



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

**Spring 2021 • Vol 41 • Issue 2**

## **BEBRF MILESTONES - A 40 YEAR HISTORY**

BEBRF began with a group of living room meetings in the spring of 1981 in the Beaumont, TX home of Founder Mattie Lou Koster. Frustrated because there was so much misinformation and very little knowledge or awareness about blepharospasm – even among medical practitioners, Mattie Lou was determined to make things better. After those initial meetings, BEBRF was formally chartered as a Texas non-profit corporation on July 23, 1981, and shortly thereafter the first Support Group Meeting was held in Tulsa, OK.

On January 13, 1982, due to Mattie Lou's persistence, the Wall Street Journal ran a front page article about blepharospasm, Mattie Lou, and BEBRF. Hundreds of patients diagnosed themselves after reading the article and called the Wall Street Journal who forwarded the calls to Mattie Lou. The text of that article is posted on the BEBRF Facebook page. That year, the first one-page BEBRF Newsletter was printed and mailed, and patients from 26 states attended the first BEBRF Seminar hosted by Dr. Robert Wilkins in Houston, TX.

BEBRF attended its first medical academy, the American Academy of Ophthalmology in Chicago, to help spread awareness of blepharospasm to physicians in 1982. Soon afterward, BEBRF attended the American Academy of Neurology for the same reason, and then BEBRF continued attending those academies annually with a booth in the Exhibition Hall. Annual attendance at Neuro-Ophthalmology and Optometry Academies was added in 2018. With funds available, the BEBRF plans to continue attending these Academies annually.

Also in 1982, BEBRF held its first Medical Conference for doctors and patients in Birmingham, AL. In 1984, Dr. Alan Scott directed a nationwide study of 48 doctors who treated 442 blepharospasm patients experimentally with injections of Oculinum, a botulinum toxin. As a result, Oculinum became the preferred treatment for blepharospasm/Meige.

The following year, Dr. Joseph Jankovic published the first double-blind, placebo-controlled trial of botulinum toxin in

blepharospasm. This was the first research grant funded by BEBRF. That same year the book *Advance in Ophthalmic Plastic and Reconstructive Surgery, Vol 4: Blepharospasm* was edited and published by Dr. Stephen Bosniac. This book reviewed everything known about the anatomy, physiology, pharmacology, and therapy of blepharospasm and related disorders. Copies of this book were sent to medical schools. In 1994 this book was reprinted with a new title *Blepharospasm and Related Disorders: A Historical Review of Etiology and Treatment*, and this new soft-cover book was made available to patients and doctors.

In January of 1986, shipments of Oculinum ceased when Dr. Scott was unable to find an insurance company willing to provide affordable liability insurance. Oculinum had not been approved by the FDA, and blepharospasm patients found themselves functionally blind again. Later that year, BEBRF went international when it held its fourth Medical Conference in Barcelona, Spain with Dr. Eduardo Tolosa as the host.

In 1989, the FDA issued the product and facility licenses to market Oculinum as a treatment for blepharospasm and strabismus, with Allergan Pharmaceuticals as its distributor. Oculinum was later renamed Botox®.

Mary Lou Thompson, Mattie Lou's daughter, became Board President in 1992. Dr. Mark Hallett of the National Institutes of Health and BEBRF Medical Advisory Board chair led three Brainstorming Seminars on blepharospasm for doctors from around the world in 1995, 2000, and 2006. In 2001, Dr. Padma Mahant and Dr. Mark Stacy conducted significant research on the "Risk Factors and Familial Occurrence of Blepharospasm Study".

In 2007, the Dystonia Advocacy Network was formed by BEBRF, Dystonia Medical Research Foundation, National Spasmodic Dysphonia Association, and Spasmodic Torticollis/Dystonia to speak with one voice in addressing advocacy issues on behalf of the dystonia community. This advocacy continues to the present day on the local, state, and federal levels.

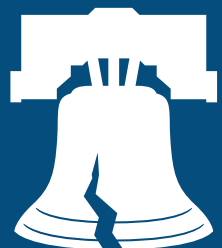
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**CELEBRATING**  
**40**  
**YEARS**  
**1981-2021**

*See you in Philadelphia*

**BEBRF 2021 SYMPOSIUM**

**FRI & SAT • OCTOBER 8 & 9 • 2021**



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
Summer	July 1, 2021
Fall	October 1, 2021

## FROM THE EXECUTIVE DIRECTOR

BEBRF has so much going on! While the staff is still working from home, there are plans to return to the office in July if all goes well with the re-opening from the pandemic.

**Symposium:** We are moving forward with the Symposium in Philadelphia on October 8 & 9. We have put together a diverse and interesting program for you and arranged for hotel rates. See the related stories in this Newsletter. For your safety, BEBRF will observe any CDC guidelines in place at the time of the meeting.



**Webinars:** All four of the Webinars held so far are now available for viewing from the BEBRF website and Facebook page. Feedback from our viewers has been very positive! The next Webinar will be on June 26th at 1:00 central time entitled: "Cranial Dystonia (blepharospasm and oromandibular dystonia) – an alternative to Meige syndrome" and presented by Dr. Joseph Jankovic. There will also be a Webinar in October titled "Everything you ever wanted to know about Medicare but were afraid to ask." More details on that Webinar will be announced soon. On May 22nd there will be a special Webinar for BEBRF Key People (District Directors, State Coordinators, Area Representatives (Support Group Leaders), and Contact People) to address changes in the Support Group system.

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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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**Support Groups:** The Zoom Support Group Meetings have been very successful. They have provided a way for people to connect in this time of isolation and lock-down. In addition, they have also given patients who either live in an area with no support group or who lack a means of transportation to have access to meeting with other patients and sharing and receiving care and information. Therefore, the National Zoom Support Group Meetings will continue even after the in-person meetings resume. Please note that for planning and security reasons, every Zoom Support Group Meeting is set up as a new Zoom meeting making it necessary to call (409-832-0788) or email me (Charlene@blepharospasm.org) to receive each meeting's unique Zoom link.

**Facebook:** We have been actively changing the focus and purpose of the BEBRF Facebook page. We envision our Facebook page as a beacon of useful and accurate information for patients with blepharospasm and its related disorders. Please visit our page and see all the articles, Ask the Doctor questions and answers, event updates, and other interesting information posted there. Most importantly, if you "Like" our page, the articles posted there will show up on your personal newsfeed.

**Focus Groups:** In the Summer 2020 Newsletter the front-page article was on the Patient Centered Outcome (PCO) Research Project about developing a smart phone app for tracking the effectiveness of botulinum toxin injections for blepharospasm patients between injection cycles. The research is being led by Dr. Sarah Pirio Richardson and is funded by the Dystonia Coalition, of which BEBRF is a member. Earlier this year, Dr. Pirio Richardson contacted me to create three focus groups from among BEBRF patients. These patients met with the researchers via Zoom and contributed their input into the development of this app. Dr. Jane Boyd, BEBRF Vice-president of Physician Outreach, and I have been attending various webinars to try to involve more BEBRF patients in projects like this PCO project as well as clinical trials.

**Medical Academies:** One of the ways that BEBRF creates more awareness and shares information with medical professionals is through the attendance of their annual specialty medical academies. Obviously, that was not possible during the pandemic. However, as things begin to open back up, we are planning to resume attending these academies with an information booth in the exhibition halls. Currently, we are hoping to attend the American Academy of Ophthalmology in New Orleans and the American Association of Optometry in Boston; both events are in November, 2021. The ultimate goal in attendance is to help patients get earlier diagnoses and earlier treatment.

**Research:** As stated on the front page of the Mid-Year Fundraising Appeal wrapper on this Newsletter, the first phase of the BEBRF funded CBD study has been completed with promising results. The researchers will now move into the second phase of their project.

**New Website:** We are very excited to unveil our new 21st century website this summer just in time for our actual 40th Anniversary! Stay tuned for more details.

#### **BEBRF BOARD OF DIRECTORS**

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*\*Patients*

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## BEBRF MILESTONES

In 2009, the Dystonia Coalition was formed. This is a collaboration of medical researchers and patient advocacy groups working to advance the pace of clinical and translational research in the dystonias. BEBRF is a charter member of the Dystonia Coalition. BEBRF has participated in, supported, and co-funded Dystonia Coalition projects on Natural History and Bio-specimen Repository for Primary Dystonia and the Global Dystonia Patient Registry (both since 2010). In addition, BEBRF and the Dystonia Coalition co-funded the Project 4 study, “Development and Validation of Clinical Diagnostic Guidelines and A Novel Severity Score of Primary Blepharospasm” (2014). Later, BEBRF elected to fund the four-year Project 4: Blepharospasm Study.

The FDA approved the botulinum toxin Xeomin® from Merz Pharmaceuticals for the treatment of blepharospasm and cervical dystonia in 2010. That same year, BEBRF held its first Symposium for patients in Salt Lake City, UT, hosted by Dr. Bradley Katz and Dr. Kathleen Digre. Until the pandemic, an annual Symposium was held in a different city every year.

Mary Lou Thompson retired in 2016, and the Board of Directors voted to hire a professional non-profit manager. Charlene Hudgins, with more than three decades of non-profit managerial experience, was hired as the first Executive Director in January, 2017. Nilda Rendino followed Mary Lou as Board President until March, 2020, when Nilda was succeeded by Heidi Coggeshall.

Since that first Support Group Meeting in Tulsa in 1981, the support group network has grown to be nationwide. During the pandemic, BEBRF successfully transitioned to Zoom Support Group Meetings which will continue even after in-person meetings resume. Likewise, when the 2020 Symposium in Philadelphia had to be postponed due to the pandemic, BEBRF instituted Zoom Webinars every couple months on a variety of topics to maintain its commitment to providing education to BEBRF patients and physicians. It is anticipated that these Webinars will continue into the future, even when the annual Symposiums resume. Videos for presentations from the Symposiums and Webinars on a vast array of topics are available through the BEBRF website.

As of 2021, BEBRF has funded over 70 research projects amounting to almost three million dollars. Since BEBRF receives no governmental funding, all the funds to pay for these research projects come directly from donations made to the Foundation. These projects have been significant in moving forward the search for the cause, treatments, and cure for blepharospasm. In fact, it was a BEBRF-funded research project that led to FDA approval of botulinum toxin as a treatment for blepharospasm.

Join us as we celebrate BEBRF's 40th Anniversary all year long. We will be launching an all-new website this summer – just in time for our official birthday on July 23rd.

## THE 2021 BEBRF SYMPOSIUM IS ON!

BEBRF is pleased to announce that the 2021 Symposium is scheduled to go forward as planned on October 8 & 9, 2021. Join us in Philadelphia on Friday, October 8th for a Meet and Greet event with appetizers and beverages in the evening, and then join us the next day for our all-day Symposium where a complimentary breakfast and lunch will be provided. There will also be a Silent Auction featuring, among other things, original art! (*see back page*) Come and meet with other patients and share your stories, and learn the latest developments regarding blepharospasm and its related disorders from the experts. The event will be held at the Doubletree by Hilton Philadelphia Airport hotel, located conveniently near the Philadelphia airport which also serves as a train station for travel from the surrounding states (*the hotel has a complimentary airport shuttle*). The program and biographies of the speakers for the Symposium are also in this Newsletter.

As usual, BEBRF has negotiated reduced room rates for the hotel. To make hotel reservations call 215-365-4150 or 800-445-8667, choose “Reservations” from the menu, then ask for the special room rate under the Group Name: Benign Essential. The cut-off date for the special room rate is September 26th. If you prefer to make reservations through an online link, BEBRF will have a hotel room reservation link on its website and Facebook page. Be sure also to register for both the Meet and Greet AND Symposium by calling the BEBRF office at 409-832-0788; there will also be a link on the website and on Facebook to register for both events. To be clear, registering for the Symposium does not reserve a hotel room; there will be two separate links: one for hotel reservations and one for registering for the Meet and Greet and Symposium. The importance of Meet and Greet and Symposium registration is so that BEBRF will know how much food to order.

There is so much to do, see, and explore in Philadelphia! Space in this Newsletter does not allow for listing them here, but BEBRF will be posting various Philadelphia attractions and activities on its Facebook page between now and the Symposium. “Like” the BEBRF Facebook page to have new postings show up in your personal Facebook newsfeed, and you can also visit the BEBRF Facebook page.

# BEBRF BOARD CHANGES



**Dee Linde** resigned this spring from the **BEBRF Board of Directors** and her role as **Western District Director**. I want to thank Dee for her years of service to the BEBRF and the dystonia patient community in general. Her service included attending Advocacy Days for 18 years and joining the Dystonia Advocacy Network (DAN) as the BEBRF representative. She also served as our Western District Director, a role which included recruiting other support group leaders in the West. In 2016, she joined the BEBRF Board. Dee will continue to help our patient community by serving on the DAN with her role through the DMRF in advocacy for dystonia.

Dee is a native of Philadelphia, serving as an Aerographer's Mate in the Navy before working as a licensed Psychotherapist for over 15 years. In 2000, she underwent Deep Brain Stimulation (DBS), which alleviated most of her dystonic symptoms including, after a while, blepharospasm. We thank Dee for sharing her personal experience with DBS, allowing others to make a more informed decision if DBS would be a health option for them. She was a panelist on our recent BEBRF DBS Webinar held April 10, 2021. The Webinar is available on our website if you missed this interesting discussion.

I asked Dee about some of the changes in DBS since she has had the surgery. She said her surgery was done in two stages: the first side took 14 hours and the second side took 9 hours. Today the whole surgery can be done in about 4 hours. She used to use a transistor radio to see if her stimulator was turned on or off and had to use a powerful magnet to turn it on and off. She now has a hand held patient programmer that allows her to turn on or off, check the battery level and adjust settings to predetermined (by programmer) parameters. Batteries can now be wirelessly re-charged. Amazing developments!

I also want to welcome **Cynthia Clark** as our **Western District Director** and to our **Board of Directors**! Cynthia lives in Los Angeles and is a patient herself. We have been working with Cynthia as Los Angeles Area Representative.

For over fourteen years, Cynthia was Principal for three high schools in California. She was then the School Improvement Director, Educational Services Division for the Sacramento City Unified School District followed by Instructional Services Division - District Director of Curriculum and Assessment for the San Mateo Union High School District. Currently Cynthia is a Certified Educational Leadership Coach for the Association of California School Administrators.



We thank both of them for their volunteer service to the **BEBRF**.  
**Heidi Coggeshall – President**

**PLEASE REMEMBER BEBRF IN YOUR WILL**

# SYMPOSIUM BIOS



**Jurij R. Bilyk, MD, FACS, Program Director**, is an attending surgeon on the Oculoplastic and Orbital Surgery Service at Wills Eye Hospital and a professor of ophthalmology at Thomas Jefferson University. His bachelor's degree in chemistry with honors is from the University of Pennsylvania, and he obtained his medical degree from Jefferson Medical College. Dr. Bilyk completed an internship in internal medicine at Jefferson University Hospital and his residency in ophthalmology at Wills Eye Hospital. His oculoplastic and orbital surgery fellowship training was completed at the Massachusetts Eye and Ear Infirmary (MEEI) of Harvard Medical School.



**Brian D. Berman, M.D.**, is a professor of neurology at Virginia Commonwealth University (VCU) and is director of the VCU Parkinson's and Movement Disorders Center. Dr. Berman completed his neurology residency training at the University of California at San Francisco and his fellowship training in movement disorders at the National Institutes of Health under the tutelage of Dr. Mark Hallett. After fellowship, he joined the neurology faculty at the University of Colorado Denver for a decade before recently moving to VCU. Dr. Berman has served on the medical advisory board for the BEBRF since 2014 and was program director for BEBRF'S 35TH Anniversary Symposium in 2016. His research pursuits include using advanced imaging techniques to study the pathophysiology of dystonia and Parkinson's disease, as well as investigating disruptions to deep sleep in Parkinson's disease and whether these disruptions lead to accelerated cognitive decline and neurodegeneration.



**Howard Krein, MD, PhD**, has two doctorate degrees and is double board certified in Facial Plastics and Reconstructive Surgery and Otolaryngology Head and Neck Surgery. He received his MD from Thomas Jefferson Medical College in Philadelphia and his PhD in Cell and Developmental Biology from UMDNJ/Robert Wood Johnson Medical School. After medical school, he completed internships in both Emergency Medicine and General Surgery as well as a residency in Otolaryngology: Head and Neck Surgery at Thomas Jefferson University Hospital in Philadelphia. Dr. Krein had a Fellowship in Facial Plastic and Reconstructive Surgery, sponsored by the American Academy of Facial Plastic and Reconstructive Surgery, at the Medical College of Virginia/Virginia Commonwealth University in Richmond Virginia. Dr. Krein is a Board Certified, Facial Plastic and Reconstructive Surgeon at Thomas Jefferson University Hospital in Philadelphia Pa.



**Beeran B. Meghpara, MD**, is a fellowship-trained ophthalmologist who specializes in cornea, cataract, and laser refractive surgery. After earning his Bachelor's degree at the University of Illinois at Chicago, Dr. Meghpara went on to graduate from the University Of Illinois College Of Medicine. He then completed his ophthalmology residency at the Cullen Eye Institute, Baylor College of Medicine in Houston, Texas. After residency, Dr. Meghpara completed a fellowship in cornea, refractive surgery, and external disease at the University of Colorado.



**Mark L. Moster, MD**, is an Attending Physician on the Neuro-Ophthalmology Service at Wills Eye Hospital and Professor of Neurology and Ophthalmology at Thomas Jefferson University in Philadelphia. He holds appointments at Drexel University, Temple University, and Einstein Medical Center in Philadelphia, where he is Chair of Neuro-Ophthalmology. He is also the Director of the Electrophysiology Lab at Wills Eye Hospital. Dr. Moster trained in Neurology at the University of Pittsburgh School of Medicine and completed a Neuro-Ophthalmology Fellowship at Wills Eye.





**Ann P. Murchison, MD, MPH** is Director of the Emergency Department at Wills Eye Hospital, associate professor of ophthalmology at Thomas Jefferson University and senior fellow at Jefferson School of Population Health. Her ophthalmology residency was at the University of Washington in Seattle and fellowship training at Emory University in Atlanta. She then went on to complete a master's in public health at Emory University's Rollins School of Public Health. Upon completing her fellowship she joined the Emory faculty as Assistant Professor in 2006. In 2008 she joined Wills Eye Hospital where her focus is on functional and traumatic disorders of the orbit and adnexa in both children and adults.



**Alison Watson, MD**, completed her internship at Lankenau Medical Center in Wynnewood, PA and her Ophthalmology Residency at Wills Eye Hospital of Thomas Jefferson University. Dr. Watson went on to complete her combined American Society of Ophthalmic Plastic and Reconstructive Surgery (ASOPRS) and American Academy of Cosmetic Surgery (AACS) accredited oculofacial plastic and orbital surgery fellowship at TOC Eye and Face in Austin, Texas. Board certified in Ophthalmology, Dr. Watson provides specialty focused care in all areas of oculoplastic and orbital surgery including both functional and cosmetic eyelid surgery, eyelid and facial reconstruction, nasolacrimal surgery, orbital fracture repair and Thyroid Eye Disease.

## BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION SYMPOSIUM

**SATURDAY, OCTOBER 9, 2021 - PHILADELPHIA, PENNSYLVANIA**

PROGRAM DIRECTOR: JURIJ BILYK, MD, FACS

<b>7:00 a.m.</b>	<b>REGISTRATION AND COMPLIMENTARY CONTINENTAL BREAKFAST</b>	
<b>8:30 a.m.</b>	<b>WELCOME REMARKS</b>	<b>President &amp; Program Director</b>
<b>8:45 a.m.</b>	<b>Overview of facial dystonias: (BEB, Cranial (Meige), Apraxia of Eyelid Opening)</b>	<b>Mark Moster, MD</b>
<b>9:15 a.m.</b>	<b>Comparison of Botulinum Toxins</b>	<b>Jurij Bilyk, MD</b>
<b>9:45 a.m.</b>	<b>Botulinum toxin injection patterns, complications and adjunctive therapies</b>	<b>Alison Watson, MD</b>
<b>10:15 a.m.</b>	<b>BREAK</b>	
<b>10:30 a.m.</b>	<b>Presenters Q&amp;A Panel Session</b>	
<b>11:00 a.m.</b>	<b>Surgical Treatment Options</b>	<b>Ann P. Murchison, MD, MPH</b>
<b>11:30 a.m.</b>	<b>Coping with dry eyes and photophobia</b>	<b>Beeran Meghpara, MD</b>
<b>Noon - 1p.m.</b>	<b>COMPLIMENTARY LUNCH</b>	
<b>1:00 p.m.</b>	<b>Update on marijuana and CBD oil</b>	<b>Brian Berman, MD</b>
<b>1:30 p.m.</b>	<b>Management of lower facial and neck dystonias</b>	<b>Howard Krein, MD, PhD</b>
<b>2:00 p.m.</b>	<b>Presenters Q&amp;A Session</b>	
<b>2:30 p.m.</b>	<b>Patient Panel on Alternative Treatments</b>	
<b>3:00 p.m.</b>	<b>BREAK</b>	
<b>3:15 p.m.</b>	<b>Breakout sessions for Patient meetings</b>	
<b>4:30 p.m.</b>	<b>Symposium ends</b>	

## PATIENT STORY - CAROLYN CLEVERLEY



I was born in Idaho but raised in south-central Alaska. When I left Alaska to go to college, I met a wonderful guy who has been my husband for almost 40 years. We have 3 living sons and just added grandchildren numbers 13 and 14 a few months ago. We have made our home in Idaho and our sons and their families live within 20 minutes of us. I love being a “full service” grandma! Since I had to retire early, I’ve started on my retirement bucket list. I’ve painted nearly all the walls in my house and started learning how to art paint. I’m very slow but am progressing nicely.

In June of 2015, I started having intense itching, burning and extreme light sensitivity with my eyes. We thought it was seasonal allergies but it continued to get worse. On June 26, 2015, it was so bad I had to hold one of my eyes open with my fingers to drive home from work. That was the last time I drove a vehicle.

My husband took me to the ER. I stumped the ER physician until she spoke with the hospital pharmacist. I had started taking gabapentin a couple of months before for neuropathy and had recently reached full dosage. The pharmacist said forms of dystonia, including blepharospasm, are known side effects of gabapentin but symptoms usually stop after gabapentin is stopped. I was given a schedule to decrease dosage to stop over the next few days but was told it may take 10 to 14 days for symptoms to stop. Two weeks later I was off gabapentin but my symptoms continued so I went to see my primary care physician who referred me to a respected neurologist who referred me to the

neurologist who diagnosed blepharospasm, general dystonia and essential tremor, and I eventually began Botox® injections. When injections were not successful, I was referred to the University of Utah Medical Center Movement Disorder Neurologists and continued Botox injections and medication trials which were also ineffective. After several sets of injections from 2 different neurologists at U of U (one of whom was the department head) and several medication trials, my condition was worse not better. On 11/02/2016 during a very tearful appointment with Dr Schrock at the University of Utah Medical Center, we decided to stop Botox injections and discussed surgical options which were not good. Dr. Schrock said she was out of options that would make it possible for me to continue my employment of 25 years and she wrote a disability letter for me. In over 25 years of treating blepharospasm, I was Dr. Schrock’s only failure.

For 25 years, I had been a Self Reliance Specialist with the Idaho Department of Health and Welfare. For my job, I determined eligibility for all forms of Welfare benefits for the disabled and elderly including assisting people in applying for Social Security and contacting the Social Security Administration regarding eligibility issues. This required building good relationships with Social Security workers to learn how to best navigate their system and process. This was helpful in working with my clientele but became even more helpful when I had to take medical retirement and apply for Social Security Disability myself.

I continued to try and work for a year and a half after the start of my symptoms. My employer was wonderful, and we tried everything to keep me working but we finally all had to admit I could not successfully do my job and had not been able to do my job correctly since the start of my symptoms. It was difficult. When I applied for Social Security my application had to be processed out of an office back east because of conflict of interest (I knew too many of the line workers in the local office). It took 15 months and 1 day from application date to the date I received my first deposit from the Social Security Administration. No appeal, no attorney. I knew and understood SSA’s process well as I had helped many clients apply for Social Security and knew what they would need to approve my application.

*Editor’s Note: Carolyn shared detailed information on how to apply for Social Security Disability in the last two issues of the BEBRF Newsletter, and she was a speaker at the January, 2021 BEBRF Webinar on Obtaining Social Security Disability for Blepharospasm; the video is now available on the BEBRF website.*



# REPORT ON THE BEBRF'S 2020 FUNDRAISING, AND ITS FINANCIAL HEALTH

BY PETER BAKALOR, VP DEVELOPMENT

For many non-profit organizations, 2020 was not a good year for donations. That is easily understandable in a year of so much uncertainty, but it does mean we need to look at how the Foundation is fairing financially. As we reported in the Newsletter four years ago, our regular donation stream does not cover our basic running cost. Fortunately, over time we have accumulated a reserve, largely from bequests made by our fellow blepharospasm sufferers.

If you value the work that the BEBRF does, then please consider adjusting your will to leave a bequest to the Foundation.

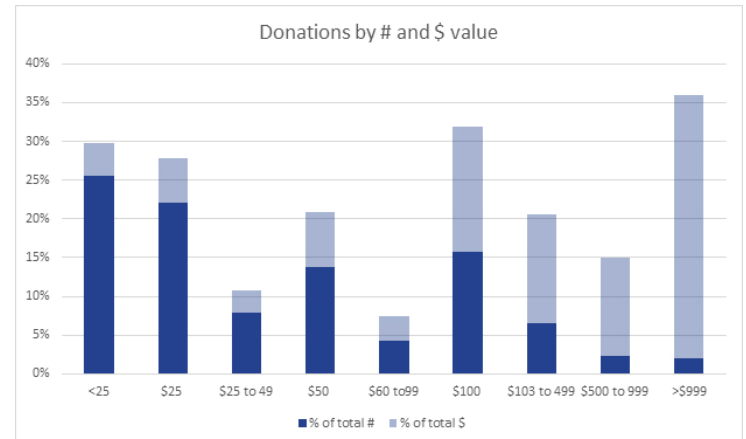
As bequests are an unpredictable source of income, we make no assumption about receiving a bequest in a particular year, meaning we budget for a deficit, and must trust that over time bequest income will average out enough to cover our needs. Each year we calculate approximately how long we can exist until the combination of our current donation income level and our reserves run out. The answer depends on how much we spend on Research, as that is always the biggest single item we consider. Some years we spend over \$100,000 on Research, and in other, nothing. It all depends on the quality and relevance of the proposals we get each year and each proposal is reviewed by our Medical Advisory Board. That said, our "lifetime before we run out" estimate is still ten years – as it was about four years ago, so we're 'holding our heads above water'.

Grants from external organizations are our other source of income, and we are very grateful to Allergan, Merz, and other companies for support of events such as Symposiums, educational booths at medical Academies, and so on. The caveat here is that so far in recent years, if we do not receive a grant for this type of work, we don't do it, so our financial exposure is minimized in these cases.

Readers of this Newsletter know that we appeal for donations twice a year, through formal midyear and end of year appeals (and we try to remind potential donors as often as we can on other announcements and on Facebook and our web page). We have tried using direct mail appeals, and we have tried just running our two appeals as cover pages on the Newsletter. So far, we have not found a provable difference between the results of one approach over the other, and as a direct mail appeal is quite expensive to run, we don't do that every time.

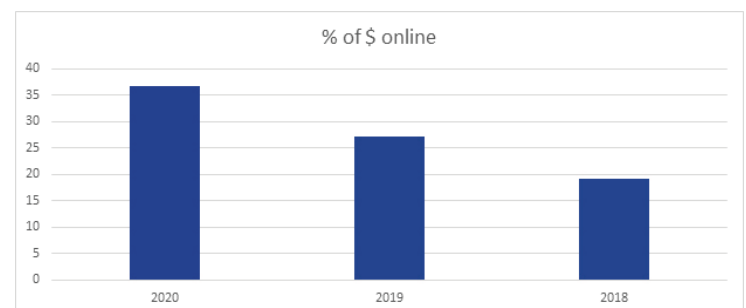
Who donates to the BEBRF? Well, mostly it is you (or us, rather, blepharospasm patients). Unfortunately, it is not a cause as appealing to the public as other serious or widespread medical conditions that people might more easily imagine they could get.

That lack of popular appeal means it is up to us and our families to donate to keep the work of the Foundation ongoing. Every donation, no matter how small, is welcome. Since blepharospasm is generally a late onset ailment; the majority of us are older. We recognize that for many that means a restricted income, so we understand if some of us cannot afford to donate. As you can see from the chart below, most of our donations are small, and deeply valuable to us. You can also see that \$25, \$50 and \$100 donations are popular amounts



among those that can afford that. Of course, like almost every non-profit, we are reliant on a small number who donate significantly higher amounts.

Another aspect of donations that is interesting is the trend towards donating online. This has grown significantly over the last few years.



Finally, on behalf of the BEBRF Board of Directors I can tell you that we are deeply grateful for the support your donations provide. Our Board members, aside from one and our Executive Director, are all blepharospasm (and often cranial dystonia) patients. The Foundation thanks you again for your generosity. Please keep it up.

If you are interested in full details of the BEBRF's financials, you can look at the IRS Form 990 that all non-profits are required to submit yearly. You can find those online at organizations like Guidestar, or by asking the office for a copy.



## ASK THE DOCTOR

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

**Q: You mentioned in the September BEBRF Webinar that the zinc supplement Zytase should improve the efficacy of botulinum toxin injections. My question is, should that efficacy be evident from the first injections following the beginning of taking Zytase, or does the efficacy improve with continued use over a longer period of injection cycles?**

**A:** I am frequently asked about zinc supplementation and botulinum toxins, and about Zytase in particular. Before going on, I need to state that I hold the patent on Zytase, but I licensed it to OcuSoft and make no income from product sales.

Here's what you need to know. All botulinum toxins (Botox®, Dysport®, Xeomin®, Jeuveau®, and Myobloc®) are proteins that REQUIRE zinc to function. If there is no zinc, then there can be no effect. If there is a little zinc, then there may be a little effect. If the zinc levels change, then the effect of the botulinum treatments may change.

During the early days of botulinum toxin manufacture and purification, it was discovered that adding zinc directly to the toxin before concentrating the protein for storage and sale rendered the toxin far less active. Thus, all of the botulinum toxins are currently manufactured and sold with zinc stripped out.

So where does the zinc come from to make the toxins work? People get zinc from their diets. If a person is zinc deficient, then the botulinum toxin may work less well or not at all. How do we know if someone is zinc deficient? The two most common ways to measure zinc levels are to measure the zinc in a person's blood or urine. The problem is that neither of these are reliable indicators of the zinc level in a particular tissue, such as the face, and zinc is not well stored in tissues so tissue levels may change considerably within just a couple of days.

The National Institutes of Health has determined that roughly half of Americans over the age of 55 are zinc deficient based upon diet unless they are also taking a vitamin supplement. But there are several problems with vitamin supplements containing zinc. First, not all forms of zinc are equally well absorbed. Second, a multivitamin that contains 100% of the DRI (Dietary Reference

Intake, which is the "new" RDA or Recommended Dietary Allowance system introduced in 1997) may not actually provide 100% of a vitamin. For example, all of the essential divalent cations (calcium, magnesium, iron, zinc, copper, and manganese) compete with one another for absorption from the gut. Thus, taking in "100% of the DRI" by mouth does not necessarily mean 100% gets into the body.

Is it a good idea to take a zinc supplement alone? Sure. Zinc citrate is well absorbed and does not have a bad aftertaste. The problem is that most people find that taking any of the divalent cations such as iron or zinc on an empty stomach causes nausea. Why not take the zinc supplement with food, or even better, eat more foods that contain zinc? There are, of course, foods that are rich in zinc, but many foods also contain molecules or preservatives that bind zinc and keep it from being absorbed. Chief among these zinc-blockers are the phytates found in seeds, nuts, beans, grains, and legumes; casein in dairy products; and other molecules in the majority of common beverages. For a good listing of the foods that are high in zinc and low in phytates, visit our website [www.plasticeyesurgery.com](http://www.plasticeyesurgery.com) where a video discussing this matter contains an excellent table.

Clearly the zinc issue is very complicated, but there are a couple of shortcuts we can take. First, if your botulinum treatments are working and providing a reliable effect each time, then you are taking in enough zinc, and there is nothing for you to worry about. I've had some patients who supplemented their zinc hoping to get their treatments to last longer, and we achieved more effect than we wanted from their injections and had to create a whole new treatment pattern. Thus, my advice is if what you are doing is working, don't rock the boat.

However, if you are unhappy with your current treatments and are wondering whether your tissues have enough zinc, then consider zinc supplementation shortly before your treatments. An easy way to do this is to take 50 mg/day of zinc citrate for five days right before your botulinum treatment. If you can't handle the zinc on an empty stomach, try taking it with fresh turkey – not turkey

with bread and not pre-sliced, packaged, and preserved turkey, but fresh turkey alone.

Zytaze contains 50 mg/day of zinc citrate combined with phytase, an enzyme that breaks down phytates. Thus, you can take Zytaze with many foods, but you should still avoid consuming dairy products, preserved foods, soft drinks, and alcoholic beverages within two hours of taking Zytaze. Zytaze is available on-line without a prescription for about \$40 or less.

I'm often asked how many zinc-supplemented botulinum toxin treatments are typically required before a benefit is seen? If a person has been zinc deficient with modest botulinum effect, then the first time zinc is adequately supplemented, the toxin

should be immediately more effective.

Does it help to take zinc after a botulinum treatment? The answer is that I don't really know. Biologically, I can't understand why it would, but I do have several patients who swear that supplementation both a couple of days before and a couple of days after treatment gives them better effect.

There are only three things that affect the botulinum treatment efficacy: the injector's technique, the toxin, and the person being injected. If there is variability in treatments, then one or more of these three must be responsible.

*Charles Soparkar, MD, PhD, Plastic Eye Surgery Associates, Houston, TX*

## ADVOCACY DAY 2021

Each year, volunteers from BEBRF join the Dystonia Advocacy Network (DAN) in Washington DC to educate Members of Congress about dystonia and how it changes lives. Dystonia advocates develop relationships with their legislative leaders to help them understand the challenges of those living with dystonia. The DAN is led by the following dystonia organizations:

- Benign Essential Blepharospasm Research Foundation (BEBRF)
- Dystonia Medical Research Foundation (DMRF)
- National Spasmodic Dysphonia Association (NSDA)
- National Spasmodic Torticollis Association (NSTA)

This year Advocacy Day was held virtually on March 3, 2021, and many advocacy activities will continue throughout the year. Over 234 – and climbing - advocates (versus 120 in 2020 and 85 in 2019) contacted their Senators and Representatives by phone and/or email to advocate for: increased funding at the National Institutes of Health, continued inclusion of dystonia as a condition eligible for study, supporting efforts to limit patient out-of-pocket costs and curb current and future payer tactics to shift costs onto patients.

### More specifically, we asked the congressional members to:

1. Support a funding level of \$46.1 billion for NIH in the FY 2022 Labor-HHS-Education Appropriations bill. This level of funding will support the progress NIH has made on medical research.
2. Continue to support the inclusion of dystonia as a condition eligible for study through the Department of Defense Peer Review Medical Research Program for Fiscal Year 2022. Traumatic injury can lead to the onset of dystonia. As our armed forces remain deployed, dystonia is becoming increasingly prevalent amongst combat veterans. However, little is known about the mechanisms of this condition and its correlation to traumatic injuries. The Department of Defense (DOD) supports research on conditions which affect military personnel through the Peer-Reviewed Medical Research Program. Unlike the National Institutes of Health and other federal medical research initiatives, the DOD peer-reviewed program only funds research into conditions that are deemed eligible for study by Congress. The eligible conditions list is renewed by Congress every year in the Defense Appropriations bill.
3. Support efforts to limit patient out-of-pocket costs and curb current and future payer tactics to shift costs onto patients such as step therapy, non-medical switching and co-pay accumulator adjustment programs.

If you are interested in helping us advocate, please contact our office. Senators and Representatives rotate on and off key congressional committees each year. We need BEBRF constituents from all states so we have the flexibility to target our advocacy effectively.





## SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before April 1, 2021, the next newsletter deadline. If you are interested in attending an online meeting but are not currently in a location with a support group leader, please contact us, and we will try to find you a meeting.

### EASTERN DISTRICT

#### **Philadelphia, Pennsylvania**

**Date:** Tuesday, April 27, 2021

**Time:** 6pm

**Location:** Zoom

Please contact Joan Nikelsky or Anne Holsclaw for invitation instructions to meeting.

**Contact Person:** Joan Nikelsky or Anne Holsclaw

**Phone:** 610-352-5685 / 610-715-3249

**Email:** jnikelsky@msn.com or  
annietop6@gmail.com

### CENTRAL DISTRICT

#### **All Texas Meeting**

**Date:** Saturday, May 22, 2021

**Time:** 1pm – 2pm

**Location:** Zoom

**Speaker:** Dr. Joseph Jankovic

Please contact Ena for invitation instructions to meeting.

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** enamwa@hotmail.com

#### **Dallas/Fort Worth, Texas**

**Date:** Tuesday, June 22, 2021

**Time:** 12pm – 2pm

**Location:** Zoom (Please contact Ena for invitation instructions to meeting.)

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** enamwa@hotmail.com

#### **Tarrant and Parker Counties, Texas**

**Date:** Wednesday, June 30, 2021

**Time:** 1:30pm – 3:30pm

**Location:** Zoom (Please contact Sharon for invitation instructions to meeting.)

**Contact Person:** Sharon West

**Phone:** 817-297-4389

**Email:** swest124@swbell.net

#### **Rockwall, Texas**

**Date:** Monday, August 9, 2021

**Time:** 11am – 1pm

**Location:** Zoom

Please contact Ena for invitation instructions to meeting.

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** enamwa@hotmail.com

#### **Dallas/Fort Worth, Texas**

**Date:** Tuesday, October 19, 2021

**Time:** 12pm – 2pm

**Location:** Zoom

Please contact Ena for invitation instructions to meeting.

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** enamwa@hotmail.com

#### **Tarrant and Parker Counties, Texas**

**Date:** Wednesday, October 27, 2021

**Time:** 1:30pm – 3:30pm

**Location:** Zoom

Please contact Sharon for invitation instructions to meeting.

**Contact Person:** Sharon West

**Phone:** 817-297-4389

**Email:** swest124@swbell.net

#### **Rockwall, Texas**

**Date:** Monday, November 15, 2021

**Time:** 11am – 1pm

**Location:** Zoom

Please contact Ena for invitation instructions to meeting.

**Contact Person:** Ena Wilmot

**Phone:** 817-488-0445

**Email:** enamwa@hotmail.com

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

## WESTERN DISTRICT

### Los Angeles, California

**Date:** Thursday, May 13, 2021

**Time:** 1:30pm – 3pm

**Location:** Zoom (Please contact Cynthia for invitation instructions to meeting.)

**Contact Person:** Cynthia Clark

**Phone:** 650-678-4132

**Email:** clark.cyl@gmail.com

## NATIONAL SUPPORT

### National Zoom SGM

**Date:** Thursday, May 14, 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

### LORA FROM NORTH CAROLINA ON ATTENDING A NATIONAL ZOOM SGM

*I thought the support group meeting went very well, lots of good comments and thank you for hosting this again. I look forward to a next one.*



### National ZOOM SGM

**Date:** Monday, June 21, 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 ZOOM SGM

#### For **CRANIAL DYSTONIA (MEIGE) PATIENTS**

**Date:** Friday, July 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 For **CAREGIVERS**

**Date:** Monday, July 19, 2021

**Time:** 1pm – 3pm

**Location:** Zoom

Please contact Charlene for invitation instructions to meeting.

**Contact Person:** Charlene Hudgins

**Phone:** 409-832-0788

**Email:** Charlene@blepharospasm.org

### 03/12/2021- CAREGIVER SUPPORT GROUP MEETING



## TARRANT/PARKER COUNTIES TX SUPPORT GROUP MEETING



## 03/05/2021 - UPSTATE NEW YORK SUPPORT GROUP MEETING

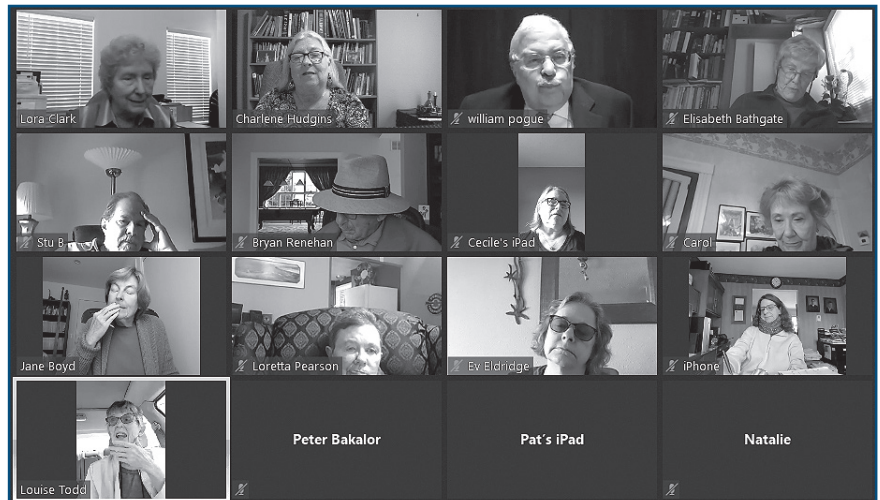


## KIM FROM NEW HAMPSHIRE ON THE MANAGING BEB WEBINAR

**“ The webinar was  
excellent; very  
useful information.  
Thank you for offering -- a  
lot of work behind  
the scenes to make  
it happen!! ”**

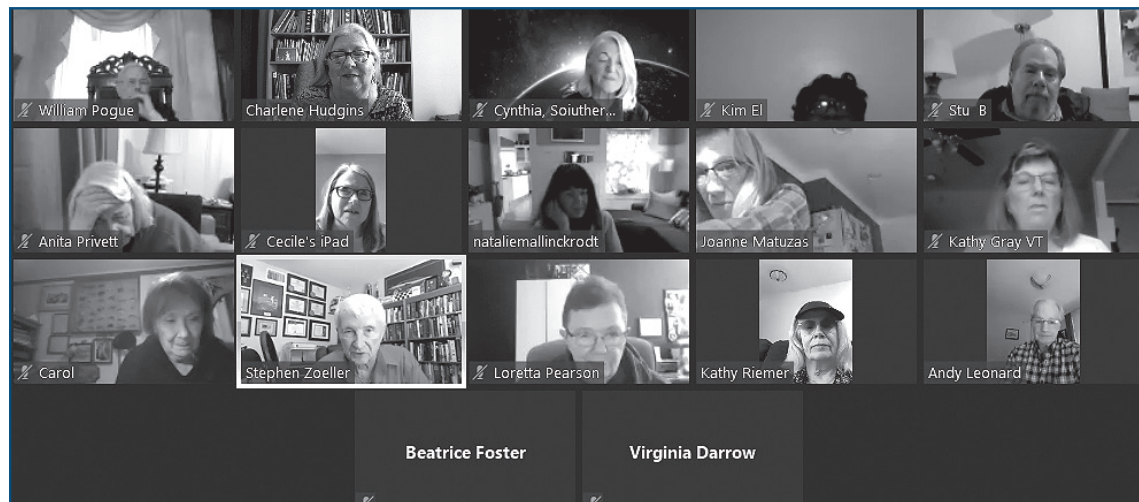


## 04/14/21 NATIONAL SUPPORT GROUP MEETING





## 01/27/21 NATIONAL SUPPORT GROUP MEETING



## 02/22/21 NATIONAL SUPPORT GROUP MEETING



## 03/20/21 NATIONAL SUPPORT GROUP MEETING



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