

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 does the procedure entail? How long does it take? Recovery time? Follow-up? Is it reversible?
- 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?

Subsequent visits:

Talk with your doctor at each visit. Offer feedback so that he/she will know what adjustments to make, if necessary.

"The more specific the patient is with her/his observations, the more likely the physician can appropriately place the injection for optimal results."

— DR. JOHN A. BURNS

Document your symptoms.

Keep a daily diary/journal of your ups and downs, behaviors and questions. Some doctors prefer an outline or calendar as it is easier for them to review during an appointment. Take this with you to your next doctor appointment to help you remember specifics and help the doctor adapt to your needs. Things to include:

- Varying eye responses and symptoms from day to day
- Activities that might have influenced the reaction in your eyes such as a stressful incident; exposure to windy day or bright lights; bad pollen day; etc.
- Your reactions to the injections:
 - How fast / slow did the BoNT start working? When did it "kick in?"
 - Could you open/close your eyes properly? Did the medication work "too well" – could not close eyes completely possibly causing irritation and dry eye? Did the injections not work well enough – could not open your eyes?
 - Are there areas that seem to pull when the spasm begins?
 - Are there locations where you experienced pain? When (time of day, after what activities)?
 - Did you bruise or swell? Where?
 - Did you have blurry or double vision? One eye or both?
 - 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 experience dry eyes / watery eyes?
 - How long were the injections effective? When did they start wearing off? When did they totally wear off?
 - For your next injection cycle-should I have returned sooner / later?
 - Take a video / photo to show progression and recession of the toxin (see previous video notes)

Ask the doctor for a copy of his/her notes from each visit. Many medical practices now allow you to view them online. The notes

will be helpful should you later need to apply for Social Security Disability or document for insurance purposes.

Next steps:

- If you are not getting the relief desired or improved quality of life after repeatedly adjusting injection doses and locations, talk with your doctor about other options such as changing brand of BoNT; increasing frequency of injections, if doctor and insurance allow it; introducing oral medications; or surgery.
- Share your point of view while remembering to be courteous. Your doctor needs to know what's working and what's not. He/she can't read your mind, so it is imperative for you to share. Mention if you feel rushed, worried, or uncomfortable. Try to voice your feelings in a positive way. For example, "I know you have many patients to see, but I'm really worried about this. I'd feel much better if we could talk about it a little more." If necessary, you can offer to return for another visit in a few days to discuss your concerns.
- If you believe your doctor is not a good listener and you are still not getting adequate results, you might need to consider changing physicians. Call the BEBRF office for the names of other injecting physicians as well as educational materials, which might help you to move forward.

*A big **THANK YOU** to our Medical Consultants
Dr. Mark Hallett, chair of the BEBRF Medical Advisory Board,
Dr. Richard Anderson, Dr. Brian Berman, Dr. John Burns,
Dr. Stephen Grill, Dr. Neil Miller, Dr. Thomas Oberg
And to all patient contributors!*

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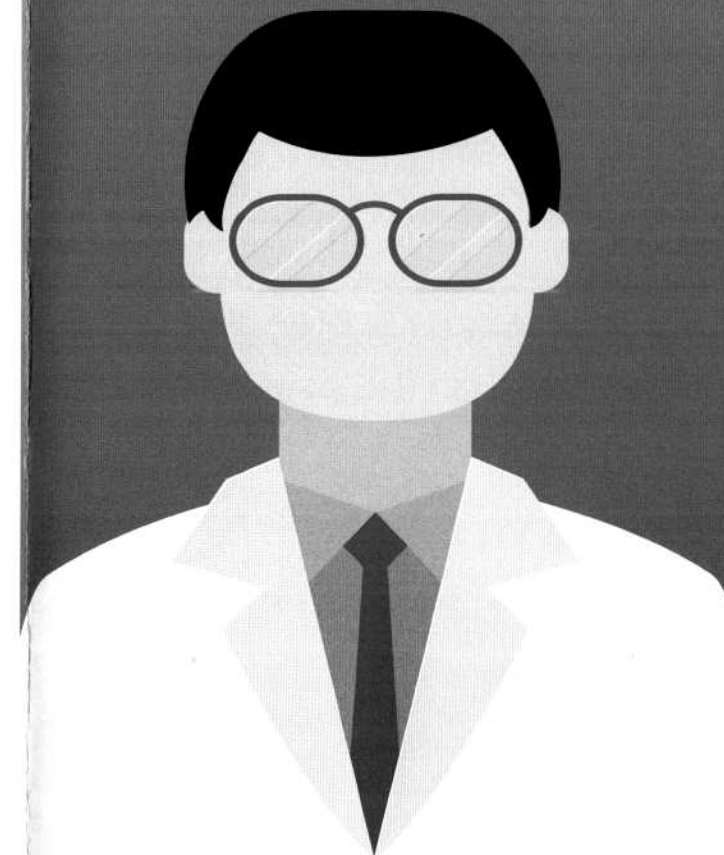
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BEBRF is an exempt organization under Section 501(C)(3). All donations are tax deductible.

Printed December 2015



How to TALK WITH YOUR DOCTOR

Communicate with your eyes wide open

**Benign Essential Blepharospasm
Research Foundation**

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?
- Are there any medical records I should take with me or send ahead of the appointment?

First doctor visit:

Doctors will often want to have a consultation prior to treating you for the first time. This will be the start of your doctor/patient relationship. Compile a list of questions/concerns you have. Always ask questions if you don't completely understand.

- Consider taking someone with you to help describe and hear the discussion.
- If possible, take a video or selfie of you spasming at your worst to show the doctor so he/she can identify exactly which muscles first twitch. (Sometimes you don't spasm in the doctor's office.)
For best results:
 - 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. Be prepared to discuss your Medical history leading up to onset

"When discussing your symptoms, be sure to include all your concerns and, particularly, your fears. The doctor can't help if he doesn't know the problems."

— DR. MARK HALLETT

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 disorder?
- Are you aware of any environmental exposures preceding the onset?

B. How are your daily activities affected?

- Driving
- Reading
- Watching TV
- Using computer
- Walking
- Balance
- Cooking/housework
- 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? What can I expect?
- d. Do you give a general starter dose or do you individualize?
- e. What is the probability of controlling my symptoms?
Location sites and dosage need to be tailored to the individual patient. It may take 2-4 injection cycles to determine what is best for you.
- f. How soon after my first treatment should I return or check-in?
- g. How will you want me to report treatment results so I can think in those terms?

- h. If I wish to be numbed in the injection area with a topical ointment, will you provide me with a prescription? If yes, how much prior to the injection time do I need to apply it?
- i. Will you give me a map of my face with your injection sites identified and amounts at each site written in? Should you ever move or change physicians, this can be used as a base and not have to start all over. Ask for another each time there is a change in your treatment.

If you have you been diagnosed previously with BEB/Meige:

- a. Share your doctor history.
- b. If you were receiving BoNT injections, what brand and how many units were you receiving per eye?
- c. How soon after the injections was there improvement?
- d. How many weeks did the improvements last?
- e. When did the BoNT start wearing off?
- f. Did you experience ptosis, weakness of the muscles, double/blurred vision, or other side effects after injections? For how long?

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? Start on a small dose and adjusted as needed?
- e. How long before I see the benefit?
- f. If this drug doesn't help me, are there others for me to try? Do I need to contact you before I stop taking it?
- g. Is there a generic substitute for this drug that I can use?