- For a laptop computer keyboard, spend a few extra dollars and get a backlight behind the keyboard letters. This makes it so much easier to use.
- If you already have a laptop, you can plug in an additional, more desirable keyboard and a larger, free-standing monitor.

F. Using the TV as a Projector Screen

Do you want to show a presentation, document, share resources, video clips and photos, or share BEBRF's website to show how to access our bulletin board for a group, or just work with a much larger monitor? Do you have a laptop or desktop and a TV? Why not use the TV as a big screen monitor? (You might want to practice at home first.) Here's how:

- If you have an older laptop and an older TV. get a VGA cable. If you have a newer laptop and a flat screen TV get a HDMI cable. If your computer and TV are not compatible, you will need to get an adapter. Ask the salespeople to help you. Take photos (with phone or digital camera) of the available connection ports with you.
- Turn off both the laptop and the TV.
- Connect each end of the cable: one to the laptop and one to the TV.
- Turn on both.
- Use the TV remote to go to the "Input Device" source codes (HDMI 1, HDMI 2, etc) and choose the port to which the cable is plugged in.
- Your laptop might show a window and ask you if it is OK to show your screen on an outside source.
- Click OK.

G. Reading Tips and Tricks

- Listen to audio books.
- Purchase an E-reader, such as a Kindle or Nook -Print can be enlarged; many publications are free. Some Kindles will read aloud to you, and there are on-line programs that will read entered text.
- Many public libraries now have books available for your E-reader, and often carry "Books-on-Tape" for
- Try using a yellow or pink highlighter on reading
- Print from your computer on yellow paper instead
- Local associations for the blind and low vision

clinics have many helpful suggestions and devices for those unable to read.

5. ALTERNATIVE TREATMENT OPTIONS

- Acupuncture may provide some relief for the tightened eye and facial muscles on a temporary
- Electric Pulse Stimulation used daily for months may provide some relief.
- Homeopathic Remedies & Supplements double blind studies have not been completed to prove that there is a known homeopathic substance that will guarantee relief. In general, these are unregulated. Inappropriate doses or impurities in the product may actually be harmful.
- Massage Therapy may provide some relaxation on a temporary basis.
- Physical Therapy learn to perform daily tasks better by improving balance.
- Rolfing (a type of massage) may provide some relief on a temporary basis.
- Facial Physical Therapy (exercises to massage and stretch the facial muscles that might be spasming/ pulling or causing pain.) Relief may be experienced on a temporary basis.

A positive attitude is very important. **Maintaining your sense of humor** is always a good thing!

For further information, contact:

BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION

P. O. Box 12468 • Beaumont, TX 77726-2468 (409) 832-0788 • Fax (409) 832-0890 **E-Mail:** bebrf@blepharospasm.org WEBSITE: http://www.blepharospasm.org/ BEBRF is an exempt organization under Section 501(C)(3). All donations are tax deductible

Benign Essential Blepharospasm Research Foundation



Written by patients for patients

HELPFUL hints

DISCLAIMER: The Benign Essential Blepharospasm Research Foundation (BEBRF) does not endorse these Helpful Hints for everyone. These collected suggestions have been effective for some BEBRF patients but not all. Everyone is different!

1. SENSORY/ COMFORT

A. To Calm Eye Spasms

- Use a tight baseball cap, hair band or sweat band around vour forehead.
- Press on your temples, end of your nose, or other parts of your face, then hold.
- Put your head back close your eyes, or look down.
- Go in a dark place and try to relax.
- Do not rub your eyes, especially the first 24 hours after injections.
- Be engaged! Sing, hum, talk, whistle, play an instrument, chew gum, bat your eyelashes, or suck on a straw.

B. Warm VS Cold - A Personal Choice

- Many feel that cold is the best on the day of injections, but should be avoided 2 hours immediately after and 15 minutes before treatments. Cold can be soothing and decrease bruising.
- Relax your eyes by washing with cool water, or hold a cold glass/bottle of ice water near your eyelids or temples. Keep this available when working out and
- If you have problems with blurry or crusty eves in the mornings, use a hot towel to help clear that
- Keep an Eye Gel Mask in the refrigerator. The Velcro strap helps hold it in place over your eyes. If using an ice pack or bag of frozen peas, place these over a cold, damp facecloth - moist cold penetrates better than drv.
- Take a warm shower. Close the door to enjoy the steam and allow the water to run directly over your closed eyes or use a washcloth as a compress.
- Try a cloth-covered eye pillow with lavender and natural grains microwaved for about 30 seconds. Then try to relax or sleep.
- You can also microwave a cotton sock filled with

raw rice for 30 seconds. Check the temperature on your wrist to avoid burns.

C. Doctor - Patient (working together)

- Help your doctor monitor your injections. Keep a daily journal of spasm and dry eye symptoms. Sixty second videos of your worst time(s) taken with you to your doctor or, better yet, sent to your doctor days before your visit, allows objective effect analysis. Your doctor can slow down the video to identify the exact muscles spasming so that adjustments can be made to injection sites.
- Nobody knows you as well as you know yourself. Study your own videos. Help your doctor make observations. Which eye is more likely to "trigger" your spasms and needs a higher toxin dose? Keep copies of your own injection charts, so you can help guide increases and decreases in your injection treatments
- Ask your doctor about applying a topical cream like EMLA to the injection sites 45 minutes prior to the injections to numb the area and ease the discomfort.

D. Drv Eves

- Make an appointment with a Dry Eve specialist for severe dry eves.
- Use a cool mist vaporizer (especially in the bed room) to help ease dry eyes.
- Use a humidifier in the home to put moisture into
- Turn the air conditioner vents away from your face when on a plane or riding in a car.
- Do not allow the dry heat from the oven or the BBQ grill to blow into your eyes when cooking.
- Use slow, complete blinks and eye drops to keep your eyes lubricated.

06/2020

E. Driving/Riding in a car

- Check with your doctor to see if it is safe for you to drive.
- Wear a soft, contoured eye mask when traveling as a passenger in cars, trains, buses, or planes to block light.

F. Miscellaneous

- It is important to get a good night's sleep and avoid getting over-exhausted.
- Try not to overdo reading, computer work, sun, exercise this could build up and be cumulative.
- Take breaks when focusing or doing detailed work.
- Find time to keep eyes closed when possible in situations that aggravate them or tend to cause fatique.
- Take time to rest your eyes by closing them, or take a short, eye-resting nap in the afternoon.
- · Listen to the radio or TV with your eyes closed.
- Blepharospasm is a neurological disorder. Therefore, stress can induce spasms, so avoid as much stress as possible. Relaxation CD's and back ground music are sometimes helpful stress reducers.
- To refresh and revitalize tired eyes while on the go, try packets of pre-moistened cool eye pads scented and infused with nutrients. Place them over your closed eyes and relax. The eye pads may be found in department stores in the "eye care" section. Cucumber or orange slice pads with Aloe are especially soothing.
- Difficulty with eye-to-eye contact? Glance at an object to the side of the person.
- When on stairs or riding on an escalator, let a companion lead. Place a hand on his/her shoulder.
 Even if your eyes close, this helps to feel the up or down movement and provides physical support.
- When watching TV, try doing a craft, crossword puzzle or something else in which you are looking down. Glance up on occasion. This may help to extend the time for watching TV.
- Concentrate on something other than your eyes. Hobbies such as painting, gardening, woodworking, computers, knitting/crocheting, are very helpful to relieve stress. Keep your hands busy!
- Use tearless or baby shampoo when washing your hair, so if some soap drips into your eyes, it will not burn them from the harsh chemicals or detergent.

- Exercise is good! Check with your doctor first, but walking, indoor spinning, or stationary bicycling (no wind or sun), and swimming are good options.
- Certain foods and drinks have not been proven to be more or less beneficial than others. Do what feels right for you.
- Alcohol may not agree with some; others may find it mellowing. Some sip a casual glass of wine to calm eye spasms and help get to sleep.
- Make your home a controlled and comfortable environment. If necessary, keep the blinds and curtains closed; keep lights behind you, and designate a dark comfortable place to go to when you need to decompress and use warm or cool compresses.
- Do your outside errands and gardening when the sun is not the brightest and is at your back.
- For oromandibular dystonia (Meige Syndrome), chew gum or suck hard candy; use a warm compress on your face, purse or hold your lips tightly to prevent mouth from spasming.
- For hemifacial spasm, touch the opposite side of the face where spasms occur.

2. LIGHT SENSITIVITY/ PHOTOPHOBIA

A. Glasses/ Lenses

- Consider colored FL-41 lenses (prescription glasses or non-prescription glasses) with 10% or darker tint. If you do not place any coating on the glasses (such as anti- reflective coating) and you are unhappy with the tint, they MAY be able to lighten or darken the FL41 coating, but check with the company first before ordering. If the color fades over time, they can be made darker again. If made too dark, you might experience difficulty in reading or driving. Ask your eye doctor, or contact the BEBRF office for more information.
- Some have found relief by getting an ultra-violetblocking coating.
- Gray gradient prescription glasses might help while reading.
- Wraparound glasses help with bright sun, wind, snow and glare of oncoming lights at night. Use only very lightly tinted glasses at night.
- Some have suggested that if you currently wear progressive lens eyeglasses, looking up over the line of reading might not be comfortable or a gaze that you can hold. Consider having 2 separate

- pairs of glasses made one for reading and one for distance. YOU can determine the level of reading or intermediate lens in your glasses. Progressive (lineless) bifocals may be more difficult to use than line bifocals.
- A few companies make sunglasses that fit over your regular glasses, thus wearing 2 pair of glasses - one prescription and this second pair to cut down glare.
- Some people wear goggles or safety glasses to cut down on dry breezes in certain situations for comfort.
- Polaroid lenses are excellent for use over the water or in snow.

B. Miscellaneous

- Shading your eyes from outdoor lighting, as well as certain indoor lighting can help. Try visors, caps, or hats with a dark underside to the brim that the sun can't shine through.
- Use frosted, pink or smaller wattage light bulbs in lamps. These give off a softer light. Avoid florescent lights.
- Try using a yellow "bug" light inside the house.
- Try a "chromalux" full spectrum light bulb which is supposed to eliminate much of the yellow light, resulting in brighter and more vibrant colors. These are sometimes used for seasonal affective disorder.
- Turn down the lights with a dimmer switch whenever possible. You will be surprised that you may not need as much light as you thought.
- Whether walking or sitting, avoid direct sunlight when possible. Using an umbrella, sunglasses, hat with brim or other device to shade your eyes can help you enjoy being outdoors.
- Retractable awnings can be installed to allow you more time outside on your porch/deck.

3. OVER THE COUNTER AIDS

A. Drops, Gels, & Ointments

- Use these particularly when eyes feel dry or scratchy.
- An excellent source to understand the different components of artificial lubricants and helping to choose the right one for you is the web site: https:// plasticeyesurgery.com/patient-resources/ patient-education/ then click on Mastering Tear Supplements under Patient Education. Be creative with supplement use. Different ones may be mixed, used in different eyes, alternated between

the eyes at application time to avoid vision blurring, and may be better when used at different times of the day or night.

- Your doctor may have samples or suggestions.
- Refrigerated drops may be even more refreshing when cool, whereas, drops kept in clothing pockets are warmed by body heat. If you are using eye drops multiple times a day and find that your eyes seem to still be irritated, you may want to try preservativefree drops. Sometimes the preservative can be irritating.
- Allergies, as well as antihistamines, can make your eyes dry, so remember to use eye drops day and night.
- Consider using a cloth covering or eye mask at night if you use gel or ointment.
- Cataract surgery and corneal refractive surgery may also cause dry eye.
- If you want to know how much dry eye contributes to your BEB, ask your doctor to put a couple of anesthetic drops in your eyes. The anesthetic will take away the irritation caused by dry eye.

B. Eye Wash

- There is a big difference between eye washes and artificial lubricants. The above Internet link explains. Know when to use which.
- Eye Cup consider using an old fashioned eye cup and rinse your eyes with either plain water or any of the herbal eye rinses when they feel particularly irritated. Remember, eye washes/rinses don't help dry eye.
- Use baby shampoo with a warm washcloth to wash the top of your upper eyelids and the bottom of your lower eyelids and lashes, and then rinse with warm washcloth. This is especially helpful when a person has anterior blepharitis, but ask your doctor. Posterior blepharitis can be made worse with eyelid rubbing.
- Use bottled eye wash and rinse your eyes, prior to inserting eye drops or eye gel. Wash your eyes when waking in the morning if you used gel or ointment the night before.

C.Tap

 If you choose, use surgical tape or cosmetic tape on eyebrows, arch of eyebrow or on corner of eyes to help keep them open. Here is how to do it: Take a 1" - 1 ½" piece of tape and place a piece under the arch of your eyebrow giving a slight lift and placing the other end on the forehead. You can also do the same thing at the outer edge of your eyebrow (closer to the hairline). Split 3/4" wide tape in half lengthwise prior to applying the tape to the arch of your eyebrow. But beware, this may make dry eye problems worse.

D. Medical Alert

 Unfortunately emergencies happen - a medical alert bracelet with blepharospasm printed on it and a phone number to call could help if you are alone and require a prolonged hospital stay.

4. TECHNOLOGY - COMPUTERS & READING

A. Reduce glare in Email

Change the color of the background of your email (Settings vary with different email browsers and operating systems - look in Tools).

B. Reduce Glare on the Screen/Monitor

Change the color of the background on your screen/monitor to reduce glare. Different computers work on different operating systems. Look for these controls in the Control Panel. You can also buy "glare guards" that stick on the front of your monitor or decrease the brightness of your monitor.

C. Increase/Decrease the Font Size on the Internet

- To <u>enlarge</u> print, press Control and "+" (plus) at the same time. This can be repeated.
- To <u>decrease</u> print, press Control and "-" (minus) at the same time. This can be repeated.
- Option: If your computer mouse has a wheel, then hold down the Control key and roll the wheel on the mouse at the same time one way to increase the font, the opposite way to decrease it.

D. Word Search

To <u>find</u> a specific word on a page, press Control and "F". You will get a box, type in the word you are looking for and press enter. Each time you press enter, you will see the word the next time it is used in the text.

E. Keyboard Tricks

 Consider purchasing a keyboard with yellow keys and large black letters like EZ Eves Keyboard.