During the Dystonia Coalition’s annual meeting in September 2012, a full day was spent discussing research priorities in blepharospasm. The goal was to summarize what we know about blepharospasm, and more importantly, what we don’t know that we need to focus more attention on. About 100 people were in attendance for this outstanding meeting, which took place in Chicago. Attendees included an international group of senior and junior investigators, pharmaceutical company representatives, patient advocacy group representatives, and representatives from the National Institutes of Health.

Experts from around the world provided stimulating presentations about what we know about blepharospasm so far, the most important unanswered questions, and how to prioritize research efforts. Throughout the day, individual speakers presented various topics and then engaged others in discussions on the topics. At the end of the day, two panel discussions were held to sum up the day’s events and to help bring into focus the key goals for research in the future. It was an invigorating and inspirational day leading to a great exchange of ideas and some clear agreements for the next research steps in the field.

The speakers and panelists for the day included Dr. Giovanni DeFazio, Dr. Joseph Jankovic, Dr. Kathleen Digre, Dr. John Burns, Dr. Alan Scott, Dr. Richard Anderson, Dr. David Peterson, Dr. Buz Jinnah, Dr. Laurie Ozelius, Dr. Alfredo Berardelli, and Dr. Craig Evinger. They discussed topics as far-reaching as genetics, animal models of blepharospasm, other disorders often confused with blepharospasm, dry eyes, surgical treatments, neuroimaging, rating scales, and the physiology of blepharospasm.

The first talk of the day was led by Dr. DeFazio. He described similarities and differences between blepharospasm and other types of focal dystonia. He particularly stressed how dystonia sometimes spreads from one body part to another, how different types of dystonia can be seen in the same family, and how some of the same genetic factors seem involved in many of the focal dystonias, including blepharospasm. It is important to understand these similarities and differences because, at times, they can allow us to borrow information from one type of dystonia.

Identification of the genetic basis of a disease is a first step toward understanding its cause and ultimately the development of specific treatments. The genetic bases of most forms of primary dystonia remain unknown and pathogenic mechanisms are poorly understood. However, genetics seem to play a significant role in different types of primary focal dystonia like blepharospasm as several studies have shown that between 10-30% of relatives of patients are also affected with some form of dystonia.

Blepharospasm is one of the most common forms of primary focal dystonia affecting between 12 and 133 people per million. However, identification of genes for blepharospasm is challenging because traditional methods of gene discovery are based on studying large families with multiple affected members who share the same disease causing gene. Such families with blepharospasm are rare, since the disease occurs later in life and has a low penetrance, meaning a person can carry a disease mutation but not show any of the clinical symptoms.

The human genome is the complete set of human genetic information stored in 23 pairs of chromosomes in the nucleus of each cell in the human body and is made up of 3 billion building blocks (also called base pairs). The recently coined term “human exome” refers to the part of the genome coding for about 20,000 human proteins (this represents about 2% of the entire genome).
The Blepharospasm Group in the United Kingdom started at the beginning of 2003, although initially the intention was not to form a group as such.

I was diagnosed with blepharospasm in 2001 – this took three years – and in 2002 joined the U.K. Dystonia Society and attended several meetings of the West Sussex Group. The Dystonia Society branch meetings are open to anyone in the local area who has any form of dystonia. There I met four other people who had blepharospasm. However, the meetings were every three months and, at that stage, I felt I needed more frequent support. I suggested that the five of us get together over a cup of tea for an interim meeting. And so on 16 February 2003 we had our first meeting, just five of us with the condition, plus two drivers. Drivers, be they husbands/wives/children/friends, have always been welcome at our meetings.

By coincidence, one of the other four who had the condition, Anne Smith, invited me early in 2003 to meet someone who was visiting the UK (also a BEB patient) and who was involved in the Benign Essential Blepharospasm Research Foundation (BEBRF). That was when we met Nilda Rendino (now 1st Vice-President of BEBRF) for the first time. Anne and I received much help and support from Nilda. And so the concept of the Blepharospasm Group came into...
It seems so obvious! Unless advances are made toward a deeper understanding of blepharospasm and medical professionals are able to come up with better treatments, a cure will not be achieved without clinical research. So who should participate in this research? You and me! If we don’t, who will? If we want medical advancements, then we need to volunteer. There are no negative or invasive procedures (except for possible drawing of blood). Volunteering only involves your time and the effort of getting there.

To participate, you first need to be fully informed of the expectations, potential risks, and benefits of being in the study before signing the consent form. Do not join a study unless these simple questions are answered:

- Who sponsors the study?
- Why is this research being done?
- What will happen during the study?
- Are there any possible benefits to you?
- What are the benefits to patients in general?
- Are there any possible risks to you?
- How will your personal health information be treated during and after the study?
- Can you withdraw from the study at any time?
- How often will you need to return for follow-ups?
- Will being in this study involve any cost? Travel?

To participate you are required to sign a consent form so be sure to first read it carefully. Please take note: you should never rely on studies to diagnose or treat medical issues.

I live near two big metropolitan areas containing both the National Institutes of Health (NIH) and Johns Hopkins Hospital (this does not mean I am privy to more research opportunities than you – many projects are done in multiple sites across the USA. In the last few years I participated in seven different trials / studies). These are just a few of the research and studies currently being conducted.

1&2: The Biorepository and Natural History studies sponsored by the Dystonia Coalition Project are currently collecting patient data around the USA. In addition to a medical history, and blood being drawn for collection, the patient is videotaped while answering a series of questions and performing certain activities. Some of the activities I was asked to do for the video are: answer questions clearly, write, and walk straight down a hallway. The subject is also observed for ALL types of dystonias. The aims of these studies are: 1) to create a repository or organized collection for future research (including DNA/genetic tests), videos, and clinical information, and 2) to help develop a new rating scale to measure the severity of the condition. My participation in this collection of research was completed in one visit that lasted about an hour. It was easy! Your history is vital to future research! And more blepharospasm patients are needed now to round out these studies. Please see additional information concerning participation and location sites in this newsletter on page 7.

3: I registered online with the Global Dystonia Registry “to support future dystonia studies, including clinical and research trials, through the collection of data on persons affected by dystonia.” Currently, 2300 are registered. Please go to www.globaldystoniaregistry.org to register and show your support.

4: I participated in Part One of the of Acetyl Hexapeptide-8 (AH-8) study (for patients receiving botulinum toxin) to determine if AH-8 can be used as part of a treatment regimen for blepharospasm. This cream is rubbed onto your eyelids twice a day. Each month my eyes were observed and I answered questions. For those who received the genuine AH-8 cream, they returned once a month for up to seven months. I visited the research site once a month for only three months; unfortunately for me, I received the placebo. But NIH was pleased with the study results and is about to begin Part Two for 24 patients who have not received botulinum toxin.

5: Between 2011 and 2012 Mount Sinai Hospital in New York City was the location for researching primary focal dystonias including blepharospasm for the purpose of investigating

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and apply it to another type of dystonia.

Later in the day, Dr. Ozelius talked about heredity and genetics in blepharospasm. In various studies, between 9.5% and 27% of people with blepharospasm reported having at least one family member with blepharospasm. Blepharospasm seems to be a disease where many genetic and environmental factors play a role in symptom presentation. This means many people may have genes that predispose them to blepharospasm, but that each gene, by itself, is not enough to cause symptoms to start. Studies to identify these genes and environmental factors could help us understand the causes better. This information would help us all know what treatments and cures should be targeted in order to be most effective.

In another talk, Dr. Peterson showed us an exciting new technology that can help identify and track blepharospasm symptoms. The technology is called CERT, which stands for Computer Expression Recognition Toolbox. CERT is a computerized rating scale that is applied to videos of people with blepharospasm. It tracks muscle movement in the face. The results can help doctors identify the disorder and determine its severity. This type of measurement could help researchers calculate how useful a new treatment is, or how a person's disease progresses over time.

Another talk that instigated many interesting conversations throughout the day was Dr. Digre's presentation on photophobia (sensitivity to light) in blepharospasm. She discussed the melanopsin pathway, which is a part of the nervous system typically thought to be involved with circadian rhythms and light response. She presented research showing that this pathway may also be involved in the blink reflex. It was generally agreed that further studies of the role of this pathway in blepharospasm might provide important new insights.

Lastly, Dr. Scott discussed botulinum toxins treatments and their limitations in blepharospasm. He is the doctor who is responsible for developing botulinum toxin as a useful therapy in blepharospasm. At the end of his talk, BEBRF's Mary Lou Thompson stood and gave a heartfelt thank-you to Dr. Scott on behalf of all people with blepharospasm for his life-altering work in the field. Her acknowledgement was endorsed by a long standing ovation from the meeting attendees. This moment epitomized the atmosphere and goals of this meeting. As one junior investigator put it: “Experiencing in person the joint effort of the patients, of the clinicians and of the researchers to build informational bridges was truly inspiring. I feel it now as a personal duty, the advancement and the explanation of the knowledge in the field.”

**USING EXOME SEQUENCING TO FIND PRIMARY BLEPHAROSPASM GENES**

The vast majority of mutations that cause diseases disrupt these gene coding regions or the "exome". However, until recently, researchers had no way to assess all the coding regions of the human genome simultaneously. Instead, traditional methods of disease gene discovery were based on finding a region or a chromosome that was shared by all affected family members and then sequencing all the protein coding parts within this region, a very time consuming and expensive method. Currently, a revolution in sequencing technology, next generation sequencing, is changing the way disease genes are discovered by making it more time and cost-effective to sequence the entire exome of an individual in a single experiment. This technology is developing so rapidly that not just the exome can be sequenced from a person but also their entire genome (all 3 billion base pairs!) at $5,000/person, whereas exome sequencing is only $1,000/person. The major advantage of exome sequencing is that large families with multiple affected members are no longer needed to find a disease gene. Instead, almost every patient can be important for genetic research, even those without a family history. Since November 2009, exome sequencing has led to the identification of over 30 new genes for human diseases. Moreover, several primary dystonia genes have been discovered using exome sequencing including CIZ1, AN03 and one from our laboratory GNAL. Although the generation of sequence has become
WHAT IS HEMIFACIAL SPASM?

Hemifacial spasm (HFS) is a neurological disorder in which muscles of one side of the face intermittently involuntarily contract, causing uncontrollable contortion of the face. HFS typically begins in the muscle surrounding the eye and can spread to involve other muscles on the same side of the face. Spasms can worsen over time in both frequency and severity, leading to nearly constant severe disfigurement with a grimacing expression. HFS can worsen in times of stress and fatigue, increasing the burden of anxiety on those who suffer from the disorder. Hemifacial spasm is restricted to one side of the face. It is extremely unusual for a person to have hemifacial spasm on both sides of the face and in these cases the spasm never starts on both sides of the face at the same time.

WHAT CAUSES HEMIFACIAL SPASM?

HFS is caused by hyperactivity of cranial nerve VII, aka the facial nerve, which originates in the brainstem and controls muscles of facial expression. The most common cause of HFS is irritation of the facial nerve from compression by an adjacent artery or vein. Rarely, a tumor or lesion in the brainstem can cause HFS.

HOW IS THE DIAGNOSIS OF HEMIFACIAL SPASM MADE?

HFS is a clinical diagnosis- the pattern of symptoms of involuntary one-sided facial twitching is used to make the diagnosis. Once a diagnosis of HFS is suspected, a person should undergo MRI of the brain with intravenous contrast to ensure that a rare tumor or brainstem lesion is not responsible for the symptoms. While MRI will sometimes show an artery or vein coursing near the facial nerve raising suspicion for the cause of facial nerve irritation, it is important to note that in the majority of people with HFS the offending artery or vein cannot be detected by imaging but is later found upon direct visualization during surgery for treatment. Therefore, while all people should have an MRI to rule out the presence of a rare cause of HFS, most people will not have the cause of their HFS seen on MRI.

WHAT CONDITIONS CAN BE CONFUSED WITH HEMIFACIAL SPASM?

Blepharospasm is sometimes confused with hemifacial spasm, but the simultaneous involvement of both eyes makes it relatively easy to exclude hemifacial spasm in these cases.

Microvascular Decompression (MVD) surgery is a neurosurgical procedure originally described by Dr. Peter Jannetta in 1984, and is the only known proven cure for HFS. MVD is a definitive treatment for HFS, providing long-term relief from facial spasms and recovery of normal facial movement. It involves the neurosurgeon placing a thin silicone tube on the side of the affected face to keep arteries from compressing against the facial nerve, which is the nerve that controls muscles of facial expression. As the silicone tube is removed, the arterial compression is relieved, allowing the facial nerve to move normally. This procedure is typically performed under general anesthesia in a hospital or medical center.

WHAT IS MICROVASCULAR DECOMPRESSION (MVD) SURGERY? WHAT ARE THE RISKS AND BENEFITS OF MVD TO TREAT HFS?

MVD is a nonsurgical procedure that alleviates facial spasms. It involves the neurosurgeon placing a thin silicone tube on the side of the affected face to keep arteries from compressing against the facial nerve, which is the nerve that controls muscles of facial expression. As the silicone tube is removed, the arterial compression is relieved, allowing the facial nerve to move normally. This procedure is typically performed under general anesthesia in a hospital or medical center. Benefits of MVD include long-term relief from facial spasms and recovery of normal facial movement.

WHAT ARE THE TREATMENT OPTIONS FOR HFS?

Medications are ineffective for treatment of HFS. Two treatment options exist: Botulinum toxin (BOTOX®) injections and surgical exploration of the facial nerve to identify and treat the site of facial nerve irritation, a procedure known as microvascular decompression (MVD). Any medication that reduces stress can reduce the occurrence of HFS, but cannot prevent or cure HFS.

WHAT IS BOTOX®? WHAT ARE THE RISKS AND BENEFITS OF BOTOX® INJECTIONS TO TREAT HFS?

BOTOX® is a temporary treatment of the symptoms of HFS. It does not treat the cause of HFS. BOTOX® is a bacterial toxin injected by needle into facial muscles that paralyzes the muscles so that they do not move when facial nerve hyperactivity occurs in HFS. While this prevents the facial grimacing seen in HFS, it also prevents normal facial movement at the sites of injection. Therefore the affected side of the face remains somewhat asymmetric, albeit much less so than if contorted into a hemifacial spasm. BOTOX® injections are temporary, with median length of effect lasting 11 weeks, and can be repeated. However, over time, BOTOX® injections have lessening effect on treating hemifacial spasm, and can cause permanent atrophy or paralysis of facial muscles. This may be a good option for some patients whose risk for surgery is unusually high or for whom temporary relief is desired.
CATARACT SURGERY AND BLEPHAROSPASM/DRY EYES: NOT AS CUT AND DRIED AS YOU THOUGHT!

Mirvat S. Sami, MD, Charles N.S. Soparkar, MD, PhD, Plastic Eye Surgery Associates, Houston, Texas

Dry eye syndrome (DES) affects as many as 20% of North American adults. Although our understanding of DES has evolved significantly over the last few decades, appreciating it as a multifactorial condition with many environmental and lifestyle risk factors, it can still often be a frustrating condition to manage.

Benign essential blepharospasm (BEB) has been closely linked to dry eye syndrome (DES). There is some debate over whether DES leads (along with other factors) to BEB or BEB leads to DES, and the reality is that probably both are true, creating a vicious, integrated cycle with progressive worsening of both BEB and DES.

Establishing and maintaining a healthy eye surface and tear film are essential for anyone with BEB, since DES creates eye irritation that triggers eye spasm. In people with BEB, a short-circuit in the basal ganglia of the brain seems to fail to stop the spasms once they start. Although we now have many treatment options for BEB, including the botulinum toxins and various medications and surgeries, avoiding DES remains an important cornerstone in BEB management.

Unfortunately, just as both the occurrence and severity of DES increases with age, so does cataract formation. For people with BEB who are already struggling with their vision, further vision impairment from cataracts can be devastating, and some forms of cataracts don’t just blur vision, but also cause glare and distortion, inducing even more eye irritation and spasm.

The good news is that cataract surgery, in the hands of an experienced surgeon, is a low-risk procedure providing great satisfaction and visual improvement. The bad news is that many cataract surgeons may not have a clear understanding of the special needs of people with BEB.

Immediately following cataract surgery the quantity, quality, and stability of tears bathing the eye is often reduced (we’ll spare you the mechanical, biologic, and biochemical explanations for why), potentially causing or worsening existing DES, which in turn may worsen BEB. Many researchers believe that tear production and quality usually return to their pre-surgical states within 3 months, but others have argued that some eyes may never regain their same pre-operative lubrication, protection, and comfort.

Although most cataract surgeons today are keenly aware of the increased risk of DES following cataract removal and attempt to diagnose and treat eye surface disease before surgery, there are several things that a person with BEB can do to improve their own surgical outcome.

Inform your cataract surgeon about your BEB and DES and current treatment. Your surgeon will be able to perform a few tests to quantify your tear film problem and maximize your management. Ask your doctor about whether or not consumption of flaxseed oil and omega-3 oil along with a sulfonated protein would improve your situation and whether eyelid scrubs would help pre-operatively. If your symptoms of DES or BEB worsen after surgery, inform your physician right away, so that greater measures may be taken to ensure your comfort and eye safety.

Remind your surgeon about the tight connection between DES/eye irritation/and BEB and avoid concomitant refractive procedures which may worsen DES. Think twice about special lenses your surgeon may offer to implant in the eye, such as multifocal lenses, which can induce glare or visual aberrations. Such problems may be mildly annoying to the average person, but devastating to someone with BEB.

Review carefully with your surgeon when is the best time to perform your cataract surgery relative to botulinum toxin injections. Surgery is probably best avoided during times when your eyes are most dry and when they are most strongly spasming.

In summary, cataract surgery is generally safe, and for many profoundly vision rehabilitative. With good physician - patient communication and appropriate preoperative assessment and planning, most people with BEB will enjoy significant vision improvement.

USING EXOME SEQUENCING TO FIND PRIMARY BLEPHAROSPASM GENES

Continued from page 4

Routine, the main challenge associated with these new techniques is identifying the disease causing mutations among the multitude of variants discovered in each exome. Variants are the single base pair difference in the DNA between different individuals. On average, exome sequencing identifies approximately 44,000 variants in African American samples and about 40,000 variants in European American samples. More than 95% of these variants are already known as neutral genetic variants, but the remaining 5% (1000-1200) are novel and thus potentially disease causing.

We are currently working to find a causative gene for blepharospasm using exome sequencing. We have sequenced several exomes from patients and families affected by blepharospasm and detected about 1000 novel variants (i.e. not detected in the online databases) per person. We are currently trying to identify which of these are shared among the affected individuals and will use computational tools to help us to predict which of these variants are located in the protein coding portions of the genome and can disrupt the protein function and therefore cause the disease.

This research will hopefully reveal a new causative gene for blepharospasm and possibly other forms of primary dystonia which should significantly advance our understanding of disease mechanism and provide a starting point for the development of new therapeutic interventions for this disabling disease.
YOU ARE NEEDED FOR RESEARCH STUDIES

The natural history study is designed to determine how the disorder starts, how it may change over the years, and how it influences the life of the person who has it.

To be eligible to participate, you must
✓ Have blepharospasm or craniofacial dystonia, (sometimes called Meige), or any other primary dystonia.
✓ Be 18 years of age or older
✓ Have had an onset of symptoms in the past 5 years.

What is expected of the participants?
✓ Answer some questionnaires about medical and family history and current state of mind.
✓ Have a neurological exam that will be videotaped.
✓ Donate about 4 tablespoons of blood.
✓ Commit to coming back for the same exam once a year for 5 years.

How much time will it take?
✓ Each visit takes about 1 hour.

The biorepository (or biobank) is a collection of samples given by patients to help researchers learn more about dystonia.

To be eligible to participate, you must
✓ Have blepharospasm, craniofacial dystonia, (sometimes called Meige), or any other primary dystonia.
✓ Be 18 years of age or older

What is expected of the participants?
✓ Answer some questionnaires about medical and family history.
✓ Have an examination by a neurologist or sometimes other specialists to reveal the features and extent of dystonia. The examination will be videotaped to serve as a permanent record.
✓ Give a sample of blood, about 4 tablespoons, that will be stored for future studies of genes and other biomarkers.

NOTE: You are not eligible if you have a secondary dystonia. In order to participate in a study, you must personally contact the study coordinator of any of the participating institutions by phone or by e-mail. Please use the following link: http://rarediseasesnetwork.epi.usf.edu/Dystonia/centers/index.htm to find a coordinator near you.

IF YOU DO NOT HAVE A COMPUTER or have questions, contact:

Ling Yan, PhD, Clinical Research Coordinator-Phone: 314-362-7148; E-mail: yanling@npg.wustl.edu

Or Ami Rosen, MS, CGC, Project Coordinator- Phone: 404-727-3381; E-mail: arosen3@emory.edu

These studies are projects of the Dystonia Coalition, of which BEBRF is a member. It is an international collaboration of medical researchers and patient advocacy groups with a mission to advance the pace of clinical and translational research in the dystonias to find better treatments and a cure.

Below are the current enrolling sites and ones that will be ready soon.

- Baylor
- Beth Israel Medical Center
- Emory
- Mayo AZ
- Medical College of Wisconsin
- Parkinson and Movement Disorder Center of Maryland
- Rush Medical Center
- U. of Alabama in Birmingham
- U. Cincinnati
- UC-Denver
- U. Florida
- U. Lubeck, Germany
- U. Montreal, Canada
- U. Maryland
- U. New Mexico
- U. Rochester
- U. Tennessee
- U. Toronto, Canada
- U. Texas
- Wake Forest
- Washington University, St. Louis
Greater Kansas City Area – A meeting was held recently at the Sabates Eye Center in Leawood, Kansas with John Mehnert, State Coordinator, facilitating. Those attending the meeting in no particular order were: David and Virginia Forbes, Marcella Muehlebach, Jean and Seth Savage, Charlene Upton, Area Representative, Jane Rehrer, Ann Mariotta, Raymond and Nancy Cowan, Carol Lee, Mary Morrison, Janelle Lazzo, Area Representative, Dorothy Lee and John Mehnert, State Coordinator.

Cadott, Wisconsin – Sara Jane Brouchoud, Area Representative, held a meeting in Cadott, Wisconsin the end of October. A video on dry eye was shown and a discussion followed. L-R: Henry Janezich, Mary LeDuc, Shirley Janezich, Sara Jane Brouchoud, Area Representative, and Dale LeDuc. Not shown: Judy Britton, Mr Britton and Norm Brouchoud, photographer.

Tri-State Meeting (Mississippi, Louisiana and Alabama) – A well-attended tri-state meeting was held in Hattiesburg, Mississippi in November. Brenda Hopkins, Mississippi State Coordinator facilitated the meeting, which was also attended by Mary Lou Thompson, BEBRF President, Fran Morgan, Southern District Director and Ellawese McLendon, Area Representative. Dr. Stan Saulny was the speaker. Patients, family and friends from Mississippi, Alabama and Louisiana participated.

Greater Washington DC Area – A fall meeting was held at Holy Cross Hospital in Silver Spring, Maryland, which was facilitated by Jennifer Kawar, Area Representative and Barbara Benton, Eastern District Director. Dr. Stephen Grill spoke about various treatment options.

West San Fernando Valley, California – A meeting with a Halloween theme was held in Northridge, California the end of October, which was facilitated by Mark Sheeler, Area Representative. Dr. Allan Wu who is a researcher spoke at the meeting about his current research project, which was funded by the BEBRF. Tom Welsh, Merz Pharmaceutical Representative, also attended the meeting.

Phoenix, Arizona – Patients, family and friends were excited to attend the first BEBRF support group meeting held in the Phoenix area in several years. In attendance were Dr. Johan Samanta, neurologist, who addressed the group, Peter Bakalor, Western District Director, and Robin Janashak, Allergan Therapeutic Representative. The meeting was held at Banner Good Samaritan Medical Center in Phoenix.
South Dakota – A meeting was held in Sioux Falls, South Dakota last fall. Robert Morecraft, PhD gave a Power Point presentation on his latest brain research and how it relates to finding connections between certain neural pathways and BEB. Deanna Hall, Area Representative, facilitated the meeting. Seated L-R: Marilyn Bolkema, Darlene Robison, Dr. Robert Morecraft, Deanna Hall and Elaine Lonneman. Standing L-R: Sherwyn Bolkema, Duane Robison, Rod Hall and Orville Lonneman.

South Florida – An October meeting was held in the office of Dr. Jan Kronish in Delray Beach, Florida. Dr. Kronish gave a Power Point presentation on blepharospasm and hemifacial spasm, which included symptoms, treatment options and research findings. His presentation was followed by an animated Q & A session. The meeting was organized by Marcia De Fren, Area Representative. Front Row L-R: Ed Raczkowski, Anne Nichols, Marilyn Echlov, Donna Hodis, Shirley Roth, Cindy Lewis and Pam Sotolongo, the doctor’s assistant. Back Row L-R: Rich Ruvido, Karen Rapprt, Jane Blaho, Dr. Jan Kronish, Marcia De Fren, Area Representative, and Don Ribatt. Al Blaho took the photo.

Southwest Virginia – The fall meeting of the Southwest Virginia support group was held at Clarence’s Restaurant in Ridgeway, Virginia. Craig Byrd, Merz Pharmaceutical Representative, gave a presentation on Xeomin. Peggy Gilley organized the meeting. L-R: Peggy Campbell, Janie Koumparakis, Margaret Adkins, Martha Love, Helen Haskins, Sally and Bob Crawford, and Peggy Gilley. Not pictured: Faye Lail

Greater Boston Area, Massachusetts – A meeting was held at the Northeast Rehab Hospital in Woburn, Massachusetts in October. Sande Young, Area Representative, was the support group organizer, and Dr. Aaron Fay was the speaker.

Philadelphia, Pennsylvania – Anne Holsclaw and Joan Nikelsky, Co-Area Representatives, held their first support group meeting at Will’s Eye Hospital in Philadelphia the afternoon before Hurricane Sandy arrived. The following intrepid people still managed to attend despite the weather: L – R: Roe and Moe Halbert, Anne Holsclaw, Joan Nikelsky, and Howard Rosenblatt. Judy Horowitz took the photo.

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Helen Keller, totally blind and deaf and a woman of great achievement and acclaim wrote in Red Cross Magazine in 1919, “The human being is born with an incurable capacity for making the best of things.” True enough. We have all witnessed and experienced the grand capacity of the human spirit to survive, and sometimes transcend life’s challenges. But yet, in our journey of making the best of things, and certainly when facing the challenge of blepharospasm, it is normal to have our ups and downs.

But do you find yourself wondering if what you are experiencing is a “normal” down or a depression, which should be addressed? What is the difference? When should we be concerned? When should we take action and seek help?

Professional counselors use the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) to diagnose depression of concern. If at least five of the following symptoms have been present for two weeks, a diagnosis of major depression may be made: a depressed or sad mood; a lessened interest in usual daily activities; a notable change in eating patterns—either not eating or overeating; a notable change in sleeping patterns—insomnia or oversleeping; agitation or the opposite—slowed speech, movements, and thoughts; tiredness or loss of energy; feelings of worthlessness or unfounded guilt; difficulty in thinking, concentrating and/or making decisions; and thoughts of death or of harming oneself.

We should also be concerned about persistent anger and irritability, excessive focus on bodily aches and pains, and a change in sexual habits. An inability to attend to our daily life tasks, whether a job, caring for our children, or attending classes, should also be cause for concern.

So what should we do if we recognize ourselves in the above? Consultation with our primary care doctor is a good place to start. Most internists, family practice doctors, and geriatricians will have the knowledge and skills to either provide care themselves, or they will know how and to whom to refer you. And what if you are not certain? Perhaps you do not have two weeks plus episodes, or you kind of experience the above, but not exactly? A good rule of thumb is, “When in doubt, check it out!” You have nothing to lose and perhaps a much happier, improved life to gain.

But what if you are reading this, and you have concluded that, based on the above, you are experiencing ups and downs, those occasional, but troublesome, blues. What can we do about, how can we minimize, those “downs” of the normal “ups and downs”? Here are some strategies that can make a difference:

1. We need to accept, and celebrate, that we are NOT our condition! It is easy to slip into chronic frustration with a chronic condition like blepharospasm, but we do have choices as to how we perceive and handle our reality. If we choose to perceive blepharospasm as a terrible tragedy that has befallen us, that is what it will be. On the other hand, if we choose to see it as a darned nuisance and just a part of our otherwise fulfilling lives, we relegate it to nuisance status. We do not like it, we would love to be rid of it, but, in the meantime, we choose to go ahead with a good life.

2. We need to live our lives with a sense of purpose. At any given time, we should have goals encouraging us forward. Our goals may be earning a college degree, learning to play the guitar, getting that north section of the yard planted with daffodils, or baking cookies for the grandkids once week. Whatever we choose, our goals should be personally rewarding and life enriching.

3. We need to work on and hone our communication skills related to our condition. How do we deal with the non-affected world as it responds to our condition? It will be helpful to first think about the various social situations that arise—the questions, remarks, expressions of concern. We can then generate assertive, respectful response options, try them out with family or friends, practice them, and be prepared when those situations arise again. Anticipating, and then handling these events in a positive way, will reward us with a satisfying sense of control.

4. We need to create and maintain balance in our lives. Do not leave out the fun, the carefree, and a bit of silliness. Do not forget the humor! Someone once wrote, “A life without humor is like a carriage without springs…jolted by every pebble in the road.” So true!

5. We need to seek out support. Whether family, friends, support groups, or our wonderful BEBRF, we need to find listening ears and comfortable shoulders. It feels so much worse when you feel alone. And we must not forget to provide the ears and shoulders when others need ours!

6. Which brings us to our need to reach out…to do good! Altruism—doing good for others—is known for lifting the spirits of the altruistic. We elevate ourselves and lessen the negatives in our lives when we reach out to help others. It just feels so good! These are just a few suggestions on how to get past the “downs” and enhance our daily lives. You may want to share this with family and friends and generate your own ideas. “Nothing can bring you peace,” Ralph Waldo Emerson wrote, “except yourself.” Whether by taking action because of depression of concern, or by enhancing our lives and minimizing the “downs” with simple daily strategies, we can make changes for the better. Let’s all go for it!

Ideas for further reading:
10TH BIRTHDAY OF THE UK BLEPHAROSPASM GROUP

Continued from page 2

being. We thought it could be a branch of the BEBRF, but that proved impracticable (although we are listed on BEBRF’s website as a UK support group).

Nilda contacted the UK members of the BEBRF and gave them our details with an invitation to contact us. This changed the parameters of the group. It was no longer ‘local.’ We were contacted by people from all over the UK and the group expanded.

When Nilda was in England in June 2004 with her husband Ron, she came and spoke at our seventh meeting which was attended by 28 people. At that time we were the only dystonia group in the UK focusing solely on one form of dystonia – blepharospasm! Nilda was also here in May 2009 and again came to speak to our group.

We meet four times a year at my home in West Sussex. Sometimes we have a speaker. Otherwise there is always plenty to talk about and news to exchange. We have a summer lunch at the home of a member of the group where we take and share food. We also have a Christmas lunch in a restaurant, which we fund ourselves.

There is a mailing list of 70 people and the average number attending our gatherings is approximately 24, although if there is a popular speaker, there are sometimes as many as 40. The Blepharospasm Group is now much wider than just those who attend the meetings. Some are in contact by email, others by occasional telephone calls. People in a single locality are encouraged to keep in contact with each other.

Many of us belong to The Dystonia Society and, in addition to the Blepharospasm Group meetings, attend local branch meetings. As a group we are unable to do much by way of fundraising because of the logistics of getting together to do so. Some members of the group, however, have organised their own events or have family members who have done so. We always hold a raffle at our meetings and the monies are sent to the Society. We have no expenses and no rentals are involved. Everyone either brings a donation for the raffle, or supports the raffle, or brings a cake for sharing. Speakers have always very generously donated their time free of charge.

We all derive much support from our meetings and from contact with one another. Sometimes a new contact will come along who has never previously spoken to anyone with the condition, and the relief they feel is so apparent. Even if they aren’t able to attend further meetings because of the distance involved, they do know that they are not alone, and can always get in touch with someone who can talk to them without needing long explanations as to what they are going through and what they are coping with. There is a strong sense of community and interaction within the group and newcomers are warmly welcomed. On 16 February 2013 we will be celebrating our 10th birthday!

FOCUS ON BEBRF MISSION: RESEARCH PARTICIPATION

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changes in the brain of patients with focal dystonias by using MRI. Many questions were asked and a health history was taken. I was able to give blood for the genetic blood bank but did not qualify for the MRI. For this I was sent a package, had my own doctor draw the blood, and mailed in my blood sample. This study is now closed and the data analysis is underway. Future studies there include other dystonias but not focal dystonias such as blepharospasm.

6: Zytaze (prescription zinc supplement with phytase to help your system absorb the zinc) is a new product on the market. Its purpose is to extend the botulinum toxin cycle. Although others have found much success with this product, I did not. Dr. Soparkar, who endorses this product, outlined specific diet guidelines when taking Zytaze; at the time that I took Zytaze I did not have these diet guidelines. I may try again. Additional news is that a study was recently published backing the research behind Zytaze.

7: Recently, Dr. Mark Hallett at NIH coordinated with BEBRF to produce a DVD for the medical community explaining benign essential blepharospasm in highly technical terms, using current patients as examples. This involved a one time all morning visit. I appear in this video.

As a participant I know I am being proactive helping myself and others. Please be aware that not everyone may qualify for all the trials; they usually come with specific parameters. But my point is to be aware of and available for those trials that fit each person's particular situation and capabilities and to volunteer whenever possible.

Two good websites to find clinical trials in your area are:

Search for Clinical Trials
http://www.clinicaltrials.gov

Research Match
https://www.researchmatch.org

Many of these research projects are in conjunction with the Dystonia Coalition. Looking toward the future: BEBRF will sponsor a “Fellow” to do research specifically on treatments and cure for benign essential blepharospasm. Donations you make to BEBRF may be directed toward research.

As a member of the American Brain Coalition (ABC), BEBRF has a complimentary membership in the American Society for Experimental NeuroTherapeutics (ASENT). Mary Lou Thompson, our president, asked me to represent BEBRF and attend the ASENT conference in late February 2013. Part of this conference will be devoted to clinical trials and their future. We are curious to hear what they have to say.

“Clinical research is a partnership between the patients and the doctors. It is impossible to make progress without patients willing to volunteer,” says Dr. Hallett. Please consider seeking out a research study near you; then follow up and volunteer if you are able. Without us, the patients, these projects cannot be completed and advancements will not be made.
Q: I recently heard about new FDA approved dry eye treatment called “Lipi Flow.” It is used in a physician office setting utilizing a heat source. How would this work for a BEB patient?

A: I had not previously heard of the Lipi Flow system, and I have no personal experience with it. I’m sure it is effective in some patients. We routinely recommend patients apply warm compresses and perform eyelid massages as clinically indicated, tailoring each patient’s treatment to their specific needs. The advantage of the Lipi Flow system is that it may be helpful for people who are unable to perform these tasks for themselves. The disadvantage is that one has to go to a physician’s office and the treatment is theoretically just once in that day. I often have patients performing these tasks 2-5 times each day. From the YouTube videos I watched, it seems that most patients who were helped had mild-moderate tear film problems, using tear supplements 4-5 times a day. Most BEB patients who need aggressive tear film help find they are not getting enough benefit from supplements used 2-4 times more often than that. Also, this is really only helpful for people who have meibomian gland dysfunction, and probably does not have much role in other tear film problems. In short, although I remain skeptical that this will provide greater help for people with severe problems who are already treating themselves at home, aside from issues of cost and physician access, I see no immediate downsides to trying the treatment.

Charles N. S. Soparkar, MD, PhD, Plastic Eye Surgery Associates, Houston, Texas

Q: I attended the recent symposium in Ohio, and one of the doctors said that with apraxia of eye lid opening, the brain is telling the lids to open and nothing is happening. What if nothing is happening because the brain isn’t telling the lids to open or if you find out you have been sitting for seconds or minutes with closed eyes, or you walk into something and you find out only because someone tells you? Otherwise, if you bump into something you think you have been daydreaming. Can a person have apraxia and not be aware of it?

A: Patients with apraxia of lid opening are aware they are making a conscious effort to open their eyes but can’t. I don’t think you’re describing apraxia.

Q: My wife suffers from Meige as well as blepharospasm. What kind of doctor would be best for her to see?

A: She should see a doctor that has a special interest in facial focal dystonias and experience in their management. That could be a neurologist, a neurologist with a special interest in movement disorders, an ophthalmologist, or an oculoplastic surgeon. He or she should routinely do full face toxin injections and use oral medications when indicated to obtain the best possible control of spasms.

John A. Burns, MD, Department of Ophthalmology, Ohio State University College of Medicine, Columbus, Ohio

Q: Please elaborate on cataracts and the “older patients” with blepharospasm.

A: Cataracts tend to occur as we get older. It can cause our eyes to be more light sensitive, and may worsen blepharospasm symptoms. Additionally, tear film abnormalities worsen as we get older also leading to blepharospasm symptoms. Once, the cataracts impede vision enough, they can generally be safely removed.

Q: After a myectomy, would it be a good idea to use Dysport® for blepharospasm with its tendency to spread after injection?

A: Yes, it can still be used. You might go with smaller doses until you see how you react following a myectomy. Also the tissue planes after a myectomy are disrupted, and the Dysport® may not spread as much.

John R. Burroughs, MD, FACS, Colorado Springs Ophthalmology, Colorado Springs, Colorado

Q: I have had blepharospasm since 2010. Now I’m worried because I have a tremor in my neck. It moves back my head continuously and I cannot control it. When I rest, it disappears, just like my eyelids. I visited the spinal specialist and he told me it has nothing to do with spinal. I wonder if it is because of blepharospasm?

A: Blepharospasm is a focal dystonia affecting the eyelids, but it can spread to involve other muscles (or parts of the body). It is common for spread to affect the neck. Hence, it is very likely that the symptoms described are a result of spread. Of course, a neurologist should be consulted to verify any diagnosis of this sort.

Q: Is it safe to say oromandibular dystonia rarely exists without benign essential blepharospasm or other cranial dystonias coming first?

Continued on next page
Oromandibular dystonia (OMD) may well exist without BEB. BEB is more common and BEB can spread to include OMD. The cranial dystonias can have mixtures of involvement of the different muscles of the face, jaw, tongue and neck.

Q: Does the trigeminal nerve or TMJ play a part in BEB?
A: There are some weak suggestions that either one of these might play a role some of the time, but generally the answer is no.

Q: My father was diagnosed with blepharospasm a few years ago, and it is progressively getting worse. Now my sisters and I are almost positive my mother is getting the beginning signs of it as well. We are wondering if maybe when they were first married and living in an apartment maybe there was some type of toxin they breathed in unknowingly which is just now presentation in their 60’s. What are the chances of 2 people with no genetic connection having this rare condition but lived together at one point in their life.
A: There is really no evidence for a delayed effect of any toxin causing blepharospasm. I do not think this a viable explanation. Albeit rare, two apparently unrelated persons can certainly get blepharospasm. There is no research that I can think of that would be valuable at this point in time.

Mark Hallett, MD, NINDS, NIH, Bethesda, Maryland

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MICROVASCULAR DECOMPRESSION FOR HEMIFACIAL SPASM

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and designed to eliminate the cause of HFS: irritation of the facial nerve by an artery or vein. The surgery involves exploring the facial nerve where it originates and exits the brainstem, where an artery or vein can commonly be found compressing the nerve and causing irritation. MVD surgery is performed by a neurosurgeon with the patient asleep under general anesthesia through an incision located one finger breadth behind the ear, extending about the length of the ear. Hair shaving is not necessary. During MVD, the neurosurgeon places small biocompatible pads between the facial nerve and any compressive artery or vein to prevent the nerve from becoming irritated and sending the hyperactive signals that cause spasm in facial muscles. MVD permanently cures HFS in the vast majority of patients, with clinical studies showing that 85 - 90% of patients achieve total remission lasting for a 10-year follow-up period. Risks of MVD related to surgery include a 1% risk of infection, 3% risk of developing leaking of cerebrospinal fluid from the surgical site which can require another surgical procedure to fix, 1.4% risk of permanent facial nerve weakness, a 3 – 4% risk of decreased hearing on the side of surgery and a less than 1% risk or stroke, which can cause permanent symptoms.

During surgery it is possible to monitor the hemifacial spasm and determine that it has resolved. This guides the surgeon to do enough decompression to relieve the problem without doing more surgery than necessary. It helps prevent complications and assists the neurosurgeon in performing adequate decompression of the facial nerve.

HOW LONG IS THE HOSPITAL STAY AFTER MVD SURGERY?
Average hospital stay is two to three days after the surgery.

HOW EFFECTIVE IS BOTOX® VERSUS MVD IN TREATMENT OF HEMIFACIAL SPASM?
Both treatments are highly effective in relieving symptoms of HFS. However, only MVD offers potential to cure HFS.

CAN I HAVE MVD IF I HAVE PREVIOUSLY HAD BOTOX® THERAPY?
Yes. However, it is recommended to wait until the effects of the BOTOX® injection have worn off (usually 3-6 months after the last BOTOX® therapy) before having MVD surgery because residual effects of BOTOX® can prevent safe monitoring of facial nerve function during surgery.

WHO IS NOT A CANDIDATE FOR MVD SURGERY?
Every person who suffers from HFS is a candidate for MVD. Each person should be evaluated on an individual basis by a neurosurgeon to determine the best treatment for his/her HFS.
1. When you rearrange the letters...
ASTRONOMER = Moon Starer
THE EYES = They see
THE MORSE CODE = Here Come Dots

2. I intend to live forever .... So far, so good.

3. Why do psychics have to ask you for your name when they begin?

4. The hardness of the butter is proportional to the softness of the bread.

5. Everyone has a photographic memory, some just don’t ever develop.

6. When chemists die, they barium.

7. I'm reading a book about gravity. I just can’t put it down.

8. I didn’t like my beard at first. Then it grew on me.

9. I used to be a banker, but then I lost interest.

10. A cartoonist was found deceased in his home. Details are sketchy.

I’d better quit while I’m still behind.

NEW ACADEMY EXHIBIT
Barbara Beckett RN, Academy Arrangements Chair

It was an exciting day as we put up our new eye-catching exhibit at the AAO (American Academy of Ophthalmology) /APAO (Asia-Pacific Academy of Ophthalmology) joint meeting in Chicago in November. We had a great corner location and we were so anxious to see how our new exhibit would look. Our purpose for exhibiting at academies is to educate doctors and find those who are treating blepharospasm, Meige and hemifacial spasm so it is important that our exhibit draw doctors in.

Because of the very well organized, high quality, scientific and educational content of this meeting, doctors from all over the world are eager to attend. This meeting is the world’s largest ophthalmic exhibition with over 25,000 attendees each year. We also exhibit at the American Academy of Neurology and the Movement Disorder Society meetings.

I felt privileged to have Richard Winslow, MD (a BEB patient) exhibiting with me as he was able to respond to nearly all the international physicians in their various languages. We also displayed a sign that indicated we spoke Spanish.

One of the highlights of our days was attending a seminar on blepharospasm by Richard Anderson, MD and Michael Yen, MD. I was especially pleased as they both expounded on the value of the Benign Essential Blepharospasm Research Foundation and how we were known to educate patients and doctors about blepharospasm/Meige. It was a great meeting in Chicago, and we feel we made many good contacts with doctors from all over the world who are eager to take information back to their patients.

MARK’S RAMBLINGS
Mark Sheeler is the Coordinator of the West San Fernando Valley, California Support Group

Q: I believe that in many cases BEB has a dental connection. Its spread often seems to lead to oromandibular problems. The jaw joint along with extraction and root canal procedures may trigger blepharospasm. Can you address this issue?

A: Patients with blepharospasm often have spasms of adjacent facial and jaw muscles. The latter is referred to as “oromandibular dystonia” or OMD. There are two major types of OMD – 1. Jaw opening and 2. Jaw closure. The jaw closure form of OMD is typically manifested by clenching of the jaws (also called “trismus”) and grinding of the teeth (also called “bruxism”). When patients clench their jaws and grind their teeth, they often sustain damage to their teeth, including wearing off the enamel, tooth fracture, and other injuries to the teeth. In addition, they exert a great deal of pressure on the joint between the lower jaw (mandible) and the skull, the so-called temporo-mandibular joint (TMJ). The best treatment of bruxism and secondary TMJ syndrome is injection of botulinum toxin into the muscles that cause the pressure on the TMJ, namely the masseter and temporalis muscles.

Joseph Jankovic, MD, Director, Parkinson’s Disease Center and Movement Disorders Clinic, Baylor College of Medicine, Houston, Texas

ASK THE DOCTOR
Continued from page 13
SUPPORT GROUP MEETINGS

To get your support group meeting in the next issue of the newsletter, Please notify the foundation office, before February 1, 2013, the next newsletter deadline.

NEW CONTACT PERSON

Jacksonville, Florida Area
Helen Rose Chestnut
77 Ponte Vedra Colony Dr
Ponte Vedra, FL 32082
Tel. (904) 543-9127

SUPPORT GROUP MEETINGS

South

Huntsville, Alabama
Blepharo-Buddies Awareness Support Group
Sunday, January 27, 2013 and Sunday, April 28, 2013 1 – 4 p.m.
Dowdle Center, 109 Governors Dr, Huntsville, AL
Speaker to be announced
Contact: Linda Webb… (256) 723-2661 Phone and Fax

Mississippi/Louisiana
Sunday, February 17, 2013 2 – 4 p.m.
Resorts Casino Restaurant, 1100 Casino Strip Blvd, Tunica, MS 38664
“Share, Care, and Fare” (you may purchase a meal from the buffet)
Contact: Brenda Hopkins…. (601) 796-3741, Email: brenda_hopkins@att.net Or Ellawese McLendon… (601) 261-0573

East

New Jersey
Spring, 2013. Specific date to be announced.
Time: To be announced.
Neptune, New Jersey 07753
Contact: Bonnie O’Rourke… (732) 922 4429, Email: tombor1@verizon.net

Long Island, New York
Tuesday, January 8, 2013 and Tuesday, February 12, 2013 5:30 – 6:30 p.m.
RSVP: Registration is required no later than 5pm the day before. Call Jovanna Little at (631) 473-1800 or e-mail jlittle@lmni.org with your name and any guest name(s).

West

San Jose, California
Saturday, March 30, 2013; 1 - 3 p.m.
Lincoln Glen Church, Fireside Room, 2700 Booksin Ave, San Jose, CA 95125
Speaker: Carlo Rob Bernardino, MD, Oculoplastics and Aesthetic Surgery, “What’s new in the Treatment of Facial Spasms”
Contact: Kathy Berg… (408) 270-9787, Email: Kberg@pacbell.net

CORRECTION TO THE NOVEMBER/DECEMBER 2012 ISSUE OF THE BEBRF NEWSLETTER

In volume 31, number 6, November/December 2012, page 14, issue of the BEBRF Newsletter, the prices quoted per unit of the various botulinum toxins for reimbursements from Medicare should have been listed as follows:

- $5.472 / unit of BOTOX®
- $4.465 / unit of Xeomin® (1 unit of Xeomin® = 1 unit of BOTOX®)
- $7.018 / 5 units of Dysport® (2.5 to 3.5 units of Dysport® = 1 unit of BOTOX®); assuming 3 units of Dysport® = 1 unit of BOTOX®, price for BOTOX® “equivalence” is $4.211 / unit
- $10.974 / 100 units of Myobloc® (40 to 50 units of Myobloc® = 1 unit of BOTOX®); assuming 50 units of Myobloc® = 1 unit of BOTOX®, price for BOTOX® “equivalence” is $5.487 / unit

Reimbursement rates change from state to state, from urban area to rural area, and from time to time.
In 1988, O.G. Bruce was elected President of BEBRF, and her outstanding leadership skills led BEBRF to new levels of recognition. In November, 1990, O.G. was invited to represent BEBRF as one of the thirteen panel members at the Consensus Development Conference on Clinical Use of Botulinum Toxin, type A. The meeting was held at the National Institutes of Health, to develop consensus on the clinical trial use of botulinum toxin. As a representative of the panel, O.G. addressed the issue that botulinum toxin, type A, was safe and effective in the symptomatic treatment of blepharospasm, Meige and hemifacial spasm. As a result of the four day meeting, the efficaciousness of botulinum toxin, type A, was established.

O.G. Bruce discovered the Benign Essential Blepharospasm Research Foundation in 1982 after being diagnosed with blepharospasm. The article about Mattie Lou Koster and BEBRF that appeared in the Wall Street Journal in January, 1982, caught O.G.’s attention and she proceeded to contact Mattie Lou. The two blepharospasm patients became friends and O.G. quickly assumed numerous responsibilities in the growing foundation. O.G. truly exemplified the caring and sharing spirit of BEBRF.

In Loving Memory of O.G. Bruce

November 18, 1928 – October 17, 2012 • Past President of The Benign Essential Blepharospasm Research Foundation (BEBRF)