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TAKING CONTROL OF YOUR BEB MANAGEMENT

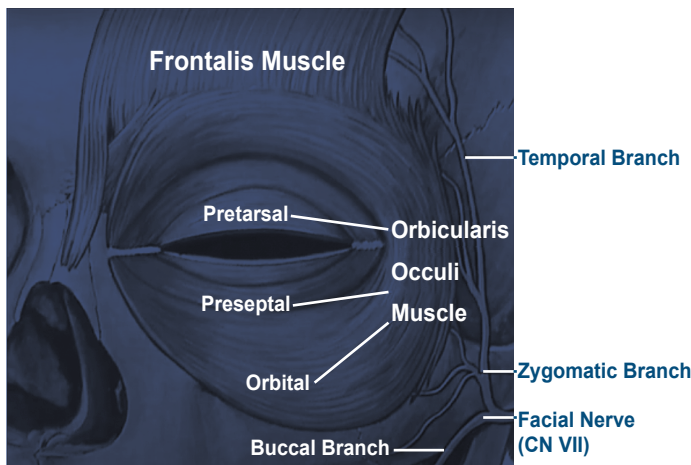
PRESENTATION BY DR. JENNIFER MURDOCK AT THE 9/26/20 WEBINAR

The goal/theme of this webinar was to give blepharospasm patients more control over their condition – in other words, how to maximize the tools available for that control. This recorded webinar is available on both our Facebook page and our website. Dr. Murdock explained some of the fundamental basics about the blepharospasm condition because knowledge is power, and the more you know, the more you can contain or control blepharospasm.



BLEPHAROSPASM: THE BASICS

External Anatomy: This part of the presentation was designed to provide a basic understanding of the anatomy involved with blepharospasm.



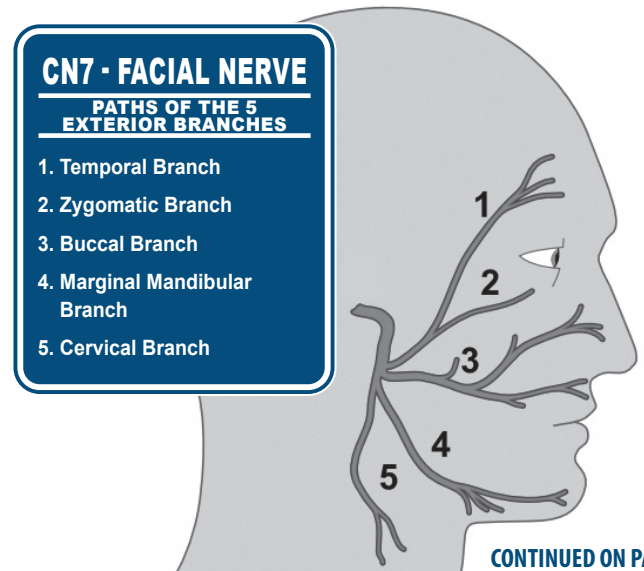
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The muscles around the eyes affected by blepharospasm include: 1. The Orbicularis Oculi muscle, or the circular muscle that comprises most of the upper and lower eyelids. This muscle is responsible for contracting and squeezing the eyelids closed. The three parts of the orbicularis oculi muscle include the pretarsal area just above and below the upper and lower lash lines, the preseptal area that encircles the

pretarsal area, and the orbital area which encircles the preseptal area, and 2. The Frontalis Muscle which is the muscle underlying the brow line and up into the forehead. The frontalis muscle is often used and overworked trying to lift the eyes open which can later create issues for blepharospasm patients.

Also important are the nerves that innervate the muscles mentioned above. The main one is the Facial Nerve (a Cranial Nerve) and it has several different branches. The three branches most relevant to blepharospasm are: 1. The Temporal Branch ((located in the forehead area), 2. The Zygomatic Branch (upper cheek below the eye), and 3. The Buccal Branch (lower cheek, between the nose and the upper lip). These are the main nerves that control these muscles. For a clearer view of these nerves, see the drawing below:

Peeling back and going a little deeper, underneath the orbicularis oculi, there are the Procerus Muscle, and the Currugator Supercilli Muscle. These muscles are in the brow and contract the eyelids down. Even deeper is the elevation muscle the Levator Muscle which lifts the eyelid up. It is directly underneath the orbicularis muscle.



CONTINUED ON PAGE 4

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
Spring	April 1, 2021
Summer	July 1, 2021
Fall	October 1, 2021

BEBRF BLURBS

Thank you so much for your donations in 2020! We appreciate that 2020 was a difficult year for everyone. While the BEBRF staff spent most of the year working from home and continue working from home in 2021, we managed not only to keep on going, but also to create new and successful programming for you that we hope to carry into the future of a non-pandemic world. AND, we couldn't have done it without you! So, thank you to all of our **donors**, all of our **volunteers**, and for all of the **patients** who have shared so much of themselves last year.

2021 is the year of BEBRF's 40th Birthday! So many events are planned for this year! Stay tuned as we share our history and our mission throughout the year. We hope to have at least one very special event every month – some educational, some rooted in support, and some that are just supposed to be fun! Stay tuned...

We now have three BEBRF Webinars available for viewing online! In addition to the September Webinar entitled **Taking Control of your BEB Management** with Drs. Charles Soparkar and Jennifer Murdock (see related stories on pages 1 and 8) and the November Webinar entitled **Opening Our Eyes to Stress Management for BEB** with Dr. Jaelline Jaffe, we now also have online our most recent Webinar – **Obtaining Social Security Disability**

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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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² *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.*

for **BEB** with Attorney Jonathan Healy and Former Idaho State Self-Reliance Officer Carolyn Cleverley (see related story on page 6). You can access these Webinars through both our website and our Facebook page.

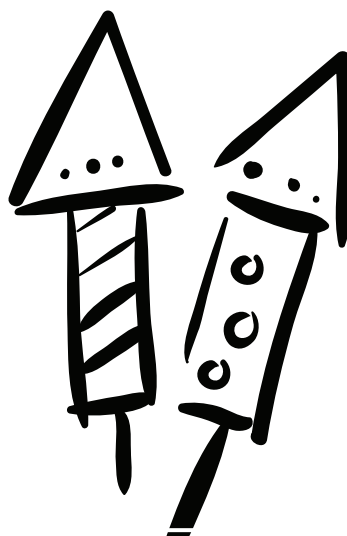
Our fourth Webinar on **Deep Brain Stimulation and BEB/Dystonia** with Dr. Sveltana Miocinovic, Neurologist with Emory University and Dee Linde, BEBRF Western District Director, Advocacy Chair, and Board Member who has undergone the Deep Brain Stimulation procedure herself, will be on Saturday, April 10, 2021 at 1:00 pm central time. Information for how to register will be on the BEBRF Website and Facebook page.

BEFR continues to host monthly National Zoom Support Group Meetings. Check the listings on pages 12-13. Also, one of those upcoming meetings, on March 12, 2021, will be just for **Caregivers!** In addition, many Area Representatives are also scheduling regional Support Group Meetings as well. If at first you have difficulty with Zoom, don't be discouraged, it does get easier...

In our last Newsletter we ran an article on how to get botulinum toxin injections more frequently. We are continuing to add supporting documents to this bundle of information. Contact the BEFR office by phone or email, if you would like to receive this information.

CALL TO ACTION

Recently, BEFR has allied with another patient advocacy group – Alliance for Patient Access (AfPA) to advocate to overturn the rule that requires all blepharospasm patients who receive their botulinum toxin injections through a hospital system to obtain pre-authorization for every injection cycle. AfPA has put together a sample letter that you can mail or email your Congressional representatives to ask for this rule to be overturned. We are asking you to take action and communicate this important message to your legislators. You can find this sample letter and instructions on how to contact your representative at this website address: www.movementdisorderspolicy.org/letterdesk. The United States has just opened a new congressional session, so now is a great time to reach out.



HAPPY NEW YEAR!



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TAKE CONTROL OF YOUR BEB MANAGEMENT

The Surface of the Eye - Tear Anatomy: There are three components to tear film: 1. Water Layer – the powerhouse of tear film, filled with the “good stuff” for the eye surface such as proteins, nutrients, healing elements, bacterial protectants, etc., 2. Underneath the water layer is the Mucin Layer which permits the even flow of tears over the eye and the adhesion of the tears to the eye, and 3. Over the water layer is the Lipid Layer which is produced by the Meibomian Glands which can affect both dry eye and blepharospasm. These are tiny oil glands along the lash shelf surface of the eye. These glands can sometimes become infected or inflamed. The lipid layer is the barrier that prevents tear evaporation, particle penetration, and provides a good optical surface.

The Anatomy of Tearing: The aqueous (liquid) portion of the tears are produced primarily in the Lacrimal Gland which is located in the outer-upper corner of the eyelid. The tears (along with lipids) bathe across the eye downward to the nose, and this is supported by the way the blink works. Once the tears have crossed the eye to the corner of the nose, there is the tear drainage system (nasal-lacrimal system). There are two eyelid holes on the upper and lower eyelids called Puncta that drain the tears down into a tube system which ultimately provides an exit to the nose. There are muscular components that surround this tube drainage system that support the flow of tears out of the eye and into the nose. Consequently, a spastic condition around the eyes can also affect how the tears drain.

Who is at risk for a tear film problem? Most of us, due to a variety of factors:

- Increasing environmental pollutants/irritants
- Decreasing androgen:estrogen ratio (hormonal changes)
- Tear gland demise over time (blepharitis)
- Increasing frequency of autoimmune diseases
- More than 30% of all medications decrease tear production
- Most chemotherapy regimens destroy tear glands

WHY ARE TEARS SO IMPORTANT?

- They bathe and protect the surface cells of the cornea. The surface should be moist and full of nutrients.
- They bring essential nutrients to the surface cells of the eye and take away metabolic waste.
- They bring important immune cells and factors to fight off bacteria, viruses, and other irritants thereby protecting the eye from disease.
- They bring important immune cells and factors to fight off bacteria, viruses, and other irritants thereby protecting the eye from disease.
- They maintain clarity of vision. The eye is designed to see through a **cornea + water (tears) + air** system. You need those three components to have clear vision. By contrast, **cornea + water (tears) – air = blurry vision** (such as, trying to see underwater), and **cornea – water (tears) + air = blurry vision**. Clear vision, therefore, relies upon maintaining a balance of all three components. If there is not enough water (tears), the eye will try to compensate by over-producing tears which can often stream down the face without becoming appropriately flushed through the tear system, leaving you with dry eye in spite of that “over-flow”.

Which medications can lead to dry eye?

- Systemic medications, such as: blood pressure medications, cholesterol modifying agents, anticholinergics, antidepressants, heart rhythm stabilizing agents, Parkinson’s disease agents, antihistamines, as well as many others.
- Topical medications, such as: drops for glaucoma and preservatives in tear supplements.

Blinking: In a normal blink, the eyelid motion starts in the upper-outer corner of the eye and ends near the nose. This helps bathe the eye in tears in accordance with the anatomy of the tear cycle beginning in the lacrimal gland and ending in the tube drainage system near the nose, mentioned above. Normally, people blink 12 times per minute, with each blink lasting one third of a second, with faster closing and slower opening of the lids. There are three different types of blinks: the spontaneous blink which is periodic and involuntary; the intentional voluntary blink; and the reflex blink in response to loud noise, light, or a sudden impulse.

Why do we blink?

- To lubricate the cornea
- To clear debris from vision
- To activate tear production from multiple glands

BLEPHAROSPASM: THE BASICS

One of the major differences in a blepharospasm patient's blink is that instead of that blink that starts in the outside upper eyelid area and closing downward toward the nose, blepharospasm patients have a flat blink, which does not encourage the normal tear pattern drainage process. Therefore, blepharospasm and dry eye go hand in hand. As mentioned above, when a normal person has an imbalance in their tear production, they will compensate with the over-flow creation of tears. Blepharospasm patients don't have this response.

Further, when an irritant is introduced to a normal eye, the response is to blink a couple times and then resume normal blinking; however, when an irritant is introduced into the eye of a blepharospasm patient, the responding blinking will continue abnormally beyond that. The part of the brain that controls the return to normal blinking does not operate the same. Irritants can include: allergens, pollutants, toxins, breeze, bright glare, eyelashes, wrong specs, or dry eye, but the brain never signals the eyelids to return to normal blinking, so the blepharospasm continues.

Dry eye exacerbates blepharospasm and blepharospasm exacerbates dry eye in a vicious cycle. In addition, other factors related to blepharospasm can interrupt the normal blink activity (blink perturbation):

- Botulinum toxin treatments can create incomplete blinks
- Eyelid inflammation can cause stasis in the creation of tears and also poor quality of the tears formed
- Poor tear film mobilization, along with the above creates Toxic Tear Syndrome
- Frontalis Antagonist Blink Syndrome – overusing the frontalis muscle (in the brow and forehead) to try to lift the eyelids. The forced effort to keep the eyes open results in decreased blink and dry eye problems

THE TRUTH ABOUT TOXINS

Botulinum toxins are derived from the clostridium family of bacteria, and they exist to help that bacteria dominate and survive in the world of other bacteria. There are eight different types of botulinum toxin, but the one that is used for the treatment of blepharospasm is Botulinum Toxin A.

Overview of botulinum toxins:

- Very fragile (to temperatures, agitation, enzymes)
- Quantified (measured) in units
- Deadly; a lethal dose of botulinum toxin is 2,800-3,500 units
- Contain charged polypeptides which allow the botulinum toxin to adhere and are aided by carrier proteins such as Human Serum Albumin (HSA)
- Need Zinc-binding Metalloproteinase (Zinc) for proper adhesion

There followed a discussion of the differences of the various types of botulinum toxin as described in the chart below:

	TOXIN	OTHER PROTEINS	CARRIERS	MARKET "ADVANTAGES"
BOTOX	Single strand, pre-processed protein	Hemagglutinin Non-Hema	HSA	The "original" "natural"
XEOMIN	Single strand, pre-processed protein		HSA	The "most pure"
JEUVEAU "NEWTOX"	Single strand, pre-processed protein	Hemagglutinin Non-Hema	HSA	The "highest tech," "made in USA"
DYSPORT	Mixed, partially processed	Hemagglutinin Non-Hema	HSA lactose	"Works faster" "spreads better, smoother"
MYOBLOC	TYPE B pre-processed protein	Hemagglutinin Non-Hema	HSA	"works in 12 hours"
DAXI	Single strand, pre-processed protein	SECRET PROTEIN RTP004	No HSA	"last twice as long"

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What happens when the botulinum toxin is injected into a muscle?

Botulinum toxin prohibits the Snap-25 protein from contracting. Zinc allows the proper interaction between the toxin and the Snap-25 protein. Targets for the toxin are the strong contracting muscles around the eyelids. First the orbiculus oculi is targeted, especially the pretarsal area, followed by the orbital areas—top, bottom, and particularly the side. Finally, there is focus on the brow muscles.

Daxibotulinumtoxin A (Daxi) is the newest botulinum toxin on the market. It has a proprietary (secret) stabilizing peptide which promotes strong binding for certain molecules. Clinical trials showed that Daxi had efficacy for 24 weeks (6 months).

LET'S TALK SOCIAL SECURITY DISABILITY – PART 2

BY CAROLYN CLEVERLEY

This article was written by a patient who was a Self-Reliance Officer for the State of Idaho and helped numerous people acquire Social Security Disability (SSD) benefits. She then was diagnosed with blepharospasm and used her experience with the Social Security Administration (SSA) to obtain SSD for herself. Further, this article is intended to complete the first article begun in the last Newsletter which covered points 1 and 2 of the five step SSD process:

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

Now, for the second part of the article:

3. Financial determination: When you set up an on line account with SSA, you will be able to view your employment and earnings record. If you do not agree with the information shown on your employment and earnings record, you can bring proof of the correct information to the interview with you. My first paying job was when I was 8 years old as a switch board operator in a Motel in Alaska. I only made 25 cents an hour so I wasn't very concerned about that job, but the job I had for 25 years I paid attention to. Self-employment, temp jobs, seasonal jobs, and frequent job changes can be difficult but for the type and amount of your benefits to be correct, your employment and earnings record must be as correct as possible.

SSA will also ask for proof of your last earnings if you recently had to stop working. There are some special situations with back dating to the date you became disabled but I think the best advice I can give you is to bring proof of the current end date of your employment to the interview with you and let SSA ask for anything else they need. They may also send a form to your most recent employer to ask for information about your disability and income. I contacted SSA enough that I knew when they sent out requests for information, I followed up with the person the request was sent to, to make sure it didn't get lost on someone's desk. When SSA asked for wage verification back to my original date of disability, I printed off my electronic payroll record and faxed it to the SSA worker two weeks before my employer responded. The financial determination was already done by the time SSA received the response from my employer.

4. Medical/Disability Determination: This stage takes the longest. The longer it takes, the more records SSA will request. Ensure you have the fax number for the worker completing your disability determination so that you can fax the worker your most current medical records (labeling them with an Exhibit Number for

reference) directly as you continue treatments while this determination is being completed.

The nurse reviewer who completed my disability determination called me when she received my medical records, and we reviewed my records together. She then called me two other times to say she needed specific records. I was able to let her know she already had each of the records she said she needed and gave her the exhibit numbers. She did have them on file each time.

There is a difference in the way SSA views disability for a 56 year old and a 24 year old. I was 56 years old when I applied for disability and had exhausted all treatment options which were reasonable and prudent for me to try in view of my age and other health conditions. I had started working outside the home when I was 8 so I had an extensive work history. Medical science was not likely to come up with any other viable treatment options for me before I hit retirement age. The situation could be viewed differently if I were 24 and without the other health issues. Ability to retrain is also viewed differently for a 56 year old than for a 24 year old.

5. Notification of approval or denial: When your disability is approved, it may still take several weeks to actually receive money. If SSA needs anything else, they will ask. If you are denied, first ask why then file an appeal as soon as possible if the issue can't be resolved.

Plan on the process taking a year and a half to two years from application date to determination date. The more information or documentation SSA has to ask for, the longer it will take.

I understand this process is long and a lot of work but it gave me purpose and a feeling of accomplishment when it was done. And I didn't have to share a portion of my lump sum from SSA with anyone. I was able to use it for my own expenses. Not everything has to be done immediately. Just obtaining my medical records and writing my treatment journal took me 2 months. That is why I didn't apply for Social Security until I had those two things done. Once you apply there are more timelines imposed so I would suggest you get everything pulled together first. With backdating to date of disability, most of the time it does not make much of a difference to what you are eligible for but makes a huge difference to if you are approved or not.

If you are someone who does not feel comfortable being an advocate for yourself in this way, this process may not be for you. There is nothing wrong with hiring a disability advocate or attorney to help you with your disability application. If you have questions about anything I have shared, I would be happy to try and answer them. My email is: cclever1@gmail.com.
NOTE: Please see the related article on blepharospasm and visual acuity for SSD.

VISUAL ACUITY AND SOCIAL SECURITY DISABILITY

According to Social Security Disability Attorney Jonathan Healy, the visual acuity requirements for SSD fall under Section 2.00 of the Disability Listings. This includes obtaining measurements relative to 20/20 vision obtained through the use of the charts with letters such as used in a regular eye exam.

According to Carolyn Cleverley, "this is not a good test for measuring blepharospasm. With blepharospasm, there is nothing wrong with my actual ability to see, I just can't use it. We had to define how often I was sighted, not if I was near-sighted or far-sighted which is what visual acuity defines. The letter my Doc wrote for SSA defines it well:"



UNIVERSITY OF UTAH
HEALTH CARE

Neurology Clinic

November 16, 2016

RE: Carolyn Cleverley

To Whom It May Concern:

Carolyn Cleverley has been known to me and in my care since February 2016, suffering from Blepharospasm, a well recognized neurologic condition characterized by episodic, spontaneous, involuntary closure of the eyes, rendering this individual bilaterally blind with the equivalence of no light perception vision during these unpredictable periods of variable duration and frequency. Unfortunately, even with regular treatments, this patient continues to suffer from statutory blindness (visual acuity worse than or equal to 20/200 in both eyes and/or profound visual field loss within 5° of central fixation) more than 50% percent of the time.

In evaluating the visual compromise in this individual who suffers from severe Blepharospasm, "best" visual acuity, "best" visual field, and "best" visual efficiency must be appropriately interpreted in the context of the devastating, unique neurologic disorder.

Four additional circumstances make this an even more compromising disorder:

1. The most significant vision impairment in Blepharospasm occurs instantly and unpredictably, making such activities as walking in public spaces and driving generally unsafe.
2. Since this patient is infrequently fully sighted; partially sighted at other times due to "squinted," constricted visual fields; and completely blind at others, most of the compensatory mechanisms usually well-developed in many partially sighted individuals are lacking, thus causing an even greater functional impairment.
3. By attempting to maintain eyelid opening by physical means, such as chronic brow elevation and manual separation of the eyelids, this patient often develops dry eyes and poor quality tear films, causing glare and dazzle from even low power light which further impairs vision.
4. Blepharospasm is incurable.

In short, it is my professional opinion that this individual meets Social Security criteria for 100% disability based upon vision compromise. If I can provide and further information, please do not hesitate to contact our office.

Sincerely

Lauren Schrock, M.D.
University of Utah Neurology
729 Arapeen Dr.
Salt Lake City, UT 84108

QUESTIONS AND ANSWERS FROM THE 9/26/20 WEBINAR TAKING CONTROL OF YOUR BLEPHAROSPASM MANAGEMENT

DR. CHARLES SOPARKAR AND DR. JENNIFER MURDOCK

The following questions were answered by Dr. Murdock:

Q: What is the best way to treat for dry eyes if your eyes don't totally close when you sleep?

A: First and foremost, lubrication – artificial tear ointment – over the counter in various brands. Also moisture goggles are helpful if you can sleep in them. An eye mask could help keep your eyes from drying out. Finally, optimize your environment with a humidifier in your room and no overhead ceiling fan.

Q: Are there possible bad side effects that can occur from long-term use of botulinum toxin injections?

A: No. These injections have been used since 1987, and so for decades they have been safe and effective.

Q: What is the latest information on using marijuana for blepharospasm treatment?

A: This is “to be continued...” While marijuana does show promise, there have been scattered case studies in the past. There are some new, larger studies to determine safety and efficacy that are about to be initiated.

Q: Are there long term side effects from taking anti-anxiety drugs, such as Lorazepam?

A: Yes. Some side effects include memory loss, confusion/brain fog, lethargy, headaches, insomnia, risk of addiction (especially of benzodiazepines) – rapid withdrawal can be very serious, impaired coordination – increased risk of hip fracture, fatigue, depression, nausea and vomiting. The longer you use these drugs, the higher the risk of these effects. The higher dosages also increase these risks.

Q: Many of the women I speak to say they had onset of BEB after menopause. Is there a connection?

A: Yes! Decreased androgens and estrogen can lead to decreased oil production and decreased tear production, lowering the threshold for the onset of BEB or exacerbating the symptoms of BEB.

Q: Are there dangers for other conditions to set in for those of us who suffer from blepharospasm? If so, could you mention things we should be on the lookout for and symptoms?

A: Other things to look out for include Meige Syndrome – contractions of the jaw and tongue, muddled speech, Spastic Dysphonia – contraction of the vocal cords, and Spastic Dystonia – the inability to relax a muscle.

Q: Some doctors have recommended avoiding the use of erythromycin ointment. What is your opinion? Would you have any suggestions on using Inveltys for burning eye symptoms with rosacea?

A: Erythromycin ointment is great for rosacea because of its anti-inflammatory properties. However, it can lead to resistant bacteria. Inveltys (Loteprednol erabonate) and other steroids are not recommended for long term use due to the risk of glaucoma, cataracts, etc. So the safest option for long term use is artificial tear ointment.

The following questions were answered by Dr. Soparkar:

Q: A doctor I went to for injections used a vibrator on my forehead supposedly as a distraction. Instead, it had the opposite effect. Have you ever heard of this?

A: Absolutely. We will frequently do things to distract the patient. It's different for different people. Some people find it to be helpful while some find it annoying. If it's helpful for you, do it. If it's not, ask them not to do that.

Q: I'm 94 and I've been getting injections for 38 years with good results. In the past year, Botox seems not to be working at all. Could stress be a factor for Botox not being as effective? Could it be my age?

A: It's not really age; absolutely stress makes blepharospasm worse. It may be a change in your diet or environment. I have not recognized that increasing age is a problem. I had a small number of patients about a decade ago that we gave a “Botox Holiday” – we gave them a different toxin for a short amount of time, and then brought them back to Botox, and that seemed to work.

Q: Two people I know say Omega 3 fatty acids have led to great improvement in their BEB. One even stopped getting Botox injections, though he's taking hemp hearts and Udo's oil/DHA 3-6-9 blend. What's the current thinking on whether Omega 3 helps with dry eyes or not (there was a NEJM article a few years back that showed no improvement).

A: Fatty acids maximize tear film, and that's very important. If this is helping you, great. It depends entirely on the individual. If you have a specific disease that is related to the oils, taking Omega 3 will help. If not, it probably won't make any difference.

Q: Aside from possible dry eye improvement, are there any other therapeutic benefits to Omega fatty acids in blepharospasm or other dystonias?

A: Nobody knows. There may be a neuro-psychologic benefit. Omega 3 will improve inflammation, but the most direct impact is on the tear film.

Q: For 8 years, my Botox injections have ranged from 2-5 months apart, averaging 3.5 months. I was

injected in February (note: this question was asked in September, 2020), and 1 month later began strict quarantine. 7 months later, I still don't need more Botox. What could account for this extended effect: (a) improved air quality due to less commuting and less car exhaust; (b) the absence of general "community" interaction (grocery store, church, post office etc.); (c) the increased attention to hand sanitizing and washing?

A: (a) Improved air quality? Absolutely. (b) Less community interaction is probably less affecting than not going into places with different temperatures, etc. that aren't aggravating dry eye. (c) I don't think the sanitizing/washing would have that much effect. The answer is stress can make BEB worse, and if you find it less stressful to be home during this pandemic, then your BEB may be better. Also your diet may have changed if you are staying home more, and that may be having an impact on your symptoms.

Q: Have you seen this decreased need for injections (mentioned immediately above) with other quarantining seniors?

A: I've seen both, cases where BEB is better and cases where it is worse.

Q: Is Neuroplasticity therapy for blepharospasm effective?

A: It is an alternative therapy. I think I may have had one patient who said that it was helpful for them. If it's good for you, I can't argue about that; if you try it and it's successful, absolutely continue to do it.

Q: I have had both spastic and pseudo-apraxic blepharospasm for 5 years. (a) With a partial myectomy in 2017, the spasms stopped, but the eyelids continued to close. (b) Ptosis repair in January 2020 provided no help. (c) Botox injections every 3 months have provided no help. (d) What else can I do? (e) Does BEB ever spontaneously disappear?

A: (a) It sounds to me like the preseptal and orbital muscles have been removed, but the pretarsal orbicularis was not removed, so you're having more pseudo-apraxia. (b) Again, the pretarsal orbicularis is not helped with ptosis repair; you've got to target that muscle right above the eyelashes. (c) It depends. If the injections are to the pretarsal orbicularis, well, that's what you should be treating. If that's not working, then maybe you need the pretarsal myectomy. (d) You might consider the pretarsal myectomy, and you might also consider the eyelid crutch spectacles. (e) I've had ONE patient who has said it suddenly went away, and I've treated hundreds and hundreds of patients where it has not.

Q: I was given Gabapentin for pain. At a higher dose, my Meige and eye spasms got much better. Any information about this?

A: Gabapentin is a neuroleptic; it slows down nerve

conduction. I would not expect that to be a universal therapy for most people. If your balance of nerve stimulation and muscle contraction would benefit from slower nerve conduction, then Gabapentin may help you. Again, it's so individualized, and I would say on balance that most people do not find relief from neuroleptics. But if it works for you, stick with it.

Q: Is there a connection between blepharospasm and rheumatoid arthritis?

A: Yes, the autoimmune disorders create more dry eye, and we know the connection between blepharospasm and dry eye.

Q: Why do many blepharospasm patients have light-sensitivity?

A: It's because you have poor quality tears. Remember, if you have a poor lipid surface, you'll be looking through oil droplets that create a glare.

Q: I notice when I am on prednisone, my spasms almost disappear. Has there been a study done with this drug?

A: Yes. The reason is you are decreasing the inflammation on the eyelids. I'm not sure if oral steroids which have systemic side effects are the best way to manage that. Think more about local, topical treatments to decrease your inflammation.

Q: Why does dystonia progress?

A: Nobody really understands. The good news is that outside of the head that blepharospasm does not really progress. It may go down to Meige or down into the throat, but it doesn't usually progress outside of the head.

Q: Do psychological issues, trauma, abuse, or PTSD cause blepharospasm or cause it to continue?

A: Yes, stress makes blepharospasm worse.

Q: Can drugs normally used for ADHD, such as Adderall, Ritalin, and Strattera lessen the symptoms of blepharospasm?

A: The answer again is – it's different for everybody. There is not a universal response to these drugs. Otherwise, they would be using them all the time. If you've tried them and they work for you, nobody's going to argue with it.

Q: Can long term use of clonazepam cause blepharospasm?

A: Unknown, probably not. Many patients think that using a certain drug caused their blepharospasm, but remember that benzodiazepines are sometimes used to manage blepharospasm.

Q: What is the best way to make botulinum toxin injections less painful?

A: Oral medication; distraction; small, sharp needles; fast treatments; don't inject too superficially or too deep; ice/topical analgesic (but these make the treatment less reproducible).

The following questions were answered by Dr. Murdock on the Q & A Zoom function during the Webinar:

Q: I was given ONABOTULINUM TOXIN A... (it is not working) What is the difference the above mentioned with BOTULINUM TOXIN A?

A: Onabotulinum toxin A is the generic name for Botox. Botulinum toxin type A refers to the entire group of toxins including Botox, Dysport, Jeuveau, Xeomin, and Daxi. The only available botulinum toxin type B is Myobloc.

Q: Botox is no longer working for me, but I found that taking Ambien does work for me. Will the foundation ever list this as an approved medication so that Medicare will pay for it? Also, are there any studies on this medication as a possible treatment for Blepharospasm?

A: Ambien promotes sleep, and blepharospasm symptoms stop when you are sleeping. So, you may notice that correlation. Ambien is not great for a day-time medication given its highly sedative effects. **(Editor's Note:** Medicare payment is unrelated to BEBRF documentation, rather Medicare bases its coverage on FDA approval of drugs for specific indications/uses.)

Q: Is this disorder taught in medical schools to inform the new doctors?

A: Different medical schools have different curricula; however, BEB is considered a rare neurologic condition. It is definitely taught within the specialties of ENT, ophthalmology, and neurology.

Q: I have had a chronic cough for years. It is not too bad, and doesn't change much, but seems a little better when my blepharospasm is better. Can this cough be a related dystonia?

A: If you have only a focal dystonia, benign essential blepharospasm, there has not been research showing an association with disorders involving cough or other pulmonary issues. If you have another type of dystonia or syndrome involving the eyelids, that could be a more complex answer.

Q: Also, my physician has done x-rays, lung function tests and more, and has found nothing.

A: Unlikely to be related to BEB

Q: Is a forehead lift something to consider for blepharospasm? I am constantly using my hand to lift my forehead to raise my eye lids to see better.

A: This is a decision that should be made with your surgeon. While it may lift the brows and possibly help to open the eyes, beware of frontalis antagonist blink syndrome. This could worsen dry eyes, thus exacerbating blepharospasms.

Q: What kind of doctor is best to see for Blepharospasm and Meige?

A: Always check to see if the physician you are

scheduling with sees patients with BEB/ Meige. Usually, specialists include oculoplastic surgeons, neurologists, ophthalmologists, ENT or facial plastic surgeons, and neuro-ophthalmologists to name a few specialties.

Q: What is the best type of eye drops? What about those with "disappearing" preservative?

A: Preservative-free artificial tears are usually preferred.

Q: Do compresses affect rosacea?

A: Warm compresses can be a double-edged sword in rosacea. Sometimes it can make inflammation worse, and sometimes it can improve inflammation by increasing circulation to the area. Remember, if it's too hot in the hands, it's too hot for the eyelids!

Q: What is the difference between Botox injections directly into the eyelids & around the eyes?

A: As explained, injections should be targeted to the muscles around the eyes that are causing your symptoms.

Q: Eating zinc rich food ahead of injections?

A: Yes!

Q: How can we receive this information in print?

A: Feel free to contact your friends at the BEBRF at bebrf@blepharospasm.org or at Plastic Eye Surgery Associates at info@pesahouston.com to request more info.

Q: Medicare only pays for Botox every 3 months. Is there an effort to advocate for more frequent treatments if needed?

A: Often, insurance will cover injections more frequently if there is a documented return of symptoms sooner. It is important to talk to your provider if you are having symptoms that return in less than 3 months. **(Editor's Note:** please see the last Newsletter that has an article that addresses how to get more frequent injections.)

Q: What kind of doctor will be able to give me a diagnosis for exactly what kind of dry eye I have and how it should be treated?

A: You can see a general ophthalmologist or corneal specialist for dry eyes. Within a cornea or anterior segment subspecialty, there are some doctors who specialize further in dry eyes. For example, here in Houston, we have Steve Pflugfelder, MD.

Q: If pain cream is bad for efficacy of treatment with Botox, what do you suggest for getting through the process? Very painful without cream.

A: You just have to balance out the risks/benefits that are important to you. While numbing cream may decrease the uptake of botulinum toxin, it may be more important for you to be comfortable during the injection instead of having a torture session every 3 months.

PLEASE REMEMBER BEBRF IN YOUR WILL

COVID-19 VACCINE AND BOTULINUM TOXIN INJECTIONS

Several patients have asked if there are any side effects from the Covid19 vaccine for people who also get botulinum injections. We reached out to medical experts (including a request for information directly from the National Institutes of Health) and other dystonia-related organizations, and this is the answer we were given:

“We have consulted with a dystonia clinical expert who has reviewed the current literature and reported that we know of NO reason that botulinum toxin treatments would interfere with or increase the risk of COVID vaccinations. Further, there is nothing to suggest that botulinum would alter response or change the risk of side effects. As always, people should consult with their personal physician to determine their personal risk for this or any medical treatment/procedure and what is best for them.”

Please note that the scope of this question was only intended to be about side effects as they specifically relate to botulinum toxin injections. Any other possible side effects are not addressed in this answer. Stay safe!



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: Has there been enough success in brain stimulation surgery to warrant this as an option?

A: Deep brain stimulation (DBS) is a neurosurgical treatment option for people with severe blepharospasm who do not respond to botulinum toxin injections and other less invasive treatments. The symptoms should cause significant disability to warrant an invasive procedure (for example, functional blindness due to frequent and severe spasms). The evidence for DBS in blepharospasm comes primarily from studies of patients with orofacial dystonia (Meige Syndrome), although there are a handful of reports of patients with pure blepharospasm responding to DBS. The published studies report average blepharospasm improvement as 50-75%, but in some people improvement may be minimal. Some patients may require

ongoing botulinum toxin injections even after DBS to achieve optimal benefit (but may require fewer or less frequent injections). DBS involves placing stimulating electrodes (wires) deep into the motor region of the brain (one on each side) and a generator in the chest. Following electrode implantation, multiple device adjustments are required in the clinic, and it typically takes several weeks to months to see the benefit. An evaluation by a neurologist specializing in movement disorders should be sought prior to considering DBS.

Svetlana Miocinovic, MD, Neurologist, Emory University, Atlanta, GA. Note: BEBRF will be hosting a Zoom Webinar on Deep Brain Stimulation for Blepharospasm on Saturday, April 10, 2021 at 1:00 p.m. central time, with Dr. Miocinovic as the featured speaker.



SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before April 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.

EASTERN DISTRICT

Milford, Connecticut

Date: Sunday, January 31, 2021

Time: 10am – 12pm

Location: Zoom

Please contact Carol for invitation instructions to meeting.

Contact Person: Carol Lively

Phone: 203-641-3895

Email: Livelycz6@optonline.net

CENTRAL DISTRICT

Dallas/Fort Worth, Texas

Date: Tuesday, February 16, 2021

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

Tarrant and Parker Counties, Texas

Date: Wednesday, February 24, 2021

Time: 1:30pm – 3:30pm

Location: Zoom

Please contact Sharon for invitation instructions to meeting.

Contact Person: Sharon West

Phone: 817-297-4389

Email: swest124@swbell.net

Rockwall, Texas

Date: Monday, April 26, 2021

Time: 11am – 1pm

Location: Zoom

Please contact Ena for invitation instructions to meeting.

Contact Person: Ena Wilmot

Phone: 817-488-0445

Email: enamwa@hotmail.com

Dallas/Fort Worth, Texas

Date: Tuesday, June 22, 2021

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

Tarrant and Parker Counties, Texas

Date: Wednesday, June 30, 2021

Time: 1:30pm – 3:30pm

Location: Zoom

Please contact Sharon for invitation instructions to meeting.

Contact Person: Sharon West

Phone: 817-297-4389

Email: swest124@swbell.net

Rockwall, Texas

Date: Monday, August 9, 2021

Time: 11am – 1pm

Location: Zoom

Please contact Ena for invitation instructions to meeting.

Contact Person: Ena Wilmot

Phone: 817-488-0445

Email: enamwa@hotmail.com

Dallas/Fort Worth, Texas

Date: Tuesday, October 19, 2021

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

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

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Tarrant and Parker Counties, Texas

Date: Wednesday, October 27, 2021

Time: 1:30pm – 3:30pm

Location: Zoom

Please contact Sharon for invitation instructions to meeting.

Contact Person: Sharon West

Phone: 817-297-4389

Email: swest124@swbell.net

Rockwall, Texas

Date: Monday, November 15, 2021

Time: 11am – 1pm

Location: Zoom

Please contact Ena for invitation instructions to meeting.

Contact Person: Ena Wilmot

Phone: 817-488-0445

Email: enamwa@hotmail.com

WESTERN DISTRICT

Los Angeles, California

Date: Thursday, January 14, 2021

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

NATIONAL SUPPORT

National Support Group Meeting

Date: Monday, February 22, 2021

Time: 1pm – 3pm

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: Charlene@blepharospasm.org

National Support Group Meeting For Caregivers

Date: Friday, March 12, 2021

Time: 1pm – 3pm

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: Charlene@blepharospasm.org

National Support Group Meeting

Date: Saturday, March 20, 2021

Time: 1pm – 3pm

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: Charlene@blepharospasm.org

National Support Group Meeting

Date: Wednesday, April 14, 2021

Time: 1pm – 3pm

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: Charlene@blepharospasm.org

National Support Group Meeting

Date: Friday, May 14, 2021

Time: 1pm – 3pm

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: Charlene@blepharospasm.org

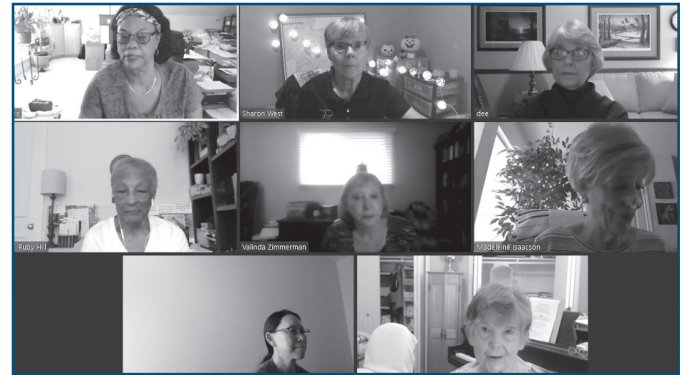
**TARRANT/PARKER COUNTIES TX
SUPPORT GROUP MEETING**



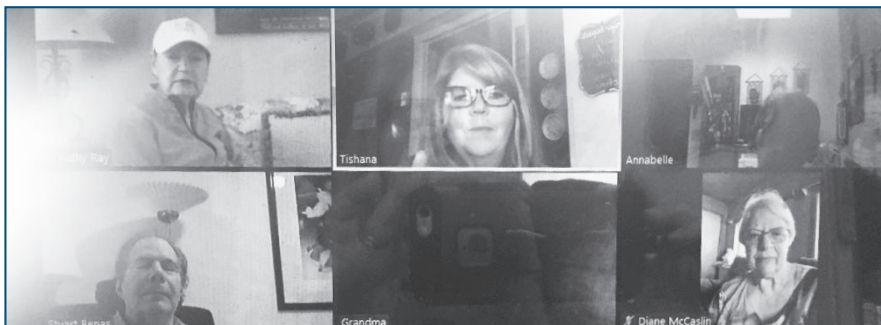
LOUISIANA SUPPORT GROUP MEETING



DALLAS/FORT WORTH, TX SGM



11/06/2020 NATIONAL SUPPORT GROUP MEETING



12/17/2020 NATIONAL SUPPORT GROUP MEETING



MEIGE SUPPORT GROUP MEETING



NEW YORK CITY 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
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Want to Make a Bigger Impact? You Can!

Recurring Donations! Many BEBRF donors give under \$50 dollars a year because living on a fixed income makes it difficult to give more, and certainly the pandemic has not helped. However, how hard would it be to give \$10, \$15, \$20, or \$25 per month? If you normally give \$20 donation per year to cover the cost of the Newsletter, just imagine giving that much on a monthly basis... That would equate to \$240 per year! If 100 people did that, their annual aggregate contribution would grow from \$2,000 to \$24,000! Imagine the funds that would become available for research, support, and education for the large number of patients who get information and support from BEBRF!

The beginning of the year is the perfect time to set up a recurring donation. Just call the BEBRF office at 409-832-0788, and we'll be happy to help you set it up. Then you don't even have to think about it again. If your life should change, just give as call, and we can help you adjust the amount per month you are giving. You can end the recurring donation any time you want as well. It couldn't be simpler. Give us a call, and help us help blepharospasm patients everywhere...

