3. Management with surgery

Surgery as a treatment for BEB should be considered only after all other options have been exhausted. You might want to ask the BEBRF for the names of other patients who have had this procedure and are willing to speak with you.

**Types of surgery for blepharospasm:** full myectomy, limited myectomy, punctal plugs, blepharoplasty, ptosis repair, brow pin

**Type of surgery for hemifacial spasm:** microvascular decompression

- How effective/successful is this procedure? Are there side effects from this surgery?
- Will I still need BoNT injections? The same dosage?
- What next if this does not solve the problem?
- Will I be able to close my eyes completely?

D. Things to consider after the first visit:

- Were you comfortable with the doctor?
- Did he/she treat you with respect?
- Were your questions answered and/or did you feel rushed?
- If you’re considering surgery, do you need a second opinion?
- How can you contact the doctor if you have a question between visits?
- Were your questions answered and/or did you feel rushed?
- Did he/she treat you with respect?
- Did you have blurry or double vision? One eye or both?
- Did you get headaches/eye aches? Was it more on one side of your head?
- Did you bruise or swell? Where?
- Did you have dry eyes/watery eyes?
- Did you feel pressure? Were your eyes heavy/tired?
- Did you feel pressure? Were your eyes heavy/tired?
- Did you get headaches/eye aches? Was it more on one side of your head?
- Did you feel pressure? Were your eyes heavy/tired?
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HOW TO TALK WITH YOUR DOCTOR
Communicate with your eyes wide open

DISCLAIMER: Contained here is collected wisdom from both patients and doctors. These steps might assist you in understanding and managing your condition, getting the best treatment(s), and feeling more in control of your situation. However, The Benign Essential Blepharospasm Research Foundation (BEBRF) does not endorse these subject matters for everyone.

Please note: This brochure will use the term “BoNT” in place of the 4 Botulinum NeuroToxins: BOTOX® by Allergan, Xeomin® by Merz, Dysport® by Ipsen, (all 3 are type A) and Myobloc® by Solstice (type B). “BEB” will sometimes be used in place of blepharospasm.

Looking for a doctor? BEFORE your first appointment:

“Call ahead to find the right doctor for you! Choose a physician who has a strong interest in facial dystonias / movement disorders and significant experience injecting BoNT”
— DR. JOHN A. BURNS

Questions to consider asking whether you are a newly diagnosed patient or changing doctors.

Before scheduling a first appointment with the doctor, ask his/her office staff:

- Does this doctor treat many patients with my condition?
- Will your practice accept my health insurance and will it cover the procedure I need (injections, surgery)?
- How does the doctor schedule BoNT injections—a particular day of the week, when patient needs it?
- Face a mirror or get someone else to do it.
- Shine a light into your eyes to eliminate shadows; this will tend to stimulate spasms.

A diagnosis is established not with tests or x-rays but rather with professional observation and discussion of symptoms.
- Identify your symptoms. When and how do they show themselves?
- Briefly mention your prior history of eye symptoms, eye & mouth/tooth surgeries, current & past medications, other illnesses, previous medical issues (such as Bell’s Palsy)
- Is there any family history of BEB/Meige, dystonia, Parkinson’s, or other neurological disorders?
- Are you aware of any environmental exposures preceding the onset?

B. How are your daily activities affected?
- Driving
- Reading
- Watching TV
- Using computer
- Other

C. Management of Symptoms
Three treatments are available: 1. BoNT injections, 2. Oral medications, 3. Surgery

1. Management with BoNT (Treatment of choice)
   a. How effective is this treatment and is it safe?
   b. How long should the effects last?
   c. What are the side effects?
   d. Do you give a general starter dose or do you individualize?
   e. What is the probability of controlling my symptoms?
   f. Is there any family history of BEB/Meige, dystonia, Parkinson’s, or other neurological disorders?

2. Management with oral medications
Before BoNT injections, oral medications and surgery were the only treatments available. Today, a few patients choose to use oral meds solely. Others choose to use them as a supplement to injections. Individual patients experience different levels of success.

   a. How effective is this treatment? How long can I stay on this medication?
   b. What are the long term and short term risks? Is it addictive?
   c. What are the side effects (sleepy / tired, weight gain or loss, memory loss, mood swings, focusing, etc.) vs. the benefits of this drug?
   d. What is the starting dose and schedule for taking it?
   e. When did the BoNT start wearing off?
   f. If this drug doesn’t help me, are there others for me to try?
   g. How long before I see the benefit?
   h. Is there a generic substitute for this drug that I can use?
   i. Is there any family history of BEB/Meige, dystonia, Parkinson’s, or other neurological disorders?