



EYEING THE FUTURE

We're in this together.

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

NEUROPLASTICITY AND ITS RELEVANCE FOR BLEPHAROSPASM

Mark Hallett, MD, Human Motor Control Section, NINDS, NIH, Bethesda, MD, USA



Mark Hallett, MD

Plasticity is the capacity to change. Neuroplasticity is the capacity of the brain to change. The brain is, in fact, highly plastic; not only can it change, it is constantly changing. Whenever a person learns something new, a new fact or a new motor skill, the brain has changed. If a

person develops blepharospasm, the brain must have changed in some way so that the eyelid movement will happen. The basic science of neuroplasticity is being actively investigated, and much is being learned about the underlying physiology. For example, the synapses between nerve cells can be modified to convey messages either more strongly or more weakly. Additionally, nerve processes can grow or shrink. The location in the brain where the alterations occur for different types of plastic changes is also being investigated. For learning a new fact, for example, there are changes in the part of the brain called the hippocampus. The site or sites of changes in relation to blepharospasm are not fully understood, but are being investigated.

There is one animal model for blepharospasm where plasticity plays a central role. In rats, if they are made deficient in the neurotransmitter, dopamine, making one eyelid weak will lead to eyelid spasms. The idea here is that if an eyelid is weak, the brain has to work harder to close the eye, and, in the setting of reduced dopamine, this leads

to plastic change of involuntary spasms. Interestingly, a similar phenomenon seems to happen in humans. Bell's palsy is a weakness of one side of the face (including the eyelid). In some patients with Bell's palsy, eyelid spasms like blepharospasm develop. This may well also be the link between eye diseases, such as dry eye, and blepharospasm. With these eye diseases, there is a stronger drive to blink, and that might get out of control and become involuntary.

So if blepharospasm results from an unwanted plastic change, might it be possible to reverse that plastic change? The brain still has its neuroplasticity, why not just go back the other way and return to normal? In other words, if there was the right training exercise, could blepharospasm be treated? This idea has been studied in several different ways with focal hand dystonia, particularly in patients with writer's cramp and musician's dystonia. These studies have had mixed success, and the idea is still being studied. Some therapists feel strongly that it works and have been promoting its use. While there is certainly some reason that such approaches can work, at least with hand dystonia there are some alternate explanations. For example, since focal hand dystonia is often task specific, if the "task" is changed, then the dystonia is not apparent. A pianist with musician's dystonia can get "better" just by altering technique – but in fact the original dystonia still remains with the original technique. Of course, this is a perfectly acceptable solution!

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.

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

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.

Blepharospasm and Meige are classified as movement disorders and are described as focal dystonias.

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

Benign Essential Blepharospasm Research Foundation
755 S. 11th St, Ste 211
Beaumont TX, 77701
P.O. Box 12468
Beaumont, Texas 77726-2468
Phone: 409-832-0788
Fax: 409-832-0890
E-mail: bebrf@blepharospasm.org
Web site: www.blepharospasm.org

Contributions may be sent to:
BEBRF
P.O. Box 12468
Beaumont, Texas 77726-2468

The Editorial Staff reserves the right to edit any and all articles. It is our editorial policy to report on developments regarding blepharospasm, Meige 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.

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FROM THE PRESIDENT

The theme for this year, "Eyeing the Future," has a sub-theme "We're in this together." In this issue, we highlight the people who provide support to patients and their families by holding support group meetings, offering a listening ear, and sharing information (page 10); as well as Bob Campbell who has served as our Webmaster for 20 years, handling our website and the Bulletin Board.

We're also fortunate to have external support from other individuals; health related organizations; BEBRF Board Members; physicians and researchers who respond to requests for articles for the Newsletter, provide answers to patient questions for the Ask the Doctor column, and make presentations at support group meetings and our Symposiums.

Our collaboration with other organizations through the Dystonia Advocacy Network (page 4) makes it possible for us to advocate for research funding and the needs of all dystonia patients.

The generosity of supporters who respond not just to our Mid-Year and End-of-Year appeals, but also throughout the year, help us in our attempts to fund the goals of the BEBRF mission. This is very much appreciated.

So, thank you all, regardless of your role, for being part of the "village" it takes to continue Mattie Lou Koster's dream. 🌍

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

Neuroplasticity and its Relevance for Blepharospasm	
Mark Hallett, MD	1
From the President	2
Dystonia Advocacy Day 2017	
Charlene Hudgins	3
Dystonia Advocacy Day 2017 Photos & Stories	4
Patient Stories	6
Ask the Doctor	8
Marijuana Use & Blepharospasm	
Charlene Hudgins	9
Support Groups & You	
Barbara Benton	10
Symposium Reminder	11
Focus on Support	12
Volunteers Needed for Blepharospasm Study:	
Your Contributions at Work	14
Support Group Meetings	15
Help the BEBRF Carry Out Its Mission	16

The opinions expressed in the articles in this newsletter are those of the authors and do not necessarily reflect the view of the BEBRF, publisher of the BEBRF Newsletter.

DYSTONIA ADVOCACY DAY 2017

Charlene Hudgins, BEBRF Executive Director



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AK, AZ, CA, CO, HI, ID, MT,
NV, NM, OR, UT, WA, WY
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Barbara Benton, Eastern
CT, DE, DC, MA, MD, ME,
NH, NJ, NY, NC, PA, PR, RI,
SC, VT, VA, WV
dir-e@blepharospasm.org
Tishana Cundiff, North Central
IL, IN, IA, KY, MI, MN, ND,
NE, OH, SD, WI
dir-n@blepharospasm.org
Barbara Benton, Acting Southern
AL, AR, FL, GA, KS, LA, MS,
MO, OK, TN, TX
dir-s@blepharospasm.org

Every year the Dystonia Advocacy Network (DAN) – a coalition made up of representatives from BEBRF, Dystonia Medical Research Foundation, National Spasmodic Dysphonia Association, National Spasmodic Torticollis Association, and ST/Dystonia, Inc. – holds a Dystonia Advocacy Day. On that day, their representatives advocate on behalf of their patients to the lawmakers on Capitol Hill. Nearly 100 advocates from all over the country gathered this year on March 22nd to participate.

As healthcare reform has been front and center in this current congressional session, this advocacy day could not have been more timely. Congress was, at that time, considering the American Health Care Act (AHCA), the proposed replacement of President Obama's Affordable Care Act (ACA). Interestingly, the AHCA was pulled from consideration within days of the DAN's 2017 Advocacy Day.

On Tuesday, March 21st, the DAN representatives, most of them patients with some form of dystonia, met to learn the most effective way to carry out their goals—primarily “just telling your story,” in other words, personalizing the cause.

They were then educated on the key issues they needed to emphasize during their visits.

1. Increase the budget of the National Institutes of Health (NIH). Investment in NIH research has led to improvements in the scientific understanding of dystonia.
2. Continue to recognize dystonia as a condition eligible for study through the Department of Defense's Peer Reviewed Medical Research Program. This request must be made every year.
3. Preserve basic patient protections listed in the ACA including:
 - a. Prohibiting insurer discrimination against pre-existing conditions,
 - b. Allowing young adults to stay on their parents' insurance until the age of 26,
 - c. Establishing out-of-pocket maximums for covered services, and
 - d. Prohibiting annual and lifetime caps on insurance coverage.

The advocates were then divided into teams by states, two states per team, and given a schedule of appointments with specific legislators or their Aides.

Each year the DAN presents a Distinguished Public Service Award to a legislator who has demonstrated a dedication to furthering the cause of dystonia research and working for the care of dystonia patients. 2017 recipients were Representative Kay Granger (TX) and Senator Jeff Merkley (OR). (See photos on page 4). 

ADVOCACY WORKS

We have just learned that \$2,596,956 was awarded to four dystonia investigators for dystonia research projects through the DOD Peer Reviewed Medical Research Program. This happened because of the dedicated efforts of dystonia advocates who helped to get dystonia on the list of eligible conditions that allowed the research community to apply for funding.

The investigators are: David Peterson, PhD in San Diego,
Cynthia Comella, MD in Chicago, Un Kang, MD in New York City,
and Mark LeDoux, MD, PhD in Memphis.

DYSTONIA ADVO



L-R: Oregon Governor Kate Brown, DMRF Executive Director Janet Hieshetter, BEBRF Advocacy Chair Dee Linde, Senator Jeff Merkley (OR), Judith, and Glenn Mason. Dee holds Senator Merkley's DAN's Distinguished Public Service Award



BEBRF group, L-R: Barbara Kimmel, Dee Linde, Charlene Hudgins, Ena Wilmot, Kristina Pasqualone, and Helen & Ray Vaslavsky



L-R: Janet Hieshetter, Annaliese & Jason Ornelis, Rep. Kay Granger (TX), holding the DAN's Distinguished Public Service Award, BEBRF Executive Director Charlene Hudgins, Ena Wilmot, and DAN Chair Emma Mattes.



"Washington DC is like no other city in America. In March, my husband and I had the honor to participate with the DAN in efforts to secure funding for research. Going to the Hill and meeting with our Senate and House leaders from Oklahoma was encouraging and inspiring. By the end of the week we were worn out, but it was a happy tired. Our Tulsa Support Group enjoyed the information I brought back and appreciated knowing there is a strong and well-organized group of dedicated people fighting for them. Thank you to all the fine hard-working people we met."

- Ray and Helen Vaslavsky



L-R: Helen Vaslavsky, Sen. James Lankford (OK), and Ray Vaslavsky

CACY DAY 2017



L-R: Emma Mattes (DAN Chair), Sen. Marco Rubio (FL), Kristina Pasqualone, and Barbara Kimmel



L-R: Charlene Hudgins, Paula Schneider, Helen Vaslavsky, and Dee Linde in front of the Three Soldiers Vietnam Memorial

“Dystonia Advocacy Day. Should I make the trek from Atlanta? Would politicians listen or care? Could I make a difference? I was hesitant and nervous, but found that putting a face on dystonia was a powerful way to raise awareness. I don’t go out much – I no longer drive and I’m self-conscious about my twitching, blinking, and spasms. Blepharospasm can be victimizing. But being part of Advocacy Day was empowering. I felt at ease, with no need to hide my symptoms from the politicians or passionate volunteers. Politicians were attentive and generous with their time, allowing us to explain our conditions and challenges. We discussed research, health care reforms, and treatment (most didn’t know Botox® had non-cosmetic uses.) It was a productive, exhilarating day, and I can’t wait to return next year.”

- Barbara Weiss Kimmel



L-R: Congressman John Lewis (GA) and Barbara Kimmel

How can you get involved?

Meeting face-to-face with lawmakers is a very powerful tool. However, there are other advocacy tools that can work just as well. Lawmakers take correspondence from their constituents very seriously, whether it is an email, letter, or phone call. Anyone can be an advocate without even leaving their home. From time to time BEBRF will send out an “Action Alert” email. These Action Alerts are a call to our patients to help advocate for a cause that will impact them directly. All you have to do is contact your Senators or House member and let them know how you feel. They listen; they work for you. Advocacy works.

Richard Winslow, MD

I have been lucky. Just last week I had my latest botulinum toxin injections from Dr. Michael E. Lee, of Group Health in Seattle, now Kaiser, and he has been my treating ophthalmologist for the past 24 years!

I came down with BEB at age 50, and as a husband, dad, and practicing psychiatrist, it became increasingly inconvenient in my personal and professional life. On the personal level, after several months I could no longer drive myself or my 2 adolescent children anywhere, and I could not look my wife or anyone else in the eye for more than 1-2 seconds when talking to them.

On the professional level, I needed to inform my patients that though I was not looking at them, I was paying full attention to what they were saying. I had to assure them that I was not on drugs, sleepy, or bored as they told me about their activities, fears, and disappointments.

As I mentioned above, I was lucky because it only took five months before I saw an ophthalmologist who was able to diagnose me with benign essential blepharospasm within a few minutes. He promptly referred me to his colleague Dr. Lee who did the botulinum toxin for the group, and he told me about the BEBRF so that I could obtain the information and support that I needed.

Only two days later I saw Dr. Lee, who tried many things over a period of several months before finally concluding that indeed I did have BEB and needed botulinum toxin. He tried hard in the following months to inject the right amount in the right locations, but to no avail, as my blepharospasm continued to be very disabling. But after 6 months of effort, he ultimately decided that surgery was worth a try, so he sent me to Salt Lake City where Dr. Richard Anderson performed the limited myectomy, and presto! I was dramatically improved.

My period of recovery was enhanced by my 15-year-old daughter, who taught me how to apply

makeup to the significant bruising around my eyes, and by my 12-year-old son and wife who were supportive as I gradually healed. Most importantly, I was soon able to look people in the eye, resume driving, and continue my practice as a clinical psychiatrist.

I still get botulinum toxin injections from Dr. Lee, almost exclusively in the area above the eyebrows, which continues to contract abnormally. And I continue to use dark glasses whenever I leave the house, even on cloudy days, and wear a baseball

cap everywhere outside - I have quite a collection of these caps, and my friends are impressed that I have such an extensive variety!

Everyone's BEB is unique, and while mine was quite disabling for the two years until my surgery, I have been able to function moderately well these past 22 years. I look only modestly different from my pre-surgical self, wear my BEB-related shades and caps, and keep my consultation room dimly lit (most patients don't ask, but if they do, I let them know straightforwardly that

my eyes are very sensitive to light). I lubricate my eyes frequently, and I tape them shut at night after using a moderately viscous substance.

What are the lessons here, if any? For me personally, one lesson is that keeping up the search, both for a diagnosis and an effective treatment, paid off in the long run. Another lesson is that having the same ophthalmologist has really helped, as Dr. Lee knows my facial musculature so well that he has learned just where to inject and how much in each site. An additional lesson is that being candid with others, both in one's personal life and professional life, can allow some of us to function reasonably well despite idiosyncrasies in what we wear and how we conduct ourselves.

Perhaps one more lesson is that the BEBRF can be an important part of one's life. While struggling to get the right treatment, it provided me with information and support so I could continue my search. After

Everyone's BEB is unique, and while mine was quite disabling for the two years until my surgery, I have been able to function moderately well these past 22 years

STORIES

treatment, I have been pleased to work at occasional ophthalmology and neurology Academy meetings staffing the BEBRF booth. And also, I have been able to speak by phone to patients who call the Foundation and would like to talk to a physician and fellow blepharospasm patient about what might be done to help them.

Finally, at age 74, I now enjoy 2 young grandchildren in addition to my wife and 2 adult children, and I continue a part-time practice as a clinical psychiatrist. 

Barbara Jones, Wales, UK

I am 77 years old, and I have had blepharospasm for 17 years now. I live with my husband. My adult children visit regularly. Most of my friends know I have ‘funny eyes’, and I was asked recently, what is actually wrong with my eyes and how does it affect me, so I thought I would try and answer.

How do I explain this condition when I don’t understand it myself? The medical explanation is that it is a type of dystonia, with uncontrollable and often painful muscle contractions around the eyes. Symptoms may include excessive blinking and involuntary closure of the eyelids, caused by incorrect messages from the brain to the muscles around the eyes. To put it in simple terms, my eyesight is quite good, but I have difficulty using it. I am classified as functionally blind.

When I am with company and engaged in conversation, my eyes are open, and I can see like anyone else, which makes it hard for people to understand. I get comments that my eyes are good today – I think to myself, if only that were true.

At church, I use a song book, as I have difficulty looking up at screens. Even when I know the songs and know all the words, the actual act of reading the words and singing them helps my eyes to stay open. Reading out loud is usually OK but reading to myself can be tricky. It improves if I get totally immersed in what I am reading.



Barbara Jones

I try not to let the negative thoughts and feelings take up permanent residence. I am determined to be independent and live life as fully as possible.

Stress is a key factor with this condition, and my eyes are a lot worse if I am stressed or worried about something. Ironically, not being able to open my eyes can be stressful. It often involves a lot of grimacing, and I am aware that people might be looking. Relaxing in those circumstances isn’t easy.

I have heard people say “I could do that with my eyes closed” – I often do. I am quite adept at household chores with my eyes closed. There are some things I don’t manage, like make-up, hair, and sewing although I did manage to sew 2 buttons on a coat last week. I won’t say how long it took. The good thing is I can still do all these things in spite of the frustrations and setbacks.

I have been asked how I cope. Truth is I don’t always cope, but I try to stay positive and am thankful for my sight. I have Botox® injections and Lundy loops in my glasses to hold my eyelids in an open position. These funny glasses are vital to my independence, but frequent adjusting of them leads to the delicate wire snapping and repairs required. I have had a brief experience of no sight and am very thankful that it was temporary. I can now truthfully say “Once I was blind but now I can see.” Yes, I have good days, and I have bad days. I try to keep the bad days under control and hidden. The tears are shed in secret. Yes, I get frustrated, embarrassed, and I sometimes feel sorry for myself, but I try not to let the negative thoughts and feelings take up permanent residence. I am determined to be independent and live life as fully as possible. 

CONTINUED ON PAGE 13



ASK THE DOCTOR

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

Q. I read a book that said that ‘low intensity laser therapy’ was good for treating blepharospasm. Is this true? Is it effective?

A. We have reviewed the medical literature, and we were unable to find supporting evidence in favor of laser being beneficial for the treatment of blepharospasm. Some surgeons (not me) have suggested lasers rather than scalpels for some eyelid surgeries, such as blepharoplasty (aka the removal of skin in eyelids). I still prefer standard cold steel incisional technique to reduce the scarring and burning of tissues that a laser causes. According to the scientific literature (and in my experience), there are two primary therapies for blepharospasm at this time: neurotoxin (e.g. Botox®) injection and myectomy surgery, in the event that neurotoxin does not improve symptoms. I developed the myectomy surgery (removal of the squeezing eyelid muscles) for blepharospasm and have performed over 3,000 of these procedures. This is the most technical and anatomically demanding procedure in our field. I feel lasers are certainly contraindicated in myectomy surgery as they burn, anatomically distort, and scar the tissues surrounding the orbicularis muscle, including the skin immediately overlying the muscle. This result is incomplete removal of the orbicularis muscle and eyelid complications from surgery.

In summary, as we strive to improve the care of blepharospasm patients, we must be careful of unproven or potentially damaging treatments. As physicians, we abide by the principle “Primum non nocere,” otherwise known as “First, do no harm.” In many instances, light of any type can worsen the symptoms of blepharospasm. The other aspect to consider with any medical treatment, especially one without scientific evidence supporting its efficacy, is cost. How much is your care provider charging for low intensity laser therapy? Will paying for a potentially ineffective treatment prevent you from taking part in other life activities that are important to you or prevent you from having other effective blepharospasm treatments? If the treatment will not be a financial burden for you, and a provider is able to show good evidence of its safety, you can consider any treatment that has a

potential benefit. Thanks to the BEBRF for supporting and evaluating treatments to improve the quality of life for blepharospasm sufferers.

Richard L. Anderson, MD, FACS and Grant H. Moore, MD-AO Surgical Arts, Salt Lake City, UT

Q. A patient posted the following on Facebook: The ophthalmologist gave me Botox® injections and the spasms did stop. However, it caused my entire eyelid to close. I have my follow up appointment on Friday and the doctor said if drinking tonic water doesn't work, the Botox® will be my best option. What would tonic do?

A. The information is not really clear as to what happened. In any event, tonic contains homeopathic levels of quinine and would not be expected to do much. Quinine in larger doses may reduce some types of muscle cramps, but it is now not recommended since there are adverse effects that exceed the possible benefit.

Mark Hallett, MD, Chief, Human Motor Control Section, NINDS, NIH, Bethesda, MD

Q. I have noticed that I have less pain and more comfort when the botulinum neurotoxin was injected SLOWLY.

A. I really don't know if there is any truth to this, but in my experience, most patients want the injection over with as soon as possible, so keeping the needle in there longer than necessary would not likely be seen as a positive to most of my patients.

Donald M. Stewart, MD, Charlotte Eye, Ear, Nose and Throat, Charlotte, NC

Q. What is Intense Pulse Light treatment? Does it help blepharospasm?

A. “Dry eye” and benign essential blepharospasm (BEB) are often tightly interrelated. Each probably contributes to the other. A common cause of “dry eye” is the “constipation” of certain oil glands called Meibomian glands. When the oil sits in the oil glands and doesn't come out, it oxidizes and becomes rancid, creating local inflammation within the eyelids, further narrowing the oil gland ducts, and making it even more difficult for the oil to leave the glands and enter the tears. Without the oil in the tears, the tears are less stable and

CONTINUED ON PAGE 13

If there can be a plasticity changing therapy with hand dystonia, might there be something similar for blepharospasm. No such therapy has been developed yet (as far as I know).

Another way of making a plastic change is with brain stimulation, such as transcranial magnetic stimulation or TMS. TMS has been FDA approved for the treatment of depression. There is some evidence that TMS might be beneficial in blepharospasm, but the experimental results so far are limited.

It was hoped when botulinum toxin therapy was introduced, that correcting the blinking pattern with the

injection might lead to a favorable plastic change that would outlast the weakness caused by the injection. Unfortunately, that doesn't seem to be the case, and points out that even if a favorable plastic change is induced, it is also critical to maintain that change.

In summary, at the heart of blepharospasm, there is an unfavorable plastic change in the brain motor networks. It may well be possible to reverse that change, but a robust method is not yet available. Likely we will have to learn more about the pathological changes before we can fully reverse them. 🌐

MARIJUANA USE AND BLEPHAROSPASM

Charlene Hudgins, BEBRF Executive Director

There has been an increased interest in using marijuana to treat BEB following the approval of its use for dystonia in Florida as well as postings on Facebook. One such patient wrote: "I have had BEB for about 4 years and have tried many techniques. I am currently using Cannabidiol (CBD), a non-intoxicating component of the cannabis plant, and it seems to help more than the Botox®. My neurologist recommended that I continue with the CBD and stop the Botox®. That was 6 months ago, and the CBD is all I am using. Good days and bad days but I am getting better at identifying triggers."

Below are three thoughts from the experts:

At the 2016 Denver, Colorado, BEBRF Symposium, Dr. Joseph Jankovic said that, to his knowledge, there has never been a formal study that marijuana helps with blepharospasm, but that is not to say that it will not help. There are many anecdotes (Some patients tell him that marijuana relaxes them and helps keep their eyes open.) but no studies that prove that it will.

Joseph Jankovic, MD, Director, Parkinson's Disease Center and Movement Disorders, Baylor College of Medicine, Houston, TX

"I agree with Dr. Jankovic that well-designed studies of CBD use for dystonia have not been conducted. We at the University of Colorado are currently running a study of CBD for tremor in Parkinson's disease, but don't have results to share yet. There has been a lot learned about conducting such a trial, and I hope to propose a CBD study in the future if certain details can be worked out. (For example, our Institutional Review Board (IRB) currently forces study subjects to not drive during CBD study, which would not be practical for a dystonia study.) I would only add that CBD seems to be fairly safe and could reduce pain associated with dystonia, but better studies are needed to know if it helps with motor symptoms of dystonia."

Brian Berman, MD, University of Colorado, Denver

"Scientists are conducting preclinical and clinical trials with marijuana and its extracts to treat symptoms of illness and other conditions. State-approved medicinal use of marijuana is a fairly new practice. For that reason, marijuana's effects on people who are weakened because of age or illness are still relatively unknown. Older people and those suffering from diseases such as cancer or AIDS could be more vulnerable to the drug's harmful effects, but more research is needed."

National Institute on Drug Abuse



SUPPORT GROUPS & YOU

Barbara Benton, District Director for Eastern and Southern Districts

BEBRF applauds our veteran Support Group Leaders (SGLs) who for years have given their time and efforts in order to support other patients. They all say it is a rewarding experience and an opportunity to “give back” to BEBRF for helping to improve their quality of life once they were diagnosed with blepharospasm, Meige, or hemifacial spasm.

Our SGL’s are patients who volunteer to organize at least one Support Group Meetings (SGM) annually and have titles of State Coordinators and/or Area Representatives. In some metropolitan areas, two persons share the responsibilities. Contact Persons are patients who do not receive patient lists or hold SGM’s but instead are available to speak to patients by telephone. They offer a listening ear and comfort, and connect new patients to our BEBRF office.

Experienced patients are an important asset when they attend SGMs because they can offer suggestions for coping and are models of how there can be a full life despite this condition. Patients share stories and become educated on the road to advocating for themselves. There is always something new to learn.

Patients who attend SGMs feel strongly about the support received. JK said, “SGMs provide comradery plus tools and support for coping with day-to-day life. The act of sharing similar symptoms with others helps me feel that a more normal life is attainable. Mostly, I leave the SGM with new hope!”

In chart 2, hone in on your home state and compare it with the current locations of SGMs and their

leaders (chart 1). Is BEBRF serving your needs? Would you prefer a SGM closer to home?

Do you feel you have a need for a SGM in your area? Please contact your District Director and let us know. Contact information is on page 3 of this Newsletter.

Newly diagnosed patients or those who are self-diagnosed (from the internet) are often desperate. We can hear it in their voices when they call. We understand these patients are in physical, mental and emotional distress, feel isolated and their lives seem to be turned upside down. They have no information, no one to turn

Chart 1: Current Locations and Support Group Leaders

State	SGM City / Area	Leader	State	SGM City / Area	Leader
AK	Anchorage	Jeanette Moser	NC	Charlotte	Jan Sellards
AL	Huntsville	Linda Webb	NC	Wilmington	Lora Clark
AZ	Tucson	Jeannie Fruean	NE	Omaha	Margaret Hoarty
CA	Canoga Park	Beverly Conradson	NJ	Central	Virginia Hill
CA	San Diego	Joanne Matuzas	NJ	Central	Rebecca Levin
CA	San Jose	Kathy Berg	NM	Albuquerque	Alfred Deguio
CO	Denver	Linda Peterson	NV	Carson City	Norma Gittelman
FL	Fort Myers	Charles Morse	NY	New York City	Helene Lauffer
FL	Jacksonville	Barbara Tobias-Cowell	NY	Upstate New York	Sandy Mincher
FL	Sarasota	Allen Brown	OH	Akron	Carole Masa
FL	Southeast FL	Marcia DeFren	OH	Columbus	Christi Gordon
FL	St Petersburg	Charlotte Sterling	OH	Parma	Richard Sarian
GA	Atlanta	Shawna King	OK	Tulsa	Helen Vaslavsky
IL	Chicago	Shelley Goddard	OR	Portland	Ruby Lambert
IL	Decatur	Bettie Hampton	PA	North central PA	Cheryl Kudlawiec
IL	Dunlap	Linda Buck	PA	Philadelphia	Anne Holsclaw
IL	Orland Park	Connie Secor	PA	Philadelphia	Joan Nikelsky
IN	New Haven	Keith Klenke	PA	Scranton	Nancy Williams
KS	Kansas City	Sharon Nowlin	SC	Taylors / Greenville	Patricia Miller
KY	Hardinsburg	Vicky Nottingham	TN	Nashville	Chuck Palmer
LA	Shreveport	Percy McCraney	TX	Dallas / Ft Worth	Ena Wilmot
MA	Boston	Sande Young	VA	Richmond	Paula Nichols
MD	Baltimore	Norman Dubin	VA	Ridgeway	Peggy Gilley
MD	GTR Wash. DC	Dana Cohen	VA	Roanoke	Siclinda Canty-Elliott
MD	GTR Wash. DC	Jennifer Kawar	VT	Burlington	Dave Johnson
MD	Columbia	Barbara Benton	WA	Seattle	Peter Bakalor
MI	Southeastern	Gloria Weir-Pearson	WI	Manitowoc	Sara Jane Brouchoud
MI	Traverse City	Carol Taberski	WI	Northwest	Mary Le Duc
MN	Minn. / St Paul	Virgil J. Koski	WI	Madison	Gail Grueneberg
MO	Saint Louis	Joan Metcalf			

to, and no answers. This is where BEBRF helps. We begin by listening to them on the phone to determine their needs. Then we look for local patient support connections.

Patients need explanations and answers. For example: sometimes patients have not been told how the toxin injections work, why injections need to be repeated or that injections are given in the muscles around the eyes and not the eyes directly. SGMs offer an exchange of ideas such as using EMLA cream before injections to numb the area and not experience the pain. When in the doctor's office, patients often don't know what questions to ask. Information is key to help patients take the step to agree to injections and improve their lives. Then patients see hope and learn how to proceed.

Sometimes caregivers and drivers also attend SGMs. They, too, become more aware of the condition and patients' needs as well as how to help in the future.

SGMs are good because they do good things for good people. BEBRF would like more meetings to reach more patients with more volunteers running them.

Would you consider becoming a support group leader (SGL)? Are you interested in stepping for-

Chart 2: Current Distribution of Patients and Support Group Meetings

STATE	# Patients in State	SGM Leaders	Contact Persons	STATE	# Patients in State	SGM Leaders	Contact Persons
Alabama	85	1	1	Montana	20	0	0
Alaska	5	1	0	Nebraska	20	1	0
Arizona	110	1	1	Nevada	30	1	0
Arkansas	50	0	0	New Hampshire	15	0	2
California	460	3	3	New Jersey	140	2	0
Colorado	80	1	0	New Mexico	45	1	0
Connecticut	55	0	1	New York	250	2	1
Delaware	20	0	1	North Carolina	150	1	0
Florida	300	5	1	North Dakota	10	0	1
Georgia	115	1	1	Ohio	165	3	1
Hawaii	30	0	0	Oklahoma	45	1	1
Idaho	30	0	1	Oregon	55	1	0
Illinois	165	4	1	Pennsylvania	165	4	1
Indiana	85	1	0	Rhode Island	20	0	1
Iowa	40	0	0	South Carolina	115	2	0
Kansas	45	1	0	South Dakota	15	0	0
Kentucky	50	1	0	Tennessee	100	1	1
Louisiana	90	1	1	Texas	315	1	2
Maine	20	0	0	Utah	45	0	1
Maryland	100	3	0	Vermont	20	1	0
Massachusetts	100	1	0	Virginia	140	3	0
Michigan	140	2	0	Washington	165	0	1
Minnesota	100	1	0	West Virginia	20	0	2
Mississippi	50	0	1	Wisconsin	115	3	0
Missouri	85	2	1	Wyoming	5	0	1

ward to help a current SGL? Your local patients might need you – might you move from a Contact Person to a SGL? Two characteristics of a good SGL are organizational skills and communication. Do you already have these skills from your profession? Your District Director will guide you through everything you need to know.

For more information or questions about this article, please contact Barbara Benton, Eastern and Southern District Director (410-884-9048) or the BEBRF Office (409-832-0788.) 

LAST CALL FOR 2017 BEBRF SYMPOSIUM

Saturday, September 9, 2017 at University of Minnesota, St. Paul Campus

The day-long Symposium is free with a continental breakfast and lunch provided. Program information is on the BEBRF website and in the Spring issue of the Newsletter. If you have not registered – **PLEASE DO IT TODAY** – online at www.blepharospasm.org or by contacting the BEBRF office at 1-409-832-0788. Do not miss this exciting opportunity to learn, share, and meet or reconnect with BEB friends.

FOCUS ON SUPPORT

NEW YORK



In front: Sandy Mincher, Back row, L-R: Emily Palmer, Marcia Hopple, Jean Duffy, and Rose Morris

SOUTHERN ARIZONA



L-R: Bernie Huston, Carol Huston, Paul Lamb, Nelma Murdoch, Jeannie Fruean, and Stephanie Jackter

NORTHWEST WISCONSIN

L-R: Kathy Reimer, Judy Britton, Chris Blaeser, Patsy Lenard, and Mary Le Duc



CAMBRIA, PENNSYLVANIA



L-R: Caroline Tobolewski, Joseph Gregorchik, Cheryl Kudlawiec, Linda Bobkoskie, Jean Krug, and Andrea Peruso

TEXAS



Seated; are Nancy and Don Good. Standing; are Tom Romano, the Allergan sales Rep, Ena Wilmot BEB State Rep, Sharon West, Linda Corley, and Linda Trahan

CENTRAL OHIO



Ena Wilmot

*State Coordinator, Arkansas,
Louisiana, Mississippi and Texas*

I was born and raised on the island of Jamaica and migrated to the USA as a young adult. I graduated from Long Island University with a BSN degree in nursing. My husband, Laurie Wilmot, and I have one grown son. Combining family and career with Laurie's many corporate moves has resulted in our living in various places from coast to coast.

I was diagnosed with BEB in early 2000, which rapidly migrated to BEB/Meige. After visits to multiple doctors and self-assessment of my condition with no definitive results, I was referred to the Movement Disorders Center at Baylor College of Medicine in Houston, Texas. Dr. Joseph Jankovic indicated that I needed better control. With increased units of botulinum neurotoxin and diazepam success came gradually.

In 2007, I attended my very first BEBRF conference in Jacksonville Florida. I learned so much there, and the people I met created a warm and friendly atmosphere. Among the many sweet people that I came to know from that meeting were: the then Southern District Director Fran Morgan, Ellawese

McLendon, Brenda Hopkins, Peter Bakalor, Shirley Barr, and Mary Smith, from the BEBRF office. I could not wait to attend the next conference.

There were no Support Group Meetings (SGM) in my area-Colleyville, a suburb of Fort Worth, Texas. I attended one that Fran conducted in another area and shortly thereafter she asked me if I would lead an SGM. Because of my faith in God, I prayed about this matter first, then told Fran that I would do so to the best of my ability. I had my very first meeting in February 2011, and we are still going strong.

Last year, after much consideration and prayer, I accepted the position of Texas State Coordinator. Then, this May, I assumed the role of State Coordinator for the adjacent states in the Southern District-Arkansas, Louisiana, and Mississippi.

I firmly believe in giving back so I'm looking forward to doing the best I can for an organization that has given so much to so many, including myself. We are here on this 'little blue/green ball' called planet earth to serve one another. 



Ena Wilmot

ASK THE DOCTOR

CONTINUED FROM PAGE 8

evaporate more quickly, creating one form of "dry eye." Intense Pulse Light (IPL) is marketed under the name "LipiFlow" as a means to heat up the eyelids and melt the Meibomian gland oil, so that the oil can slip through the small duct openings and into the tears. A relatively small study done on Asians in Singapore in 2016 determined that a single treatment with LipiFlow intense pulse light was roughly equivalent to twice daily applications of warm compresses to the eyelids over 3 months. From my perspective, the main problem with this study is that the method of warm compresses used by the participants was inadequate for maximum benefit. So the primary question remains as to whether or not LipiFlow or IPL helps blepharospasm. The short answer is that for some people, probably yes, and I see no reason not to try it. The long answer is that I'm not yet

convinced that IPL is as good as, or better than, correctly performed warm compresses. Whatever method is chosen should provide CONTINUOUS MOIST heat for at least 10 minutes, and we usually advocate for three compresses a day, once in the morning upon awakening, once when first returning home, and once right before bed. There is an overall relaxing benefit to these compresses as well, and we know that for many stress exacerbates BEB. Finally, minimizing the oil-dependent type of "dry eye" with either IPL or warm compresses is probably a reasonable idea for everyone with BEB to try, but melting the stagnating eyelid oil is not uniformly highly effective in improving BEB for everyone.

Charles N.S. Soparkar, MD, PhD, FACS, Houston, TX

VOLUNTEERS NEEDED FOR BLEPHAROSPASM STUDY: YOUR CONTRIBUTIONS AT WORK

DYSTONIA COALITION PROJECT 4: BLEPHAROSPASM TOOLS

PURPOSE? To develop the best way to distinguish blepharospasm from other disorders, and to measure the symptoms and impact of blepharospasm so that the value of any newly proposed treatments can be properly tested.

WHO ARE THE ELIGIBLE PARTICIPANTS?

- You must be at least 18 years old
- There are 3 different groups of people in this study.
 - People with blepharospasm or Meige syndrome
 - People with other facial or eye disorders
 - People with no facial or eye problems or other neurological complaints

WHAT IS EXPECTED OF THE PARTICIPANTS?

- Answer some questionnaires about medical and family history and current state of mind
- Have a neurological exam that will be video recorded
- This study visit takes up to 1.5 hours.
- Donate a small blood sample

There are participating centers located in the U.S., Canada, and Europe. For additional information or to volunteer, please refer to the contacts on the list below:

PROJECT 4 RECRUITING SITE LOCATIONS

COLORADO

University of Colorado Denver

Aurora, Colorado,
United States, 80045
Contact: Erika Shelton, B.S.
303-724-5865
erika.shelton@ucdenver.edu

GEORGIA

Emory University

Atlanta, Georgia,
United States, 30329
Contact: Gina Bell and Adam
Kassem 404-727-3381
rbell6@emory.edu;
akassem@emory.edu

ILLINOIS

Rush University

Chicago, Illinois,
United States, 60612
Contact: Samantha Ruehl
312-942-4500
Samantha_Ruehl@rush.edu

MARYLAND

Johns Hopkins University

Baltimore, Maryland,
United States, 21287
Contact: Aathman Swaminathan
410-955-6672
aswamin2@jhmi.edu

National Institutes of Health

Bethesda, Maryland,
United States, 20892
Contact: Elaine Considine, RN
elaine.considine@nih.gov

MISSOURI

Washington University in St. Louis

Saint Louis, Missouri, United
States, 63110
Contact: Jo Wright 314-362-
7148 wrightl@npg.wustl.edu

TEXAS

Baylor College of Medicine

Houston, Texas,
United States, 77030

Contact: Farah Ismail
farah.ismail@bcm.edu

CANADA, ONTARIO

Toronto Western Hospital

Toronto, Ontario, Canada
Contact: Brandon Rothberg
416-603-5800 ext 3120
brothber@uhnresearch.ca

GERMANY

University Hospital of Schleswig-Holstein

Contact: Susanna Langeloh +49
451 3101 8216 susanna.lan-
geloh@neuro.uni-luebeck.de

ITALY

University of Bari

Contact: Angelo Gigante
gigante@yahoo.it

University of Rome

Contact: Giovanni Fabbrini, MD
giovanni.fabbrini@uniroma1.it

This study is being conducted with the aid and support of the Office of Rare Diseases/National Center for Advancing Translational Sciences (ORDR/NCATS) and the National Institute for Neurological Diseases and Stroke (NINDS) at the National Institutes of Health (NIH) and the Benign Essential Blepharospasm Research Foundation.



SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before October 2, 2017, the next newsletter deadline.

EASTERN DISTRICT

Upstate New York

Pot Luck Luncheon – Bring small dish for 5-6 people
Date: October 17, 2017
Time: 12:30 p.m.
Location: 46 Harris Road, Waterford, NY 12188. Contact: Sandy Mincher.
Phone: 518-542-2328
Email: simplisand@hotmail.com

Greater Washington Area

Date: October 22, 2017
Time: 1:30 p.m. – 3:30 p.m.
Location: Holy Cross Hospital
1500 Forest Glen Rd
Silver Spring, MD 20910
Speaker: Dr. Stephen Grill
Contact: Jennifer Kavar
Phone: 301 229-4038
Email: jennifer_kavar@yahoo.com

NORTH CENTRAL DISTRICT

Warrensville Heights, Ohio

Date: August 25, 2017
Time: 3:00 p.m.
Location: 4829 Galaxy Parkway – Suite M
Warrensville Heights, OH 44128
Speaker: Dr. David Riley
Contact: Carole Masa
Phone Number: 330-666-2807
Email: carolemasa@roadrunner.com

Tulsa, Oklahoma

Date: Saturday, October 21, 2017
Time: 11 a.m. – 1 p.m.
Location: Dr. Denslow's office
4606 E 67th St., Bldg. #7
Tulsa, OK
Lunch will be provided
Speaker: TBA
Contact: Helen Vaslavsky
Phone: 918-455-2133 (H); 918-636-7334 (cell) Email: helen123@cox.net

SOUTHERN DISTRICT

Ena Wilmot: Now State Coordinator for Arkansas, Louisiana, Mississippi, and Texas.
Phone: 817-488-0445;
Email: enamwa@hotmail.com

Huntsville Alabama Blepharo Buddies Awareness Support Group Meeting

Date: October 22, 2017
Time: 1:00 p.m. – 4 p.m.
Location: Dowdle Center – South Huntsville Hospital
109 Governors Dr
SE Huntsville, AL 35801
Speaker: TBA
Contact: Linda Webb
Phone Number: 256-723-2661

Dallas/Fort Worth, Texas

Date: October 24, 2017
Time: 12:00 p.m. – 3:00 p.m.
Location: Dallas Baptist University – Colleyville Campus
110 Grapevine Hwy
Hurst, TX 76054
Contact: Ena Wilmot
Phone: 817-488-0445
Email: enamwa@hotmail.com

**IF YOU WOULD
LIKE TO START A
SUPPORT GROUP
IN YOUR AREA, CONTACT
YOUR DISTRICT DIRECTOR
OR THE BEBRF OFFICE
FOR ASSISTANCE.**

REMEMBER BEBRF IN YOUR WILL

It is our editorial policy to report on developments regarding BEB/Meige and related disorders but 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.**

P.O. BOX 12468

BEAUMONT, TEXAS 77726-2468

409-832-0788

Dated Material Enclosed

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U.S. Postage
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Beaumont, Texas
Permit #299

HELP THE BEBRF CARRY OUT ITS MISSION

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



The polo shirts are 50% cotton/50% polyester with a white embroidered logo (Help Us Keep Our Eyes Open & BEBRF) on a sapphire blue shirt. They are available in limited quantities in Medium, Large, X-Large, and XX-Large for \$25.00 plus s&h*

Shirts may be purchased by check or credit card using the form to the side and mailing it to: P.O. Box 12468, Beaumont TX 77726-2468; or by phone at 409-832-0788; or through the BEBRF online store:
<http://blepharospasm.org/bebrf-online-store.html>

ORDER FORM

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

Number of shirts _____ X \$25.00 plus s&h* \$ _____

Amount enclosed \$ _____

*Shipping & handling per shirt (\$3.30 in the U.S.; \$4.80 in Canada; \$8.50 in Mexico; \$10.50 other Intl. mailing)

Circle Shirt Size: **M L XL XXL**

Mail order form and check made payable to BEBRF should be mailed to: **P.O. Box 12468, Beaumont TX 77726-2468**

IF BY CREDIT CARD (VISA OR MASTERCARD):

Card # _____

Expiration Date _____ Security Key # _____

Name on Card _____

Signature _____