BENIGN ESSENTIAL **BLEPHAROSPASM** RESEARCH FOUNDATION

RESEARCH to find a cure. SUPPORT because we care. EDUCATION to enlighten.

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GETTING THE MOST OUT OF YOUR BOTULINUM TOXIN INJECTIONS FOR BLEPHAROSPASM

A BEBRF WEBINAR

On August 26, 2022, BEBRF Executive Director Charlene Hudgins presented a Webinar with the above title. She opened with a disclaimer that she was not a doctor, but through her role with BEBRF, she has spoken with thousands of patients and doctors, and attended hundreds of workshops, webinars, and lectures on blepharospasm. The Webinar was a culmination of all those experiences with the goal for patients to get a better experience out of their botulinum toxin injections. More specifically, **how to help your doctor help you**.

The webinar was designed for: 1) the newly diagnosed, 2) patients who hope to find more success with their on-going injections and 3) patients who once had success with injections but are now experiencing diminishing efficacy.

Many newly diagnosed patients are informed by their doctors that they have an incurable neurological disorder, but "don't worry, there's a treatment that will fix you right up!" Consequently, newly diagnosed patients go into their first injections expecting to completely resume their normal lives, but, sadly, this is not usually the case. There are many variables that affect the success of the injection process.

Newly diagnosed patients should:

- Set realistic expectations of what that first injection cycle is going to be like, which can also be true for long-time blepharospasm patients seeing a new doctor for the first time.
- Realize it may take 4-6 injections cycles to get the correct variables including: 1) injection sites, 2) injection dosage, 3) injection techniques, and 4) botulinum toxin used. There are two types of botulinum toxin currently approved by the FDA for use for blepharospasm – Botox® and Xeomin®. There are two other botulinum toxins available in the United States: Myobloc® and Dystport®, which are not approved for blepharospasm in the US, but are used in other countries. If your doctor decides, for whatever reason, to try Dysport on you, be aware that it will be used "off-label" which means your insurance might not pay for it.

Xeomin and Botox both contain botulinum toxin type A. They have the same active ingredient but there are differences in how they are formulated. Botox contains accessory proteins (just as the botulinum toxin exists in nature). Xeomin, however, has a manufacturing process which strips away these proteins and so contains a "naked" form of botulinum toxin. Xeomin is designed to deliver the toxin without any protein additives. This purified structure may help prevent antibody resistance, a problem that has been seen with some botulinum toxin injections administered over time.

Every time you change doctors, you are starting over on the discovery of the best combination of variables. Working with your doctor is a relationship that builds success over time.

The patient needs to understand these variables so that he/she can help the doctor find the best set of variables. Charlene strongly recommended that you DO NOT 'DOCTOR HOP.' Every time you change doctors, you are starting over on the discovery of the best combination of variables. Working with your doctor is a relationship that builds success over time. The doctor has to learn the patient and his/her needs, and the patient has to learn how to communicate with the doctor. Remember, doctors want to do a good job for you.

Ways you can help your doctor:

- Record a 90 second video of your symptoms on your worst symptomatic day because you probably

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will not look your worst during your appointment. Do not try to narrate your video because the act of narration will probably alter your symptoms. A video ensures your doctor is not relying solely on your verbal description of your symptoms.

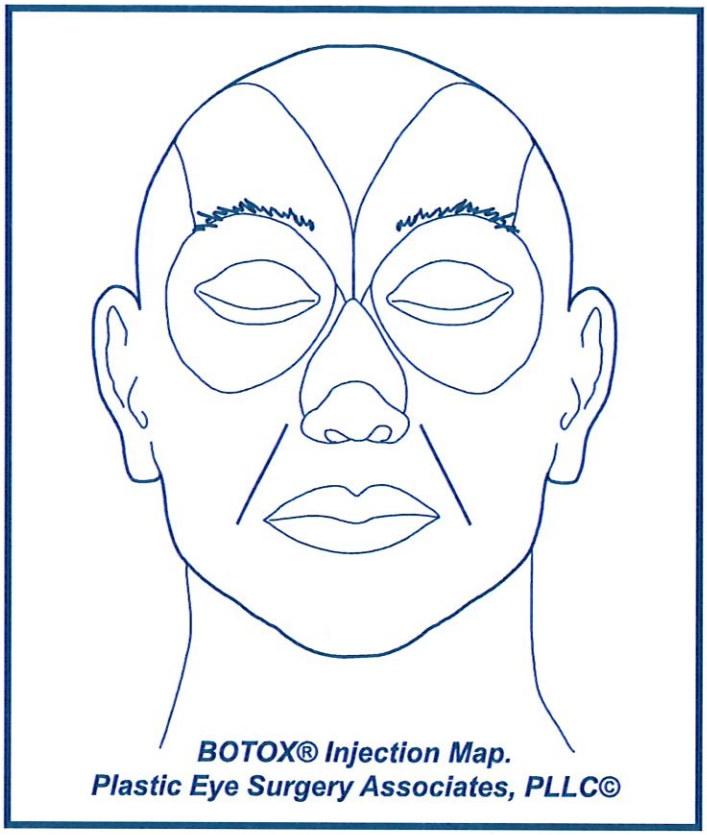
- Leave the injection appointment with a facial map clearly marking each injection site with the dosage at each site. You may obtain blank facial maps from the BEBRF Website, to be discussed later, or by calling the BEBRF office. Be sure to add the appointment's date on that facial map. The map can serve as the first page of your record of this injection cycle.
- Document your injection cycle. Things to consider:
  - o What is the format for your documentation? It is up to the patient, but suggestions include a daily diary or writing important information on a wall calendar. You do this so that you will remember the important things to tell your doctor at the next injection cycle, three months later.
  - o Note side effects – when they came on and how long they lasted. Typical side effects include blurry or double vision, drooping eyelids (ptosis), unusual sinus issues, eyelids that do not close at all, and anything else that is unusual.

Write it all down because if something unusual happens two weeks into your injection cycle, what are the odds you will simply remember the information 2 ½ months later at your next injection appointment? Because your doctor does not have time for you to wade through your journal for the last three months of data in the appointment, review your journal ahead of time and summarize the important findings to tell your doctor.

The most important things to document (to inform dosage amounts):

- When the botulinum toxin kicked in (i.e. The first moment you felt any effectiveness from the injections, remembering that it can take up to two weeks to feel the effects.)
- When the botulinum toxin reached peak effectiveness, if you can tell.
- When the botulinum toxin started to wear off.
- And very importantly when the effects of the botulinum toxin were completely worn off.

The BEBRF Website is helpful to document your injection cycle. It includes injection advice and tips, how to journal and journal formats, common injection patterns and techniques – diagrams and videos, how to get your injections more frequently (a packet of information that your doctor can use to appeal to your insurance carrier to medically justify more frequent injections), how to fill out your injection journal, blank facial maps and a blank injection calendar.



BOTOX® Injection Map.
Plastic Eye Surgery Associates, PLLC©

If you have dry eye, you must be treating it in order for your botulinum toxin injections to have full effectiveness. The incidences of the diagnosis of Extreme Dry Eye (EDE) have tripled in the last decade due to the proliferation of digital devices, and the age of the diagnosis is skewing younger and younger. Consequently, if someone is pre-disposed to have blepharospasm, there may be a coordinating downward age trend for people whose blepharospasm is triggered (as opposed to caused) by EDE. There are all manner of products – lenses, drops, gels, goggles, etc. – to help alleviate dry eye. The BEBRF Website contains several lectures on coping with dry eye under the videos tab.

Doctors differ as to the use of numbing creams prior to the botulinum toxin injections. Some doctors believe that numbing creams diminish the effectiveness of botulinum

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toxin injections whereas others do not. One doctor suggested that if the idea of not using a numbing cream creates an exorbitant level of anxiety in anticipation of pain before the injections, it is better to use the cream than not.

Doctors are also divided on the necessity of boosting the body's zinc supply before injections. Some doctors have stated that they have not seen evidence that zinc has any effect on the injections, while other doctors believe there is a need to build up the body's zinc retention level. They believe the zinc can chemically react with the botulinum toxin in order to spread and adhere where the botulinum toxin needs to be.

A high percentage of adults do not receive enough zinc through their diets, or they eat foods that deplete zinc storage or absorption. In case your body needs zinc to help the botulinum toxin, one option is to take a 50 milligram zinc supplement (not a lozenge which is poorly absorbed, see the Ask the Doctor question on Page 12 of this Newsletter for detailed information about zinc) five days before the injections and the day of the injections.

Another option for zinc is with the diet. There are some foods that deplete the absorption of zinc in the body, and there are some foods that boost and preserve zinc in the body. For the five days before every injection cycle that you are taking the zinc supplement or eating zinc in food, avoid foods made from grains – such as bread, cereal, rice, etc.; avoid nuts of all kind; and avoid legumes. Foods that are good to eat to preserve and boost zinc in the body include turkey (not processed), potatoes, and fruits such as apples, bananas, and pears.

Patients are often confused about which types of doctors treat blepharospasm with injections. Treating doctors include neurologists, ophthalmologists, neuro-ophthalmologists, and oculoplastic surgeons. However, not all doctors in these broad categories of medical practice are familiar with blepharospasm and how to treat it. Not all qualified treating doctors will be movement disorder specialists, and conversely not all movement disorder specialists are experienced in treating blepharospasm specifically. Therefore, the important question to ask a prospective doctor is, "how many blepharospasm patients do you treat?"

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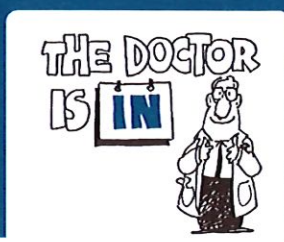
Patients should consider if they have apraxia of eyelid opening. Apraxia is the inability to willfully open your eyes (in the absence of spasms and squeezing), and therefore, the patient begins to overwork the brow (frontalis) muscle in an effort to get the eyes open. A video on injecting for apraxia, which you can download and take to your injecting physician, is available on the BEBRF Website. The 'old school of thought' held that injecting along the lash line (the pretarsal area), especially in the center, would cause ptosis, but recent research has shown that the opposite is true for apraxia, and that injecting in the pretarsal area may work best. If after seeing the video, your doctor is still skeptical about injecting along the lash line, BEBRF can provide you with a research article that demonstrates the efficacy and safety of injecting there.

Is there ever a valid reason to change doctors? While generally discouraging doctor-hopping, there are a few reasons to change doctors. A doctor who will not listen to you or even consider your input may be a reason to change. If the doctor is genuinely listening to you but continues to have no success with the injections over a period of time (4-6 injection cycles), it may be time to look elsewhere.

Newly diagnosed patients often have the misconception that blepharospasm treatment is EITHER botulinum toxin treatments or surgery. This is not the case. The myectomy surgery, where a part of the eyelid muscle is permanently removed, is designed to help your botulinum toxin injections work better. Since the surgical treatment is permanent (and can often have results that can be problematic), it is referred to as the treatment of last resort.

How do you address diminishing effectiveness of injections? Follow the same procedures as a newly diagnosed patient, such as taking a video of your symptoms on your worst symptomatic day. Over time spasms may change the way they manifest, or your face may change with age. The doctor may need to make adjustments using the new video. Ideally, if you saved your video from when you began treatment, the doctor can see the differences between then and now, which can also be helpful.

Due to the constraints of space, the Q & A portion of the Webinar will be presented in the next Newsletter.



ASK THE DOCTOR

Disclaimer: Neither the BEBRF nor members of the BEBRF Medical Advisory Board has examined these patients and are not responsible for any treatment.

Q: You have said that in the days before injections, that a patient should eat turkey to maintain their zinc levels. Do you know of a plant-based protein equivalent for vegetarians?

A: Re This is a great question. As background, all the botulinum toxins require zinc to function. If there is no zinc, then there is no function. The NIH has estimated that half the people in the U.S. over the age of 50 years are zinc deficient based upon diet alone. Choosing a zinc supplement is a little complicated. First, not all zinc compounds are well absorbed. Perhaps the most controversial is zinc picolinate. Zinc picolinate is felt to be the best absorbed, but the binding of picolinic acid to zinc is so tight, that there is a question about how bioavailable the zinc is within tissues. Zinc bisgylcinate or zinc glycinate is a relatively new player on the market, and although the studies show good absorption, the longitudinal experience with this compound is a bit limited. Zinc sulfate is typically the least expensive form of zinc, but it is relatively poorly absorbed and may cause more stomach irritation and nausea. Perhaps the best tolerated forms of zinc with minimal controversy over absorption and availability are zinc citrate and zinc gluconate.

Multivitamins pose another problem. All the divalent cation minerals (iron, calcium, magnesium, zinc, etc.) compete with each other for absorption. Remember the RDA (Recommended Dietary Allowance) developed and updated by the U.S. government? If you are taking a supplement that contains "100% of the RDA for zinc, iron, and calcium," you are most likely not absorbing 100% of anything, because these minerals are all competing with one another for uptake in the intestine.

Do we have to take zinc in a pill? Of course not. Many foods are rich in zinc. Fresh turkey is a favorite, but red meat, chicken, seafood, shellfish (especially oysters), beans, nuts, and whole grains are good sources. The problem is that there are many foods that will bind zinc, so that we can't absorb it. For a more complete list of foods that contain zinc and ones that inhibit its absorption, you may wish to check out this link to our website **https://plasticeyesurgery.com/wp-content/uploads/2021/06/Food-and-Factors-Affecting-Zinc.pdf**

Since legumes, nuts, and whole grains are heavily laden with phytates (a chemical compound that strongly binds zinc and inhibits its absorption), how can we access the zinc from these foods? The answer is destroy the phytates. This can be done in several ways. Soaking foods for 12-18 hours or more in water with a couple of rinses is quite effective in destroying phytates as well as dangerous lectins (a whole other discussion). The longer the soaking time, the more phytates are destroyed, especially if the water is heated at first to about 140 degrees Fahrenheit. Even longer soaking in warm water with the addition of a bacterial starting culture (powdered culture, whey from yogurt with live cultures, kombucha, etc) will result in fermentation, a very powerful disrupter of phytates. Alternatively, after soaking for 12-18 hours, the foods can be rinsed and placed in a sprouter (sprouters are easy to make and inexpensive to buy). Sprouting is an excellent way to break down phytates as well.

Importantly, if you obtain phytate-diminished, zinc-laden foods and then consume them with milk, wine, carbonated soft drinks, or preserved foods, you will inhibit zinc absorption by other methods. (OCuSoft is a company that makes Zytaze, a zinc citrate preparation that contains phytase (an enzyme that efficiently breaks down phytates). The point of this combination is that one can take this supplement with foods that contain phytates, so that a zinc supplement isn't taken on an empty stomach. But like the zinc-laden, phytate-diminished foods, if the supplement is taken with other foods that bind zinc, then the zinc won't be absorbed. Importantly, although I conceived of Zytaze and patented the formulation, I openly licensed the idea to OCuSoft and make no profit from their sales.)

- Charles Soparkar,
Plastic Eye Associates of Houston, TX