BENIGN ESSENTIAL **BLEPHAROSPASM** RESEARCH FOUNDATION

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

Summer 2020 • Vol 40 • Issue 3

DYSTONIA COALITION: PATIENT-CENTERED OUTCOME PROJECT

BY SARAH PIRIO RICHARDSON, MD

The Dystonia Coalition is a National Institutes of Health-funded collaboration between dystonia researchers and dystonia patient advocacy groups. BEBRF is a charter member. The overall goal of the coalition is to advance research in the dystonias to understand more about the condition and how it changes over time as well as to find better treatments in the future. Currently, one of the projects that we are pursuing is to develop a patient-centered outcome measure for the most common focal dystonias.

In the development of new therapies and treatments for all disease, including dystonia, researchers need to measure the severity of the disease process they are aiming to treat so that they can show evidence that a treatment works (or doesn't). There are a variety of ways of measuring disease severity currently in dystonia. For example in cervical dystonia, we have physician-rating scales where a physician either in person or through a videotaped examination can determine the severity of dystonia symptoms by observation. Likewise, there are devices such as smart watches that can measure tremor through "objective" measurement through a wearable device that can transmit data about the symptom. Finally, there are also ways to measure disease severity that is best described or reported by the patient directly—these are called patient-reported or patient-centered outcome (PCO) measures. Pain rating scales are a good example of a PCO---as the patient is in the best position to rate the severity of the symptom of pain as they are the ones experiencing the symptom, and although there are outward signs of pain (grimacing, etc.), they might not be a reliable sign of the severity of pain experienced by the patient. We are interested in developing PCO measures for cervical dystonia, blepharospasm, and for laryngeal dystonia (which affects the vocal cords) as we want to capture the benefit of therapy directly from the patient perspective.


Sarah Pirio Richardson, MD

We currently have an FDA-approved therapy for cervical dystonia, blepharospasm, and laryngeal dystonia which is botulinum toxin. We know that botulinum toxin injections improve motor symptoms (like eye spasms or eye closure) and can improve overall quality of life for patients with dystonia. Yet—we know that many patients, even up to 1/3 of patients, discontinue use of botulinum toxin therapies. This may be due to many factors including: cost, lack of insurance coverage, side effects and potentially due to the therapy not meeting patient expectations of what they wanted to get better with the treatment. In addition, one of the challenges of botulinum toxin injection therapy is what is known as the "yo-yo" effect of treatment. In the ideal setting, after a patient is injected with botulinum toxin, they typically will have a good response such

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ATTENTION ALL MEDICARE PATIENTS

As of July 1st, Medicare is requiring a 7-day pre-authorization for botulinum toxin injections for blepharospasm. Most doctors are having no problem filing the necessary paperwork; however, some doctors are having issues getting approval.

Be sure to call your doctor's office well in advance to see if they have the proper authorization for you in place. If they have been denied authorization, please contact the BEBRF office (**409-832-0288** or **bebrf@blepharospasm.org**), and we will help connect them with a pharmaceutical company representative who can assist in the paperwork where possible.

NOTE: Some types of medical practices may be exempt from this ruling, but to be safe, check with your doctor's office in advance to see if you have any needed pre-authorization.

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
Fall	October 1, 2020

BEBRF BLURBS

These are truly uncertain times; however, BEBRF is operating with minimal disruption by having its staff continue to work effectively from home. If you need to find a new doctor, don’t hesitate to give us a call, and we’ll do all that we can to help. While we are able to do most of the things we would normally do if we were working from the office, some things take a little longer. For example, we can’t make bank deposits as often and as quickly as normally, this Newsletter may be a little later than it would normally come out, and some deadlines may be extended. Thank you for understanding.

Speaking of extended deadlines… **We have extended the Mid-Year Appeal through August 31st.** If you have already made a contribution, THANK YOU! If not, please consider making a donation. Due to the world pandemic situation, most non-profit organizations anticipate financial shortfalls on their annual budgets. BEBRF has seen a significant decline in donations as well. Anything you could give would be helpful and appreciated. If these times have hit you hard financially, please know that we understand.

BEBRF has also **extended the deadline for Research Proposals for this year to September 30th**. The Dystonia Coalition (see story on page 1) held a webinar in early June. The Dystonia Coalition is sponsored in part by the National Institutes of Health (NIH) and is comprised of researchers, research organizations, and patient advocacy groups like BEBRF. They amass research data that can be used by researchers as well as sponsor ongoing research into the causes and treatments for all kinds of dystonia, including

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PROTECTING PATIENT INFORMATION:

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

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blepharospasm. If you are interested in learning more about these research databases – if you are a researcher, or learning more about their clinical trials and ongoing research – if you are a patient, please go to this link and view the webinar in its entirety: https://www.rarediseasesnetwork.org/cms/dystonia/News-Events.

BEBRF is also creating a Clinical Database. We included the survey in the Winter Newsletter earlier this year. If you have filled it out and returned it, THANK YOU! If you have not, then please do. If you need us to send you a copy, contact us at bebrf@blepharospasm.org or call us at 409-832-0788, and we will send you a copy. It is our intention to create the largest blepharospasm database that can be used for research. When you complete the survey, please mail it to us at P O Box 12468, Beaumont, TX 77726.

If you are interested in participating in research in another way, you can donate your brain for dystonia research. Contact the office to find out how.

Throughout this issue of the Newsletter you will find information about **BEBRF's Zoom Support Group Meetings**. These have proven very successful as a way for patients to come together during this pandemic, social-distancing time. Many Support Group Leaders are organizing for the patients in their area, but through Zoom you can join just about any meeting. To that end, BEBRF is organizing several National Zoom Support Group Meetings. If there are no close Support Groups in your area, of if transportation to meetings has been a problem in the past, here is your solution! Please check the listings for meetings in this Newsletter, the BEBRF Website, and BEBRF's Facebook page. Meetings are always being added so check back frequently. If you "like" our Facebook page, any new things posted there will show up on your Facebook newsfeed.

Did you know you don't have to have a computer to join a Zoom Meeting? Anyone can join by phone. Please let us know if you need help in joining a Support Group Meeting this way.

Due to the pandemic, we had to postpone our 2020 Symposium. **Good news: it has been re-scheduled for October 8 & 9, 2021 in Philadelphia.** Stay tuned for updates as we get closer to that date. Meanwhile, BEBRF is pleased to announce that we will be hosting an online webinar this year to help people stay updated on the latest information regarding blepharospasm. The speaker for this Webinar will be Charles Soparkar, MD, PhD, from Houston, TX. In addition to serving on the BEBRF Medical Advisory Board, Dr. Soparkar is very knowledgeable about a range of topics related to blepharospasm. Check the BEBRF website or Facebook page for exact details as they are announced. If you would like Dr. Soparkar to answer your questions at the webinar, please submit them to bebrf@blepharospasm.org in advance.

Finally, BEBRF is pleased to announce that **staff member Angel Roberts has been promoted to Office Manager**. Angel, who has a bachelor's degree in graphic design from Full Sail University, has brought amazing organization, skills, and experience to BEBRF. Congratulations, Angel!

PLEASE DO ALL THAT YOU CAN TO STAY SAFE AND HEALTHY!

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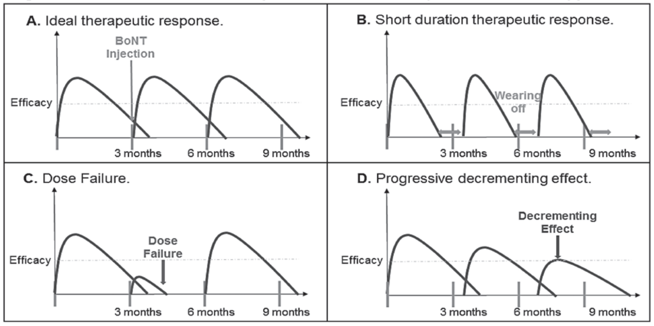
DYSTONIA COALITION: PATIENT-CENTERED OUTCOME PROJECT

as less eye spasms and improved ability to see over the next few weeks and then will continue to have benefit for two months. Close to the next dosing cycle, they will have wearing off of the benefit and then will go in for the next injection cycle. Even in the ideal setting, there is often some wearing off of benefit where patients are waiting for their next injection for therapeutic benefit. In less ideal settings, there can be very short duration of effect where the botulinum toxin produces benefit but only for weeks to a month as well as other variations—like doses not kicking in at all, called dose failures. This "yo-yo" effect is well known to patients and researchers alike---who are currently working toward add-on therapies that might reduce the ups and downs with this therapy.

Figure 2. Fluctuations in severity over time and complications of therapy.



We are working on developing a PCO which can capture this "yo-yo" effect so that we can understand more about how our current therapies benefit patients as well as areas we need to work on to improve dystonia symptoms. We also want to be able to do this in a way that patients can report on their response to therapy on a frequent/weekly basis and to do this, we will be developing an App that will be accessed on a smartphone.

We also want to be able to do this in a way that patients can report on their response to therapy on a frequent/weekly basis and to do this, we will be developing an App that will be accessed on a smartphone.

In developing a PCO, as implied in the name, we need the patient perspective in order to ensure that the measure can capture dystonia symptoms that are important to patients. To this end, we started with previous information on disease severity collected from 600 dystonia patients previously in the Dystonia Coalition. We have also assembled expert panels for each of these dystonias that consists of dystonia researchers/clinicians, patients and patient advocacy representatives. We are also planning patient focus groups to ensure we have included all symptoms and concerns in our PCO. We will finally pilot the PCO in patient groups.

We are excited to move forward on this project and to improve our ability to measure dystonia symptoms and to measure benefit from new and existing therapies to ensure we are addressing the symptoms most bothersome to patients with dystonia.

BARBARA BENTON RETIRES AS EASTERN DISTRICT DIRECTOR

It has been a great run! I have been Eastern District Director since July 2011. I helped to run the Silver Spring Symposium in early July 2011. Having proved my interest and capabilities, and with Nilda Rendino playing two roles of both First Vice President and Eastern District Director (EDD), I was asked if she could pass the EDD role to me. I was thrilled! As in most positions it takes about a full year to learn the ins and outs, expectations, and protocols. And I've been there ever since.

Some of my accomplishments include helping to run the Pittsburgh Symposium; starting a new model in which State Coordinators (SC) can be a SC in more than one state; establishing co-Area Representatives (support group leaders) in large metropolitan areas; serving as the point person for the Helpful Hints and the Talk With Your Doctor brochures, speaking at multiple support group meetings,

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overseeing two districts for two years; participating in Advocacy Day on The Hill, and advocating for all support group leaders and patients. I also serve on the BEBRF Board of Directors.

It is my choice to step down from this EDD position, but I will remain on the Board of Directors. My responsibilities have been very rewarding, and I would recommend all to consider taking a more active role in BEBRF.

Bryan Renehan has been "in training" to take over the role beginning September 1, 2020. Let us give him a warm welcome and much support. I am confident he will do his absolute best to be your new EDD.

Barbara Benton

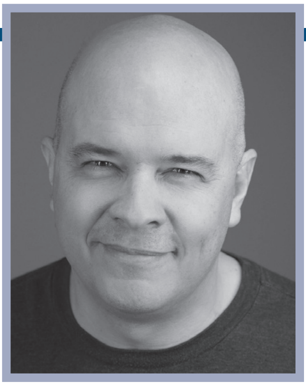
It has been such a pleasure getting to know Barbara, and I am humbled by her asking me to assume the Eastern District Director role for BEBRF. Her devotion to the foundation for the last 9 years and all the things she has accomplished are remarkable. I only hope with her continued guidance that I can advance the goals of the Foundation half as well as she has.

Bryan Renehan • Eastern District Director, BEBRF Board of Directors Member

I would like to thank Barbara for her significant time and dedication to the organization and patients like ourselves. I met her at my first Support Group meeting. She was so enthusiastic about the organization and how it could help patients like me that I wanted to also volunteer with the organization. As I became more involved in the organization, I also learned how much work she had put into our educational materials that we provide to any patient or physician to help them navigate through the disorder. She has given years of volunteer time, and I thank her for both her time and her impact on patients and the organization itself.

Heidi Coggeshall • President of the BEBRF Board of Directors.

PATIENT STORIES: DOUG PATT, JR.



I had ambiguous symptoms for years but was suddenly blinking uncontrollably in meetings. I saw a neurologist at the end of 2017, but I knew what I had. I watched my father's condition deteriorate in his early fifties. Dad, his twin brother and their mother have / had dystonia. My father has Meige syndrome, his twin brother has blepharospasm and their mother had spasmodic dysphonia. Even though my symptoms were mild at the time, my neurologist confirmed that I likely had blepharospasm and told me that my best course of treatment was botulinum toxin when ready.

My father had a partial myectomy, and I did not want the same. I searched for alternatives. I found Dr. Joaquin Farias' name mentioned in the footnotes of the Wikipedia page on blepharospasm. I discovered that he treats dystonia patients, of all types, with neuroplasticity training. I read both of his books and began incorporating his teaching about four months before I met him in Toronto in September 2017. It was a four day workshop with a group of eight. He taught us about our condition and neuroplasticity. Neuroplasticity is the brain's ability to re-map itself. Dr. Farias has a solid track record, and I found that his training methods induced neuroplastic change that allow gradual motor control recovery. In other words, in my opinion, Dr. Farias helps dystonia patients get better or even fully recover.

As is the case with many dystonia patients, my symptoms worsened. I am an architect. I meet with a lot of people. From the outset my symptoms could be partially suppressed by talking or chewing. By January 2019, that was no longer the case. My symptoms had reversed and become severe. I had facial spasms and could barely watch TV, read, or use my phone or computer. I also couldn't walk, talk, or eat without my eyes closing consistently. I was diagnosed with Meige in 2019 and decided to get Botox®. It was helpful for painful spasms but not a long term solution for me. I've received injections only twice. All the while I have continued to practice what I learned about neuroplasticity.

I am now in recovery. In my case, I believe it's due to a consistent mindfulness regarding symptoms and strategy. For example, when tension builds in my face, I relax. When my eyes close I get them open (I "think" them open by sheer force of will or look up). If my eyes don't want to stay open, I use the muscles around my eyes to keep them open. I breathe through my nose rather than my mouth to keep Meige at bay. When my condition was most pronounced my breathing was

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shallow, halting, and noisy. I learned to breathe quietly and calmly. I've been doing all of these things, and much more, for the last three years and hundreds of times a day, every day. I also do things on purpose that make my eyes close, however, I don't accept the 'eyes closed' outcome. I read. I read out loud. I walk. I go to the grocery store. I engage my family in conversation. To most people these are simple activities, but for a blepharospasm patient, they can be excruciating. I still have triggers, and my eyes close on occasion but not like before. My symptoms are slowly disappearing. I'm even learning to ride my mountain bike again!

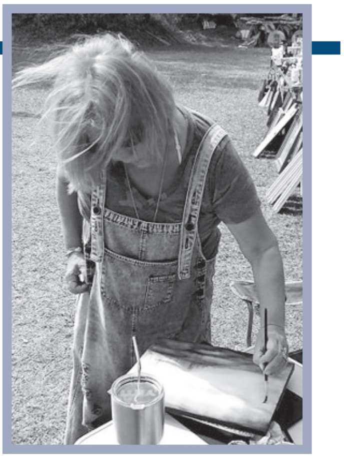
My name is Doug Patt Jr. I live in Allentown, Pennsylvania. If you'd like to hear more about my recovery or Dr. Farias and his workshops please email me at dpatt@icloud.com.

PATIENT STORIES: TRACY STEINER

I was at my Grandson's birthday party, and my father was questioning my eyes. "What is wrong with your eyes? You can't stop blinking." I went to my eye doctor and was told (like most of you) that it was a case of dry eyes. I was placed on multiple eye drops and was advised to soak my eyes.

Shortly after my cancer pills were changed, it seemed my body broke down at the same time. My eyes were blinking, shutting down and extremely light sensitive. I also was diagnosed with IBS, diverticulitis and colitis. I could not move my neck, had severe migraines and insomnia. I thought to myself, this is worse than my breast cancer and bilateral mastectomy. What is happening to me? Why is this happening?

I retired from teaching before I had gotten BEB. I taught ESE (children with different disabilities) and VPK (voluntary pre-kindergarten) in Florida prior to my retirement. I loved teaching. However, it was my second love; my first love was always as an artist. For as long as I can go back, my desire to draw and paint has been with me. My life has taken me on different paths in order to bring me back full circle as you will see in the rest of my story.



Tracy has painted the cover of the new greeting cards for BEBRF. To see a full-color version visit our website or our Facebook page. They will be available for purchase soon.

After a year of being told it was dry eyes, my eye doctor sent me to a specialist who diagnosed me two years ago with BEB. Then I was sent for botulinum toxin, which didn't work well for me. I went for five sessions. My eyes were drier than before, I had blurred vision, my face fell, I still was light sensitive, and my eyes would swell up from the injections. I decided to take matters into my own hands, stopped the injections, and started doing research on this horrible debilitating neurological disease. I found BEBRF online and ordered every brochure they had. I highlighted everything that could help me in the brochures and gave them to my team of doctor's. I began to wean myself off Xanax. I also found an acupuncturist/chiropractor (Dr. Amit Patel) who studied in neuroplasticity, and he suggested removing gluten from my diet. He would give me eye exercises, worked on my neck. I still see him on a weekly basis. I showed him that there was a neuroplasticity cervical dystonia platform online. Dr. Patel suggested I take it. After three months I began to feel improvement.

My neurologist put me on a low dosage of Ritalin; I'm ADHD but never took medication for it. The Ritalin reduced my blinking even more, took away my headaches, and I no longer have insomnia. I started to meditate daily (Yoga Nedra works best for me) as well as self-hypnosis (which is on Dr. Farias' platform). My eyes were feeling better day by day. I decided to pick up watercolor painting after 40 years and that became my

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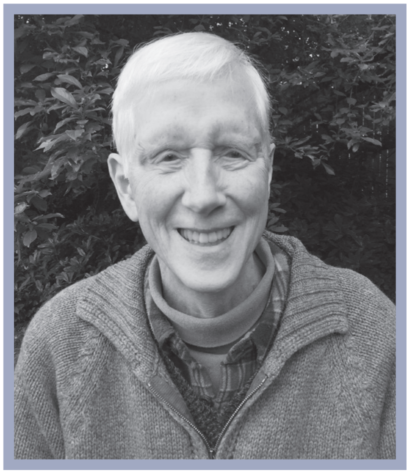
CPR for my eyes. They started feeling better more each day! I try to paint or sketch everyday as well as my eye exercises and meditation. My eyes are now 80% better than they were, I am no longer light sensitive and can drive short distances. I feel so blessed to have found BEBRF. They started me out on my journey of feeling better, by receiving their resources, and I am ever so honored to do their art. While teaching, my student's would ask me "What do you want to be when you grow up?" I always answered "When I grow up, I want to be an artist again."

PATIENT STORIES: DR. RICHARD WINSLOW



Reading the patient stories in the most recent BEBRF Newsletter, I was astounded by how difficult it has been in the 2000's and even 2010's for patients to get the right diagnosis and be on the way towards meaningful treatment.

A homeopathic doctor in northern India diagnosed it?! A sister-in-law diagnosed it?! Ten different doctors failed to?! Thirty different doctors failed to?!!

Many times in the last decade I sat in the BEBRF booth, with the now-retired Academy Chair, the marvelous Barbara Beckett, at annual ophthalmology and neurology academies. Barbara had worked at these academies for two decades with our beloved founder Mattie Lou Koster, and after Mattie Lou died, often worked alone. I ended up thinking that, because of the many doctors we talked to and gave BEBRF literature to, nearly all ophthalmologists and neurologists were now aware of blepharospasm. Oh how wrong I was.

So now I am even more convinced than before. My conviction is this: education of physicians is a very crucial part of what BEBRF does. And more importantly, that education must go on and on, perhaps forever, because no matter what efforts BEBRF makes, it is now obvious that most medical schools and residency programs, even in specialty areas like ophthalmology, simply do not teach about blepharospasm.

Part of the problem are the academies themselves. The multimillion- and multibillion-dollar drug and medical equipment companies have huge, colorful, almost intrusive displays in the middle of the gigantic convention floors. We of the BEBRF are relegated to a small area in a distant back spot, along with about 12 other very worthy nonprofit patient-oriented groups. It almost seems that doctors come across our booth while they are wandering from one commercial display to another or looking for where the food is dispensed.

I was extremely lucky, at age 50 in 1993, when my blepharospasm began. My family doctor and my optometrist missed the diagnosis, but less than five months after the symptoms began, I saw an ophthalmologist who within five minutes of listening to me told me I probably had blepharospasm. He promptly referred me to his colleague, who did botulinum toxin injections, and referred me as well to the BEBRF. In my particular case, injections from 2 different doctors did me little good, so two years after symptoms began, I was lucky to receive a limited myectomy, which has made all the difference for me. I have been able to continue, now part-time, my work as a clinical psychiatrist.

I still have some symptoms, of course, and I need to utilize many of the basic techniques which are used by those with blepharospasm: wrap-around dark glasses everywhere outside, a baseball cap whenever I leave the house, driving only when it's light, frequent eyedrops during the day and taping my eyelids shut when I go to bed at night. And I still get botulinum injections, which help in some ways, once every 9 to 12 months, from the same treating ophthalmologist who I first saw in June 1993, Dr. Michael Lee of Kaiser in Bellevue, Washington.

I will close by repeating the need for BEBRF to make ongoing vigorous efforts to educate the medical profession about blepharospasm and related dystonic disorders. In this day and age, patients should not have to suffer for several years, see 10 to 30 doctors, travel to northern India, or get the good word from a relative in order to learn that they have a neurological disorder for which there is some moderately effective treatment.

ZOOMING WITH BEBRF - F

BY TISHAN

Shortly after our world began to shut down due to the rampant spread of COVID-19, BEBRF began conducting our Support Group Meetings in a whole new way. We began to Zoom!

As you read the reflections of just a few who have participated in a recent meeting using this relatively simple format, you will recognize some things these folks have in common. They are vibrant men and women, seeking a way to connect with others both to be helped and to share help. They are lifelong learners. They are looking always for The Silver Lining.

LINDA TRAHAN • Northeast Texas Area Representative, Rockwall, TX

Though we are all going through anxious and uncertain days, I am thankful that we live in a time where we have access to technology that allows us to still assemble as a group, even if it's through virtual means like Zoom meetings. As a support group, we are a necessity to many of our BEBRF friends, and it's so nice to be able to provide Zoom options so that we may continue to make connections and support each other. In fact, because of its convenience, I'd like to see if we can provide this option post-COVID, since many of the patients in our region live quite far from where meetings are usually held. Every cloud has a silver lining.

Linda practices Social Distancing in beautiful Palm Beach.

Sharon models a fundraiser t-shirt.

SHARON WEST • West Tarrant and Parker Counties (TX) Area Representative

I "Zoomed" twice in June: the first time as a member of the DFW (Dallas/Fort Worth) Group, and the next time as facilitator for the new SGM for folks in West Tarrant and Parker Counties. Both were fun and interesting experiences, spending time with friends new and old, and getting caught up on BEBRF news and on-going activities. Being on Zoom has got to be the next-best thing to meeting in person, as we can all see each other, talk, and share, just like we're accustomed to doing. I'm so grateful the BEBRF has provided us with this platform!

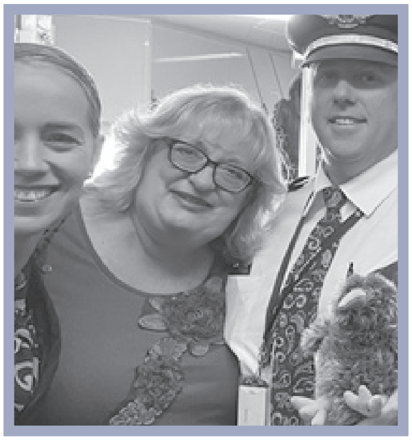
CLARA TREVINO • Houston Area Zoom Participant

I liked the Zoom Meeting because it's a virtual way to share experiences and help each other. I hope to see you all soon!

Clara (in the back) wears her sunglasses as she enjoys spending time in her "happy place" with her family.

NATALIE WEST • Houston Area Zoom Participant

I'm a member of the Houston Contingent, and we had our Zoom call which was very helpful. Carlas, Charlene, and Ena were great as well as the other participants. It's amazing how much we can help each other just by listening to other experiences. I look forward to more meetings to come!



In January 2020, Natalie, a world traveler, celebrated her 60th birthday with a trip to New Zealand. During her trip, Air New Zealand's crew named Natalie an honorary Lolly runner.

INDING THE SILVER LINING

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CARLAS POWELL
Houston Area Representative

As one of the Houston Area Representatives, this was the first meeting that I hosted, and I would like to thank all of the participants as they made it an easy transition for me. What I personally enjoyed about our first Zoom Call was the openness of everyone to share their experiences and upon request, provide personal insight to others on topics of discussion. It was a great Zoom SGM, and all who attended want to continue in the future!

Carlas enjoys cooking with his new Father's Day Gift (Traeger Pellet Grill) - smoker in the backyard.

ENA WILMOT • State Coordinator for Texas, Arkansas, Louisiana, and Mississippi, Colleyville, TX

The ZOOM meetings were a great way for me to connect with several patients in one setting, also a reminder of how interconnected we all are. We talked about how they are doing, how they are feeling, what's going on in their lives. First and second quarters of 2020 have been trying so far. We need to focus on the best ways to stay safe, reduce the stress in our lives, and find our happy place, peace, and joy.

Even though she was saying goodbye to her beloved oak tree, Ena enjoys learning the workings of the arborist's tractor. Ena says, "I was like a kid at Disney World riding on Space Mountain."

SHARON NEARY • Dallas/Fort Worth Area Zoom Participant

The Zoom meeting was very good. It was great seeing some of the folks; as I am sure we are all tired of not having human contact. We talked about the Symposium that is postponed for September and will be on the books for the next year. The date was given. I joked with my roommate, Sharon West, that she would have to wait another year to share a room with me. Ena stated since I have been to Philadelphia before I could set up sightseeing for a group. Personally I will miss seeing people from around the country. It is always a nice weekend.

Sharon joins her AA flight attendant daughter for a Florida beach adventure. Sharon says, "Salt air, waves, and sand clears my mind of all troubles."

HELEN VASLAVSKY • State Coordinator for Oklahoma, Broken Arrow, OK

I believe that ZOOM is going to be the new normal for communications as more and more people are starting to feel comfortable experimenting with this concept. Thank you BEBRF for making this available for all our patients and your passion for keeping us all connected.

Helen enjoys traveling and a bite of crawfish boil. She has been a jewelry designer for about 20 years. When people ask how she can make jewelry with blepharospasm, she says, it is, "easy if I only have to LOOK down. My motto: either we control it OR it will control us."

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ZOOMING WITH BEBRF - FINDING THE SILVER LINING

DEE LINDE • Western District Director, Canby, OR

It was great "meeting" others from my district on our Zoom meetings, and I would like to thank the brave leaders who dared to lead us into the unknown! Thanks BEBRF for helping us keep our lines of communication open during these trying times.

Here Dee, an official "Oregon State Master Gardener Volunteer", enjoys her relaxing hobby beside just a few of her wide variety of beautiful exotic plants. Dee also paddles on the first (but far from the only) all breast cancer survivor Dragon Boat team in the country.

CYNTHIA CLARK
Greater Los Angeles Area Representative

Zooming without all the COVID-19 protective gear has been a definite plus! Staying safe...

HOSANNA DERDERIAN • Zoom Participant from Cranston, RI

I was very much interested in being part of the Zoom Support Group Meeting and hearing the discussions amongst the participants and to realize the challenges that people with BEB are facing in their everyday lives.

SANDY MINCHER • Upstate NY Area Representative, Waterford, NY

I LOVED it! I cannot drive and so this is a way for anyone to participate. I am usually the host with our meeting here at my home. One of our Zoom attendees lives nearby but was in FL and still able to attend via Zoom. I would welcome anyone around the world. We plan on our next meeting in Oct. No date set yet. Watch the website.

Sandy and her husband, Greg, join here as they celebrated their 40th wedding Anniversary (7/19/2020) in Alexandria Bay, Thousand Islands, NY. Sandy says of Greg, "He is my rock, and I am his."

RUBY HILL • Dallas/Fort Worth Area Zoom Participant

I am a few months away from entry into my ninth decade on this earth. I have glaucoma, and blepharospasm of the eyelids (so far, no other movement disorder). I pride myself on being "a life-long learner". Therefore, believe that being able to keep up with consumer technology is a blessing. Zoom is the latest iteration of keeping up, and a silver lining in these troubled times.

Nothing can completely replace person to person in-person contact, especially when that contact would be with warm and loving persons like the ones in the DFW SGM BEBRF, but Zoom is the next best thing. It is amazing to hear and see someone who is hundreds of miles away.

Ruby is learning line-dancing through the use of her smart phone and tablet. She notes beyond the good exercise, "I even spent some time learning video editing. Learning keeps the cobwebs away from the brain."

> ***It was great "meeting" others from my district on our Zoom meetings, and I would like to thank the brave leaders who dared to lead us into the unknown!***

EDUARDO RUIZ • Dallas/Fort Worth Area Zoom Participant

The Zoom support group meeting is a great way to connect with others and share their own experiences.

Eddie has been living with blepharospasm for several years. He attended his first Symposium in Houston last year. Eddie was so impressed with the different doctors' presentations and all the attendants and noted,"All these people have what I have."

Nothing can replace person-to-person contact . . . but Zoom is the next best thing.

JEAN GORMAN • Zoom Participant from Upstate New York

It was so great to meet with fellow blepho gals. Let's do it again soon.

Jean shows off her catch of the day.

LAURIE MCGEE • Dallas/Fort Worth Area Zoom Participant

I participated in the recent Dallas area Zoom meeting. As always, it was a very informative meeting, and it was nice to see some familiar faces who share the same crazy conditions I deal with every day. I love learning new things and meeting new people at each of our gatherings. Hoping we can all meet in person very soon!!

Laurie enjoys get-away time with her family.

TISHANA CUNDIFF • Central District Director/ BEBRF Vice-President, Liberty, KY

Hosting these Zoom events and helping train others has been a pleasure. Participating in a Support Group Meeting on Zoom with others, some literally thousands of miles away, has been a fabulous way to connect folks. As we know, many we work with do not drive. This format allows people to meet from the comfort of their own home.

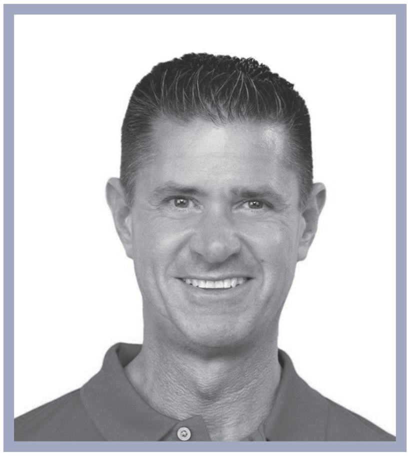
It may not be in person, but it definitely is face-to-face.

Tishana enjoys traveling and blogging about her adventures. Following her myectomy and the passing of her husband, she appreciates the blessing to be able to drive distances again.

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

A STEP FOR MAKING SELF-CARE MORE OF A PRIORITY

BY TOM SEAMAN



For a lot of us, self-care is difficult. This is for a lot of reasons, some of which might be guilt, not enough time, putting others before ourselves, not sure what self-care activity to do or what is best for us, etc. Whether you have a specific health issue or not, in my case it is chronic pain from dystonia, everyone needs self-care. But how can we do that in a way where we feel good about it? Before answering this question, I want to share with you the things that I do that I consider self-care.

Self-care for me includes eating well, exercise, quality sleep, massage, listening to music, resting by the pool, at the beach, or in my yard, meditation, prayer, avoiding toxic people, refraining from activities and events that overtax my body, taking breaks from my computer and phone, walking in the park, reading inspirational books, watching my favorite movies and TV shows, and spending time with people who lift me up.

I have been able to implement many of these self-care activities throughout my day, mainly because I have made them part of my routine and lifestyle. However, it wasn't always easy. I had to first try different things to see what might help and then do them daily, without guilt. That was the sticking point…guilt! I felt guilt for taking time for myself or doing what I perceived as nothing, until I realized just how helpful it was for my health and how much better it made me for others. If you struggle with guilt or anything else that prevents you from self-care activities, I want to share an idea that might be different than how you have approached self-care in the past.

For a lot of us, we only utilize self-care activities and behaviors when we find the time. In other words, we fit it in around everything else. **What I think is maybe a better approach is to pick one self-care activity that you implement every single day and schedule everything around that activity.** It's the opposite of how most of us do it. It could be the same thing every day or a different thing every day of the week. Whatever it is, commit yourself to that ONE self-care activity, which makes it a priority versus something we get to if we find the time.

I know how cliché it is to say this, but we have to take care of ourselves in order to take care of everything else in our lives and everyone else in our

> ***I know how cliché it is to say this, but we have to take care of ourselves in order to take care of everything else in our lives and everyone else in our lives for whom we are responsible.***

be kind to yourself.

lives for whom we are responsible. It's also very cliché to use the following example, but it is a great metaphor for life: when we are on an airplane, we are always told in case of an emergency, to first secure our oxygen mask before helping others. This is what more of us need to be doing in our everyday lives.

Determine that one self-care activity or tool that will help you feel better or that you want to do and implement that one thing into your life to see how it makes you feel. Not just how the self-care activity makes you feel, but how you feel about making self-care more of a priority. From there you can determine what next self-care activity you can implement. The important step for many of us is to first get comfortable practicing self-care, so take it slowly.

ASK THE DOCTOR

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

Q: I have a question about Klarity eye drops mentioned in the Winter 2020 BEBRF newsletter. On page 11 in the Q and A section [from the 2019 BEBRF Symposium in Houston], Dr. Weikert mentions Klarity drops can be purchased through some online pharmacies, and a three month supply is about $50. Could you provide me with some of the online pharmacies that have Klarity for this price?

A: Klarity is the name of the cyclosporine formulation by Imprimis. They can go to their website: imprimisrx.com

Mitchell Weikert, Cullen Eye Institute, Baylor College of Medicine, Houston, TX.

PLEASE REMEMBER BEBRF IN YOUR WILL

SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before October 1, 2020, the next newsletter deadline. If you are interested in attending an online meeting but are not currently in a location with a support group leader, please contact us, and we will try to find you a meeting.

EASTERN DISTRICT

Orlando, Florida
Date: Saturday, July 11, 2020
Time: 1 p.m. – 3 p.m.
Location: Zoom - Please contact Joanna for invitation instructions to meeting.
Contact Person: Joanna Smith
Phone: 407-234-8565
Email: beb.joannashad@gmail.com

New Jersey
Date: Saturday, August 1, 2020
Time: 1 p.m. – 2:30 p.m.
Location: Zoom - Please contact Rebecca or Virginia for invitation instructions to meeting.
Contact Person: Rebecca Teichman/Virginia Hill
Phone: R:201-240-0946 / V:732-566-0947
Email: rebecca.teichman01@gmail.com
veh118@aol.com

CENTRAL DISTRICT

Louisiana
Date: Thursday, August 13, 2020
Time: 6 p.m. – 8 p.m.
Location:
Please contact Percy for invitation instructions to meeting.
Contact Person: Peter McCraney
Phone: 318-289-0869
Email: pmccraney@gmail.com

Northeast Texas
Date: Tuesday, September 29, 2020
Time: 12 p.m. – 2 p.m.
Location: Zoom - Please contact Linda for invitation instructions to meeting.
Contact Person: Linda Trahan
Phone: 214-563-7937
Email: linda.trahan@sbcglobal.net

Dallas/Fort Worth, Texas
Date: Tuesday, October 20, 2020
Time: 12 p.m. – 2 p.m.
Location: Zoom - Please contact Ena for invitation instructions to meeting.
Contact Person: Ena Wilmot
Phone: 817-488-0445
Email: enamwa@hotmail.com

WESTERN DISTRICT

Los Angeles, California
Date: Thursday, September 10, 2020
Time: 1:30 p.m. – 3 p.m.
Location: Zoom - Please contact Cynthia for invitation instructions to meeting.
Contact Person: Cynthia Clark
Phone: 650-678-4132
Email: clark.cyl@gmail.com

NATIONAL SUPPORT

National Support Meeting
Date: Wednesday, July 29, 2020
Time: 1 p.m. – 3 p.m.
Location: Zoom - Please contact Charlene for invitation instructions to meeting.
Contact Person: Charlene Hudgins
Email: charlene@blepharospasm.org

National Support Meeting
Date: Friday, August 14, 2020
Time: 1 p.m. – 3 p.m.
Location: Zoom - Please contact Charlene for invitation instructions to meeting.
Contact Person: Charlene Hudgins
Email: charlene@blepharospasm.org

National Support Meeting
Date: Tuesday, August 25, 2020
Time: 1 p.m. – 3 p.m.
Location: Zoom - Please contact Charlene for invitation instructions to meeting.
Contact Person: Charlene Hudgins
Email: charlene@blepharospasm.org

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

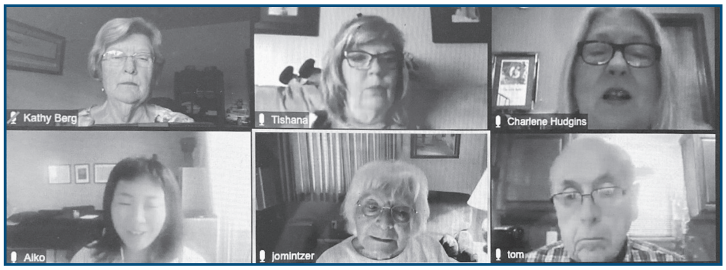
MISSISSIPPI SUPPORT GROUP MEETING

Pictured from L - R: Ena Wilmot, Gary Sirucek, Louis Bontly, Heidi Sirucek, Marlene Bontly, Steve Carraway, Lisa Carraway (new patient), and Dr. Milton Baxter

NORTHWEST U.S. REPRESENTATIVE MEETING

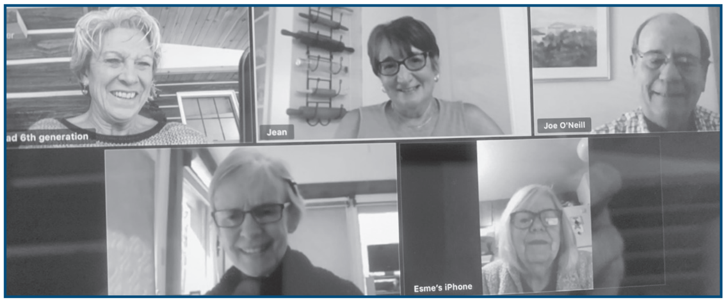
Top, L-R: Peter Bakalor, Maureen McGannon, and Ruth Anderson. Middle, L-R: Linda Barnes, Patricia Monk, and Marguerite Blue; Bottom, L-R: Evelyn Eldridge and Constance O'Brien

SAN JOSE SUPPORT GROUP MEETING



Top L-R: Kathy Berg, Tishana Cundiff, and Charlene Hudgins. Bottom L-R: Aiko Chikaba, Jo Mintzer, and Tom Baca

UPSTATE NEW YORK SUPPORT GROUP MEETING



Top Row L - R: Sandy Mincher, Jean Duffy, and Joe O'Neill. Bottom Row L - R: Marcia Hopple and Esme Potskowski

DALLAS/FORT WORTH - TEXAS SUPPORT GROUP MEETING

Top Row L - R: Ruby Hill, Linda Trahan, and Sharon West Bottom Row L - R: Ena Wilmot, Carol Cox, and Laurie McGee

HOUSTON - TEXAS SUPPORT GROUP MEETING

Top Row L – R: Willia Royster, Carlas Powell, and Ena Wilmot. Bottom Row L – R: Natalie West, Ann Medlin, and Clara Trevino.

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.
P.O. BOX 12468
BEAUMONT, TEXAS 77726-2468
409-832-0788

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Deadline Extensions

In light of the ongoing pandemic, please note the following BEBRF deadline adjustments:

August 31st
BEBRF MID-YEAR APPEAL

September 30th
DEADLINE FOR RESEARCH PROPOSALS

Learn more in this issue's edition of BEBRF Blurbs beginning on page 2