



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

Fall 2022 • Vol 42 • Issue 4

GETTING THE MOST OUT OF YOUR BOTULINUM TOXIN INJECTIONS FOR BLEPHAROSPASM

A BEBRF WEBINAR

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

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

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

Newly diagnosed patients should:

- Set realistic expectations of what that first injection cycle is going to be like, which can also be true for long-time blepharospasm patients seeing a new doctor for the first time.
- Realize it may take 4-6 injections cycles to get the correct variables including: 1) injection sites,

2) injection dosage, 3) injection techniques, and 4) botulinum toxin used. There are two types of botulinum toxin currently approved by the FDA for use for blepharospasm – Botox® and Xeomin®. There are two other botulinum toxins available in the United States: Myobloc® and Dystport®, which are not approved for blepharospasm in the US, but are used in other countries. If your doctor decides, for whatever reason, to try Dysport on you, be aware that it will be used “off-label” which means your insurance might not pay for it.

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

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

Ways you can help your doctor:

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

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

The 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, 2023
Spring	April 1, 2023
Summer	July 1, 2023
Fall	October 1, 2023

FROM THE EXECUTIVE DIRECTOR

The **2022 BEBRF Symposium** was held in Phoenix, AZ on October 21 & 22. The videos of the presentations are available on the BEBRF Website; in addition, the next Newsletter will have summaries of these presentations as well. Special thanks to Dr. Johan Samanta, Dr. Obada Subei, Dr. Virgilio Evidente, Dr. Francisco Ponce, and Dr. Indu Subramanian for their outstanding presentations, and most especially to Dr. Padma Mahant who not only gave an excellent presentation, but also put together the whole program. Also, thank you to AxonOptics for being present and donating glasses to the Silent Auction, and to Merz Therapeutics for their presence at the Symposium and underwriting this important educational program.



Support Group Meetings are still available through Zoom. Check the BEBRF Website or Facebook page for the upcoming ones including national meetings as well as meetings for cranial dystonia and United

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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.

TABLE OF CONTENTS

Getting the Most Out of Your Botulinum Toxin Injections for Blepharospasm	1
From The Executive Director	2
The 6th International Dystonia Symposium (IDS6), Dublin, Ireland	6
Dystonia Coalition: Developing Specific Recommendations For Diagnosis and Classification of Blepharospasm.....	6
Advocacy: BEBRF Signs-On To Two Congressional Letters.....	7
U.S House Resolution.....	9
My Rock: Stories From Blepharospasm Patients	10
First Addex Drug Study Completed.....	10
Help Support A Better Medicare Authorization Process	11
Meeting With New Medical Advisory Board Chair	11
Ask The Doctor	12
Support Group Meetings & Photos	13
Next Issue: The 2022 Symposium in Phoenix, Arizona	16

Kingdom residents. We are slowly beginning to return to in-person support group meetings. If you would like to help us coordinate one for your area, please contact the office, and we will either connect you with a support group leader or help you start a group yourself. Zoom meetings will also continue into the future.

BEBRF attended the **American Academy of Optometry** in San Diego, CA Oct. 26 – 28. More information about that will be contained in the next Newsletter.

On August 26, I presented a Webinar on “Getting the Most Out of Your Botulinum Toxin Injections for Blepharospasm”. The written summary of that presentation begins on page 1 of this Newsletter, and the Webinar is available for viewing online at the BEBRF Website, along with all the other Webinars presented since September 2020. Symposium presentations since 2010 are also available on our Website.

It is once again time for the **BEBRF Year-End Appeal**. With the exception of a grant to cover the cost of the Symposium, BEBRF depends almost entirely on donations to provide support for patients, education for both patients and doctors, and research into the cause, treatments, and cure of blepharospasm and its related disorders, such as cranial dystonia and hemi-facial spasm. Please give as generously as you can.

I would like to introduce **Kelly Pruitt**, BEBRF’s new Administrative Analyst. Kelly is replacing Angel Roberts, so he has some big shoes to fill. He comes to us from BDP Visionary, a promotional and fund-raising company. Originally from Georgia, he is a graduate of the Art Institute of Atlanta, and lives in Nederland, TX with his wife and four kids. He is currently immersing himself in all things blepharospasm and BEBRF. Welcome aboard Kelly!



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GETTING THE MOST OUT OF YOUR BOTULINUM TOXIN INJECTIONS FOR BLEPHAROSPASM

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

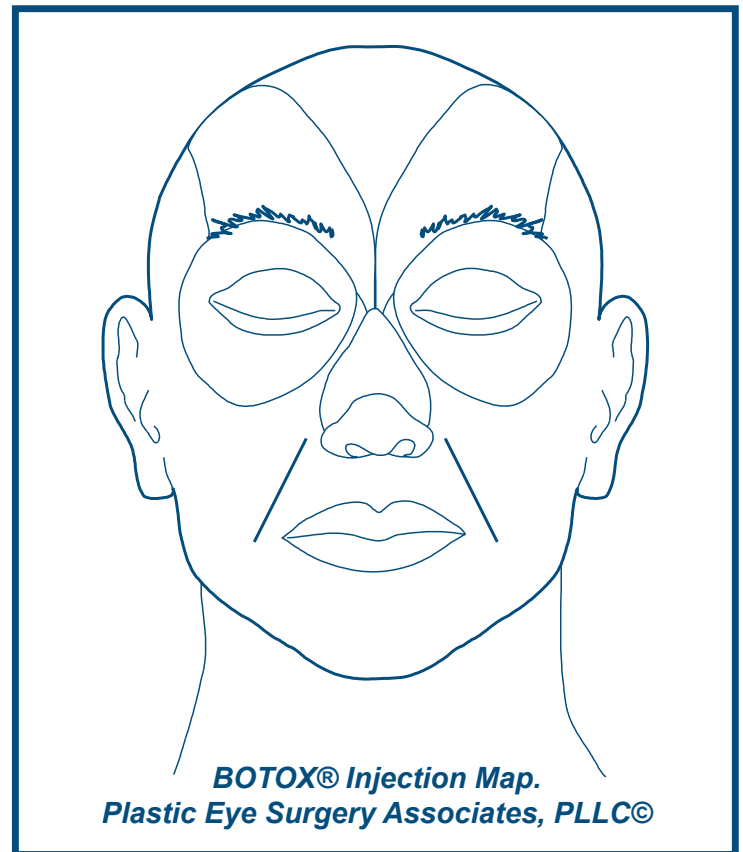
- Leave the injection appointment with a facial map clearly marking each injection site with the dosage at each site. You may obtain blank facial maps from the BEBRF Website, to be discussed later, or by calling the BEBRF office. Be sure to add the appointment's date on that facial map. The map can serve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

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

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

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

The BEBRF Website is helpful to document your injection cycle. It includes injection advice and tips, how



to journal and journal formats, common injection patterns and techniques – diagrams and videos, how to get your injections more frequently (a packet of information that your doctor can use to appeal to your insurance carrier to medically justify more frequent injections), how to fill out your injection journal, blank facial maps and a blank injection calendar.

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

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

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GETTING THE MOST OUT OF YOUR BOTULINUM TOXIN INJECTIONS FOR BLEPHAROSPASM

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

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

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

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

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

Not all qualified treating doctors will be movement disorder specialists, and conversely not all movement disorder specialists are experienced in treating blepharospasm specifically.

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

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

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

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

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



THE 6TH INTERNATIONAL DYSTONIA SYMPOSIUM (IDS6) DUBLIN, IRELAND

The 6th International Dystonia Symposium (IDS6) will be held in Dublin, Ireland on June 1-3, 2023. This meeting will bring together the leading dystonia researchers from around the world to assess the current state of dystonia research and to identify the best paths forward to achieve the collective goal of a cure for dystonia.

The program was developed by a DMRF Scientific Program Committee and co-chaired by Drs. Buz Jinnah and Antonio Pisani. Dr. Jinnah is also a member of the BEBRF Medical Advisory Board. Registration began October 3, 2022, and the website for this important meeting is www.internationaldystoniasymposium.org.

Engaging young investigators is so important to our research efforts. To help young investigators,

junior faculty, fellows and trainees attend, dystonia related research foundations were asked to make a commitment to support scholarships that would allow them to travel to Dublin.

BEBRF has agreed to cover one scholarship for \$2,000. Because of our participation, BEBRF will be able to provide information on our research funding program and what we do for patients to all those in attendance. Our goal is to attract more grant requests from the medical community to both BEBRF and blepharospasm research in general to find both a cure and better treatments for our patients. We also want the medical community to be aware of our services and to direct patients who need support and education to our organization.

Thank You to Merz Therapeutics

Manufacturer of Xeomin®, for sponsoring the 2022 BEBRF Symposium in Phoenix, Arizona.

DYSTONIA COALITION: DEVELOPING SPECIFIC RECOMMENDATIONS FOR DIAGNOSIS AND CLASSIFICATION OF BLEPHAROSPASM

Blepharospasm is a rare disorder characterized by spasms of muscles surrounding both eyes with excessive blinking and squinting. It is the second most common form of dystonia (involuntary muscle twitching) and often spreads to other regions of the body. Currently, guidelines for diagnosis and classification are ambiguous.

In this study, researchers aimed to provide more specific recommendations for diagnosis and classification of blepharospasm. Data were obtained from the Dystonia Coalition for patients diagnosed with all types of isolated dystonia. The team evaluated these data to determine how examinations recorded by movement disorder specialists were used to classify

blepharospasm as focal, segmental, or multifocal.

Results showed much variability in expert opinion regarding the diagnosis of blepharospasm, which was often inconsistent with existing guidelines for the diagnosis and classification of focal blepharospasm. This study highlights the need for more specific guidelines, which are provided in the publication.

This summary is based on a paper published in the Journal of the Neurological Sciences on August 15, 2022, titled "Diagnosis and classification of blepharospasm: Recommendations based on empirical evidence."

Read the paper here: [https://www.jns-journal.com/article/S0022-510X\(22\)00181-2/fulltext](https://www.jns-journal.com/article/S0022-510X(22)00181-2/fulltext)



ADVOCACY

BEBRF SIGNS-ON TO TWO CONGRESSIONAL LETTERS

The BEBRF is a member of The American Brain Coalition (ABC). The ABC is a nonprofit organization comprised of the United States' leading professional neurological, psychological, and psychiatric associations and patient organizations. Together, they seek to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through public education and advocacy. Other non-profit members include the Michael J. Fox Foundation for Parkinson's Research, the Dystonia Medical Research Foundation, and the National Spasmodic Dysphonia Association.

Recently the BEBRF (through the ABC) signed and submitted two letters to Congress as part of our

advocacy work and we will keep you posted as to their progress:

1) Neurology Drug Program Sign-on Letter: The Senate Agriculture-Rural Development-FDA draft bill included \$3 million to support a Neurology Drug Program at the FDA to help speed the delivery of safe and effective treatments for brain diseases, disorders, and injuries. This letter to the chairs and ranking members of the Senate and House Agriculture appropriations subcommittee expresses our thanks for including this funding in the Senate draft and encourages them to maintain this funding in the final FY 2023 spending package.

SEPTEMBER 7, 2022

Dear Chair Baldwin, Ranking Member Hoeven, Chair Bishop, and Acting Ranking Member Harris,

The undersigned members of the brain health community write to express our gratitude for the inclusion of \$3 million in funding and accompanying report language in support of the Neurology Drug Program at the Food and Drug Administration (FDA) in the Senate Committee's draft fiscal year (FY) 23 Agriculture, Rural Development, FDA, and Related Agencies Appropriations bill. As the House and Senate work together to negotiate final FY23 appropriations legislation, we strongly encourage you to maintain this critical funding and language, which will help speed the delivery of safe and effective treatments for brain diseases, mental health conditions, and brain injuries.

As you may know, conditions of the brain impact more than one billion people worldwide and more than 100 million individuals in the U.S. live with psychiatric conditions or neurological diseases and disorders.¹ However, despite the tremendous burden of brain diseases, brain injuries, and mental health conditions, there remains a dearth of treatments for common and rare brain diseases. Research and development for conditions of the brain is hindered by high costs and associated risks², but more streamlined and transparent regulatory processes have the potential to help mitigate these concerns, facilitating speedier delivery of critical, life-improving treatments that individuals with psychiatric conditions and neurological disorders so desperately need.

The burden of brain conditions and diseases on the U.S. economy is also staggering. Brain conditions and diseases cost the U.S. economy more than \$1.5 trillion per year.³ Seven of the twenty-one chronic conditions tracked by the Centers for Medicare & Medicaid Services (CMS) are related to the brain, at an average annual cost of \$23,325 per Medicare beneficiary—higher than the average cost for other chronic conditions.⁴ Additionally, studies also show that the FDA approval process is

38 percent longer for central nervous system (CNS) drugs, which includes treatments for people living with mental illness, when compared to non-CNS drugs.⁵ The economic burden of brain diseases, combined with the emotional toll that patient live with as they deal with the longer regulatory approval timelines for CNS treatments highlight the need for swift action to accelerate the development and approval of new treatments for neurologic and psychiatric conditions. The draft Senate appropriations legislation would provide critical funding to create the Neurology Drug Program at FDA to better prevent, detect, and treat diseases and conditions of the brain.

Accompanying report language encouraging the agency to develop policies and guidance that keep pace with scientific discovery in these areas will assist those living with these diseases, researchers, and providers in advancing promising treatments and cures. As we work together toward these goals, we also ask both Congress and FDA to ensure that the agency's activities associated with the Neurology Drug Program, involve all areas of neuroscience, including brain diseases, mental health conditions, and brain injuries. The complex interrelationship of these maladies requires that they be approached with unity.

Again, our organizations strongly support the Neurology Drug Program funding and language in the Senate's draft bill and appreciate its inclusion. As the House and Senate work towards a bipartisan end-of-year funding bill, we encourage you to include this provision and ensure the program's applicability to the broad range of neurologic and psychiatric conditions affecting the brain, to advance innovative treatment options for all brain diseases, including mental health conditions, and brain injuries.

Thank you for your work on this important issue. We look forward to continuing to work together towards the goal of speeding the delivery of safe and effective treatments for individuals living with psychiatric conditions and neurologic diseases.



ADVOCACY

BEBRF SIGNS-ON TO TWO CONGRESSIONAL LETTERS

2) Medical Marijuana and Cannabidiol Research Expansion Act Sign-on Letter: This bipartisan, bicameral legislation passed the House immediately before the August recess, and the sign-on letter urges Senate to consider and pass this legislation as soon as possible. The bill would provide for research on medical marijuana and CBD and new therapeutic options for patients based on that research.

With an established presence in Washington, DC, ABC is a strong and powerful voice for the 100 million people living with disabling brain disorders, bringing together organizations that represent concerned and interested patients, families, and professionals. This voice is used to advocate for increased support of research that leads to better treatment, services, and support that improves patients' quality of life; as well as a national commitment towards finding cures for individuals with disabling neurological and psychiatric disorders.



AMERICAN
BRAIN
COALITION

SEPTEMBER 7, 2022

The Honorable Chuck Schumer
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
U.S. Senate
Washington, DC 20510

Dear Majority Leader Schumer and Minority Leader McConnell,

The American Brain Coalition (ABC) and undersigned members of the brain health community respectfully request that you take up and pass H.R. 8454, the Medical Marijuana and Cannabidiol Research Expansion Act, after the August recess. This bipartisan, bicameral legislation will combat the current obstacles scientists face to understanding the potential effects of utilizing medical marijuana and cannabidiol (CBD) for patients facing brain diseases and disorders by allowing researchers to manufacture, distribute, dispense, or possess them for the purposes of medical research.

Our organizations are committed to reducing the burden of brain diseases and disorders, which affect over 100 million US citizens. More than 700 million individuals globally live with psychiatric or neurological conditions.¹ Americans suffering from neurologic, psychiatric, and psychological conditions are awaiting new treatments, and research is costly and inherently risky. Medical marijuana and CBD could provide many patients real relief if we fully understood the associated benefits and hazards. If adopted, this legislation will lift the regulatory and supply barriers currently impeding scientists and potentially provide new therapeutic options for patients with a full range of neurological conditions including epilepsy, multiple sclerosis-related spasticity, sleep apnea, Tourette syndrome, anxiety, and post-traumatic stress. Besides supporting needed research, this bill would ensure patients with brain injuries and disorders can discuss the positive and negative effects of medical marijuana and CBD as a treatment option with their physician.

The Medical Marijuana and Cannabidiol Research Expansion Act is essential to ensuring the millions of Americans suffering from brain diseases and disorders have access to all forms of treatments. Our organizations urge the passage of this legislation as soon as possible. If you have any questions or wish to discuss further, please contact Katie Sale, ABC's Executive Director at ksale@americanbraincoalition.org.

Expressing support for designation of September 2022 as “National Dystonia Awareness Month” and raising awareness and understanding of the disorder of dystonia.

IN THE HOUSE OF REPRESENTATIVES
SEPTEMBER 30, 2022

Mr. SMITH of New Jersey (for himself and Ms. SCHAKOWSKY) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for designation of September 2022 as “National Dystonia Awareness Month” and raising awareness and understanding of the disorder of dystonia.

Whereas dystonia is the third most common movement disorder, affecting no fewer than 300,000 people in the United States and millions worldwide;

Whereas dystonia is a neurological movement disorder presenting in various forms, characterized by involuntary muscle contractions causing repetitive or twisting movements;

Whereas symptoms of dystonia can range from very mild to severe and may affect only one muscle, only one group of muscles, or muscles throughout the body including those that move the foot, hand, neck, eyes, and mouth;

Whereas people with dystonia may experience physical pain, depression, and anxiety, and dystonia can impede the ability to perform daily tasks;

Whereas there are limited treatments for dystonia, and there is currently no cure;

Whereas dystonia is commonly misdiagnosed, delaying access to appropriate medical care for those affected;

Whereas caregivers and family members provide physical, emotional, and financial support associated with caring for persons living with dystonia;

Whereas the severity of the symptoms of dystonia

and the limited public awareness of the disease can cause isolation for people with dystonia;

Whereas National Dystonia Awareness Month will raise public awareness and understanding of the disorder of dystonia, a disorder affecting people of all ages, races, ethnicities, genders, and socioeconomic classes;

Whereas National Dystonia Awareness Month will also increase awareness and knowledge of the impact that the various forms of dystonia have on those affected and their caregivers and families;

Whereas the dystonia community is united in raising awareness throughout September; and

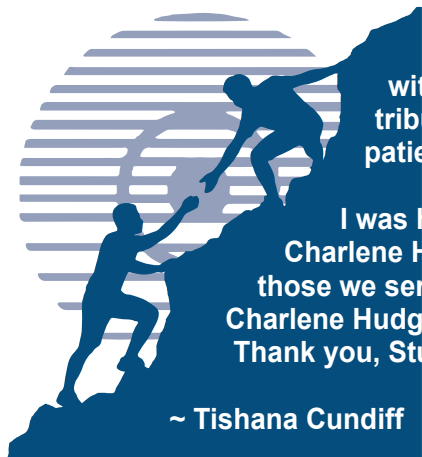
Whereas the Benign Essential Blepharospasm Research Foundation, the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, and the National Spasmodic Torticollis Association are dedicated to—

- (1) conducting research to find treatments and a cure for dystonia;
- (2) fostering public awareness and understanding of the disorder;
- (3) educating patients and their families about dystonia to improve their quality of life, treatment opportunities, and care; and
- (4) providing support and encouraging people to become advocates, including through annual patient education conferences, school-based educational programs, and local events to raise funds for dystonia research, education, advocacy, and awareness: Now, therefore, be it

Resolved, That the House of Representatives—

- (1) supports the designation of “National Dystonia Awareness Month”;
- (2) supports the goals and ideals of National Dystonia Awareness Month to raise public awareness and understanding of dystonia;
- (3) recognizes the need for additional research to find a cure for all forms of dystonia; and
- (4) encourages all people in the United States and interested groups to support National Dystonia Awareness Month through activities to promote public awareness of dystonia and foster the understanding of the impact of dystonia in people living with it and their caregivers and families.

MY ROCK: STORIES FROM BLEPHAROSPAM PATIENTS



As Vice President of Education & Support, I occasionally attempt to connect with patients, seeking personal stories of their journey with Blepharospasm or tributes to their “ROCK”, a person who has provided a level of support. Generally, patients are quick to think of a spouse or family member.

I was honored to have received the below patient story. Our Executive Director, Charlene Hudgins was, “blown away,” and very humbled to receive it. I suspect many of those we serve would agree with Stuart’s gratitude and sentiments towards our very own, Charlene Hudgins. Like Stuart, we think she is a Rock Star!
Thank you, Stuart!

~ Tishana Cundiff

I was diagnosed with Benign Essential Blepharospasm in the Spring of 2019 by my ophthalmologist. He referred me to the only practitioners that he knew who could help me with my condition. The appointments available were 6 months away and I was anxious to be helped sooner.

I started researching my condition on the internet and found a wealth of information about Blepharospasm, but no help in finding treatment. That was until I found the Benign Essential Blepharospasm Research Foundation site. I contacted the organization and was fortunate to speak to Charlene Hudgins, the Executive Director. She spent a lot of time over numerous phone calls over the years assisting me with my concerns about treatment and future obstacles I might encounter in my treatment. She listened to my issues and showed great compassion and empathy in helping me with this strange disorder. She referred me to message boards, upcoming symposiums, webinars by eminent doctors, treatment options, the names of practitioners who could treat me in my local area and expressed genuine concern and support.

The Zoom support group sessions with Ms. Hudgins and other patients have given me awareness of invaluable resources concerning new research in treating Blepharospasm. The bulletins that she coordinates for the foundation contain up to date important information and patients’ stories of their experience. Her kindness and professionalism have been important factors in helping me deal with my condition. I know so many others have been helped by Ms. Hudgins’ tireless efforts and they too hold her in high regard. I know this because many tell her so in the interactive Zoom sessions. She has become my guiding light and has been the most help in assisting me with my Blepharospasm.

- Stuart Benas, Staten Island, NY

NOTE: If you have a personal story or a ROCK you wish to share for publication, please let us hear from you. Send your stories to bebrf@blepharospasm.org or to tishana333@yahoo.com.

FIRST ADDEX DRUG STUDY COMPLETED

The drug company Addex Therapeutics in concert with Emory University has completed a pilot study of 15 blepharospasm patients. This was an initial study of the drug “dipraglurant” which is being evaluated for possible treatment of dystonias and Parkinson’s Disease. Five patients were given a high dose of dipraglurant, five patients given a low dose and five patients given placebo. Results were inconclusive as to whether the drug was helpful. One of the patients in the placebo group unexpectedly improved which

threw off the statistical comparisons between the groups.

The good news is that there were no negative side-effects of the drug. Before the next study is done, the measurement tools of this study are being reviewed and re-evaluated. This will help tailor the design of further studies. We will continue to follow the research on this potential new treatment. Thanks to all who participated in this important study!

HELP SUPPORT A BETTER MEDICARE AUTHORIZATION PROCESS

BEBRF wants to make you aware of an advocacy opportunity in Congress. In September, the U.S. House of Representatives passed H.R. 3173, the Improving Seniors' Timely Access to Care Act. This is critical to ensure patients enrolled in Medicare Advantage plans can access their medications. In summary, the legislation stipulates that Medicare Advantage plans must:

1. **Establish** an electronic prior authorization program that meets specified standards, including real-time decisions
2. **Annually publish** specified prior authorization information, including percentage of requests approved and the average response time
3. **Meet** other standards that may be set by the

Centers for Medicare & Medicaid Services.

The bill passed the House and has been transmitted to the Senate. The Alliance for Patient Access, of which BEBRF is a member, encourages both individuals and organizations interested in advocacy to engage with their Senator to convey their experience and expertise in patient advocacy.

There is only a short amount of time left in the 117th Congress, and we ask for everyone's help to push this across the finish line. If you have any questions, please do not hesitate to reach out.

All US Senators have contact information, including their email addresses and phone numbers, online. Simply Google the name of your Senator for that information.

MEETING WITH NEW MEDICAL ADVISORY BOARD CHAIR

On September 28, 2022, the Executive Committee* (EC) of the BEBRF Board of Directors met with Dr. Brian Berman**, new chair of the BEBRF Medical Advisory Board (MAB). The purpose for this meeting was to discuss the future direction of research.

A number of topics were discussed including the objectives for both BEBRF and the MAB. Dr. Berman pointed out that the objectives include increasing awareness, increasing information and expanding and targeting research. The Executive Committee and Dr. Berman discussed various ideas to attract more research grant applications, including possible partnerships with other research foundations.

There were discussions of ways for BEBRF to more efficiently be aware of non-BEBRF funded research being done about blepharospasm and its related disorders. A consideration for the organization is to create a fellowship program allowing BEBRF to form a long-term relationship with a future researcher or clinician. The logistics, benefits, challenges and cost-effectiveness of a fellowship program were raised and require further analysis.

These ongoing discussions with the MAB will continue to lead BEBRF in new and exciting directions. Again, we welcome Dr. Berman to the Chairmanship of the MAB. We would also like to thank Dr. Mark Hallett, our outgoing Chairman, as well as the other members of the MAB for their time and support.

**The EC is comprised of Executive Director Charlene Hudgins, President/Treasurer Heidi Coggeshall, Vice President of Development Peter Bakalor, Vice President of Physician Outreach Dr. Jane Boyd, and Vice President of Education and Support Tishana Cundiff.*

*** Dr. Berman is Professor of Neurology and Director of the Parkinson and Movement Disorders Center at Virginia Commonwealth University.*

WE WOULD LIKE TO THANK

Matthew Swift

FOR REMEMBERING US IN HIS WILL.





ASK THE DOCTOR

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

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

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

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

Do we have to take zinc in a pill? Of course not. Many foods are rich in zinc. Fresh turkey is a favorite, but red meat, chicken, seafood, shellfish (especially oysters), beans, nuts, and whole grains are good sources. The problem is that there are many foods that will bind zinc, so that we can't absorb it. For a more complete list of foods that contain zinc and ones that inhibit its absorption,

you may wish to check out this link to our website <https://plasticeyesurgery.com/wp-content/uploads/2021/06/Food-and-Factors-Affecting-Zinc.pdf>

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

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

- Charles Soparkar,
Plastic Eye Associates of Houston, TX



SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before January 1, 2023, 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

Central Texas

Date: Friday, October 28, 2022

Time: 11am – 12:30pm central time

Location: Zoom

Please contact Carlas for invitation instructions to meeting.

Contact Person: Carlas Powell

Phone: 409-363-2206

Email: carlas.powell@gmail.com

West Dallas/Fort Worth, Texas

Date: Wednesday, November 16, 2022

Time: 1pm – 3pm central time

Location: Zoom

Please contact Sharon for invitation instructions to meeting.

Contact Person: Sharon West

Phone: 817-297-4389

Email: swest124@swbell.net

NATIONAL/INTERNATIONAL SUPPORT

NATIONAL Support Group Meeting

Date: Friday, November 18, 2022

Time: 1pm – 3pm central time

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: Monday, December 12, 2022

Time: 1pm – 3pm central time

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: charlene@blepharospasm.org

UK Support Group Meeting

Date: Thursday, January 19, 2023

Time: 1pm – 3pm central time

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: Thursday, January 26, 2023

Time: 1pm – 3pm central time

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 Cranial Dystonia and Meige

Date: Thursday, February 9, 2023

Time: 1pm – 3pm central time

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: Tuesday, February 21, 2023

Time: 1pm – 3pm central time

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

Email: charlene@blepharospasm.org

PLEASE REMEMBER BEBRF IN YOUR WILL

CONTINUED ON
NEXT PAGE

NATIONAL Support Group Meeting

Date: Thursday, March 23, 2023

Time: 1pm – 3pm central time

Location: Zoom

Please contact Charlene for invitation instructions to meeting.

Contact Person: Charlene Hudgins

Phone: 409-832-0788

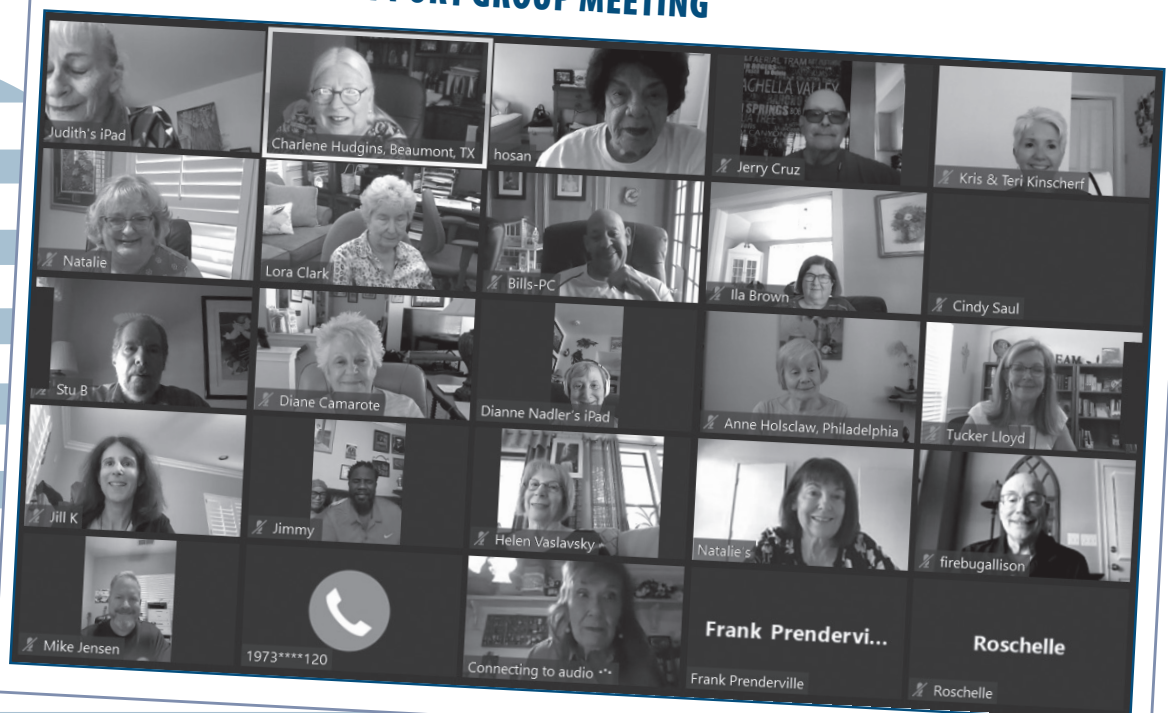
Email: charlene@blepharospasm.org

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

08/19/22 NATIONAL SUPPORT GROUP MEETING



10/14/22 NATIONAL SUPPORT GROUP MEETING



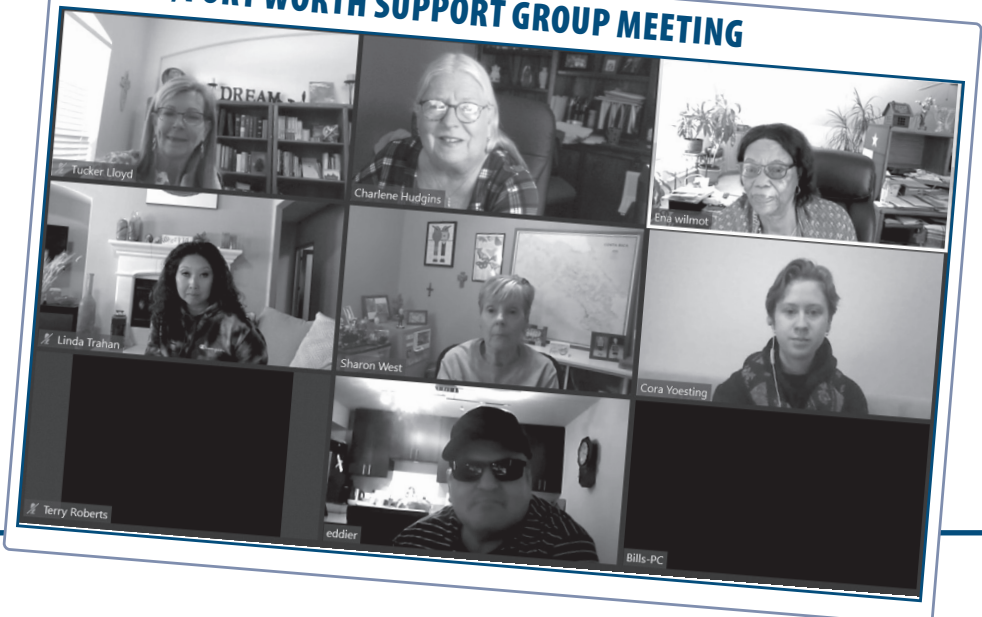
09/15/22 NATIONAL SUPPORT GROUP MEETING



NORTH EAST TEXAS SUPPORT GROUP MEETING



DALLAS/FORT WORTH 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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**The next BEBRF Newsletter will
be all about the 2022 Symposium
in Phoenix. Stay tuned...**

