterial loop pressed against the seventh (facial) nerve where it exits the brain stem. In rare cases, it can be caused by a small tumor or aneurysm compressing the nerve. An MRI is run to rule out these rare causes.

HOW IS HEMIFACIAL SPASM TREATED?

Therapies include drug therapy, botulinum toxin injections, or microvascular decompression (MVD) surgery. In this surgical procedure, using microsurgical techniques, the surgeon places a pad between the nerve and the blood vessel in an attempt to inhibit the cause of the spasm.

WHAT CAN YOU DO IF YOU HAVE BEB, MEIGE OR RELATED DISORDERS?

Your attitude toward the disorder will be one of the most important factors in deciding how it affects you. It will not kill you, but if you let it get you down, it may spoil your life. It is quite natural, when you learn of the nature of your disorder, to go through stages of shock, anger, despair and depression. Acceptance may take time. Until a more effective treatment is discovered, people with BEB/Meige and related disorders must learn that it is they who still control their lives rather than allowing the symptoms to control them. Contacting other patients who have successfully adopted this philosophy and attending support group meetings are great motivational assets to newly diagnosed BEB/Meige patients as well as to those who are still struggling for acceptance. Remember, help is available. After all, happiness and beauty come from within.

WHAT RESOURCES ARE AVAILABLE TO BEB AND MEIGE PATIENTS?

The BEBRF:

- Maintains a list of highly qualified scientists, neurologists and ophthalmologists who are seriously interested in these problems and are actively participating in treating the symptoms of these disorders.
- Assists patients in finding doctors who treat BEB/Meige or hemifacial spasm.
- Publishes quarterly newsletters and informational pamphlets. Other materials are available upon request.
- Maintains a medical video, CD and DVD lending library as well as audio tapes from past conferences. These are provided to keep patients and doctors informed on the newer therapies available. Many of these can be viewed and downloaded at the BEBRF web site: **www.blepharospasm.org**
- Makes available to patients and doctors a publication containing patient stories entitled, "Patients' Stories, Volume 2."
- Holds symposiums so that BEB, Meige, and hemifacial spasm patients, their families, and doctors who treat these disorders will have the opportunity to expand their knowledge. (See page 17 for a listing.)
- Maintains a web site: www.blepharospasm.org that provides both up-to-date information on blepharospasm/Meige and hemifacial spasm and a forum (bulletin board) where patients can talk to one another about various aspects of these disorders. This has developed into an online support group. The BEBRF email address is: bebrf@blepharospasm.org
- Holds area support group meetings across the U.S. These groups are a source of considerable help for sharing information, experiences and encouragement. Volunteer State Coordinators, Area Representatives and District Directors help make these support groups possible (See page 9 for list of District Directors). A District Director represents each of the three districts in the United States, coordinating activities and offering support.

RAISING AWARENESS

The BEBRF is represented at the American Academies of Neurology, Ophthalmology, Movement Disorders, and Neuroscience meetings/congresses each year. Our goal at these meetings is: to create a greater awareness of BEB, Meige and hemifacial spasm and the BEBRF, and to promote research through the dissemination of materials and conversations with neurologists, ophthalmologists, researchers and investigators from around the world.

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RESEARCH

STEPS TOWARD RESEARCH...

BEBRF WORKSHOPS: Five major medical workshops to assess current knowledge and to promote research have been held.

BEBRF is working with other dystonia groups to help solve the mystery of dystonia by participating in a brain tissue collection at the Harvard Brain Tissue Resource Center at the McLean Hospital in Massachusetts (HBTRC). The Harvard Brain Bank is responsible for collecting, preserving, and distributing human tissues to qualified scientific investigators who are conducting important dystonia research. Since the majority of scientific research studies can be carried out on a very small amount of tissue, each donated brain provides a very large amount of tissue that can be used by many different researchers at institutions throughout the U.S. and the world.

Meetings between representatives of the National Institutes of Health (NIH), National Institute of Neurological Disorders and Stroke and research scientists have been held.

An epidemiology study of BEB and Meige was done by John G. Nutt, M.D., Oregon Health Sciences University, Portland, OR in conjunction with Leonard Kurland, M.D., Mayo Clinic, Rochester, MN.

Padma Mahant, M.D. and Mark Stacy, M.D. Phoenix, AZ, (now in Greenville, NC) conducted a study to develop a genetic database of BEB and Meige patients. Elizabeth Ulrich Peckham, D.O., the first Mattie Lou Koster Fellow, conducted genetic research with blepharospasm/Meige patients. Other neurotoxins are being investigated.

Pharmacological research in the use of drug therapy has been conducted by a number of investigators. Positron Emission Tomography (PET) scan studies are being used in an effort to identify the site of the brain abnormality. Functional Magnetic Resonance Imaging (fMRI) studies were also conducted.

The BEBRF is in partnership with the Dystonia Coalition and the Global Dystonia Registry to advance clinical research on primary focal dystonias (BEB and Meige are focal dystonias).

HIGHLIGHTS OF RESEARCH GRANTS FUNDED BY BEBRF

(For complete listing of Research Grants, contact BEBRF Office)

1985 - **Botulinum Toxin Injections to Relieve BEB-Meige and Related Disorders**, Joseph Jankovic, M.D., Baylor College of Medicine, Houston, TX (First research grant funded by BEBRF).

1990 - **Sensorimotor Processing in Benign Essential Blepharospasm**, Joel S. Perlmuter, M.D., Washington University School of Medicine, St. Louis, MO. "Mattie Lou Koster Scholar."

1992 - **PET Studies of Patients with Blepharospasm and Meige Syndrome**, John C. Mazziotta, M.D., Ph.D., U.C.L.A. School of Medicine, Los Angeles, CA. "Mattie Lou Koster Scholar."

1995 - **Clinical Research - Closed International Brainstorming Seminar**, Mark Hallett, M.D., National Institute of Neurological Disorders and Stroke, Bethesda, MD (Chairman, Medical Advisory Board). Representing 6 foreign countries and the US, 38 doctors attended. Funded by the Mattie Lou Koster Research Fund.

2000 - **Clinical Research - Closed International Brainstorming Seminar**, Mark Hallett, M.D., National Institute of Neurological Disorders and Stroke, Bethesda, MD. Representing 5 foreign countries and the US, 40 doctors attended. Funded by the Allergan Foundation.

2001 - **Risk Factors and Familial Occurrence of Blepharospasm**, Padma Mahant, M.D., Barrow Neurological Institute, Phoenix, AZ

2003 - **Novel Immunotoxin Therapy for Muscle Spasm Disorders**, Andrew R. Harrison, M.D., Stephen Christiansen, M.D., and Linda K. McLoon, Ph.D., University of Minnesota, Minneapolis, MN

**2004 - Mattie Lou Koster Fellowship Established Elizabeth Ulrich Peckham, D.O., under the following Mentors:

Andrew Singleton, M.D., and Mark Hallett, M.D., NIH, Bethesda, MD, Characterization and Collection of Families With Blepharospasm: Facilitating the Identification of Genetic Defect(s) Causing Blepharospasm

2004 - **FL-41 Tinted Spectacles in the Management of Blepharospasm**, Bradley J. Katz, M.D., Ph.D., and Kathleen B. Digre, M.D., University of Utah, Salt Lake City, UT

2004 - **Study of Cerebral Glucose Metabolism and Benzodiazepine Receptors in Patients With Essential Blepharospasm**, Motohir Kiyosawa, M.D., Tokyo Metropolitan Institute of Gerontology, Tokyo, Japan

2006 - Clinical Research - Closed International Workshop, Mark Hallett, M.D., Chairman, Houston, Texas. Representing 6 foreign countries and the US, 35 doctors attended.

2007 - **Whole Genome Association Studies to Identify a Blepharospasm Gene**, Laurie J. Ozelius, Ph.D., Mt. Sinai School of Medicine, New York, NY

2008 - **Subthalamic Nucleus Deep Brain Stimulation for the Treatment of Cranial-Cervical Dystonia (Meige Syndrome)**, Jill L. Olstrem, M.D. and Philip A. Starr, M.D., Ph.D., University of California San Francisco, CA.

2010 - **Potentiating Botulinum Toxin A Effectiveness Using Co-Treatments**, Andrew Harrison, M.D., Linda McLoon, Ph.D., and Michael Lee, M.D., University of Minnesota, Minneapolis, MN

2010 - **Development and Validation of Clinical Diagnostic Guidelines and a Novel Severity Rating Scale for Primary Blepharospasm**, Giovanni Defazio, M.D., University of Bari, Bari, Italy (in partnership with the Dystonia Coalition)

2011 - **Identification of a Primary Blepharospasm Gene Using Exome Sequencing**, Tatiana Fuchs, Ph.D. and Laurie Ozelius, Ph.D., Mt. Sinai School of Medicine, New York, NY

2013 - **Corneal Mechanisms of Pain During Photophobia**, David R. Copenhagen, M.D., University of California, San Francisco.

2013 - **A Novel Treatment for Benign Essential Blepharospasm**, L. Craig Evinger, PhD, Stony Brook University, Stony Brook, NY

2013 - **Neural Mechanisms of Reflexive Blinking and Eye Muscle Spasms in Blepharospasm: An event-related fMRI study**, Brian Berman, M.D., MS, University of Colorado Denver, Denver, CO

2013 - **Neuropathology of Blepharospasm**, H. A. Jinnah, M.D., PhD, Emory University, Atlanta, GA

2014 - **Pharmacology of the Modulation of the Eye Blink Reflex Probed by High-Speed Two-Photon Calcium Imaging**, Quoc Nguyen, PhD, NeurAccel Biosciences, San Diego, CA

2014 - **Genetics of Blepharospasm**, Mark S. Ledoux, MD, PhD, Univ. of Tennessee, Memphis, TN,

2014 - **Combined Effects of rTMS and BotulinumToxin in Benign Essential Blepharospasm**, Aparna Wagle Shukla MD, University of Florida, Gainesville, FL

2015 - **Diagnostic & Rating Scales for Blepharospasm**, Dystonia Coalition Project, Atlanta, GA

2017 - **Improving the Diagnosis of Blepharospasm and Related Disorders**, H. A. Jinnah, M.D., PhD, Emory University, Director of the Dystonia Coalition

2018 - **Longitudinal Analysis of Patients with Blepharospasm**, Alfredo Berardelli, Giovanni Defazio, Giovanni Fabbrini, and Antonella Conte, Sapienza University of Rome, Italy

2019 - **Non-invasive inhibitory neurostimulation for the treatment of blepharospasm: A pilot study**, Brian Berman, M.D., MS, University of Colorado

** Funded by NIH

Our knowledge continues to increase through research studies.

WHAT IS THE ORIGIN OF THE FOUNDATION?

In 1981, the Benign Essential Blepharospasm Research Foundation was established by a blepharospasm patient, Mattie Lou Koster, out of her distress over a lack of interest, information and treatment of blepharospasm. Her prime objective was "to undertake, promote, develop and carry on the search for the cause and a cure for BEB, Meige and other related disorders." BEBRF, with its headquarters in Beaumont, Texas, was granted its charter on July 23, 1981. The following months were spent enlarging the Board of Directors, appointing a Medical Advisory Board and organizing, studying and preparing materials and plans for future growth.

Doctors became more aware and joined forces with BEBRF to implement the program of the Foundation. One year after the Foundation started, a seminar was held in Houston, Texas. In attendance were 40 doctors from various sections of the country and BEB and Meige patients from 26 states. Now, BEB, Meige and hemifacial spasm patients, their families and the doctors who treat these disorders have the opportunity to expand their knowledge by attending BEBRF Symposiums. The symposiums are held in various locations throughout the country. The latest medical information is presented by outstanding doctors (see page 17 for a current list of symposiums).

The first two years of the Foundation were committed to awareness programs and in subsequent years, additional emphasis was on research of BEB, Meige, treatment options, blink reflex and the brain. Today, we continue the challenge to search for the cause and a cure for these disorders.

SUMMARY

BEB, Meige and hemifacial spasm are variably incapacitating disorders and a matter of deep concern for many people. This creates much frustration and anxiety for patients and their families. In addition, the possible disability of these patients as workers, family members and citizens becomes society's loss.

Medical science continues to seek answers to these problems. In the meantime, the patients are not forgotten. As noted in this booklet, there are measures to help patients and their families in coping with these difficulties, and the patients have access, through the Foundation, to current information as it is developed.

With such help, patients can realistically approach the future. Eventually, a treatment or cure will be found. In the meantime, the work of the Foundation continues within the limitations of present knowledge. Patients are encouraged to live each day as fully as possible. Much progress is being made in the awareness of these little known conditions, both nationally and

internationally. As this base is broadened, prospects for a cure increase and hope is nurtured.

DRUGS THAT MAY EXACERBATE BEB/MEIGE

Editor's Note: This drug list is intended to provide information only. We do not advocate any particular treatment option. Therefore, it is strongly suggested that patients do not change their method of treatment without first consulting with their physician.

Drugs belonging to a class called "dopamine receptor blocking agents" (DRBAs) can cause dystonia, including blepharospasm and Meige. The following is a list of such drugs:

Generic	(Trade Names)
Acetophenazine	(Tindal®)
Amoxapine	(Asendin®)
Chlorpromazine	(Thorazine®)
Fluphenazine	(Permitil®, Prolixin®)
Haloperidol	(Haldol®)
Loxapine	(Loxitane®, Daxolin®)
Mesoridazine	(Serentil®)
Metoclopramide	(Reglan®)
Molindone	(Lindone®, Moban®)
Perphenazine	(Trilafon® or Triavil®)
Piperacetazine	(Quide®)
Prochlorperazine	(Compazine®, Combid®)
Promazine	(Sparine®)
Promethazine	(Phenergan®)
Risperidone	(Risperdal®)
Thiethylperazine	(Torecan®)
Thioridazine	(Mellaril®)
Thiothixene	(Navane®)
Trifluoperazine	(Stelazine®)
Triflupromazine	(Vesprin®)
Trimeprazine	(Temaril®)

A complete listing of drugs that may exacerbate BEB/Meige is on file at the BEBRF office.

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GLOSSARY

- apraxia of the eyelids** - difficulty in opening the eyes in absence of spasms.
- blepharitis** - inflammation of the eyelids and lash line.
- botulinum toxin** - a toxin derived from bacteria which, when injected into muscles, temporarily weakens the injected muscles.
- **BOTOX**® (onabotulinumtoxinA)
 - **Dysport**® (abobotulinumtoxinA)
 - **Xeomin**® (incobotulinumtoxinA)
 - **Myobloc**® (rimabotulinumtoxinB)
- blepharoplasty** - also known as eyelid lift is an aesthetic and reconstructive procedure which removes excess skin and muscle from the eyelids to sometimes improve vision and/or appearance. In aesthetic cases, fat may be removed or actually added to enhance the appearance.
- dystonia** - a movement disorder that causes the muscles to contract and spasm involuntarily.
- forms of focal dystonia** -
- **cervical** - (spasmodic torticollis) - Involuntary spasms resulting in abnormal pulling of neck muscles
 - **cranial** - combination of blepharospasm and Meige (oromandibular dystonia)
 - **laryngeal** - (spasmodic dysphonia) - involuntary spasms in the larynx area causing a tight, strained voice or breathy, whispering voice
 - **oromandibular** - (Meige Syndrome) - involuntary muscle spasms of the lower face and jaw and possibly tongue protrusion
 - **focal hand dystonia** (writer's cramp)
- EMLA and betacaine** - topical anesthetic creams that can be used prior to botulinum toxin injections.
- epidemiology** - science of the causes and natural history of disease
- etiology** - cause of disorder
- exacerbate** - to intensify, aggravate or worsen
- genetic** - hereditary
- Idiopathic** - cause unknown
- myectomy** - surgical procedure to remove some, or all, of the squeezing muscles of the eyelids.
- ptosis** - prolapsed or drooping of the upper eyelid
- syndrome** - a group of signs or symptoms that indicate a disorder
- tonic spasm** - constant, unceasing

NOTES

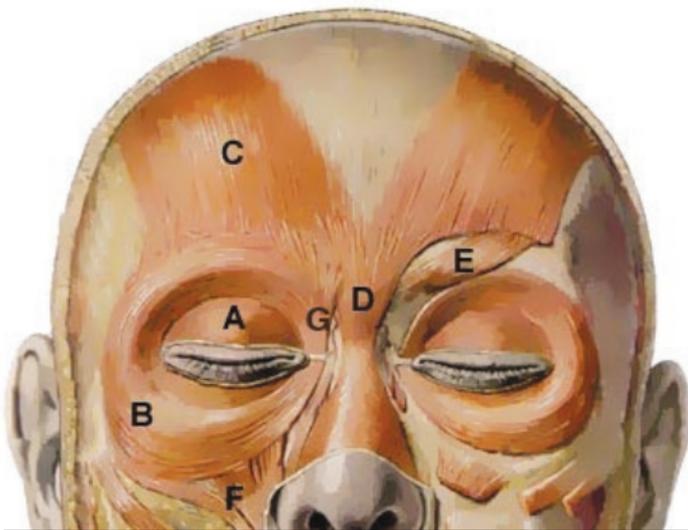
BEBRF STATE COORDINATOR

BEBRF AREA REPRESENTATIVES

LOCAL DOCTOR

LOCAL SUPPORT GROUP MEETINGS

THE EYELID AND FACIAL MUSCLE



A	Orbicularis Muscle (palpebral portion) - Both upper and lower eyelid closing muscle
B	Orbicularis Muscle (orbital portion surrounding the eye) – Eyelid closing muscle
C	Frontalis Muscle – Forehead muscle
D	Procerus Muscle – Muscle that lowers brows
E	Corrugator Muscle – Muscle that brings brows together
F	Midfacial Muscles – Muscles of the cheek
G	Depressor Superciliaris Muscle – Important in BEB as it lowers brow.

Note: The **preseptal orbicularis** is located between **A** and **B** on the above chart. The **pretarsal orbicularis** is located closer to the lid margin (eyelashes) in **A** on the above chart.

If you have other questions about BEB,
Meige or hemifacial spasm,
please contact:

**BENIGN ESSENTIAL BLEPHAROSPASM
RESEARCH FOUNDATION**

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