



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

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## TAKE CONTROL OF YOUR BLEPHAROSPASM

SUMMARY OF THE BEBRF WEBINAR PRESENTATION BY CHARLES SOPARKAR, MD, PHD

SEPTEMBER 26, 2020

PART ONE REPORTED BY TISHANA CUNDIFF



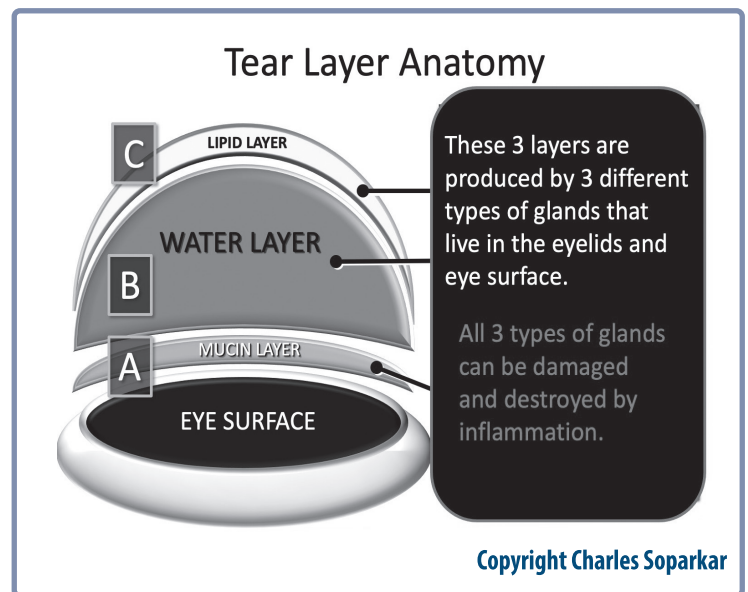
*Charles Soparkar,  
MD, PhD*

Dr. Sopakar proceeded to share a wide variety of, “Things You Can do Yourself to Help Yourself” and, “Things You Can do to Help Your Doctor Help You.” He noted there are, “currently 4 approaches to address BEB.” Those four address: Various Irritants including ‘Dry Eye, Inflammation, The Brain, and The Blink.

To attempt to reduce ocular surface irritants, Dr. Sopakar first shared ideas related to examining the eye’s own mechanical irritants possibly created by the eyelid and eyelashes. If those are detected and addressed, he then suggested addressing the actual tear layer problems, reminding viewers of the anatomy of tear layers (from the eye’s surface outward - Mucin, Water, and Lipid ) produced by three different types of glands. Within this portion of his presentation, Dr. Sopakar reminded the audience that neither he, nor Dr. Murdock, MD were dry eye specialists, but he encouraged viewers to consult one.

If tears have too little MUCIN, they will not stick to the eye’s surface. These patients may have a Vitamin A deficiency causing night blindness. The treatments he shared to address TOO LITTLE MUCIN included using special eye drops such as Trehalose or Hyaluronic Acid.

On the opposite end of the spectrum, if the patient has TOO



***The Treatment(s) should be tailored to the gland and tear layer that is damaged.***

MUCH MUCIN, they may possibly produce thick, ropey strands of mucus around the eye. One possible treatment for this concern was taking N-acetylcysteine 600 mg/day, requiring a consult with a heart doctor.

When the tear problem lies within the WATER LAYER, this typically requires, “complex tear supplementation.” Patients with this concern were advised

against the use of drops intended to, “take the red out,” address allergies, or those considered an “eye rinse” or “eye wash.” Again, viewers were reminded to see a dry eye specialist to assist with treatment on the type of lubricant eye drops that may be most helpful. These vary generally in their

***... viewers were reminded to see a dry eye specialist to assist with treatment on the type of lubricant eye drops that may be most helpful***

The Benign Essential Blepharospasm Research Foundation (BEBRF) is a non-profit, 501 (c) (3) organization founded in 1981 by Mattie Lou Koster, a blepharospasm patient.

Blepharospasm (BEB) means eyelid spasm. The eyelids unpredictably and involuntarily clamp shut in both eyes, leaving the victim functionally blind until the spasm ceases in a few seconds or a few minutes.

Cranial dystonia (Meige) is a similar condition in which involuntary muscle spasms in the lower face and jaw cause grimacing and jaw movements.

Blepharospasm and cranial dystonia (Meige) are classified as movement disorders and are described as focal dystonias.

Hemifacial spasm generally begins as an involuntary contraction around one eye that gradually progresses down one side of the face to the cheek, mouth, and neck. It is not a form of dystonia.

BEBRF is a member of the National Organization For Rare Disorders (NORD), American Brain Coalition, Dystonia Advocacy Network, Dystonia Coalition - ORDR, and The Harvard Brain Tissue Resource Center (Laurie Ozelius, PhD is the BEBRF Representative).

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The Editorial Staff reserves the right to edit any and all articles. It is our editorial policy to report on developments regarding blepharospasm, cranial dystonia and hemifacial spasm, but we do not endorse any of the drugs or treatments in the Newsletter. We urge you to consult with your own physician about the procedures mentioned.

The Blepharospasm Newsletter is published quarterly and mailed to patients, families, doctors, friends of the Foundation, and health care providers around the world.

**Newsletter suggested donation \$20.00 USD**

**NEWSLETTER DEADLINE DATES**

ISSUE	COPY DUE DATE
Winter	January 1, 2021
Spring	April 1, 2021
Summer	July 1, 2021
Fall	October 1, 2021

# BEBRF BLURBS

**Webinars:** The Webinar held on September 26th with Dr. Charles Soparkar and Dr. Jennifer Murdock provided a wealth of information for managing your blepharospasm. If you missed it, not only do we have a summary of the information presented in this issue of the Newsletter, but also you can view it online. The link to viewing it is on both our Facebook page and our website.

Based on the success of the September Webinar, we will be hosting more Webinars in the future! Next up, on Saturday, November 14th, BEBRF will be presenting Dr. Jaelline Jaffe, a psychologist who is also a blepharospasm patient, in a presentation entitled “Opening Our Eyes to Stress Management for BEB.” The program will include several stress management exercises and activities woven in with concepts about what causes stress and anxiety and how to reduce both. It will include such things as mindfulness meditation, Progressive Muscle Relaxation, importance of attitude, mind/body connection, and ways to manage around specific stressors (like holidays, election results, and the pandemic). We also anticipate creating a resource guide for people to use going forward.

**Calling all artists:** Many blepharospasm patients use some form of art for therapy. BEBRF would like to celebrate that with an exhibit of the artwork at the 2021 Symposium in Philadelphia. To do so, we are asking all

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**PROTECTING PATIENT INFORMATION:**

The Benign Essential Blepharospasm Research Foundation respects the privacy of patients. Patient information is not shared outside the BEBRF organization.

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<sup>2</sup> The opinions expressed in the articles in this newsletter are those of the authors and do not necessarily reflect the views of the BEBRF, publisher of the BEBRF newsletter.

of our artists – whether you are a painter, sculptor, jewelry maker, quilter, knitter/crocheter, wood carver, maker of artisanal soaps or candles, or however your creative juices lead you – to consider donating a work of their art for this exhibit. We want to also include these creations in the silent auction at the Symposium to raise money for blepharospasm research. Contact Charlene at the Foundation office to find out more information.

**Anyone can join Zoom Support Group Meetings!**: Even if you don't have a computer or smart phone, you can join a Zoom Support Group Meeting. Contact Charlene at the Foundation office to find out how.

3-Part Article: Blepharospasm patient Carolyn Cleverley, who is something of an expert on navigating the Social Security Disability process, submitted a Patient Story which included a detailed description of how she got her disability. There was so much information in her Patient Story, that we have broken it down into three separate articles in this and the next two Newsletters.

**Information Bundles**: BEBRF is putting together Bundled Packages of information on specific topics, especially for the related disorders. So far we have created Bundle Packages for Meige, hemifacial spasm, dry eyes, and a new package on how to get your injections more frequently than every 3 months (see story on page 13). We will be adding more Bundles in the future. Contact the BEBRF office for more information.

**Radio/Podcasts**: Creating awareness of blepharospasm for both patients and medical professionals is one of the overriding goals of BEBRF. To that end, BEBRF has started recording radio programs and podcasts. If you have a contact at a radio station in your area, please let the BEBRF office know so that these broadcasts can be shared. FYI, radio stations are required by law to have a certain amount of time each week dedicated to public service. These BEBRF radio programs would perfectly fit into that requirement.

**HAPPY HOLIDAYS FROM EVERYONE AT BEBRF!**



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## TAKE CONTROL OF YOUR BLEPHAROSPASM

### TYPES OF LUBRICANTS

**CELLULOSE – BASED**

Refresh tears and liqigel, Genteal, Thera Tears

**GLYCERIN – BASED**

Optive, Visine Dry Eye Relief

**CELLULOSE + GLYCERIN – BASED**

Tears Naturale, Advanced Eye Relief

**OIL – BASED**

Refresh Endura, Soothe

**GLYCOL – BASED**

Systane

**HYALURONIC ACID – BASED**

Oasis, Omnivision, Hylo

**Hydroxypropyl cellulose inserts**

**We can't always predict who will benefit most from which type of lubricant, but a "dry eye" specialist should be able to help.**

[www.plasticeyesurgery.com](http://www.plasticeyesurgery.com) Mastering Tear Supplements

Copyright Charles Soparkar

### Lubricants are categorized by their base

base and how they help.

Dr. Soparkar then shared a variety of "Lifestyle Changes" such as increasing humidity, avoiding things that dry eyes such as wind, dry heat, high altitude, etc. as well as wearing eye shields or goggles to block irritants. In addition, he shared ways to conserve the actual tears by use of medical devices or procedures such as punctal occlusion, Tarsorrhaphy, PROSE prosthesis (previously known as Boston Scleral Lens), or simply applying Press 'n Seal/SuranWrap over the eye during periods of rest.

Concerns with the LIPID Layer of the tears may result if the oil is too thick, the opening of the gland is too small, or the opening is clogged. Simple suggestions to try included warm moist compresses and commercial eyelid scrubs. Other suggestions would involve your doctor for possible prescriptions of Doxycycline (to thin the oil), Corticosteroids (to decrease eyelid inflammation), or topical antibiotics (to decrease bacterial plugging).

Dr. Soparkar moved then to the approach of decreasing the inflammation. While many of these would involve treatment coordinated by your doctor, some dietary measures including supplements were shared.



### Dietary measures that MAY decrease inflammation



- Avoid gluten (leaky gut syndrome?)
  - Wheat, barley, rye, B's yeast
- Minimize dairy
  - Foods containing casein
- Beets (betalains)
  - Steamed for < 15 minutes
- Brightly colored fruits and veggies
- Blueberries, raspberries
- Garlic
- Green Teas (polyphenols)
- Pomegranates (polyphenols)
- Ginseng
  - Red ginseng, Korean ginseng, panax ginseng, Asian ginseng, KRG
- Taurine (1 gram/day)
- Curcumin (turmeric)
  - W/ pepperine (black pepper) or cyclodextrin coating, or BCM 95
- Glutathione
  - W/ n-acetyl cysteine
- Pycnogenol (pine bark)
- Vitamin A 25,000 IU/day
- Vitamin C (1 gram/day)
- Vitamin D3
- Vitamin E 400 IU/day

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### Simple dietary measures MAY decrease inflammation

The third approach shared was to, "Decrease the response of the brain to ocular irritants." While some, like Deep Brain Stimulation, would require surgery, others like humming, singing, speaking, and head tilt seem to help many patients. He also shared devices that have proven to help some like PressOp that clip to the side of glasses to provide a slight pressure beside the eye. Others shared were Prism Spectacles, FL-41 lenses, and direct soft light to reduce glare.

The final approach presented was to, "decrease the ability of the body to respond to the brain's misdirection." The most common treatment in this approach involves injections of Botulinum toxins such as Botox or Xeomin to temporarily impede the nerves involved in blinking.



**The rest of the September 26, 2020 Webinar, including a summary of the presentation by Jennifer Murdock, MD and the Q&A, will be included in the next Newsletter.**

# DR. SOPARKAR'S WEBINAR PRESENTATION PART TWO

REPORTED BY HEIDI COGGESHALL

There are things you can do at your visit with the doctor to improve the effectiveness of your botulinum toxin treatment. Help your doctor help you.

- 1) Keep copies of your treatment maps and bring them with you. Keep a copy of the medical record yourself.
- 2) Insist on drawn maps from your doctor. If you do not receive one, insist on receiving one as descriptions are different for everyone and don't translate from doctor to doctor or patient to patient. The drawings should show marks where you specifically receive each shot on the face/neck and the amount of toxin per shot. If the doctor does not have a drawing, bring a picture template with you, and ask the doctor to mark it up so anyone can understand the injection locations/quantity. Keep the map yourself for use again, including with the same or different doctor.
- 3) Avoid changes in chilling and anesthetic as they diminish the toxin effect. Dr. Soparkar did a study where for the injections they used an anesthetic on one side of the face and a placebo on the other side. 12% of patients said the anesthetic side did better but 87.5% said they the placebo side did better. They did the same study for patients using botulinum toxin for cosmetic reasons and got similar results. After next explaining how the toxin/biochemistry works, he said cold within the first hour of injection probably decreases the efficacy of the toxin. You don't want to chill before or after the injections. Anesthetics (topical or injected) probably greatly decrease the efficacy of the toxin. Moving the desired muscles (squeezing, contracting) and activating the relevant nerves within the first hour seems to increase the efficacy.

**Zinc** must be present in the body or there will be no effect. A NHANES III study by the NIH said 45% of the population consumed less than 75% of the RDA of Zinc, assuming people were taking their dietary supplements. People over 55 were especially at risk. Different zincs absorb differently. So, for example, the Zinc from a cold lozenge is

specifically designed to be a poorly absorbed Zinc. If you take dietary supplements that says they are 100% RDA for Zinc, they are not because the divalent cations in them compete for absorption.

**Botox** does work in people over 65 but because many times they have lower levels of Zinc, it can be less effective. It is difficult to easily tell your Zinc level (for example, blood or urine levels are not predictive of tissues levels). There are many factors adversely affecting Zinc levels including age (< 18 or > 50 years), increased metabolic demand (pregnancy or acute, severe illness), malabsorption syndromes (frequent diarrhea, liver disease, frequent laxative use, competing divalent cations and GI maladies such as Sprue, Ulcerative Colitis and Chron's Disease), dietary factors ((low Zinc in diet typically vegetarianism and red meat avoidance, high phytate, alcohol, casein (milk-based products), phosphates (soft drinks), EDTA, E391 preservatives in many foods and finally dietary supplements (poorly absorbed forms of Zinc, high fibre, vitamin A and because of the competing divalent cations if you take them at the same time: iron, calcium, copper, magnesium and manganese)). He recommends you work with a dietician/nutritionist to create an effective diet.

**Phytates** bind Zinc and prevent its absorption in the gut. Some helpful low phytate foods include oysters and turkey (alone – not with bread) whereas some high phytate foods are soy, wheat, cereals, seeds, and nuts. If you eat, for example, one half of a whole grain roll at the same time as eating a steak, you will absorb none of the Zinc from the steak.

Zinc is generally good before the injections. 92% of a survey showed an increased duration of about 30% longer for the toxins and half state "significantly better" than before Zinc supplementation. However, it is not good to take Zinc before injections if you are already taking much of it every day for other reasons because it can lead to toxicity. If you have a good working

*If you eat, for example, one half of a whole grain roll at the same time as eating a steak, you will absorb none of the Zinc from the steak.*

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injection routine and you are happy, don't suddenly now take Zinc and change it.

How does one take Zinc? Zinc Citrate (50 mg/day) can be taken 4 days before and after of treatment. Some patients double the dose. Some take half before and half after the injection. Take it without other foods or other supplements but if you want to take it with a meal because of an upset empty stomach, take it with plain turkey, for example. Or add Phytase to the meal to breakdown the phytates. Because it is hard to find Phytase, he came up with a combination of Zinc and Phytase. Dr. Soparkar noted in full disclosure that he patented this combination (he doesn't make any money from what you buy) and leased it to a company which makes a commercial preparation.

The following influences the botulinum toxin effect: toxin type (brand, standardization), toxin preparation (ie, do they shake it up a lot and destroy the toxin), preparation (alcohol wipes, cold, anesthetic), injection placement, toxin dose, treatment frequency, toxin dilution amount (dilution spreads it more), injector's technique, the patient (amount of swelling, diet, post-treatment movement) and other factors such as other medications, allergens etc.

- 4) Insist on an individualized treatment program.
- 5) Keep a diary of dry eye symptoms and overall spasm treatment efficacy. Don't just say "I can't open my eyes". Choose a scale and note on the diary how effective the spasm control was each day using that scale. Also mark each day how dry the eyes were. Circle the days that were good days and analyze what happened in the bad days (such as diet, environment, or stress that was different than compared to a good day) as only

you can figure it out. Careful analysis can help determine causes. The diary also helps prove to insurance that treatment is a necessity and helps to provide treatment adjustment.

Many of the spasms are worse until the toxin fully kicks in and then again before the next injections. Ideally you can receive injections when required versus at every 12 weeks, thus, another purpose of tracking your spasms and dry eye in more details.

- 6) Take videos of your spasms. It helps in documentation for insurance and helps the doctor help you. The videos allow for slow-motion study of muscle groups and better assessment than the literally '5-minute' exam on one day at one moment in time. The videos should be short (1-2 minutes max). The doctors want to know what your spasms are like at two weeks

and when is the best and worst time during the cycle. Take a video at the end of a treatment cycle when your spasms are at their worst. Finally, send the videos to your doctor well in advance of your visit.

There are two types of BEB, Spastic and Apraxic, and the type affects the location of the injections. Frontalis Muscle and Orbital and Preseptal Orbicularis is injected for the former and Pretarsal Orbicularis for the Pseudo-Apraxia (and is more difficult to treat).

- 7) Finally, if you have an injection pattern that works, don't accept from a doctor that "I don't do it that way". It is OK to try something new but just make sure everyone involved is willing to go back.

So in summary, take your own care into your own hands, maximize your eye comfort, become aware of what impacts your BEB, be creative and innovative in your care, don't wait for the physicians to figure it out - so help them and provide them with essential data and finally, remember Happiness is a Choice.

*Take videos of your spasms. It helps in documentation for insurance and helps the doctor help you.*

**PLEASE REMEMBER BEBRF IN YOUR WILL**

# LET'S TALK SOCIAL SECURITY DISABILITY – PART 1

BY CAROLYN CLEVERLEY

For 25 years, I was a Self-Reliance Specialist with the Idaho Department of Health and Welfare. I determined eligibility for all forms of Welfare benefits but was a benefit specialist in programs for the disabled and elderly. Part of my job was assisting people to apply for Social Security and contacting the Social Security Administration (SSA) regarding eligibility issues with our shared clientele. This required building good relationships with Social Security workers to learn how to best navigate their system and process. This was helpful in working with my clientele but became even more helpful when I had to take medical retirement and apply for Social Security Disability due to my own journey with blepharospasm.

It took 15 months and 1 day from application date to the date I received my first deposit from the Social Security Administration. No appeal, no attorney. I knew and understood SSA's process well as I had helped many clients apply for Social Security and knew what they would need to approve my application. That is what I would like to share with you.

First of all I need to say my intent is not to voice an opinion on the Social Security system or process but to share information on what their process and rules are to help you advocate for yourself if you choose to do so.

Basic Social Security process (*due to space, this article will cover steps 1 & 2, the rest will be in the next BEBRF Newsletter*):

1. Apply online or in-office
2. Interview in-office or by phone
3. Financial determination done
4. Medical determination done
5. You are notified if you are approved or denied

There is a vast difference between having a disability and having a disability that is severe enough to meet the Social Security Administration's definition of disability.

Their simplified definition: "The law defines disability as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

If, after developing BEB, you are able to continue working, you may not be approved for Social Security. I would never discourage anyone from applying, but you would want to decide if it is worthwhile for you to do so.

For SSA purposes, you are claiming functional blindness if you are claiming disability because of BEB. **BEB is a diagnosis recognized by SSA BUT they will not approve disability just using this diagnosis so they look at the result of your individual BEB.** There are technical measurements associated with this you will want to discuss with your physician to see if the severity of your BEB meets the measurements required by SSA to approve disability based on functional blindness. There is information on functional blindness and SSA on the BEBRF website and a measurement letter. The single, most important piece of medical evidence I provided to SSA was a "Doctor's letter supporting disability application." I downloaded the template for this from the BEBRF website. It clearly defined the severity of my BEB, and gave SSA the measurements needed to determine me disabled. On the BEBRF website you click on Patient support, then click on Disability information.

**If you can't prove your level of disability using your medical records, you are not disabled.** If your medical records do not reflect the level of your disability, you will need to resolve this with your medical provider before you can be evaluated for disability. Nobody with SSA is allowed to take your word for anything. Your approval is dependent on the proof you provide.

Now let's discuss the stages of an SSA application in greater detail.

**1. The application.** You can still apply in your local office, but they will simply set you up on a computer and have you apply online. I strongly encourage you to set up an online account with SSA and apply in the comfort of your own home. If you are like me, my eyes don't respond well to any type of computer screen, so I have to take frequent breaks, and it takes me forever.

Other advantages to online accounts with SSA: I learned I was approved online a couple of weeks before receiving letters. If you sign up for automatic deposits, you can have deposits into your bank account before receiving the benefit letter from SSA (oh, happy day!). Therefore, I strongly encourage you set up an online account with SSA.

**2. Interview.** Depending on your local office, you may be offered an in-office or phone interview. If at all possible, **TAKE THE OFFICE INTERVIEW.** To explain why, we will need to discuss things you will have to do before the interview.

**First**, you need to obtain your medical records. You can have SSA request your medical records,

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## LET'S TALK SOCIAL SECURITY DISABILITY – PART 1

BUT a large percentage of Social Security disability applications are denied because of lack of medical documentation to prove disability, because of records SSA requested but never received and which you would have no way of knowing about. How can you effectively advocate for yourself if you have no idea what exact records SSA is looking at? I didn't apply for SSA until I had enough medical documentation, in hand, to prove I was disabled.

Your medical records are more accessible to you than to anyone else. When you ask for your medical records from your medical provider, ask for everything: every progress note, physician's note, report, test result, everything. Again, the single most important medical document I gave to SSA was a disability letter written by one of my neurologists based on the template I downloaded from the BEBRF website. Also, the better you can organize your records for SSA, the faster and easier your approval will be.

Next put your medical records in chronological order. Number them with big numbers – start with number one, and so on, written in pen on the front page of each separate document. These are your numbered exhibits. Each medical record from each contact with a medical provider is an exhibit. Be sure to avoid writing over any numbers or letters. The records must be readable and the numbers must be easy to see. As an example:

I numbered my emergency room report as #1. It was my first medical care for BEB. I numbered my treatment summary with my primary care physician as #2. And so on.

**Next, write a treatment journal** as factually as possible. The treatment journal is to show how you were diagnosed and what medical treatments you have obtained. This is your primary means to tell SSA how this happened to you, how you have progressed to being disabled, and what treatments have or have not done for you. You will record how BEB

has changed your life at a later stage; this particular step is just about the medical care you have received. In your journal, you are going record your contacts with your medical providers. List the date, name of contact, where contact was, what was discussed, and the result of each treatment or conversation and reference the medical record (exhibit number) to support the contact. I am including a copy of one of my journal pages so you can see what it looks like (below). This journal and medical records will become invaluable in the disability determination phase. If you were diagnosed with BEB but decided not to obtain treatment, this may be a problem. Part of what SSA evaluates is your level of function after commonly recognized and accepted treatment for the disability you are claiming.

Nobody with SSA is going to know anything about BEB. They will look it up on google which may not be helpful to you. The BEBRF website has good articles about BEB. Print off as many of them as you feel would give SSA a better understanding of your situation. You want SSA to know as much as possible about how difficult and disabling BEB is for you.

Two more documents to go. Go to SSA.gov and print off forms SSA- 3380-BK Function Report-Adult-Third Party and SSA-3373-BK Function Report. You complete the Function Report and the person who has the most

information about your day to day life completes the Third Party form – in my case, my husband. This is where you describe what BEB has done to your life. You MUST be as detailed and honest as possible. Use the back of the page, margins, or any other blank area on the form to list everything from not being able to drive to face planting in the driveway while taking the garbage out because the sun hit you in just the right spot even with dark glasses on and you missed the curb. Or cutting your fingers instead of the onions to have with dinner because your eyes shut when your hands move.

\*Mark Boerner MD 111 W Main Street Suite 200 Boise, ID 83702  
208-344-3220.

Dr Boerner prescribed botox injections which is the accepted course of treatment for blepharospasm. Botox injections started on 09/11/2015 and repeated on 10/23/2015 and 01/27/2016. Botox side effects made working even more difficult and were not very helpful. Dr Boerner referred me back to neurologist as treatment not successful. RECORD OF VISITS ENCLOSED AND MARKED AS #4

12/07/2015 Visit to Dr Michael Djernes MD for other treatment options. Address and phone number above. Dr Djernes referred me to Neurologist at University of Utah Medical Center. Suggest I go ahead and have injections with Dr Boerner on 01/27/2016 while I wait for U of U to contact me. VISIT NOTES ENCLOSED AND MARKED AS # 5.

First visit to University of Utah was 02/22/2016 was with Behrang Saminejad MD. He prescribed more Botox injections and medication trials. Dr Saminejad said they inject in different sites than Dr Boerner and he wanted to try different sites and doses and do medication trials. He started botox injections and medication trials on 05/10/2016 then he moved out of state and I continued care with Lauren Schrock MD. She also prescribed botox injections and medication trials on 08/09/2016. Botox again on 11/02/2016 and 02/07/2017. Was also diagnosed with essential tremor and general dystonia with blepharospasm.

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729 Arapeen Dr Salt Lake City, Ut 84105 801-585-2746

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Include the social differences, too, with examples, such as, I hated going out because people would comment on me wearing dark glasses in stores and at church. Emphasize the isolation and loss of independence. Include the daily struggle to remain productive and some days' simply failings. I included things such as my lack of hand movement control and "dropping stuff is my new normal". It is all very important to share with SSA, and this is your place to do that. This is your voice.

Copy everything! NEVER give SSA your only copy of anything. Take both copies to your interview with SSA. There is no such thing as being "lost in the mail" if you hand deliver everything. You can also review the records with the SSA worker and make notes on your copy as needed. The SSA worker may ask questions so they can classify the documents you provided into their electronic document storage system.

Take an empty notebook to the interview with you. During the interview, start an SSA contact log. Record every date, time, name, title, phone number, fax number, and email address and what was said during each contact with SSA. If a worker tells you "your application

is in process for the next month", and that is the same answer they gave you a month ago, then this is how you hold them accountable. It works very well. If you are told an action will be taken within a certain time, follow up. It is easy for them to get lost in the volume of work they process, but you will want to refocus their energy on your application when needed. I have found SSA staff helpful and kind when I am the same, and the contact log makes it easier to stay firm and factual. Make sure you record the name, title and contact information of the person(s) who are completing work on your application. This is very important. Your results improve when you can say, "I spoke with Mr. Smith on 01/01/2010 at xxx-xxx-xxxx number at 3:30 pm central time and he said xyz". You can also send the worker email requests but be reasonable with this. If they say it will take 3 weeks to do something, please wait the 3 weeks.

*The Financial determination (Step 3), Medical determination (Step 4) and Approval/Denial Notification (Step 5) will be continued in the next BEBRF Newsletter – stay tuned!*

## PATIENT STORY – SHIRLEY BARR

I started my journey with blepharospasm in 1999, when I was 47 years old. My symptoms progressed rather rapidly, to the point that I was functionally blind, within a few months' time. I actually got a quick diagnosis from my excellent Optometrist, but then finding a physician to agree with the diagnosis and get treatment was a frustratingly long and drawn out process. Even then, the treatment results were far from adequate, with injection results worsening my eye closure. Fortunately, I did find the BEBRF, their website and their bulletin board, early in my journey.

Although it has been a very rough road at times, the BEBRF has always been there for me. I had been in the medical field as an RN for twenty plus years but had never heard of Benign Essential Blepharospasm (BEB). In talking to friends that I worked with and other medical contacts, there simply was no forthcoming information. The knowledge base that I finally got, regarding the disorder, all came directly from the foundation, website and their wonderful volunteers who helped guide me through the hurdles. Without them and what they offered to me in the way of support, information and research, I would have been totally lost.

I'm just very glad that they were there for me and others and still are, even though funds are often tight for the foundation. Much of the work is done by volunteers but the foundation still needs donations to keep going.

What I found to be the easiest way for me to donate to the BEBRF was to do it through my bank, as an automatic monthly disbursement. It was very quick and easy to set up and once done, I could just forget about it. I decided on a dollar amount that I could afford every month and that was it. I think at this point, most of us do some online bill paying/ automatic bill paying so it should be a breeze to set up. If you choose to donate to the BEBRF in this way, I'm sure that if you have any difficulties or questions, your bank would help you out. The foundation would also be available and happy to help you. Just give them a call.

Simply put...the BEBRF can only continue to help us if they have adequate funds. It is OUR foundation! Please support it.



# LIKE A ROCK...

## *Patient Support*



### ENA WILMOT – MY ROCK

I am happy to write an article on support for the BEBRF newsletter. Support, to me, is the giving of psychological and emotional encouragement during a crisis. This includes comfort, empathy, reassurance, and sympathetic understanding.

My husband Laurie, an engineer, and I, an RN, were just an average working couple balancing home and family. We were not yet empty nesters, when suddenly the rug was yanked from under my feet. My eyelids suddenly began blinking rapidly and frequently. Then came the rapid migration to my lower jaws (oromandibular). Shortly after that my neck (cervical) was showing signs of twisting, bobbing, and weaving with severe pain. As hard as I tried, I was unable to control these involuntary movements. It soon became noticeable to family, co-workers, and friends. Finally, I made an appointment with my Primary Care Physician who referred me for an MRI and a CT scan which revealed nothing helpful, followed by a check with an ophthalmologist showing that my vision was twenty/twenty. The only recommendation at that time was that I should get reading glasses, since I was spending many hours on the computer.

As my symptoms persisted, Laurie, my best support, suggested it was time for a second opinion. This was back in 1999 when there was not much information available for the public concerning blepharospasm. I read every article I could possibly locate. In 2000 I saw multiple doctors from one coast to the other, I was searching for answers. I felt bewildered; however, I refused to accept that this would be the end for me. I really thought this would be short term and with medical intervention I would return to my normal self and be able to perform all my usual duties and activities. Little did I know that this would be a long journey.

Job relocation took us to the northern California area; there I was able to get an appointment with a

neurologist (Dr. Klingman) who first diagnosed me and gave me the first toxin injection. Though I was being injected quarterly, my symptoms only got worse. The doctor suggested that I see his professor and mentor Dr. Jankovic at the Baylor College of Medicine (BCM) in Houston Texas. With our faith that God is in control and the strong support I had we were able to relocate to Texas, there I got an appointment with Dr. Jankovic. He determined that I was not getting enough medication. He made the necessary adjustments, and I have been seeing him ever since.

The keys to success for spousal support are communication, role changes, and getting some help when in need. Laurie balances his life by scheduling my injection dates around his activities at work, family time, and most importantly finding time for himself. I also keep a keen eye on his health, making full use of my time while my eyes give me a break before and after my injections. I try not to wear him down, and I encourage him to take a break when he needs to while I spend hours on the phone supporting someone. Laurie is my rock; he is my anchor, and during my adjustment in dealing with my disorder, he held my hand when my eyes closed on me. He tells me it will be okay; your eyes will soon open.



Since I have better control of my situation, I have turned my despair into something meaningful, and I have developed a passion for supporting other BEB/Meige patients with similar issues because I have been there before. We are sharing coping strategies to feel more empowered and to create a sense of community.

It is now the fourth quarter of our 'vision year 2020', plus we are in the midst of a global pandemic which has resulted in far reaching loss, yet BEBRF has continued to fulfill its mission via electronically connecting patients with BEB and other related disorders.

Service brings a sense of gratitude to my own life. By supporting others, it takes away your focus from yourself to see the needs of others and motivates me to do something about it. Laurie would often say to me "that's what you signed up for isn't it?" and together we have embarked upon this journey to help others have a better day. There is much joy in serving others who are sharing the same journey. I am reminded of the Bill Withers song, "we all need somebody to lean on."

*Ena Wilmot, BEBRF State Coordinator for Texas, Arkansas, Louisiana, and Mississippi.*

## SANDY MINCHER – MY ROCK

My first symptoms appeared in the summer of 2002. I went to my ophthalmologist with this complaint – "Bilateral eye closure and spasms lasting a few to many long seconds without me wanting this"! I was officially diagnosed in 2003 at the age of 45 when I started Botox every 12 weeks with only 60 to 70% eye-opening! I was an RN working per diem. I progressively got much worse where Botox did not take affect at all, and I experienced much more frequent spasms.

My husband was my ROCK, and I was his ROCK! He had already experienced life-threatening surgery with a severe disability early in our marriage in 1983. He literally is a walking miracle! It was 2004 when I had to stop driving! How devastating for me as I was only 46 years old! I was a very active mom with three very active teenagers and still working 3 to 4 days per week. I never missed a day of work thanks to my ROCK, my chauffeur, my constant supporter, who never gave up on me despite many challenges. My family, friends, and coworkers were amazing!

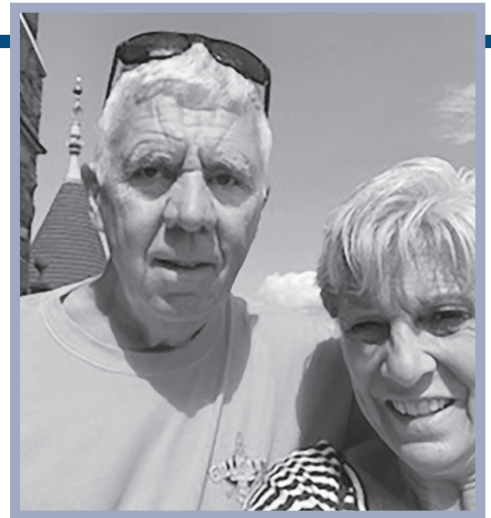
For seven years my husband drove me EVERYWHERE! ...to and from work every day and anywhere I had to go. I left my last job in 3/2011 after being let go a third time for "being too slow in my job duties". I stopped working upon my husband's recommendation and support and enjoyed preparing for and planning 2 daughters' weddings six weeks apart in 10/2011 and 11/2011. During that year I gathered all of my pertinent medical records and in 1/2012 I applied for

Social Security Disability. I was approved right away with the assistance of a lawyer specializing in Social Security Disability cases.

I made the BEST out of what I DID have – a beautiful supportive family, a beautiful home, and an elderly mom who needed my help. I was so grateful I was right next-door to her! She drove me to my appointments, and I went with her to hers. I was there for her when she needed me most. God puts you where you need to be when you need to be there. I certainly did not expect to have to stop working at the age of 53, but my life was filled with many other BLESSINGS! I really focused on the POSITIVE. I was, and still am, very BLESSED for what I did have, and still now have in my life.

My family, and most of all my ROCK, my husband Greg, married now 40 years, got me through a very hard time in my life, and I had gotten him through his. Life is filled with many challenges, but it is so necessary to try to let go of the challenges, and focus on the Blessings.

*Sandy Mincher, BEBRF Area Representative, Upstate New York.*



**IF YOU ARE INTERESTED IN STARTING A SUPPORT GROUP OR ATTENDING AN ONLINE ZOOM MEETING, CONTACT THE BEBRF OFFICE AT 409-832-0788.**



# BOTULINUM TOXIN UPDATES

## WHAT A PLEASANT SURPRISE

BY TISHANA CUNDIFF

Imagine my pleasant surprise when I recently opened my mail to read, “Happy Anniversary...Congratulations! You’ve been part of the BOTOX® Savings Program for 9 year/years, and have saved \$3,170.56 on BOTOX treatments since you enrolled.”

Congratulations were indeed in order! I paused for a brief moment to consider the possible ways I have enjoyed these thousands of dollars returned to my pocket. My dollar amount could have been even higher had I addressed the necessary submissions early on in my treatment. Little did I know, and that is why I am sharing now.

The process is simple. I complete the three short forms from BOTOX® Savings Program, scan them with my phone for my personal files, and mail the forms

along with a copy of my insurance Explanation of Benefits. Although I can request the funds go directly to my treating physician, I pay my doctor and request the reimbursement be sent directly to me. My checks are in the exact amount I paid.

The program is open to those over 18 who receive treatment in the United States or Puerto Rico and are covered under commercial health insurance or commercial prescription drug insurance. Unfortunately, this program excludes Medicare/Medicaid. The reimbursements are available for those receiving treatments for Blepharospasm, Cervical Dystonia, Chronic Migraine, and other conditions.

**Editor’s Note:** The following is information on both the Botox® and Xeomin® reimbursement programs:

## BOTULINUMTOXIN TREATMENT ASSISTANCE PROGRAMS

The **BOTOX PATIENT ASSISTANCE® PROGRAM** is dedicated to helping financially eligible patients. There are certain financial and other requirements that must be met to qualify for the program. Patient must:

- Be uninsured or underinsured
- Have income less than or equal to 500% of the Federal Poverty Level
- Be a resident of the United States or Puerto Rico

More information is available at: <https://www.botoxone.com/PatientAssistanceProgram> or by calling the Botox hotline: **1-800-44-BOTOX (1-800-442-6869)**. A Reimbursement Counselor can help answer any questions and send you an application.

The **XEOMIN® PATIENT SAVINGS PROGRAM** is designed to support eligible patients with their actual out-of-pocket XEOMIN medication costs and related administration fees, up to a maximum amount of \$3,500 per rolling 12-month period. The initial 12-month period begins with a patient’s acceptance into the Program (no earlier than July 1, 2016). To be eligible, patient must:

- Be a clinically appropriate patient for therapeutic treatment with XEOMIN, as determined by your doctor
- Be prescribed XEOMIN®
- Be at least 18 years of age
- Have commercial insurance that covers XEOMIN medication cost
- Not be enrolled in a state or federally funded prescription insurance program. Further restrictions apply to eligibility and reimbursable expenses.

More information is available at <http://www.xeomin.com/consumers/patient-resources/patient-savings-program> or by calling **1-888-493-6646** between 8 am and 8 pm ET.

## MORE FREQUENT BOTULINUM TOXIN INJECTIONS? A POSSIBILITY

Jane Boyd, MD, the BEBRF Vice President for Physician Outreach, assembled some materials that patients and/or physicians can use in appealing to insurance companies to allow injections more frequently than every 12 weeks. In putting this together she stated, "this is near and dear to my heart because my first injector was dogmatic that my injections should last 12 weeks, and he made me feel crazy when I told him they didn't (I get injected every 10 weeks now with a different physician). In my case, it wasn't an insurance issue.... just ignorance and a lack of humility on the part of my physician."

Dr. Boyd went on to explain that many insurers follow protocols which can be overruled if patients and/or doctors take the time to appeal. She says that when she was practicing medicine, that she spent a lot of time each week speaking to the medical directors of various insurance companies (in her case, mostly Medical HMO's) to get things approved (drugs, procedures, visits to specialists, etc.) that were not covered on their protocols/algorithms. She found all of the medical directors very receptive to her appeals, especially, when they were given data that supported her position.

If someone's physician is unwilling to spend the time to make an appeal, insurance companies have phone numbers and procedures in place for patients to register their own complaints/appeals.

The assembled documents include:

1) an article from the BEBRF newsletter July/Aug/Sept 2015 Volume 34 Number 3

2) an abstract from the journal Neurology 1987 Volume 37:616-623 by Dr. Jankovic and Janet Orman which notes that the duration of beneficial effects from botulinum toxin in blepharospasm and oromandibular-cervical dystonia ranges from 5 to 28 weeks with a mean of 12.5 weeks.

3) Results from the 2019 BEBRF survey of 285 blepharospasm patients

4) an article from Dr. Richard Anderson et.al. Ophthalmic Plastic and Reconstructive Surgery 1998 Volume 14, #5, pages 305-317 (page 312 contains information about botulinum toxin duration)

If you would like to obtain these documents, a link to them will be posted on the BEBRF Facebook page and Website, or you can contact the BEBRF office at 409-832-0788 or by email at [bebrf@blepharospasm.org](mailto:bebrf@blepharospasm.org).



### 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:** I have been receiving Botox for over 30 years approximately four times a year. However, the last 36 months I have been going much longer between injections since my ability to keep my eyes open is much worse after injections. After approx. two months my eyes slowly improve so I can see much better, I have now gone for six months and 12 days since my last injections and am functioning quite well. My question is do the muscles deteriorate/atrophy after 30+ years of Botox injections?

**A:** Your observation is not uncommon as many patients note longer duration of response to BTX after years or decades of treatment. The explanation for this phenomenon is not clear but

may in part be related to age-related atrophy of the injected muscle, although repeat injections may also contribute. In some cases the severity of blepharospasm gradually improves and, rarely, some patients actually achieve spontaneous remission. We have noted this observation especially during the pandemic when patients were forced to postpone their injections and some discovered that the prior injection has lasted longer than expected. Most patients, however, require to be injected every 3-4 months.

*Joseph Jankovic, MD, Professor of Neurology, Baylor College of Medicine*



# SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before January 1, 2021, the next newsletter deadline. If you are interested in attending an online meeting but are not currently in a location with a support group leader, please contact us, and we will try to find you a meeting.

## CENTRAL DISTRICT

### Dallas/Fort Worth, Texas

**Date:** Tuesday, October 20, 2020

**Time:** 12pm – 2pm

**Location:** Zoom

Please contact Ena for invitation instructions to meeting.

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** [enamwa@hotmail.com](mailto:enamwa@hotmail.com)

### Tarrant and Parker Counties, Texas

**Date:** Wednesday, October 28, 2020

**Time:** 1:30pm – 3pm

**Location:** Zoom

Please contact Sharon for invitation instructions to meeting.

**Contact Person:** Sharon West

**Phone:** 817-297-4389

**Email:** [swest124@swbell.net](mailto:swest124@swbell.net)

### Houston, Texas

**Date:** Saturday, November 7, 2020

**Time:** 10:30am – 12:15pm

**Location:** Zoom

Please contact Ena for invitation instructions to meeting.

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** [enamwa@hotmail.com](mailto:enamwa@hotmail.com)

### Louisiana

**Date:** Thursday, December 10, 2020

**Time:** 6pm – 8pm

**Location:** Zoom

Please contact Percy for invitation instructions to meeting.

**Contact Person:** Percy McCraney

**Phone:** 318-289-0869

**Email:** [pmccraney@gmail.com](mailto:pmccraney@gmail.com)

## WESTERN DISTRICT

### Los Angeles, California

**Date:** Thursday, January 14, 2020

**Time:** 1:30pm – 3pm

**Location:** Zoom

Please contact Cynthia for invitation instructions to meeting.

**Contact Person:** Cynthia Clark

**Phone:** 650-678-4132

**Email:** [clark.cyl@gmail.com](mailto:clark.cyl@gmail.com)

## NATIONAL SUPPORT

### National Support Group Meeting

**Date:** Friday, November 6, 2020

**Time:** 1:00pm – 3:00pm, central time

**Location:** Zoom

Please contact Charlene for invitation instructions to meeting.

**Contact Person:** Charlene Hudgins

**Phone:** 409-832-0788

**Email:** [Charlene@blepharospasm.org](mailto:Charlene@blepharospasm.org)

### National Support Group Meeting

**Date:** Thursday, December 17, 2020

**Time:** 1:00pm – 3:00pm, central time

**Location:** Zoom

Please contact Charlene for invitation instructions to meeting.

**Contact Person:** Charlene Hudgins

**Phone:** 409-832-0788

**Email:** [Charlene@blepharospasm.org](mailto:Charlene@blepharospasm.org)

### National Support Group Meeting

**Date:** Wednesday, January 27, 2021

**Time:** 1:00pm – 3:00pm, central time

**Location:** Zoom

Please contact Charlene for invitation instructions to meeting.

**Contact Person:** Charlene Hudgins

**Phone:** 409-832-0788

**Email:** [Charlene@blepharospasm.org](mailto:Charlene@blepharospasm.org)

**IF YOU ARE INTERESTED IN LEARNING MORE ABOUT STARTING  
A SUPPORT GROUP, CONTACT THE BEBRF OFFICE AT 409-832-0788.**



## NORTHEAST TEXAS SUPPORT GROUP MEETING



## ORLANDO SUPPORT GROUP MEETING



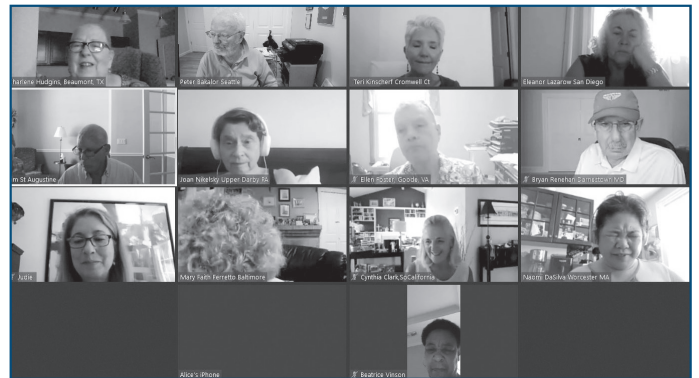
## 9/30/2020 NATIONAL SUPPORT GROUP MEETING



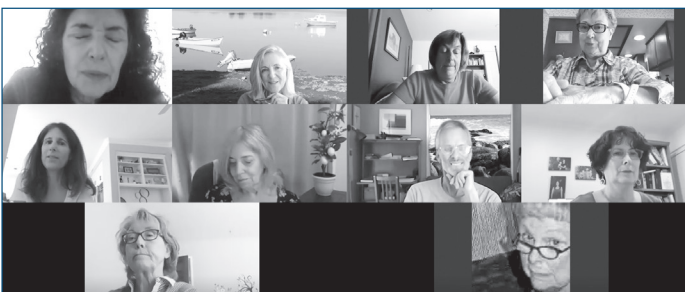
## 7/29/2020 NATIONAL SUPPORT GROUP MEETING



## 8/25/2020 NATIONAL SUPPORT GROUP MEETING



## LOS ANGELES SUPPORT GROUP MEETING



It is our editorial policy to report on developments regarding BEB/Meige and related disorders, but we do not endorse any of the drugs or treatments in the Newsletter. We urge you to consult with your own physician about the procedures mentioned.

**BENIGN ESSENTIAL BLEPHAROSPASM  
RESEARCH FOUNDATION, INC.**

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# New Dystonia Diagnosis Research Study

An article was posted online recently titled: “A micro-structural neural network biomarker for dystonia diagnosis identified by a DystoniaNet deep learning platform”. The link to the article is as follows:

<https://www.pnas.org/content/ear-ly/2020/09/30/2009165117>

This new dystonia diagnosis method raised some questions for blepharospasm patients, and **Dr. Mark Hallett, NINDS, NIH, and Chair of the BEBRF Medical Advisory Board** explains the implications below:

“In some circumstances it is difficult to make the diagnosis of whether someone has blepharospasm. This study shows that a routine brain MRI analyzed with this special technique can support or refute the diagnosis with a very high degree of certainty. That is good, but that is also all that we know this special technique can do -- at least so far. To repeat, the test can answer the question “blepharospasm or normal”. It cannot answer other possible questions, such as “blepharospasm or hemifacial spasm” or “blepharospasm or increased blinking due to dry eye”. More work will be needed to answer these other questions. So for anyone who already has a secure diagnosis of blepharospasm, it is not helpful. Where it should be most helpful is for a person with mild symptoms for whom the diagnosis is not clear, but honestly it has not really been tested in that circumstance yet. This method is still in its early stages, and, hopefully, it will be able to answer more questions as it is further developed.”

