

Blepharospasm: suggestions for new patients – 20111107 update

Compiled by Peter Bakalor from suggestions by patients and participants in the BEBRF bulletin board: www.blepharospasm.org/forums/beb.

A set of suggestions for people newly diagnosed with Blepharospasm/BEB – the collected wisdom of the frequenters of this bulletin board.

If you are newly diagnosed with Blepharospasm, the following suggestions come from the many participants on this board, who believe these are important or helpful steps that you can take to assist in getting the best treatment, and in helping you feel more in control of your situation.

It is unfortunately true that many Blepharospasm patients take a number of rounds of treatment to identify their best injection locations and strengths, and much of the following will help you help the doctor get it right. Also, sometimes people have to go to a different doctor, and your notes will help the new doctor adapt to your needs more rapidly.

Proper diagnosis of Blepharospasm is important, and secondary causes like eye irritation, dry eye etc need to be dealt with before one can know if one truly has Benign Essential Blepharospasm. Do the research suggested here, and talk to your doctor to make yourself sure that the diagnosis is correct.

- 1) Keep a diary of some kind that helps you remember what has happened, and how the symptoms and responses to treatment vary from day to day. This can be as simple suits you, but here are a few things to think about tracking
 - a. Spasm frequency: constant; frequent; occasional
 - b. Spasm intensity: uncomfortably strong; strong; medium; light
 - c. Length of time the eyes are closed each time: many seconds, a few seconds, not much
 - d. Other: can you watch TV? Can you read? Can you work on a computer? Can you drive?

(These are things that vary from patient to patient, but that also change during the treatment cycle – and also change from when you first have the symptoms of Blepharospasm, until they settle down to a more constant state after you have had it for a while).

- 2) When you get Botox shots, ask your doctor for a copy of the diagram that they should be making of where your injections are, and what the injection

strength is. There are examples of these diagrams on the BEBRF web site in the photo album, which you can reach via this link to Non-surgical aids page 2: [Injection Diagram examples](#). The [[Photo Albums](#)] link on the bulletin board page, at the top right will get you to the full content of the Photo Album.

3) Take photos, or brief videos, with a camera phone or other camera, to show how the spasms affect you. You might be able to do this by taking the photo while facing a mirror, or you can get someone else to take them for you. These also help the doctor understand what you are going through. Unfortunately many of us cannot replicate what happens at home when we are sitting in the doctor's office.

4) If you have not done so yet, contact the BEBRF (Benign Essential Blepharospasm Research Foundation) by email or by phone - (409) 832-0788; bebrf@blepharospasm.org - and ask to be put on the mailing list for the newsletter, and ask for the new patient information pack.

5) Find out if there is a BEBRF support group in your area, and contact the person that runs it so they know you are there and are interested in what the group is up to. You can find the list of support groups from the web site main page, which will lead you to this link: [BEBRF Support Groups](#)

6) If you find bright lights give you difficulty (usually called photophobia), investigate FL41 coatings for your regular glasses, or for dark glasses. If you use the Find function at the top of the BEBRF bulletin board page, and enter FL41 and a time period of say 180 days, you will get plenty of material to review. You can also find information at [Moran Eye Center](#). Another source is [BPI](#) - BPI are a manufacturer of the tint, and in the US any optician can order the tint from BPI if they don't already carry it.

7) Get to know and understand more about BEB, Meige and HFS from the information on the web site. Explore all the links you can follow from the web site main page - there is a mountain of helpful information there.

8) Check out the books on BEB by doing a search on [Google Books](#) .

9) Post questions on the bulletin board about anything that puzzles you; post a note when you are feeling down, or feel like a pity party; post a note when something good happens - all of these posts are things others have found have helped them - and those that read the postings learn from them too.

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