BENIGN ESSENTIAL **BLEPHAROSPASM** RESEARCH FOUNDATION

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

Fall 2021 • Vol 41 • Issue 4

40 YEARS OF EDUCATION AND SUPPORT

From its very beginning, BEBRF has been dedicated to education and support for its patients, their friends and family, and to the medical community as well. Below is a look at some of those endeavors.

EDUCATION

In the beginning, founder Mattie Lou Koster embarked on a 'publicity campaign' aimed at two audiences: patients and doctors. Almost immediately she recruited 'her' doctors, the Houston physicians who were knowledgeable about blepharospasm to help her arrange a seminar to gather together their medical acquaintances to discuss and share their knowledge. She also invited as many patients as she could reach. The first meeting in 1982 is known as the Houston Seminar and preceded the first Conference which took place the following year in Alabama.

Conferences and Symposiums. Thereafter BEBRF Conferences were held annually for both patients and doctors to learn more about blepharospasm and its related disorders. Eventually these Conferences began to focus more on just patient education, and they became the Symposiums that are now held in a different city every year. The most recent Symposium was held in Philadelphia with Dr. Jurij Bilyk as the program director, and it was a success in spite of the ongoing pandemic. The doctors and researchers met separately to discuss blepharospasm research and progress through their Medical Advisory Board meetings.

Newsletter. The first Newsletters were distributed in 1981 in a one-sheet flyer format. Over the years, the Newsletter increased in size and was distributed every two months. When the Newsletter finally expanded to the size it is today, it was decided that it would be distributed quarterly. The Newsletter contains educational information and updates on what is happening with blepharospasm and the BEBRF.

Patient Education Brochures. At its beginning, BEBRF created educational brochures for both patients and doctors. Over the years, these brochures have been professionally designed and printed, and they are all available on demand. Some of these brochures include, among others: How to Talk to Your Doctor, Helpful Hints, Blind but With Perfect Vision, Questions and Answers, and the BEBRF Blue Book that shares information for patients, families, friends, and doctors.

Informational Packets. BEBRF has accumulated information over the years that is helpful for newly diagnosed patients and patients who are seeking disability. The BEBRF organized this information and created The New Patient Packet and The Social Security Disability Packet. Both of these packets have useful articles , brochures, and sample letters to aid the patients. They are both available in hard copies and digitally.

Academies. It is very important to also educate doctors about blepharospasm. Even today, many medical professionals are still unfamiliar with the disorder and its treatments preventing a prompt accurate diagnosis. To that end, the BEBRF began attending medical academies in the early 1980's. For many years BEBRF had booths at both the ophthalmology and neurology academies. In recent years the neuro-ophthalmology and optometrist academies were added. In 2021, BEBRF will also attend for the first time the oculo-plastic surgeon academy. This is so important because early diagnosis leads to earlier treatment.


2014 Pittsburgh Symposium Attendees

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

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

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

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

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

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

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

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

Newsletter suggested donation $20.00 USD

NEWSLETTER DEADLINE DATES

ISSUE	COPY DUE DATE
Winter	January 1, 2022
Spring	April 1, 2022
Summer	July 1, 2022
Fall	October 1, 2022

FROM THE EXECUTIVE DIRECTOR

Charlene Hudgins

The 2021 BEBRF Symposium in Philadelphia has now come and gone, and it was a huge success in spite of the pandemic. I want to thank Dr. Jurij Bilyk from the Wills Eye Hospital and the rest of his medical colleagues for spending the day with us. The feedback from those attending was excellent and they were thankful for getting this opportunity to learn more about blepharospasm, related conditions, and treatments from this esteemed panel! The videos of the presentations are now available on our NEW Website (see the related story on page 5). The next Newsletter will contain write-ups detailing all of the presentations as well. Now on to planning the 2022 Symposium!

In addition, all of the BEBRF Webinars are also available from our new Website, including the Medicare Webinar from September 25th. The next Webinar will be in January, 2022 on Surgical Procedures for Blepharospasm, and it will be presented by Dr. Julie Woodward, Chief of Oculoplastic Surgery at Duke University.

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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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As we come to the end of the year, we are asking you once again to make a donation. Please see the Wrapper on this Newsletter for more details.

We are continuing our online Zoom Support Group Meetings. We are very hopeful that we will be able to resume in-person meetings soon as well. Upcoming meetings are listed in this Newsletter, on our new Website, and on our Facebook page.

On October 30th BEBRF hosted its first in-person meeting of our Medical Advisory Board in Houston, TX. The meeting was held to decide on research grant applications, hear the latest information about ongoing research projects that impact blepharospasm patients, and to formulate a strategic plan for the future of BEBRF. This meeting was sponsored by a Focus Grant from the Allergan Foundation.

In November, Dr. Jane Boyd and I will attend the back-to-back Academies for Oculoplastic Surgeons and Ophthalmologists in New Orleans. Dr. Rona Silkiss will make a presentation at the Ophthalmology Academy on her CBD study funded by BEBRF. We look forward to attending more academies in the future so that we can continue to educate doctors about blepharospasm, its related disorders, and the treatments available to patients.

Earlier this year, BEBRF helped find blepharospasm patients for participation in focus groups for a Patient Centered Outcome research project funded by the Dystonia Coalition (see related story on page 13). The project is now moving into the next phase: a survey derived from the results of the focus group discussions. Please take a moment to take that survey so that the project investigators can have as much data as possible. Information for participation is in that article. There are also links to the survey on our new Website and our Facebook page.

I would just like to take a moment to remind you that BEBRF receives no government funding. Our research, Newsletters, and other operations related to education and support (see related story on page 1) are funded by donations. As we come to the end of the year, we are asking you once again to make a donation. Please see the back of the wrapper on this Newsletter for more details. And remember, a $25 donation given monthly becomes an annual donation of $300! Please consider becoming a recurring donor.

A special thank you to Allergan Pharmaceuticals for sponsoring the 2021 Philadelphia Symposium and to all who helped with the Symposium and to all who donated to the Silent Auction. Those people include:

Nancy Atkinson
AxonOptics
Barbara Benton
Sue Bowles
Susan Engels
Kathy Erickson
Alan Goodman
Carolyn (Moe) Halbert
Anne Holsclaw
Charlene Hudgins
Sandra Mincher
Fran Mannell
Fran Morrell
Joan Nikelsky
Joe and Nancy O'Neill
Larry Phelps
Angel Roberts
Arnold Steinman
TexJoy Coffee Company

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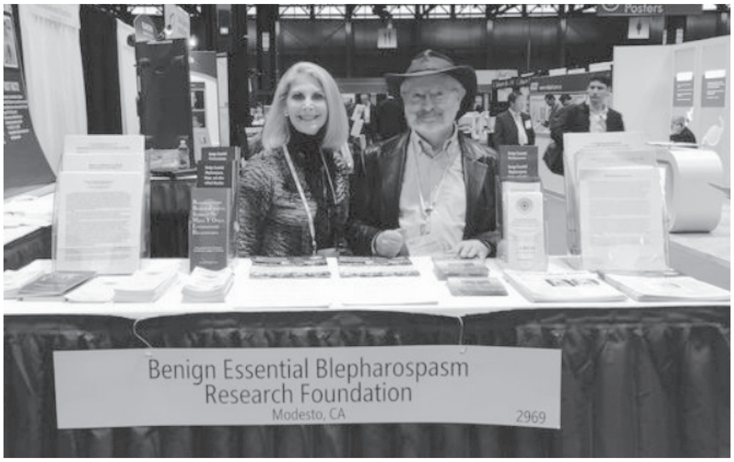
40 YEARS OF EDUCATION AND SUPPORT

Website and Facebook. Since 1996, BEBRF has maintained a comprehensive, content-rich website. This website was created and maintained by Robert Campbell, PhD, a blepharospasm patient. The website was redesigned in 2021 by BEBRF Office Manager Angel Roberts and has recently launched. The new website is still content-rich with numerous articles and videos which patients and doctors will find very useful. The address for the website is **www.blepharospasm.org**. In addition, BEBRF has recently re-purposed its Facebook page to also contain helpful educational material and links.

SUPPORT

Support Group Meetings. Knowing the feeling of isolation blepharospasm patients have, Mattie Lou set about organizing a patient network of District, State, and Local groups. Wherever two or more patients could be found to be living near each other, they were encouraged to get together to share their experience. The first support group meetings were held in 1981, the year the Foundation was created, and they continue today across the country. The meetings are led by Area Representatives (aka Support Group Leaders) in many cities around the nation. If you are looking for a support group near you or would help coordinate one in your area, contact the BEBRF office for information.

During the pandemic, these meeting went online. In addition to local and regional meetings, BEBRF Executive Director Charlene Hudgins began holding National Zoom Support Group Meetings which provided opportunities for including many patients who were newly diagnosed, patients who did not have a local support group, and for patients who experience transportation problems. In addition, these Zoom Support Group Meetings were able to go international with meetings for patients in the UK, Canada, and Australia.



Peter Bakalor and Shelley Goddard work the BEBRF booth at the American Academy of Ophthalmology.

The BEBRF also hosts virtual support group meetings for specific topics, ie. Meige/Cranial Dystonia and Caretaker Support for a Blepharospasm Patient.

Website, Facebook, Newsletter. In addition to the educational roles filled by the Website, Facebook, and the Newsletter, there are numerous support opportunities provided within these as well, including the opportunity to ‘Ask the Doctor’ questions regarding your disorder and its treatment. Patient Stories are printed in the Newsletter and posted on both the Website and Facebook. Many patients have found these individual stories very helpful in facing their own struggle with blepharospasm.

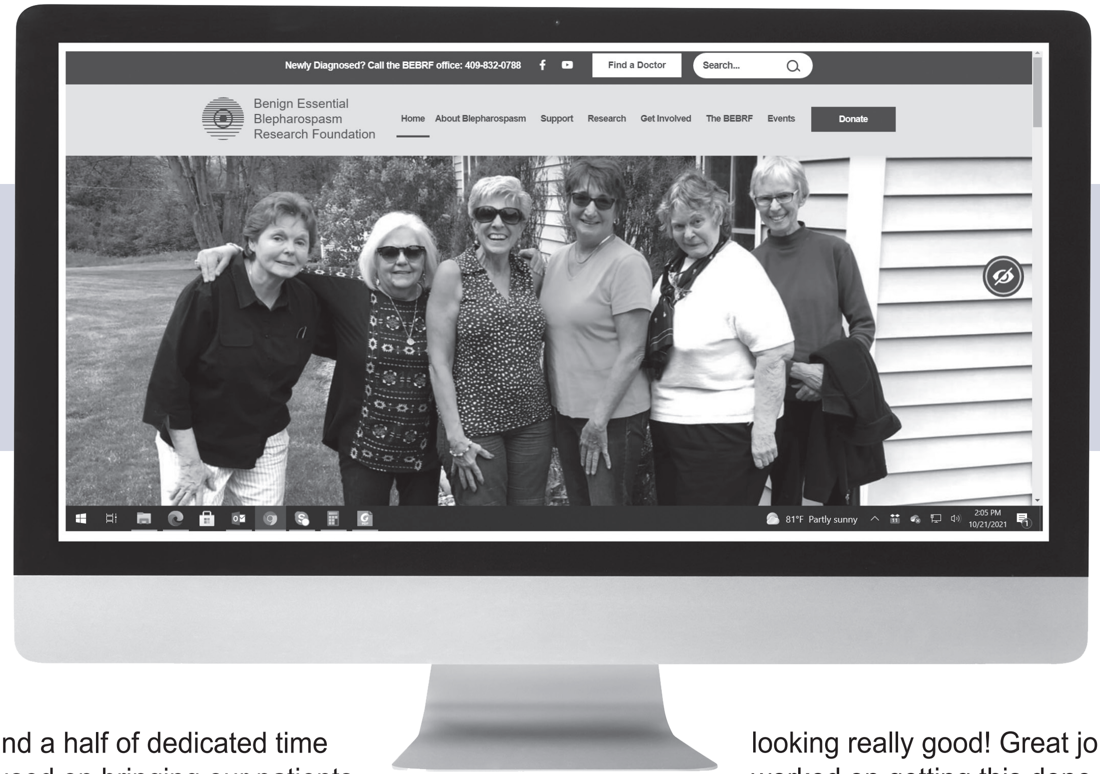
Doctor Database. BEBRF maintains a national database of doctors who treat blepharospasm and its related disorders. Simply call or email the office to get help in finding a doctor. There is also a link to get this help on the new Website. And if you have a doctor recommendation, please let us know so we can add it to our list.

Finally, the Office Staff. The BEBRF office staff is only a phone call or email away if you need help or support. The staff can help you find a doctor, find information, sign you up for the Newsletter, help you find a support group, send you brochures or packets, etc. Probably most importantly, the office staff spends hundreds of hours every year counseling patients. All you have to do is call…

South Florida Support Group Meeting, 2013

INTRODUCING THE BRAND NEW BEBRF WEBSITE!

BY ANGEL ROBERTS, BEBRF WEBMASTER



After a year and a half of dedicated time and energy focused on bringing our patients a brand-new website, BEBRF is pleased to announce the official launch of the newly redesigned **www.blepharospasm.org** website!

BEBRF has always prided itself in having a wealth of information for our patients on the website. So, it was no simple task to filter through all of that information and organize it in a way that would be the most beneficial to each person that might access the site at any given time. We assembled a small team of office staff and board members to develop a warm and inviting site that still held the most relevant and helpful information possible in a way that was going to be easier to use. One way that we were able to do that is by adding a feature on the site called an Accessibility Menu that will make the site easier on your eyes by adjusting the contrast of the screen, or making the text larger for you to read. You can access this feature by clicking on the icon of the eye with a line through it on the center-righthand side of the website screen.

Every inch of the new website was designed with you in mind – even down to the smallest details such as the best fonts and colors specifically for blepharospasm patients. Linda Peterson, our former volunteer BEBRF Board First VP said when she got a sneak peek of the new website: “The look, the arrangement, fonts, etc. are impressive. Thank you to all who participated.” Other encouraging sentiments were echoed by members of our Medical Advisory Board. Dr. Brian Berman said: “The update is looking really good! Great job … team that worked on getting this done.” Dr. Charles Soparkar: “I absolutely agree with Brian. This looks very clean and professional. Congratulations Peter [Bakalor], Bob [Campbell], Angel, and everyone else involved in putting this together!” and Dr. Julie Woodward: “The website looks excellent!”

We know that some of our more tech savvy patients like to use iPads and phones to access the website, so we have even made sure that our new website would be completely mobile-friendly for anyone that would like to use our site this way. Dr. Andrew Harrison of our Medical Advisory Board tested it out for us: “The site is SOOO much better and cleaner. I tried on phone and computer and worked well. Thanks for the great work!!”

All of us at BEBRF are excited for you to experience everything that our new website has to offer. Be sure to check out our Contact Form that can be used to help you find a doctor, request the newsletter, or just reach us in general. Depending on the subject you click on, the form will ask the needed questions to help us better assist you in a timelier fashion.

Happy browsing!

Note: Executive Director Charlene Hudgins would like to thank Peter Bakalor, Robert Campbell, Heidi Coggeshall, Barbara Kimmel, as well as Angel Roberts, for all the hours devoted to this strategic project. We could not have done this without our volunteers!

PATIENT STORY - MARK FREEMAN

Mark Freeman and his wife Marie

"I'm not interested in whether the glass is half empty or half full. I'm interested in figuring out how to fill the glass." For most of us patients suffering from Meige or Bleph, we long for the normal life (or full glass) we used to have. We live in hope for a cure that will bring lasting normalcy to a slightly malfunctioning nervous system. However, our body and brains' ability to adapt may be a key for us to live with the condition now. I was diagnosed with Meige in 2006 at age 51 and this is a summary of my journey.

EXERCISE, MUSCLE CONTROL

I started Botox in 2006, attended the 2007 BEBRF meeting in Florida and was accepted into a research study. After meeting many other patients and doctors, I started exercising again. I ran on track teams in HS and college so running was a natural outlet. But long distance running and dystonia involve repetitive motions that can lead to injury. Runners typically cross train with other sports and stretch to help lessen injuries. By 2010, I regained complete control of my eyelids, dropped weight and noticed the tightness in my shoulders and (back of) neck was gone. Was this change due to increased flow across the blood/brain barrier, did I regain "muscle memory", did I strengthen compensatory muscles while Botox weakened a specific muscle, or what? I would love to discuss these issues with a kinesiologist. However, I still could not ride a bicycle due to balance problems. I have employed exercise and Botox injections regularly since 2006 but do not exercise (hard) for a week after injections. I have sustained normal eyelid control since 2010 and I have driven myself for Botox injections, 360 miles round trip, since 2017. Yes, it is worth the effort.

SENSORY TRICKS, NEURONS AND RELAXING

About 2005, I lost the ability to speak clearly and developed problems with aspiration (liquids entering the airway), chronic fatigue and bruxism. In 2007, I started taking Artane with a resulting negative effect on my cognitive and memory skills, along with dry mouth syndrome. This was not good as my job at the Univ of CA office in Fresno was developing and supervising research/ extension efforts to support the local nut crop and citrus industry. Besides losing my speaking ability, I now could not think clearly, communicate precisely or solve problems effectively. After 30 fun years of enjoyable work it was time to switch gears.

I gave up on Artane and Baclofen and started relying more on my body to control anxiety and promote relaxation. Running taught me a kind of relaxed focus to deal with the boring miles, so using mindfulness was relatively easy, focusing on just breathing and what my body signaled. Diaphragmatic breathing (or belly breathing) relaxed me. Sensory neurons send messages back to the brain like pain which I could use. I experimented and learned some sensory tricks, like where to touch my forehead for temporary control of my eyelids. While shaving, I noticed that some of my upper lip (levator, anguli oris) and neck (platysma) muscles would contract involuntarily. For me, placing my tongue on my molars would stop it.

Singing did not help me directly. However, after running or exercising enough to sweat, singing and talking was much easier. I also had symptoms of "brain fog" and chronic fatigue. Botox shots did not ease these symptoms, but exercising and taking short naps during the day sure helped. I also used rest days in between hard exercises. I needed a clear mind, strong enough to make choices and the motivation to follow through but that was difficult to maintain. I used distraction techniques when I was suffering, taking my mind off stress. Laughing at yourself and at the world helps. Dogs are great running partners and will distract you every chance they get with their antics.

ADDITIONAL SUPPORT NEEDED, ART WITH SCIENCE

Improvement slowed as other symptoms developed. My bruxism became worse and I developed a type of laryngospasm (airway closes) while running. It was a weird feeling as it disappeared when I resumed walking. I was forced to walk after running a short distance, recover, and then run again. Running was no longer a pleasant distraction. My original neurologist

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PATIENT STORY - MARK FREEMAN

did a wonderful job to this point as I was his first Bleph patient. However, I needed and found another MD with more experience treating Meige. Before that happened, I had cracked 2 molars (due to bruxism?) which led to 2 root canals. Masseter and temporalis muscles are the strongest muscles in our body by weight. My injections now target those muscles and we gradually increased the dosages. We also worked together to target specific spots on my platysma where individual strands would contract more, creating a pulling sensation. References to a log book helped as my symptoms changed over the last 15 years. I tried to notice what is just a "twitch" or temporary sensation of pain versus something more serious that gets worse.

My current neurologist is a wonderful listener and scientist. I probably ask him too many questions, but he is open to modifying treatments within reason when I ask for his advice. In 2019, I was able to go 14 months between Botox injections but we subsequently resumed a regular 3 month interval to lessen symptoms. My hope (that I could gradually increase the injection interval) was not a working hypothesis, yet. So, the present strategy is using the "old" 3 month Botox plan and increasing my exercise and other tools to give me more normalcy and control. I have developed techniques to measure my progress or lack of it. The bruxism, aspiration and speech symptoms are decreasing and the running/breathing experience is slowly improving. But after 15 years, it is hard not to think, "resistance is futile."

> *I firmly believe that medicine is both an art and a science, even with stuff other than injections. Our senses and emotions are intimately involved with healing.*

I firmly believe that medicine is both an art and a science, even with stuff other than injections. Our senses and emotions are intimately involved with healing. My wife, an RN, and one son, finishing his DPT degree, are my medical allies along with another son, an engineer, who also helps me cope. I like to think that my Meige is teaching all of us about the "art" of medicine since the scientific cure isn't ready. From my Dad's experience as an MD for over 50 years, he told me that people don't care how much you know until they know how much you care. He also shared data on how much "science" happens in our body without malfunctioning. The more you read, the more you realize how incredible and amazing our bodies are. Let's take advantage of it, both science and art.

ANNOUNCING AN EXCITING NEW RESEARCH TRIAL

The drug company ADDEX together with Dr. Buz Jinnah of Emory University (who serves on our Medical Advisory Board and the Medical and Scientific Advisory Council for DMRF) is launching a trial of a new class of medications known as allosteric modulators. The name of the drug they will use is dipraglurant. It is being studied for possible use with Parkinson's disease and dystonias.

The study will be a small pilot trial of about 15 patients. The patients will take an oral medication and then stay at Emory University for several hours of observation, followed by a second dose. The next day, a third dose will be given. Participation would require 2 days at Emory University in Atlanta.

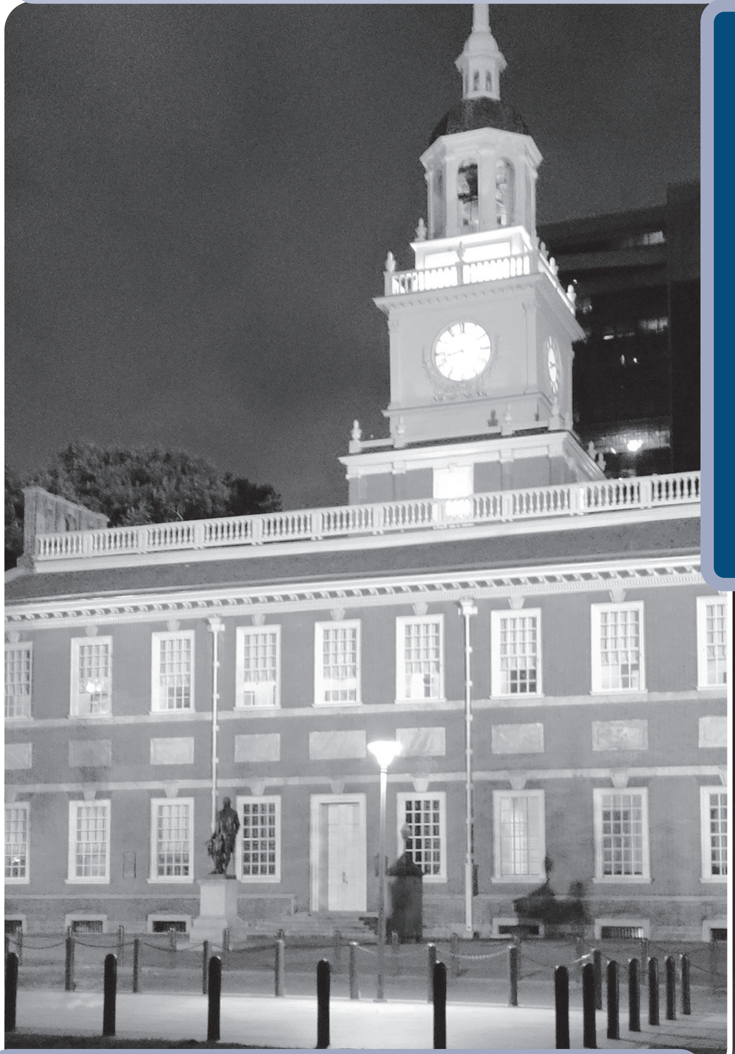
If you are interested in participating in this research, please contact Cameron Injoo for further information: **cameron.injoo.yeo@emory.edu**

2021 SYMPOSIUM COMMENTS

Great reports on so many levels. Always a pleasure and fun to see and talk with each of you on the Board.

Have a great week and thanks again to Charlene and Angel and everyone on the Board for your time and talents moving BEBRF forward.

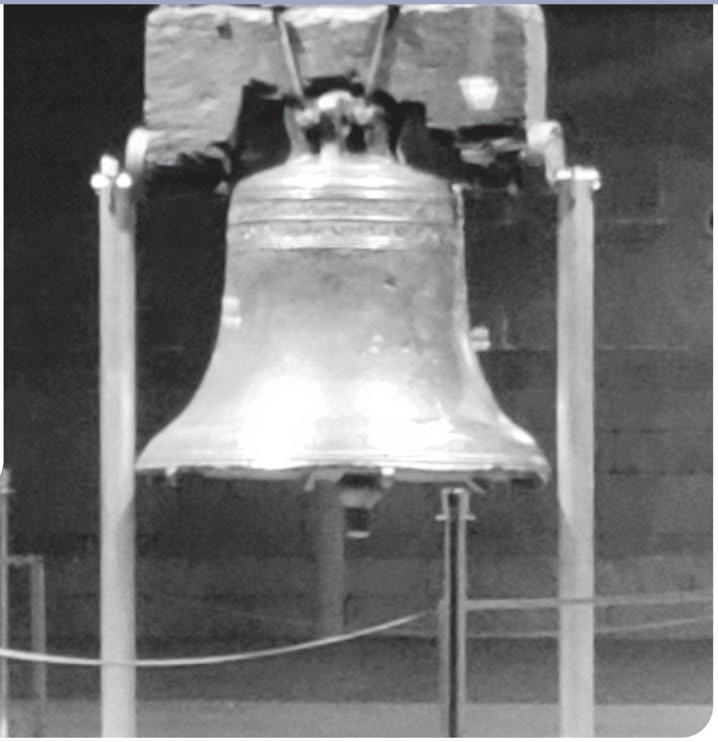
Jon (Healy)



This has been a game changer for me. Thank you for all the hard work
From a Symposium evaluation

It was great meeting you in person as well. Thanks for inviting us to the Symposium . . . It seems like the audience found the information helpful. A lovely group of patients. Also great to see the supportive spouses and friends

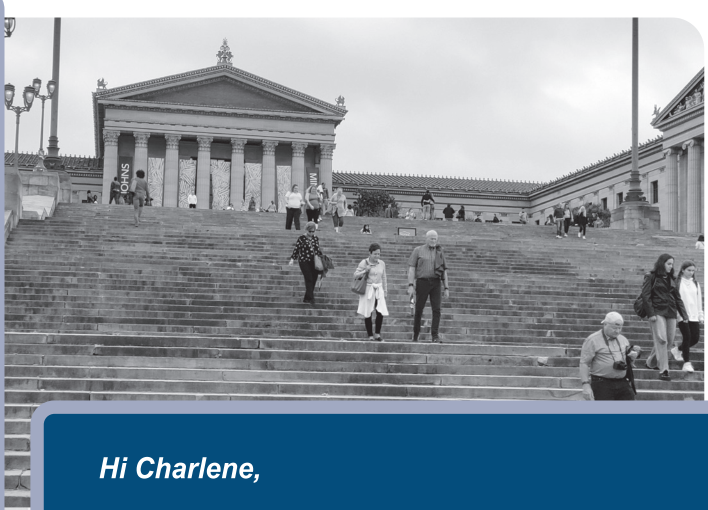
Jurij Bilyk, MD, Program Director



I so appreciate all of the friendly, professional collaboration on this my first symposium.

Cynthia (Clark)

IN PHILADELPHIA



It was fabulous to see each of you...face to face. Thank you, Charlene and Angel, for your organizational efforts towards making this symposium a huge success!

In addition, I want to thank each of you for your contributions to this true team effort. Although I never feel I do enough, I do enjoy working alongside as we strive to change the world in some small way.

Until we meet again, be safe!

Tishana (Cundiff)

Hi Charlene,

I thoroughly enjoyed the symposium. It was very educational. Thank you for all the work you do for us.

Fran Mannell

Great experience! Thank you for making this event a valuable learning/ sharing opportunity

From a Symposium evaluation

Thank you to Dr. Bilyk and the BEBRF for another great Symposium! Having an opportunity to hear from a panel of doctors and patients makes a difference understanding the disorder. I also value the Meet and Greet/meals as opportunities to talk with other patients to learn about their experiences, including their personal coping mechanisms.

Thanks – Heidi (Coggeshall)

You guys are awesome. Thank you for all your work and love the Silent Auction.
Great Symposium

From a Symposium evaluation

RESEARCH TALK FOR BEBRF SYMPOSIUM PHILADELPHIA 2021

PRESENTED BY JANE BOYD, MD, BEBRF VICE PRESIDENT OF PHYSICIAN OUTREACH

HOW DO WE GET RESEARCH DOLLARS FOR BLEPHAROSPASM?

1) Directly through donations to the BEBRF

Since 1985, BEBRF has funded research totaling close to 3 million dollars with over 70 research projects. One of these projects led to the original FDA approval of botulinum toxin for blepharospasm in the 1980's. Dr. Hallett, the head of our BEBRF medical advisory board and a member of the NIH (National Institutes of Health) wrote an article for our Summer, 2021 Newsletter on the highlights of this research. On our website, you can find a list of ALL the projects we have funded over the years with researchers as far away as Germany and Italy.

Our most recent funded project is headed by Dr. Rona Silkiss of San Francisco who is looking at whether CBD (the non-psychoactive component of cannabis also known as marijuana) can offer additional improvement in patients who are already on stable doses of botulinum toxin. This study uses an FDA approved form of CBD called "Epidiolex" which has been used in preventing childhood seizures. Study results are being analyzed at present but we've been told they were promising and importantly, there were no adverse events. A follow-up study with a higher dose of CBD is underway. Full results of these studies will be reported at the annual Academy of Ophthalmology meeting in New Orleans in November.

Educate your friends and family about blepharospasm and consider asking them to donate in your honor for a birthday or other significant event.

2) US government (not available directly to BEBRF)

Dystonia (including blepharospasm) is a small part of the federal budget of the National Institutes of Health (NIH), and in addition, due to the efforts of our advocates who lobby Congress, the Dystonia Advocacy Network, to date, a total of $23 million has also been awarded to investigators through the Department of Defense (DOD).

With this funding, Dr. P. Jeffrey Conn at Vanderbilt University is investigating a new class of anticholinergic drugs. Anticholinergic drugs, such as trihexyphenidyl (Artane®), can be effective at controlling dystonia symptoms but are not a viable treatment for many patients because the side effects, including memory difficulties, sedation, or even hallucinations, can be unbearable. These unwanted effects occur because existing anticholinergic drugs act on many receptors in the brain, not just the receptors associated with dystonia symptoms. If the drugs acted more precisely, and targeted only the receptors associated with dystonia, this would eliminate the side effects.

Also with this funding, Dr. Calakos of Duke University is leading a study to see if ritonavir or other antiviral drugs which have been used to treat HIV can be used in dystonia patients. In a mouse model, using a unique mechanism that is DIFFERENT from the mechanism that slows HIV infection. ritonavir corrected the brain abnormalities in the striatum which are seen in dystonia.

3) Pharmaceutical companies

Drug manufacturers occasionally fund research on new drugs they hope to promote for blepharospasm treatment. One such study in the pipeline will be a joint effort with the drug company ADDEX and Emory University. Dr. Hyder 'Buz' Jinnah who is on our BEBRF Medical Advisory Board has been involved with this project. The drug name is dipraglurant and it's being investigated for the treatment of Parkinson's disease and dystonias. The study was to commence in the latter part of this year. If you are interested in participating, you can contact Cameron Injoo at the following Email address:

cameron.injoo.yeo@emory.edu

HOW CAN YOU HELP PROMOTE RESEARCH ON BLEPHAROSPASM?

Because blepharospasm is a rare condition and one that is not fatal, it can be challenging to get contributions from the general public in contrast to conditions such as cancer which are much more common and can be life-threatening. Therefore, it is up to us as a community to encourage research on our condition. Several ways you can help:

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RESEARCH TALK FOR BEBRF SYMPOSIUM PHILADELPHIA 2021

1) Donate to the BEBRF. Donations can be unspecified which means your money is spent both in supporting our daily operational costs (our two paid employees and the running of our Beaumont, Texas office, the Newsletter, patient support, etc.) AND research, OR, if you desire, your contribution can be specified for research only. Donations can include bequests in your will of money or stock.

Another very important project that your donation will help fund BEBRF activities such as the planned "summit" meeting of the top blepharospasm researchers in Houston in October, 2021. This type of meeting has not occurred for quite a while. The researchers will get together and discuss the current state of our understanding of blepharospasm, what directions for future research to pursue, and how to broaden the community of doctors and scientists who do blepharospasm research.

2) Educate your friends and family about blepharospasm and consider asking them to donate in your honor for a birthday or other significant event.

3) Participate in our yearly advocacy day to lobby Congress for government funding of research through the NIH and DOD. This involves sending emails or making phone calls to your specific representatives. You are provided a scripted letter with a blank section where you fill in a few paragraphs with your own story.

4) Volunteer to participate in studies.

WE CANNOT DO IT WITHOUT YOU!

BEBRF REMEMBERS BARBARA BECKETT

It is with great sadness the BEBRF reports that long-time volunteer Barbara Beckett passed away on August 27, 2021. For many, many years Barbara and her husband Charles represented BEBRF at various national medical academies in order to educate attendees about both blepharospasm and BEBRF, as well as serving as Western District Director.

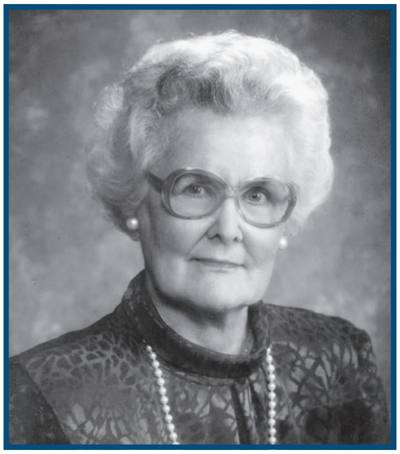
Her daughter reports that Barbara spent her last days reminiscing about how much the BEBRF meant to her, her relationship with our founder Mattie Lou Koster, and her time spent attending academy meetings with Charles.

As Academy Arrangement Chair, she was dedicated to our physician education program. She served as the contact person with the academy representatives (many of whom inquired about her as BEBRF registered for attendance in 2021), always ensuring that they would give the BEBRF a prominent location at the venue. When LaShon Smith of the American Academy of Ophthalmology found out that Barbara had passed away, she sent an email that said, "I am so sad to learn of Barbara's passing. My sincere condolences and prayers of love and comfort to her family, friends, and colleagues." We fondly remember her and Charles taking care of our large, awkward display at each Academy because Barbara knew it would serve to draw physicians to our area so she could share materials about the BEBRF. We are fortunate and thankful that Barbara and Charles were able to educate so many physicians over the years at these academies about a condition that many of them were not very familiar with or knew how to treat.

Attendance at these medical academies is of paramount importance in making blepharospasm more recognizable to medical professionals. Barbara paved the way for BEBRF participation and interactions with neurologists and ophthalmologists. Early diagnosis leads to early treatment. Thank you for all of your hard work, Barbara.

PLEASE REMEMBER BEBRF IN YOUR WILL

WHO WAS MATTIE LOU KOSTER?



As we celebrate our 40th Anniversary, the BEBRF fondly remembers our founder Mattie Lou Koster. She was a blepharospasm patient who would not accept that there was nothing to be done for her rare neurological disorder. Mattie Lou has often been referred to as “a force of nature…” and we share with you thoughts on her life, her vision and the impact she has made on all our lives:

“Mattie Lou will be remembered as a courageous, feisty woman who would not accept having blepharospasm brushed aside and who continued to fight for more research.”

Sally Holt, blepharospasm patient

“She was a strong pioneering lady who was way ahead of her time. Although Mattie Lou might have had difficulty with her eyesight, she nevertheless had the vision, deep insight, and drive to begin and propel the success of a national organization that would impact those with blepharospasm and related problems.”

Marianne Poruchynsky, PhD

“My introduction to Mattie Lou Koster came at the 1983 meeting of the American Academy of Ophthalmology. Mattie Lou, in her incredibly persuasive manner, pulled my arm as well as the arms of many ophthalmologists into her booth which contained about 10 patients afflicted with benign essential blepharospasm and Meige syndrome. She conveyed a strong message that this condition was real and not psychological, caused substantial deterioration in the quality of life, and is often not recognized or appreciated by practicing ophthalmologists and neurologists.

I realized Mattie Lou demonstrated something far beyond the ordinary tremendous enthusiasm in helping others, and leadership and drive to change the world regarding how patients with this condition were recognized and treated. She did the job!”

Gary Borodic, MD
Senior Surgeon, Mass Eye and Ear Infirmary
Assistant Clinical Professor, Harvard

“She was a true American who knew that it only takes one to accomplish great feats – one who dreams that anything is possible; one who has a vision and doesn’t let anything stop her; one who persists so that all of us could reap benefits of her compassion, knowledge and hard work.”

Colleen Dennis

Mattie Lou with Dr. Jankovic

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WHO IS MATTIE LOU KOSTER?

"By example and teaching, she helped forge the mettle in her daughter that would prepare her to withstand the tests of life and carry on the work of the Benign Essential Blepharospasm Research Foundation."

Mary Lou Koster Thompson (Mattie Lou's daughter)

Dr. Joseph Jankovic, a founding member of the BEBRF Medical Advisory Board, who led many 'firsts' for BEBRF had this to say about Mattie Lou: "Because of my close association with Mattie Lou she often referred to me as her second son which made her daughter, Mary Lou, my sister. I was honored to be invited to speak at Mattie Lou's Memorial":

The Memorial

> ***I will always hold onto the memory of this most remarkable woman and be eternally grateful to her for the legacy she left behind, especially her daughter Mary Lou and the army of loyal followers.***
>
> ***Joseph Jankovic, MD • 10/30/01***

YOU CAN PARTICIPATE IN RESEARCH

Earlier this year several BEBRF patients participated in focus groups for a Patient Centered Outcome (PCO) research project developing a phone app that will track the efficacy of botulinum toxin injections from injection cycle to injection cycle. The project has been created by Drs. Sarah Pirio Richardson (University of New Mexico) and Brian Berman (Virginia Commonwealth University), both on the BEBRF Medical Advisory Board. This project is funded by the Dystonia Coalition. They are ready to move on to the next phase of the project, and you can help.

They are currently collecting data from patients with blepharospasm and now want to hear from YOU!

The Goal: To gather data that will be essential for developing future novel treatments for dystonia.

How they are doing it: By learning more about the symptoms and activities that can be troublesome for people with blepharospasm, understanding which aspects of this condition are most relevant to you, and identifying which aspects of this condition you would most want to see a treatment for.

How you can help: By filling out this survey! As they develop tools to gather this information, feedback from patients like you is essential. This survey can be accessed by scanning the QR code below or by typing **https://www.surveymonkey.com/r/LXL7T2** into a search browser on your smartphone or computer. There are also links to this survey on both BEBRF's Website and Facebook page.

NEVER USED A QR CODE? HERE'S HOW!

USING AN IPHONE:

1. Open your phone's camera app
2. Focus the camera on the QR code by tapping the screen
3. Click the link that will pop up on the screen and take the survey.

USING AN ANDROID PHONE:

1. Open your phone's camera app
2. Focus the camera on the QR code by using the Google Lens function which looks like this ⊙
3. Click the link that will pop up on the screen and take the survey.

SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before January 1, 2022, the next newsletter deadline. If you are interested in attending an online meeting but are not currently in a location with a support group leader, please contact us, and we will try to find you a meeting.

CENTRAL DISTRICT

Dallas/Fort Worth, Texas
Date: Tuesday, October 19, 2021
Time: 12pm – 2pm
Location: Zoom
Please contact Ena for invitation instructions to meeting.
Speaker: Dr. Elizabeth Peckham
Contact Person: Ena Wilmot
Phone: 817-488-0445
Email: enamwa@hotmail.com

Rockwall, Texas
Date: Monday, November 15, 2021
Time: 11pm – 1pm
Location: Zoom
Please contact Linda for invitation instructions to meeting.
Contact Person: Linda Trahan
Phone: 214-563-7937
Email: linda.trahan@sbcglobal.net

NATIONAL ZOOM - 9/10/21 SUPPORT GROUP MEETING

NATIONAL SUPPORT

National Support Group Meeting
Date: Monday, November 29, 2021
Time: 1pm – 3pm, Central Time
Location: Zoom (Please contact Charlene for invitation instructions to meeting.)
Contact Person: Charlene Hudgins
Phone: 409-832-0788
Email: charlene@blepharospasm.org

National Support Group Meeting
Date: Thursday, December 16, 2021
Time: 1pm – 3pm, Central Time
Location: Zoom (Please contact Charlene for invitation instructions to meeting.)
Contact Person: Charlene Hudgins
Phone: 409-832-0788
Email: charlene@blepharospasm.org

National Support Group Meeting
Date: Friday, January 21, 2022
Time: 1pm – 3pm, Central Time
Location: Zoom (Please contact Charlene for invitation instructions to meeting.)
Contact Person: Charlene Hudgins
Phone: 409-832-0788
Email: charlene@blepharospasm.org

DALLAS/FORT WORTH SUPPORT GROUP MEETING

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SAN DIEGO SUPPORT GROUP MEETING

CRANIAL DYSTONIA SUPPORT GROUP MEETING

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

ADVOCACY WORKS!

Every year the Dystonia Advocacy Network (DAN), of which BEBRF is a member, advocates to state and federal representatives on behalf of dystonia patients in the United States. One of the important parts of this advocacy is for congressional support of funding for the National Institutes of Health (NIH) and the Department of Defense (DOD) Peer Reviewed Medical Research Program.

The pandemic created interesting challenges for this advocacy, but the DAN is happy to report that they instituted a successful virtual advocacy program. This virtual advocacy allowed people who can't travel to participate, and, in fact, the number of advocates in 2021 doubled!

The DOD funding lists specific medical conditions every year that they will be funding for research, and the list changes from year to year. DAN has successfully lobbied congress to include dystonia every year. In fact, the DOD has funded more than $23 million in dystonia research. Recently, a $2.6 million grant was awarded to Dr. Christian Schlieker of Yale University for dystonia research. Recent grants have been focused on developing new therapeutics for the treatment of dystonia.

The DAN's next efforts will focus on working toward carving out dystonia research funding through the Veteran's Administration – separate from the DOD funding.

The DAN hopes to have people from every congressional district contacting their representative and senators. If you would like to participate in these advocacy efforts please contact the BEBRF office at 409-832-0788 or bebrf@blepharospasm.org.

CORRECTION TO BEBRF HISTORY FROM SPRING NEWSLETTER

From 1988-1990, prior to Mary Lou Thompson becoming President, a woman named O.G. Bruce had that position.

The fact that Mattie Lou had trusted her with that responsibility said a lot about O.G.'s dedication to the BEBRF.

She was especially proud of having had the opportunity to testify in Washington DC for approval of Oculinum, later known as Botox, for medical purposes. BEBRF would like to acknowledge and honor O.G.'s contributions to the Foundation.

Videos from the
2021 BEBRF SYMPOSIUM

The symposium consisted of 10 formal presentations on topics relevant to blepharospasm patients. In addition, there were two question and answer sessions. The videos are on YouTube so if you can watch other videos on YouTube, you should be able to watch these too. After you have finished viewing a video, use your browser's "Back" button to return to the index page.

The videos can be accessed from the BEBRF website: **www.blepharospasm.org**

Overview of facial dystonias: BEB, Cranial (Meige), Apraxia of Eyelid Opening

by April Lao, MD

Comparison of Botulinum Toxins

by Jurij R. Bilyk, MD, FACS

Botulinum toxin injection patterns, complications, and adjunctive therapies

by Alison Watson, MD

2021 BEBRF Symposium
First Question and Answer Session

Surgical Treatment Options

by Ann P. Murchison, MD, PhD

Coping with dry eyes and photophobia

by Aditya Kaneas-Thasan, MD

2021 BEBRF Symposium
Second Question and Answer Session

Update on marijuana and CBD oil

by Brian Berman, MD

Management of lower facial and neck dystonias

by Howard Krein, MD, PhD

Patient Panel on Complementary/Alternative Therapies