BENIGN ESSENTIAL **BLEPHAROSPASM** RESEARCH FOUNDATION

EYEING THE FUTURE

We're in this together.

SPRING 2017 • VOL. 37 • ISSUE 2

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

JOIN US AT THE 2017 BEBRF SYMPOSIUM

SYMPOSIUM WELCOME

Andrew R. Harrison, MD, Program Director 2017 Symposium

Andrew Harrison, MD

Welcome to the third BEBRF Symposium held in Minneapolis, Minnesota! The last symposium was here 10 years ago. This year's symposium will be entitled "What's new in Blepharospasm?" and will cover the latest and greatest in blepharospasm research and treatment. The symposium will take place in the University of Minnesota Continuing Education Conference Center on the St. Paul Campus of the University of Minnesota. It will be a free event, including a continental breakfast and boxed lunch.

The symposium will include experts from the University of Minnesota in the fields of neuro-ophthalmology, oculoplastic surgery, neurology and visual rehabilitation. It will also feature talks by Charles Soparkar, MD, from Houston, Texas. He is a world expert in treatment of eyelid spasms and botulinum toxins. He is the inventor of Zytase to prolong the efficacy of botulinum toxin injections. He is a brilliant, dynamic speaker with a lot of experience to share with us.

We will also have an update on research in blepharospasm by Linda McLoon, PhD, one of the foremost experts on the orbicularis oculi muscle that is affected by BEB. There will also be talks on the latest in surgical and medical treatments for blepharospasm.

Our low vision specialist at the University of Minnesota will discuss low-vision treatments that can help blepharospasm patients. We will have several panel discussions where YOU get to ask the experts all YOUR questions. September is a glorious month in Minnesota, so please come join us with your friends and family for this wonderful symposium.

WELCOME TO MINNEAPOLIS/ST. PAUL

Virgil & Shirley Koski, Local Arrangement Chairs

We're happy to welcome you to the third BEBRF meeting to take place in Minnesota. Dr. Andrew Harrison has put together an outstanding group of participants for the Symposium, which will be held on Saturday, September 9th at the University of Minnesota Continuing Education Center. The Center is located on the Farm Campus in St. Paul. When driving in, you may see horses and cows along the way.

The Minneapolis/St. Paul area offers many interests for everyone. We have the Minnesota Zoo, Mall of America, the Minnesota Textile Center, Walker Art Center, Guthrie Theater, Minneapolis Institute of Arts, Mill City Museum, Stone Arch Bridge, Minnesota Orchestra and Frederick R. Weisman Art Museum, to list a few. When it comes to sports, the Vikings, U of M Gophers, Minnesota Twins, St. Paul Saints, and The Wild Hockey teams all have new stadiums since the last BEBRF meeting here in 2008. In addition to the above, we have a new professional soccer team called

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Virgil & Shirley Koski

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

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

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

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

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

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

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Beaumont, Texas 77726-2468

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

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

Newsletter donation:
$15.00 U.S. $20.00 elsewhere.

NEWSLETTER DEADLINE DATES

ISSUE	COPY DUE DATE
Summer	July 3, 2017
Fall	Oct 2, 2017

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

PRESIDENT'S LETTER

Deborah Drago

Eyeing the Future often results in changes. I am pleased to announce some that have recently taken place at the Foundation.

- At its last meeting, on March 17, 2017, the BEBRF Board of Directors approved some changes to the Bylaws. The Bylaws now stipulate that a minimum of two Board members must be blepharospasm or Meige sufferers or a relative of a sufferer. This is to ensure that the concerns of patients are always taken into consideration. There are currently five patients on the Board.
- We welcome Deborah Drago, Program Director, Southeast Texas Nonprofit Development Center, in Beaumont, Texas, to the BEBRF Board. She has more than 15 years of leadership experience combined with a master's degree and collegiate-level teaching experience in business.
- Charlene Hudgins, BEBRF Executive Director, joined the Board as an Ex Officio member.
- Since the previous office location was causing health related problems, the Foundation has moved to a new home: 755 S. 11th St, Suite 211, Beaumont, TX 77701. However, we ask that you continue to use P.O. Box 12468, Beaumont TX 77726-2468 for mailing donations and other communications.

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NEWSLETTER HIGHLIGHT:

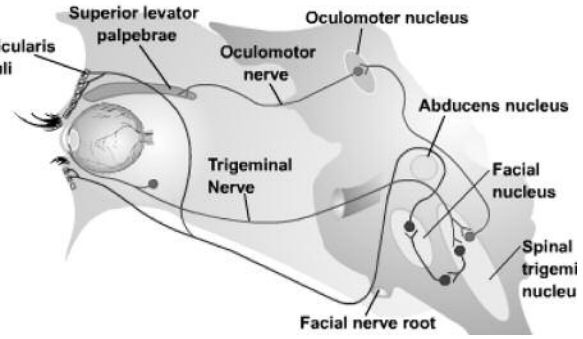
We welcome you to join us as we prepare for the 2017 BEBRF Symposium, held in Minneapolis, Minnesota. Learn about the events and speakers beginning on the front page.

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. Doctors seem to refer to the 5th cranial motor nerve and the trigeminal nerve interchangeably. Are they the same thing? If not, what are their individual functions?

A. The answer to the question is basically "yes." The Trigeminal Nerve and the 5th Cranial Nerve are terms that describe the same nerve in the brain. This nerve communicates sensory information to the brain from the face, and particularly the eye and eyelid. The BEBRF has supported numerous research efforts devoted to the Trigeminal (5th Cranial) Nerve, particularly when the emphasis was on the blink reflex. Blinking may be triggered by a number of stimuli that are not dependent on light striking the retina – the part of the eye that encodes vision. These include stimulation of the Trigeminal nerve with touch, vibration, temperature and painful stimulation of the face, eyelash, cornea or globe (eyeball). The other sensory nerve that can produce blinking is the 8th Cranial or Vestibulocochlear Nerve. This nerve transmits acoustic (loud noise) or vestibular information (spinning) to the brain.



Mark Stacy, MD, Professor of Neurology, Vice Dean for Clinical Research, Duke University, School of Medicine

Q. Does TMJ play a role in blepharospasm or oromandibular dystonia?

A. Temporomandibular joint syndrome (TMJ) is a painful disorder that involves the joint connecting the lower jaw to the skull, allowing for movement of the jaw. The pain of TMJ is often localized to the cheek above the joint. The causes include arthritis in the joint, grinding of teeth or clenching of the jaw.

Dystonia of the eye muscles (isolated blepharospasm) causes involuntary movements of the muscles around the eyes and is not associated with TMJ. Oromandibular dystonia is dystonia involving the jaw and perioral muscles. The movements associated with that oromandibular dystonia include jaw opening, jaw clenching or deviation of the jaw to one side or the other. Approximately half of the patients with oromandibular dystonia will have symptoms of TMJ due to the jaw movements. Sometimes the dystonia of blepharospasm can spread to the lower face and jaw, and cause TMJ. TMJ is not a dystonia, although sometimes people who have symptoms of TMJ will have it secondary to oromandibular dystonia.

Cynthia L. Comella, MD, Professor, Department of Neurological Sciences, Rush University Medical Center

Q. A topic that's getting a lot of attention in parts of the BEB community now is neuroplasticity training. Several patients have begun working on exercises that, through modified behavior, attempt to reverse plasticity in order to improve their symptoms.* What are your thoughts on this?

A. Neuroplasticity could work. We have done work with focal hand dystonia with some success and it could be adapted for blepharospasm. A clinical trial might be a good idea, but would need a decision about the best exercises and might well require a very long trial period. I don't know much details about exercise programs that have been tried and are being used.

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

** See article by Jill Edwards, MD on page 8*

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Andrew Harrison, MD

Program Director, 2017 Symposium

Symposium Topic: "Diagnosis of Eyelid Spasm Disorders"

Dr. Andrew Harrison is currently an Associate Professor of Ophthalmology and Visual Neurosciences and Otolaryngology Head and Neck Surgery and the director of Oculoplastic and Orbital Surgery at the University of Minnesota. He directs a two-year fellowship in oculoplastic and orbital surgery and is also the medical director of the Adult Eye Clinic at the University. His current research involves finding a way to prolong the action of Botox® as well as minimally invasive surgery for thyroid eye disease. He serves on the Medical Advisory Board of the BEBRF and has received two grants for his research involving new treatments for BEB.

Paul Tuite, MD

Professor and Neurologist, Department of Neurology, University of Minnesota

Symposium Topic: What's New in Imaging and Medical Treatment of Blepharospasm?

Since arriving at the University of Minnesota in 1996, Dr. Tuite has directed more than 30 clinical trials related to Parkinson's disease (PD) and other movement disorders. In addition to evaluating new therapies, his interests include the development of novel brain MRI and nuclear imaging tests that may aid in the diagnosis of PD, increasing our understanding of the disease, and monitoring the effects of treatment.

Collin McClelland, MD

Assistant Professor and Physician, Department of Ophthalmology and Visual Neurosciences, University of Minnesota

Symposium Topic: "Diagnosis of Eyelid Spasm Disorders"

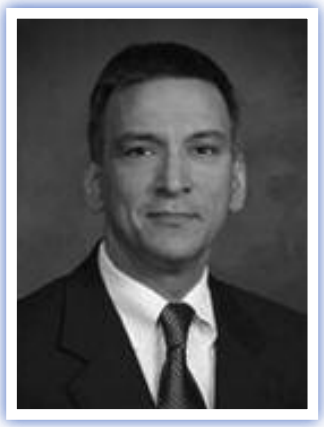
Dr. McClelland sees patients with a variety of neuro-ophthalmic problems, including double vision, giant cell arteritis, hemifacial spasm/blepharospasm, neuro-ophthalmology, pseudotumor cerebri and strabismus.

Ali Mokhtarzadeh, MD

Assistant Professor and Physician, Department of Ophthalmology and Visual Neurosciences, University of Minnesota

Symposium Topic: "What's New in Surgical Management of Blepharospasm?"

Dr. Mokhtarzadeh did a fellowship in oculoplastic and orbital surgery at the Mayo Clinic in Rochester, followed by an American Society of Ophthalmic Plastic and Reconstructive Surgery fellowship at the University of Minnesota. He sees patients at the University of Minnesota adult and pediatric clinics, as well as the MHealth Ophthalmology Clinic in Maple Grove. His clinical interests include the breadth of oculoplastic and orbital surgery including eyelid, lacrimal and orbital disorders.



Charles Soparkar, MD

Plastic Eye Surgery Associates, PLLC (Houston, Texas)

Symposium Topics: "What's New in Botulinum Toxins?" and "Management of Dry Eye in Blepharospasm"

A native of Massachusetts, Dr. Soparkar received both his PhD in molecular biochemistry and his medical degree from the University of Massachusetts. An avid pupil and instructor, he has trained, taught, and published in the fields of plastic and aesthetic surgery, oculoplastic surgery, molecular biochemistry, ocular pathology, ophthalmic oncology, and ocular and peri-ocular aging and has been invited to lecture across five continents. Today Dr. Soparkar focuses on identifying and merging cosmetic, aesthetic and functional solutions for all his patients. Over half his practice is devoted to correcting issues resulting from prior surgeries. Dr. Soparkar believes that patient education is the cornerstone of successful care.

Linda McLoon, PhD

Professor - Department of Ophthalmology and Visual Neurosciences

Symposium Topic: "What's New in Blepharospasm Research?"

Dr. McLoon received her B.S. degree in biology from the State University of New York at Binghamton. She received her PhD in anatomy from the University of Illinois at the Medical Center in Chicago, studying regeneration in the developing peripheral nervous system. Dr. McLoon did postdoctoral studies with Dr. Raymond Lund at the University of Washington and the Medical University of South Carolina, using a transplantation paradigm to study developing visual system connections.

Mary Ruff

OTR/L Eye (Ophthalmology) Clinic – University of Minnesota

Symposium Topic: "What's New in Low-Vision Therapy That Can Help You Today?"

Mary Ruff, Occupational Therapist, provides low vision services to children and adults with permanent visual impairment. She was involved in the planning and development of the Visual Rehabilitation Center at the MHealth Eye Clinic in 1999, and has provided clinical care in visual rehabilitation since that time. Mary has given numerous presentations on visual rehabilitation topics to regional and national organizations. She contributes to the education of occupational therapy students and medical residents, and she has participated in low vision research in collaboration with the Minnesota Laboratory for Low Vision Research.

THREE WAYS TO REGISTER FOR THE BEBRF SYMPOSIUM:

ONLINE	BY EMAIL	OR CALL
www.blepharospasm.org	**bebrf@blepharospasm.org**	**1-409-832-0788**

PLEASE MAKE YOUR RESERVATIONS AS SOON AS POSSIBLE

BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION SYMPOSIUM

SATURDAY, SEPTEMBER 9, 2017 • MINNEAPOLIS/ST. PAUL, MINNESOTA

ANDREW R. HARRISON, PROGRAM DIRECTOR

8:30 a.m.	Registration and Breakfast	
9:00 a.m.	Welcome	*Andrew Harrison, MD*
9:05 a.m.	Diagnosis of Eyelid Spasm Disorders	*Collin McClelland, MD*
9:25 a.m.	What's New in Imaging and Medical Treatment of Blepharospasm?	*Paul Tuite, MD*
9:45 a.m.	What's New in Surgical Management of Blepharospasm?	*Ali Mokhtarzadeh, MD*
10:05 a.m.	Coffee Break	
10:20 a.m.	What's New in Botulinum Toxins?	*Charles Soparkar, MD, PhD*
10:50 a.m.	Panel Discussion	
11:30 a.m.	Management of Dry Eye in Blepharospasm	*Charles Soparkar, MD, PhD*
12:00 p.m.	Lunch	
1:00 p.m.	What's New in Blepharospasm Research?	*Linda McLoon, PhD*
1:20 p.m.	What's New in Low-Vision Therapy That Can Help You Today?	*Mary Ruff, OT*
1:40 p.m.	Panel Discussion	
2:15 p.m.	Farewell	

This program funded through an education grant from Merz Pharmaceuticals

SYMPOSIUM VENUE

UNIVERSITY OF MINNESOTA, ST. PAUL CAMPUS

CONTINUING EDUCATION CONFERENCE CENTER (CECC) • 1890 BUFORD AVE., ST PAUL, MN 55108

2017 SYMPOSIUM HOTEL SUGGESTIONS

Please contact the hotels directly for reservations or questions. We have not reserved room blocks at the hotels listed below.

Radisson Hotel*

2540 Cleveland Ave, Roseville, MN
651-636-4567
- Axel's Restaurant on site
- Breakfast not included
- Shuttle available to Symposium meeting at Continuing Education & Conference Center (CECC) and within 5 miles of hotel

**Lodging for BEBRF Board members & District Directors as well as site for Meet & Greet September 8*

Courtyard by Marriott

2905 Centerpoint Drive, Roseville, MN
651-746-8000
- Saturday shuttle can be negotiated for a fee.

Home 2 Suites

2020 Iona Lane, Roseville, MN
651-925-8600
- Shuttle available to CECC

Holiday Inn Express

2715 Long Lake Road, Roseville, MN
651-294-7200
- Shuttle available to CECC

Hampton Inn

2050 Iona Lane West, Roseville, MN
651-209-3000
- Shuttle available to CECC

2017 SYMPOSIUM SPECIAL INVITATIONS

The BEBRF Symposiums provide an opportunity not only to hear from experts, but also to meet other people who are affected with blepharospasm and oromandibular dystonia (Meige).

On Friday, September 8, there will be an informal "meet and greet" at the Radisson Hotel at 2540 Cleveland Avenue, Roseville, MN from 5-7 pm. Light hors d'oeuvres and beverages will be provided, compliments of Allergan Pharmaceutical. **Please RSVP when registering for the Symposium (See page 5).**

On Saturday, September 9th, immediately following the close of the symposium, the District Directors will hold district meetings. These sessions will last approximately one hour and are designed for the attendees to hear important messages about the Foundation as well as ask questions or share experiences.

AIRPORT INFORMATION

Located about 10 miles from downtown Minneapolis and downtown St. Paul, the Minneapolis-St. Paul International Airport (MSP) is the busiest airport in the Upper Midwest. It is a joint public-military airport, has two terminals, and serves as a hub for Delta Air Lines and Sun Country Airlines.

The most economical way to travel to the hotels from the airport is to use Super Shuttle, which costs about $25.00 and is much less expensive than a taxi.

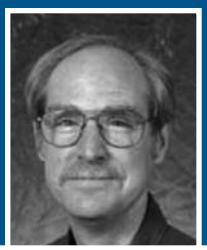
THINGS TO DO IN MINNEAPOLIS/ST. PAUL

Saint Paul has been called the last city of the East primarily because early developers built it to fit Eastern standards: city squares or parks, towers and turrets, lofty arches, Baroque domes and elaborate adornments abound. Ideal for families and those who like to explore on foot, the capital of Minnesota offers big city attractions with small town manageability. It's an easy and scenic stroll along the banks of the Mississippi River from the Children's Museum to the Science Museum. The kids (and the young at heart) will love them both. Nearby are the grandiose State Capitol, designed by esteemed architect Cass Gilbert and the historic Como Park, which includes lovely picnic areas, a zoo and a conservatory. Also in the mix are modern museums, stately old mansions, interesting natural wonders and unique shops to browse around. Be sure to check out the stellar collection of contemporary works by local artists at the Minnesota Museum of American Art. From four-star luxury to affordable and family-friendly, Saint Paul offers a variety of lodging and dining possibilities making it a great destination for all tastes and budgets.

Shopping is a top activity when people travel, and some travel just to shop. Mall of America is a major destination in Minnesota, but other shopping centers draw visitors as well. Bargain hunters will find plenty of satisfaction at four outlet malls close to the Twin Cities.

Weisman Art Museum-Housed in a striking stainless steel and brick building designed by architect Frank Gehry, the Weisman Art Museum offers an educational and friendly museum experience. The museum's collection features early twentieth-century American artists, such as Georgia O'Keeffe and Marsden Hartley, as well as a diverse selection of ceramics and contemporary art. Located on the campus of the University of Minnesota, this museum features fine arts from the contemporary period. Parking is available in the parking garage located under the museum. Limited meter parking is available on the street.

Address: 333 E River Rd, Minneapolis, MN 55455-0367; Phone: 612-625-9494; Closed Mondays; Free admission



ANIMAL MODELS ARE CENTRAL TO TREATING BRAIN DISEASES

L. Craig Evinger, PhD, Professor Neurobiology & Behavior, State University of New York, Stony Brook, NY

To understand why animal models of human disease are critical for the development of new treatments, you need to appreciate the distinction between clinical and basic research. One way to understand this difference is to think about the apps on your cell phone. If a researcher takes an existing app and improves its function or gives the app new features, that's like clinical or translational research. On the other hand, if a researcher creates an entirely new app, this action is equivalent to basic or fundamental research. Basic research creates scientific explanations for how a normal brain becomes diseased. Translational research takes these scientific data and develops new treatments or improved treatments for the disease.

Animal models of brain diseases are an essential component of basic research into disorders like blepharospasm. The often-repeated declaration that animal models of disease can't tell us anything about human disease because humans respond differently to disease than do other animals is simply not true. Our long, shared evolutionary history results in humans and other mammals having more in common than different. These shared characteristics are most obvious when looking at the brain. For example, a fundamental difference between rodents and people is that rodents walk on four legs, whereas people walk on two. Nevertheless, the nervous system associated with walking is very similar between rodents and people. When four legged animals like rodents or your pets walk, the left hind limb and the right forelimb swing together alternating with the right hind limb and left forelimb. When a person walks, the left arm swings with the right leg and the right arm swings with the left leg. Although humans walk on two legs, we still swing our arms as if they are forelimbs. This shared pattern results from a nearly identical neural circuit among mammals that controls walking. Evolution just tweaked the circuit so that humans could walk upright.

> ***. . . combining a predisposing condition and an environmental trigger can cause blepharospasm . . .***

Parkinson's disease and blepharospasm are two disorders for which basic animal research have furthered our understanding of disease mechanisms. While we know that the death of dopamine containing neurons causes Parkinson's disease, we don't know how dopamine loss changes brain activity to disrupt movement. Neurons in the basal ganglia region of the brain exhibit synchronized bursts of activity in Parkinson's disease. One hypothesis is that this exaggerated synchronized activity may 'clog up' brain function analogous to how people in a huge crowd can't move effectively when the doors open at Urban Outfitters at 5:00 AM on Black Friday. We have demonstrated the hypothesis' validity in an animal model by showing that artificially exaggerating synchronization of basal ganglia activity in a normal rat causes the rat to exhibit Parkinsonian-like abnormalities that disappear when we remove the synchronization. This kind of basic research can only be done in animals.

Even though we understand the basis for Parkinson's disease, we don't know what causes blepharospasm. Clinical research suggests the 'two-hit' hypothesis in which blepharospasm arises when two conditions occur, a predisposing condition that makes a person susceptible to blepharospasm and an environmental trigger that initiates blepharospasm. In rats, we have tested this hypothesis directly by combining a small loss of dopamine neurons with a mild dry eye. In this situation, rats develop the characteristics of human blepharospasm. This animal research demonstrates that combining a predisposing condition and an environmental trigger can cause blepharospasm, which helps to focus translational research to identify the predisposing condition and environmental trigger. In humans, investigators are searching for the genetic basis of the predisposing condition while epidemiological studies try to identify possible environmental triggers such as dry eye or eye irritation. In rats, we investigate what changes in brain activity might be caused by the genetically based predisposing condition. We find that creating exaggerated synchronization in the basal ganglia just before inducing a mild dry eye causes rats to develop blepharospasm-like characteristics. Thus, animal models identify a brain change for which genetic analyses may determine the cause and provide direct evidence supporting epidemiological studies indicating that dry eye is an environmental trigger for blepharospasm.

Animal research enables scientists to identify the fundamental causes of disease in ways that are not possible in human studies. These scientific data provide a framework for clinical and translational research to identify treatments to improve the quality of life for patients.

MY JOURNEY WITH BEB

Jill H. Edwards, MD

Developing BEB and Meige has been life changing for me. Though I am a pediatrician, I can honestly say that I had never even heard of this disorder until 7 years ago, at age 47, when I developed uncontrollable blinking, photophobia, and dry eyes. This progressed quickly to eyelid spasms and then facial spasms. Once I had the diagnosis confirmed, I figured that Botox® would just fix things and I'd be on my way. Unfortunately, it has not been that simple.

Botox® gave me some relief, but only for a few weeks of each cycle. And I still had problems with "pseudo-apraxia" that caused my lids to simply drift closed. I had to physically hold my lids up, or tip my head back to see through my "slits". It was exhausting. My fourth doctor tried pre-tarsal injections, and these opened my eyes great! However, my eyes then became miserably dry and painful. The spasms then spread to include my face as well. I began injections for this, but soon faced either having a wildly spasming face or a frozen face. I didn't like either option.

I eventually got to the point where I wasn't leaving the house much at all. I quit trying to socialize - it was just too embarrassing to not be able to control my eyes and face. I needed someone to walk with me outside or in brightly lit stores. Driving was impossible. Many days I wanted to just crawl into a hole. I HATED this disorder.

Then came the turning point for me. With inadequate relief from Botox®, and eyes too dry for surgery, I would need to look elsewhere for relief. I learned about how BEB may develop due to "maladaptive neuroplasticity" in the brain. The blinking had started as a reflex to protect the cornea – but over time, repeated use (and other factors) caused this circuit to become hyperactive. The more you use a circuit in the brain, the stronger it becomes. The less you use it, the weaker it becomes – a concept described in neuroscience as "use it or lose it". Unfortunately, Botox® does not stop the faulty circuit - it is still misfiring in the brain even when the muscles cannot respond due to the toxin. Botox® is a welcome band-aid, but does not get at the root of the problem.

I wondered, could I "lose" the faulty overactive circuit by figuring out ways to use it less? I studied the stories of people who had gone into remission. I read books about neuroplasticity. I experimented with how I could calm my hyper-excitable brain circuit. I experimented with scleral contact lenses to help my corneas feel less dry and sensitive. I learned how to activate areas of my brain that calmed spasms – all with the goal of using the faulty circuit less so that it would regress.

It has been a slow process, but I have had an encouraging response. I am now 60% improved– and no Botox® for 15 months now.

It has been a slow process, but I have had an encouraging response. I am now 60% improved– and no Botox® for 15 months now. I can do many things I could not do a year ago. I am getting my life back!

I am part of a Facebook group, "Neuroplasticity Therapy for blepharospasm" with many members experimenting with re-training, and sharing our success with various techniques. We have created a "files" section with resources and recovery journals. This group has been an amazing support for me, giving me hope when I needed it most. Anyone is invited to join and follow our work in progress.

Note: Dr. Edwards is no longer a practicing pediatrician.

ASK THE DOCTOR

CONTINUED FROM PAGE 3

Q. Is Oromandibular dystonia ever found by itself, without some other focal dystonia?

A. Oromandibular dystonia does occur in isolation, and dystonia can even affect one's jaw, tongue or other lower facial muscles in isolation. Dystonias are often classified by the body region affected. For example, focal dystonia is used when only one body region is affected (e.g., blepharospasm, oromandibular dystonia, etc.), segmental dystonia is used when two or more contiguous body regions are affected (e.g., blepharospasm with oromandibular dystonia, oromandibular dystonia with cervical dystonia, etc.), and generalized dystonia is used when the trunk and at least two body regions are affected. We know the body distribution of focal dystonia can change or spread over time, and some forms of dystonia frequently occur together such as blepharospasm and oromandibular—the condition often referred to as "Meige syndrome." More research is needed, however, to help us understand what causes adult-onset forms of dystonia to affect specific body regions and why dystonia spreads in some individuals.

Brian Berman, MD, University of Colorado, Denver, Colorado

FUNDING THE BEBRF

Peter Bakalor, BEBRF Treasurer

NON-PROFIT FUNDRAISING

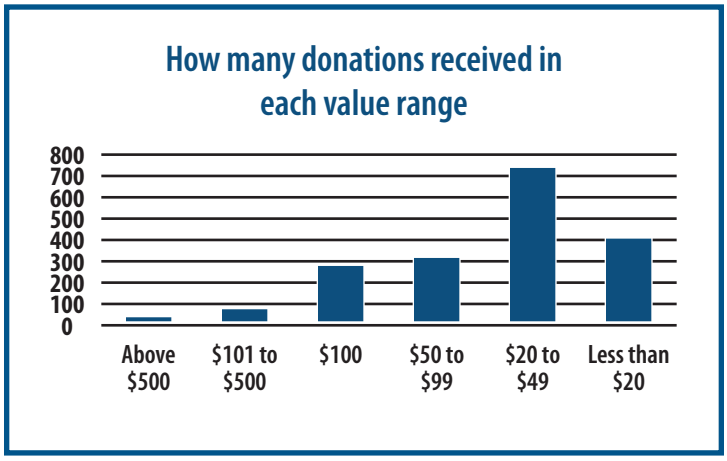
We are all familiar with fundraising appeals from non-profit organizations. Sometimes the flow of appeals is incessant, by mail, email, or phone. Hopefully at the BEBRF we strike the right balance with our appeals. Although we are happy to accept donations at any time, we focus on two appeals a year - at midyear and the end of the year. That keeps our costs down and we hope avoids bothering our donors too much.

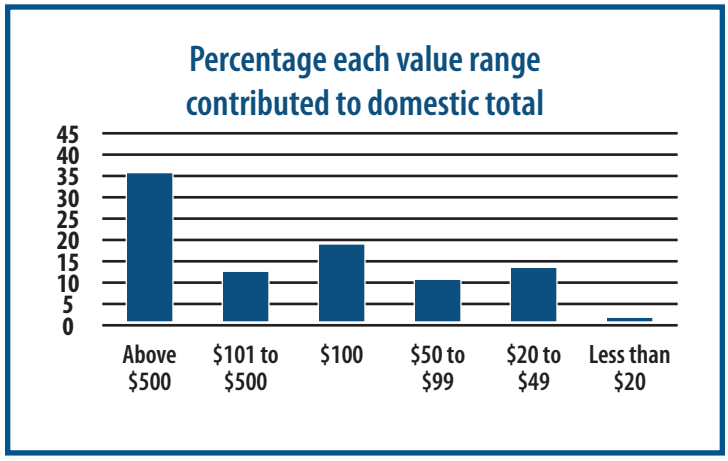
Since our disease affects a relatively small number of older adults (not cute animals or young children) and most people have never heard of blepharospasm, our donors are largely ourselves, fellow patients and our supporters.

There are other sources of income for non-profits, and how those impact the BEBRF we will discuss below.

YOUR DONATIONS

So how have we done? Thanks to you, we have done a little better over the last couple of years. This may be because the economy has improved a bit or because we changed the way we send out our appeal. Now it goes as a separate letter, rather than as an insert in our Newsletter. We hope this makes it more convenient for donors to respond. Every donation counts, from the smallest to the largest. To give you an idea, here's the spread of how many donations we get in a range of values. You can also see how important that smaller number of larger donations is to the Foundation.





BEQUESTS

Over the years, bequests have provided much of the funding that allows us to invest in research. Building reserves through bequests is very important. For obvious reasons, bequests are unpredictable, and sometimes we have gone a few years with nothing from bequests. Remembering the BEBRF in your will is perhaps the greatest thing you can do for the Foundation.

INVESTMENT INCOME

We also get some income from investments. However, interest and related income have dropped by two thirds to three quarters since 2007. We are very conservative in the way we invest the funds which are not needed for day to day expenses, and safe investments have paid very badly over the last 10 years.

CONTINUED ON NEXT PAGE

FUNDING THE BEBRF

CONTINUED FROM PREVIOUS PAGE

GRANTS

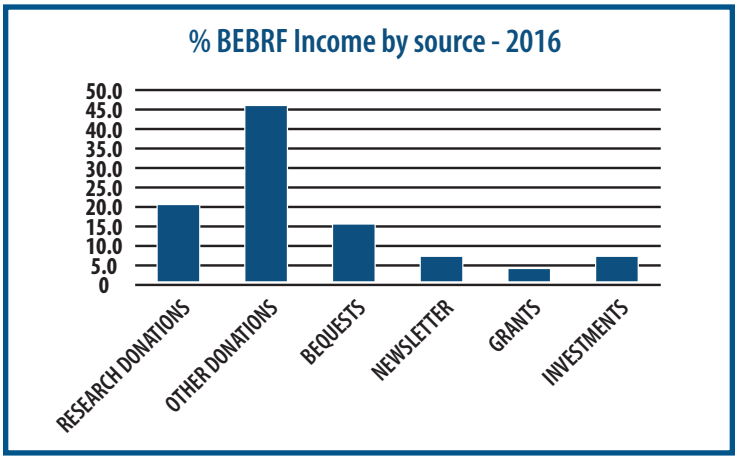
All non-profits try to raise funds for programs from third parties. Often, these are supportive charitable foundations or companies with an interest in the cause the non-profit supports. In our case, both Allergan and Merz (alphabetical order, no favoritism implied) have supported BEBRF activities such as our Symposiums. Our goal for funding future programs is to find additional organizations and foundations whose sympathies align with our objectives.

FUNDRAISING EFFORTS OF VOLUNTEERS AND SUPPORTERS

Many nonprofits get significant income from locally run events such as charity walks, fundraising dinners and the like. There has been very little of this within the BEBRF community, and that's something we are hoping to change going forward. The BEBRF Bylaws and Policies allow the Board to approve appropriate types of fundraising events, and in some cases to help fund them. We are very interested in hearing your ideas. If you've done this sort of thing before, and would be willing to help us with planning events, please contact our Executive Director, Charlene Hudgins, in the BEBRF office (409-832-0788), to discuss ideas.

WHAT DOES ALL THIS DO FOR US?

Typically, about 25 percent of your donations are designated to Research. Those funds are set aside into a reserve account which cannot be used for anything else. In a normal year, that comes to well under half the amount we budget for spending on Research, assuming we get proposals that are approved for funding by our Medical Advisory Board. That leaves us with a Research funding deficit, which is filled from reserves.



Our remaining income (including contributions for the Newsletter) does not cover the rest of our non-Research annual running costs, and as with Research, that is covered from reserves. How we did for income in 2016 is shown in the chart above.

CONCLUSIONS

The good news is that today BEBRF is in reasonable shape financially, thanks to you, our donors, both through contributions to our campaigns, and through bequests. You can see how important those bequests are to us, to fill the gaps in our program income. Still, to fund more research and programs in support of patients, we must find ways to increase our income. We are working on ideas and will appreciate any suggestions you can make. Thank you for your past – and we hope, future donations and support.

If you've any questions or comments on this, email me at treasurer@blepharospasm.org, or send me note via the office.

WELCOME TO MINNEAPOLIS/ST. PAUL

CONTINUED FROM FRONT PAGE

Minnesota United. The Super Bowl will be held in Minneapolis in 2018.

Fall, when the colors start to change, is a beautiful time to be in Minnesota. All of you would enjoy taking a drive along the Mississippi River.

The U.S. acquired eastern Minnesota from Great Britain after the Revolutionary War and 20 years later bought the western part from France in the Louisiana Purchase of 1803. It became a state on May 11, 1858 and was first settled by Swedes, Germans and Norwegians, followed by Finns, Poles and Czechs. Northwest Angle, Minnesota is the northernmost point in the 48 contiguous states, and Minnesota is known as the North Star State and the Gopher State. It consists of nearly 80,000 square miles, of which over 7,300 square miles are fresh water lakes; hence, it is also called the Land of 10,000 lakes.

The Minneapolis, Minnesota BEBRF Support Group and the University of Minnesota are delighted to be able to host you at our upcoming Symposium in September.

NEW SUPPORT GROUP LEADERS

Christi Gordon

I was born and raised in Columbus, Ohio. I was diagnosed with BEB in my early 40's (2013). Within this short time, I had tried multiple dosages of Botox® (both for blepharospasm and migraines), oral medications for migraines, and oral anxiety medications to help with controlling the spasms between the injections.

On December 21, 2016, I had a bilateral limited myectomy and have had great success with it thus far. I still take oral medications for migraines, as needed, but no longer need injections. I have opted to continue taking the anxiety medication as a precaution.

I am looking forward to starting to work as a new representative for the Ohio area-- getting to know the patients in Columbus and the surrounding areas.

CONTACT INFORMATION FOR CHRISTI: email: cjkgordon@gmail.com; phone: 740 412-0829

Carole Masa

I have been a lifelong resident of the greater Akron, Ohio area. Since I was diagnosed in 2009, I have been through several different procedures and treatments and have an empathy with anyone who is either recently diagnosed or has been dealing with the life changing symptoms of blepharospasm. With two adult children who live in the area and two grandchildren in their teens, I now have time to devote to other pursuits. It is time now to make some additional time for blepharospasm and for those who would like a support group.

My current passion is gardening, although I also do office work a couple of days a week for the company owned by my husband and son.

CONTACT INFORMATION FOR CAROLE: email: carolemasa@roadrunner.com; phone: 330 666-280

Chuck Palmer

At age 54 in 2005, I was diagnosed with BEB. After going through six doctors and various medications including Botox® it was determined that I should go to the movement disorder center at Vanderbilt. I was functionally blind for 9 months and on disability from work. Dr. Cooper at Vanderbilt determined that I was allergic to Botox®. He recommended a drug from Dublin, Ireland called Tetrabenazine. After 2 weeks on the drug, I was released to go back to work with no symptoms. I continue to have success with this drug until today. I have been a part of the support group here in Tennessee since Sonya Miller started as the leader. I was asked by Sonya to take over as the group leader effective 3/11/2017. I have recently retired from Walgreens after 25 years. Before that, I had retired after 21 years in Florida Law Enforcement. I look forward to continuing with our group in TN.

CONTACT INFORMATION FOR CHUCK: chuck147palmer@gmail.com; phone: 615-631-3546

Currently, the Foundation needs District Directors for the Southern and Western districts. Contact Linda Peterson at lindabebrf@msn.com or at 303-940-9409 to discuss qualifications and responsibilities.

FOCUS ON SUPPORT

TEXAS SUPPORT GROUP

Front row, L to R: Sharon West, Sharon Neely, Ruby Hill, and Linda Trahan. Back row, L to R: Ena Wilmot (leader), Paula Ruland, Barbara Hanish and her Support, Rudy Vester, Liz Simons.

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

SOUTHERN ARIZONA SUPPORT GROUP

L to R: Paul Lamb, Sandy Sugimoto, Nelma Murdoch, Jeannie Fruean, Helen Hess(speaker), Mary Davis

KANSAS SUPPORT GROUP

Front Row, L to R: Sharon Nowlin, Millie Mehnert, Virginia Forbes, Myrna Landherr, and Ann Margiotta. Back Row, L to R: Dr. Robin Larsen (guest speaker), John Mehnert, David Forbes, Alex Margiotta, Carol Lee and Dottie Lee.

TULSA, OKLAHOMA SUPPORT GRP.

SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, please notify the Foundation office, before July 3, 2017, the next newsletter deadline.

EASTERN DISTRICT

Waterford, New York
Pot Luck for 7-9 people
Date: April 27, 2017
Time: 12:30 p.m.
Location: 46 Harris Road
Waterford, NY
Contact: Sandy Mincher
Phone: 518-542-2328
Email: simplisand@hotmail.com

Tinton Falls, New Jersey
Date: May 6, 2017
Time: 12:00 noon – 3:00 p.m.
Location: Seabrook Village-Town Square-2nd Floor
300 Essex Road
Tinton Falls, NJ 07753
Contact: Rebecca Levin
Phone: 732-222-1713
Email: rlreb8@gmail.com

Boston, Massachusetts
Date: May 7, 2017;
Time: 1:00 – 4:00 p.m.
Location: Newton – Wellesley Hospital
2014 Washington Street
Newton, MA 02462
Contact: Sande Young
Phone: 617-527-1726
Email: ssyspts33@aol.com
Guest Speaker: Dr. Nutan Sharma – Neurologist

New York City, New York
Date: May 7, 2017
Time: 11:00 a.m.– 1:00 p.m.
Location: Mt. Sinai West/Roosevelt Hospital, 1000 Tenth Ave., New York, NY 10019
Speaker: Matthew Swan, MD, Neurologist, Mt. Sinai Beth Israel Hospital
Contact: Helene Lauffer
Phone: 212-496-0294
Email: hlauffer@earthlink.net

Philadelphia, Pennsylvania
Date: May 7, 2017;
Time: 1:00 – 3:00 p.m.
Location: Wills Eye Hospital
840 Walnut Street 8th floor
Philadelphia, PA 19107
Speaker: Sharon Hill, OT, Visual Problems Specialist
Contact: Joan Nikelsky
Phone: 610-352-5685
Email: jnikelsky@msn.com

NORTH CENTRAL DISTRICT

Northwest Wisconsin
Date: Saturday, April 24, 2017
Time: 12 noon to 3:00 p.m.
Location: Vets Club, Cadott, WI 54727. (Corner of Main St. & Chippewa St.). Lunch served at noon. Contact: Mary Le Duc, Please RSVP. Phone: 715-289-4513, 715-313-0111, email: m.leduc5.7.1@gmail.com

Columbus, Ohio
Date: May 21, 2017;
Time: 2:00 – 4:00 p.m.
Location: The Eye Center
262 Neil Ave
Columbus, OH 43215
Speaker: Kenneth Cahill – "Essential Tremor"
Contact: Christi Gordon
Phone: 740-412-0829
Email: cjkgordon@gmail.com

Madison, Wisconsin
Date: May 3, 2017
Time: 11:30 a.m.
Location: Lunch meeting-Nile Restaurant, 6119 Odana Road, Madison, WI 53719
Contact & RSVP: Gail Grueneberg
Phone: 608-271-0313
E-mail: grnmtn2@gmail.com

Southeastern Michigan
Date: July 15, 2017
Time: 10:00 a.m. -12:00 p.m.
Location: Beaumont Hospital (Botsford Campus) Administration & Education Center – Class. C, 28050 Grand River Farmington Hills, MI 48336
Speaker: Richard M. Trosch, M.D., Parkinson and Movement Disorder Center, Farmington Hills, MI, Q&A session
Contact: Gloria Weir-Pearson
Phone: 248-381-5348
Email: weirg@hotmail.com

SOUTHERN DISTRICT

Huntsville, Alabama
Date: July 23, 2017;
Time: 1:00 – 4:00 p.m.
Location: Dowdle Center
South Huntsville Hospital
109 Governors Drive
Huntsville, AL 35801
Contact: Linda Webb
Phone: 256-723-2661

Fort Myers, Florida
Date: April 29, 2017;
Time: 10:00 a.m. – 12:00 noon
Location: Eye Care Center of Florida
4101 Evans Avenue
Fort Myers, FL 33901
Contact: Charles Morse
Phone: 239-561-1356
Email: chuck147palmer@gmail.com

Greenville, South Carolina
Date: Monday, May 15, 2017;
Time: 10:00 a.m.
Location: St. Francis Eastside Hospital, 125 Commonwealth Dr., Ste. # 201, Greenville, SC
Speaker: Grant Brown, Senior Optician, GHS Eye Institute
Topic: "Visual Function vs. Functional Vision"
Contact: Pat Miller
Phone: 864-354-4699
E-mail: patmiller05@bellsouth.net

WESTERN DISTRICT

San Diego, CA
Date: Saturday, June 3, 2017
Time: 1:00 – 3:00 p.m.
Location: UCSD Shiley Eye Center
9415 Campus Point Drive
La Jolla CA 92037
Contact: Joanne Matuzas
Phone: 858 395-4609
Email: jmatuzas@aol.com

Seattle Area, Washington
Date: Sunday, July 23, 2017; Time: 2:00-4:00 p.m.
Location: Swedish Medical Center,
Cherry Hill Campus
James Tower Education Center, Room B
500 17th Ave, Seattle WA 98122
Speaker: TBD
Contact: Peter Bakalor
Phone: 206 219 9053
email: pbakalor@outlook.com

CORRECTIONS TO THE WINTER 2017 NEWSLETTER

The Texas Support Group Meeting mentioned on page 7 of the Winter Newsletter, did not hold a raffle. The $75 were donated to the BEBRF by the group.

The Dystonia Brain Collective was formed by dystonia organizations to promote brain donations. The Harvard Brain Tissue Resource Center located at McLean Hospital in Belmont, Massachusetts, is responsible for collecting, preserving, and distributing human tissues to qualified scientific investigators who are conducting important dystonia research.

The correct link for the "Living with Chronic Conditions" video mentioned on page 10 of the Winter 2017 newsletter is: **www.blepharospasm.org/video-library.html**

I USED TO LOVE TO READ - NOW WHAT?

"More than at any other time, when I hold a beloved book in my hand, my limitations fall from me, my spirit is free." - Helen Keller

For those who love to read, one of the most disappointing aspects of living with blepharospasm deals with giving up reading as we knew it. Fortunately, there are options not available to Helen Keller.

LARGE PRINT BOOKS - Many books, including bibles, are available in large print for purchase or through the local libraries.

EBOOKS - An electronic version of a printed book that can be read on a computer or handheld device designed specifically for this purpose. Kindle and Nook are the more familiar e-readers. The books must be purchased or obtained through a library service. The advantage to ebooks is that the font size can be increased, making it easier to read.

TALKING BOOKS - Are recorded materials—most often books or magazines in audio format—that are available on free loan to people who are blind, visually impaired, or otherwise unable to read or use standard printed materials.

A variety of materials, such as popular books and best sellers, magazines, scholarly literature, instructional texts, musical scores, and other specialized materials for adults and children, are available as Talking Books. Topics cover a wide range of subjects such as the Bible and religion, business and economics, career and job training, computers, cooking and homemaking, drama, fantasy, folklore, gardening, health, history, humor, music appreciation, the occult and supernatural, philosophy, sports, science fiction, and travel.

Any resident of the United States or American citizen living abroad who is unable to read or use normal print materials because of temporary or permanent visual or physical limitations may receive service through National Library Service for the Blind and Physically Handicapped, Library of Congress. Talking Book cassettes must be played on special playback equipment, which is supplied at no cost by the Library of Congress and its cooperating libraries.

Phone: 888-NLS-READ (888-657-7323)
E-mail: nls@loc.gov • Web site: www.loc.gov/nls

OVERDRIVE - This popular app facilitates borrowing both ebooks and audio books through your local public library-anywhere, anytime. All you need is a library card and the app, which may be downloaded from www.overdrive.com. Help is available through the library and online.

AUDIBLE.COM - Books must be purchased and downloaded or streamed for listening on phones, tablets, MP3 players, or a computer. For more information and to determine whether the Audible files can be listened to on your device, go to www.audible.com

REMEMBER BEBRF IN YOUR WILL

It is our editorial policy to report on developments regarding BEB/Meige and related disorders but do not endorse any of the drugs or treatments in the Newsletter. We urge you to consult with your own physician about the procedures mentioned.

BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION, INC.
P.O. BOX 12468
BEAUMONT, TEXAS 77726-2468
409-832-0788

Dated Material Enclosed

HELP THE BEBRF CARRY OUT ITS MISSION

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

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

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

ORDER FORM

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

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

Amount enclosed $ _____

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

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

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

IF BY CREDIT CARD (VISA OR MASTERCARD):

Card # _____

Expiration Date _____ Security Key # _____

Name on Card _____

Signature _____