



BEBRF's Information Packet to Assist those Applying for Social Security Disability Insurance (SSDI)

The **B**enign **E**ssential **B**lepharospasm **R**esearch **F**oundation frequently receives inquiries from patients regarding information and support to apply for disability benefits with Social Security (SS). To this end, BEBRF assembled these materials to assist in pursuing these benefits as efficiently as possible, equipping you with appropriate expectations and information.

The degree to which blepharospasm is disabling varies with the individual. Symptoms may or may not get worse with time and treatments may or may not continue to be effective. Some patients become so impaired by blepharospasm or other dystonia symptoms that they are unable to continue working productively and may qualify for special disability benefits under the Social Security program.

Included in this packet you will find:

1. This cover page with general information
2. Questions and Answers regarding and covering the Social Security Disability claims process
3. A definition of "functionally blind"
4. A list of blepharospasm patients who succeeded in being approved for Social Security Disability benefits. You have their permission to contact them
5. Excerpts from the Social Security impairment list
6. A checklist of information to have available for your SSDI application
7. Sample disability letters from physicians you may share with YOUR doctors for the purpose of submitting with your application
8. Personal stories by blepharospasm patients who have been successful in being approved for Social Security Disability Insurance
9. Medical articles you might wish to include in your Social Security claim packet (if appropriate to your medical condition). Additional articles are available as needed and can be ordered from the BEBRF office (free).
10. Medical Source Statement that your doctor can quickly and easily fill out to help with your disability case
11. Medical Glossary

The URL for a Social Security disability guide is <https://disabilityapprovalguide.com>. It is a useful resource for Social Security Disability benefits information and application. Please note that this website is not affiliated with SSA or any other government agency. It is sponsored by attorneys and advocacy groups.

If you do not have computer access, maybe a relative can help you or you might use a computer at your local library. If not, contact your local Social Security office.

Please refer to this BEBRF Social Security Disability Insurance guide as a supplement to any information directly from the Social Security government offices.

Medical Source Statement Regarding Blepharospasm for Social Security Disability Claim

Patient: _____ SSN: _____ DOB: _____

Blepharospasm is a well recognized neurologic condition characterized by episodic, spontaneous, involuntary closure of the eyes, rendering this individual bilaterally blind with the equivalence of no light perception vision during these unpredictable periods of variable duration and frequency. Unfortunately, even with regular treatments, this patient continues to suffer from statutory blindness (visual acuity worse than or equal to 20/200 in both eyes and/or profound visual field loss to within 5 degrees of central fixation) **for approximately:**

- ____ Less than 10% of a typical work day
- ____ Between 10-25% of a typical work day
- ____ Between 25-50% of a typical work day
- ____ Between 50-75% of a typical work day
- ____ Most of a typical work day

Check all that are present

- ____ Vision impairment occurs instantly and unpredictably throughout a typical day
- ____ Limits ability to distinguish detail, read, or do fine work
- ____ Limits ability to perceive visual stimuli in the peripheral extent of vision
- ____ Patient develops dry eyes and poor quality tear films, causing glare and dazzle

In your opinion, as the treating physician/vision specialist for the above patient, do you believe he/she is able to sustain a 40-hour work week on a consistent and regular basis due to his/her Blepharospasm disorder? **YES or NO**

Comments: _____

Date: _____ M.D., O.D.

(Print Name)

The Social Security Disability Process

“What in the world is blepharospasm, Mr. Healy?” That was a question I was asked by a Federal Administrative Law Judge (ALJ) who was about to decide the social security disability case for one of my clients. My client was unable to work on a full-time basis due to her blepharospasm condition and we were hoping the ALJ would rule in our favor that day. Everything worked out just fine for my client and she was awarded disability benefits to help replace some of her income.

I have practiced social security disability law for 17 years and have represented several thousand clients with various physical and mental conditions. Blepharospasm is a condition that is not commonly seen in many disability hearings. I would like to give a brief overview of what the Social Security Administration (SSA) is looking for to award disability benefits in general and then we can zero in on blepharospasm and how SSA looks at this condition.

SSA has a five-step process when evaluating a case for disability benefits.

1. **Substantial Gainful Activity:** Is the individual currently working and earning a certain amount each month? If an individual is working and earning over \$1180 (2018 limit) in income per month, SSA will consider them not to be disabled, regardless of any disability (20 C.F.R*. 404.1520 (b)).
2. **“Severe” Medically Determinable Impairment:** At step two, impairments are “severe” if they significantly limit a person’s ability to perform day to day work activities (20 C.F.R. 404.1520 (c)). Step two also has a durational requirement where a condition has lasted or is expected to last for more than 12 months or is expected to result in death (20 C.F.R. 404.1521).
3. **SSA Listings:** Step three is where SSA determines whether a claimant meets any of the “Listings.” The Listings are descriptions of various conditions and the impairments they cause (20 C.F.R. Part 404, Subpart P, Appendix 1). Blepharospasm falls under Listing 2.00; however, there is not a specific Listing for blepharospasm only. The vision Listings are 2.02 through 2.04 and deal with loss of central visual acuity, contraction of the visual fields in the better eye, and loss of visual efficiency.
4. **Past Relevant Work:** At step four, SSA determines whether an individual can do the work they used to do before the impairment interfered with full-time work. If the impairment keeps an individual from doing their past relevant work, then the process proceeds to step five. If SSA or the ALJ finds that an individual can do their past work, then the individual is not entitled to benefits (20 C.F.R. 404.1520 (f)).
5. **Any Other Work:** At the final step, if SSA or the ALJ finds there is no past relevant work, then they determine if there are other jobs in the national economy that an individual can do on a regular and full-time basis with the skills he/she has acquired in the past fifteen years (20 C.F.R. 404.1520 (g)).

The Listings for SSA get updated and/or reviewed every five to ten years. Blepharospasm was specifically mentioned in the 2013 Code of Federal Regulations* (C.F.R.); however, the 2018 C.F.R. does not have a specific subsection for

blepharospasm. This is what the 2013 C.F.R. mentioned about blepharospasm so you can have some insight into the SSA thought process. "This movement disorder is characterized by repetitive, bilateral, involuntary closure of the eyelids. If you have this disorder, you may have measurable visual acuities and visual fields that do not satisfy the criteria of 2.02 or 2.03. Blepharospasm generally responds to therapy. However, if therapy is not effective, we will consider how the involuntary closure of your eyelids affects your ability to maintain visual functioning over time" (20 C.F.R. Part 404, Subpart P, Appendix 1, 2.00 A(8)(b), 2013 edition).

One of the keys to winning a disability case for blepharospasm or any severe medically determinable impairment is to get a medical source statement from a treating physician explaining that the condition is affecting an individual's ability to sustain a 40-hour work week. Many physicians will put blepharospasm in their treating notes and that is helpful; however, a more effective tool is a statement via a paragraph or two from a physician stating how blepharospasm specifically affects that patients' day to day activities in the work force and around the house.

One question to think about is will the blepharospasm condition keep an individual OFF TASK for more than 15-20% of the work day? Employers pay for an employee to be productive and ON TASK. If an employee is off task for even 10-15% per day, that will affect production and an employees' ability to stay employed in many instances. If an employee can show through medical records, employer records, or a statement from a physician or supervisor that they are off task more than 15-20% of the work day, then the ALJ will often find this information compelling in his/her final analysis. At the end of the day, a social security disability case hinges on whether the disabling condition is severe enough to keep an individual from working on a regular and sustained basis.

A final thought on pursuing a social security disability claim for blepharospasm or any number of physical or mental conditions. You don't have to have an attorney represent you at a social security disability hearing; however, an attorney who specializes in disability cases is the first thing to look for if you decide to hire an attorney. Don't hire an attorney who practices 7-10 different areas of law. He/she won't be in front of ALJ's enough to keep up with the changing disability process. Most attorneys do not charge a fee unless they are able to win your case. Feel free to call the attorney you are thinking about hiring for your disability case and ask them if they have handled a blepharospasm case. If the attorney asks, "What in the world is blepharospasm?", then you may want to keep looking.

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UNDERSTANDING DRY EYE DISEASE -

“The whole is greater than the sum of its parts” – Aristotle

Mirwat S. Sami, MD, J. Randall Patrinely, Jr., Charles N.S. Soparkar, MD, PhD

Dry eye disease is one of the most prevalent ocular conditions worldwide and is emerging as a leading reason for visits to eye care professionals. What was first defined as a condition due to a decrease in the water content of tears, is now considered a puzzling and multifactorial condition with associations to everything from lifestyle to general health issues.

It was first coined as a medical condition in the 1950s by Swedish ophthalmologist Henrik S. C. Sjogren, who named it keratoconjunctivitis sicca, or “dry inflammation of the cornea and conjunctiva”. Though used interchangeably with the term Dry Eye Disease (DED), however, keratoconjunctivitis sicca more specifically denotes dry eyes secondary to decreased tear production as seen with aging changes, autoimmune conditions such as rheumatoid arthritis, Sjogren’s syndrome, systemic lupus erythematosus, sarcoidosis, postradiation fibrosis and certain types of medications.

As our understanding, not to mention acceptance, of DED has evolved, so has the nomenclature of its etiological factors...keratoconjunctivitis sicca, meibomian gland dysfunction, posterior lid margin disease, blepharitis, the terms used to define a cause of the dryness. Though it all sounds very confusing, it makes sense that DED is a multifactorial and complex condition, wherein no one treatment is the magical cure. We hope to take some of the mystery out of this diagnosis for our readers by breaking the sum down into its various parts, so to speak.

Let’s start off by remembering the components of our natural tear film: aqueous or water, oil and mucin. Water is by far the largest part of the tear film but both the other components, though making up approximately 4-6% of the tear film, are equally important in ensuring a good “quality” tear film. The oil in tears prevents excessive or rapid evaporation of tears, and the mucin layer holds the tear film across the surface of the eye. If even one of the components is deficient, the tear film is considered “poor quality” and is ineffective at eye lubrication, resulting in dry eyes.

So what makes dry eyes so complex and multifactorial?

DED is more than simply a supply and demand issue... quality is just as important in this case as is quantity. We know this from the advances we have made in the study of the tear film and its components. To make matters a little more complicated, let us introduce yet another factor for consideration: Distribution!

Demand:

In some cases, dry eyes develop due to an increase in demand. Many times this is due to a change in the position of the eyeball or the eyelids, resulting in increased exposure of ocular surfaces to the elements and to evaporation. Conditions such as thyroid eye disease, orbital tumors, eyelid malpositions, apraxia, eyelid laxity and scarring can result in increased exposure. Besides medical conditions, lifestyle factors can also increase evaporation of the tear film resulting in dryness, such as decreased blinking from watching TV, computer reading, driving, poorly regulated humidity in temperature-controlled environments (such as office, car air conditioning).

Supply:

This is where **quality** and **quantity** both play an important role.

A decrease in **quantity** can be seen with ageing, postmenopausally in women, in orbital inflammatory conditions such as thyroid eye disease, sarcoidosis, Sjogren’s syndrome, lupus, and other autoimmune conditions. Sometimes this decrease in aqueous production can be secondary to medical treatments such as postradiation fibrosis, medications such as anti-histamines, sedatives, diuretics, beta-blockers, oral contraceptives, nasal decongestants and opiates, to name a few. Another medically-induced cause of DED is laser refractive surgery, where corneal nerves are cut during the surgical process, leaving the cornea less sensitive to dryness. As tear production is inherently driven by corneal stimulation, this

can result in decreased tear production through decreased feedback from the corneal nerves. In most cases, this is short-lived but in some it can result in more permanent dryness.

As mentioned earlier, any change in the balance of the 3 components of the tear film will result in “poor **quality**” and thus DED. Such as having less oil in the tear film will cause it to evaporate faster, thus making it ineffective in lubricating ocular surfaces. In these cases, though the cornea up-regulates tear production, the new tears formed continue to be poor quality and so a vicious cycle starts, resulting in more volume of these tears. This increase can, in turn, overwhelm the tear drainage system that cannot right away accommodate the volume and so the residual tears will find their way out of the eye by flowing down the cheek, resulting in tearing. That probably sounds counterintuitive but is known to be a big factor in tearing issues.

Conditions that decrease the amount of oil or mucin in the tear film, and in turn the quality, include blepharitis, rosacea, meibomian gland dysfunction and ocular surface inflammatory conditions. Other factors such as apraxia, incomplete eyelid blink and lagophthalmos (incomplete eye closure) can result in decreased oil being pumped out of otherwise normal oil glands into the tear film.

Distribution:

Just like in any situation of supply and demand, even if the supply is appropriate, an equally adequate distribution is important. This is where our eyelids and our lifestyles come into play. Though we attribute so many aesthetic and emotive characteristics to eyelids, their *raison d'être* is simply and succinctly ... eye protection. They not only cover the eyes but also distribute tears across the ocular surface with each blink and then pump the remaining tears and debris down the lacrimal drainage system. For eyelids to function in this way, they must have a brisk and complete blink response and the conditions that can affect this are eyelid malposition, spasms, apraxia, eyelid laxity and scarring. In these situations, the tear film is not properly distributed to all ocular surfaces. Also, as these tears are not pumped down the tear drain properly by the poorly functioning eyelids, they can result in ...tearing!

Our lifestyles play an important role in adequate tear-film distribution as well. Activities like extended computer use, television viewing, reading and driving can all result in a delayed and poor blink response. Also, with decreased blinking, the oil glands do not pump out oil into the tear film as effectively and we end up with a poor quality tear film as well.

Having explained the various factors that can result in DED, we hope readers find it easier to understand its complex nature, varied presentation and extreme variability even within the same person. The fact that not only can each one of us identify several causes of DED in our lives and that most of these factors only get worse with age, certainly does not help in dealing with this intricate disease process. It is critical for eye doctors to elicit a careful history of DED presentation and associated factors, a detailed examination with testing of tear film quality and quantity when necessary and possible referral to an ocular surface specialist when needed for surgical management... all before permanent damage to the ocular surfaces is sustained due to DED.

In the setting of blepharospasm, it is imperative for patients and treating physicians to recognize the strong association between BEB and DED. The causal relationship, that is, does one promote the other, is still poorly defined, but what remains clear is that appropriate recognition and treatment of DED will decrease severity of blepharospasm and so should always be undertaken simultaneously to ensure best treatment results. Also, as both dry eyes and blepharospasm are known to worsen with increasing age, it makes sense to periodically re-evaluate the treatment plans for both conditions.

Neural Mechanisms of Reflexive Blinking and Eye Muscle Spasms in Blepharospasm: An event-related fMRI study

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The cause of blepharospasm (BSP) is unknown and its pathophysiology, like other focal dystonias, remains poorly understood. Presently there is no cure for the disorder and most oral medications are only minimally helpful. Botulinum toxin injections are often an effective treatment, but this involves discomfort associated with repeated injections and the relief is only temporary. An increased understanding of the pathophysiology of BSP is needed so better treatment options can be developed.

Prior electrophysiological studies suggest that the trigeminal nerve system – a brain system that transmits sensory information from the eye to the facial nerves that trigger blinking – may be abnormal in patients with BSP. To date, however, an exploration into trigeminal nerve system function together with an examination of activity that occurs throughout the rest of the brain during blinking in BSP has not been performed.

While a wide variety of imaging studies help support the presence of basal ganglia dysfunction in focal dystonia, the sensorimotor cortex, thalamus and cerebellum may also play a role in its pathophysiology. Indeed, a network model with abnormal interactions between the basal ganglia and cerebellar circuits has increasingly been proposed as a central problem in dystonia. An investigation into brain circuit functioning during individual dystonic muscle spasms in BSP, however has not previously been conducted.

In this BEBRF research project, we aim to fill in gaps in our knowledge of the brain mechanisms that drive blinking and underlie dystonic muscle spasms in BSP using functional MRI (fMRI). We will first test the hypothesis that spontaneous and reflexive blinking is associated with an increase in activity of the trigeminal nerve system in BSP patients relative to healthy controls. Second, we will test the hypothesis that basal ganglia circuit dysfunction leads to the triggering of dystonic spasms while cerebellar circuit dysfunction determines the severity of spasms.

Fifteen adult patients with BSP will be recruited. Patients must not be on medications that might alter brain activity. Additionally, patients need to be symptomatic so they must not have been injected with botulinum toxin within the prior three months. Fifteen matched healthy controls without neurologic or psychiatric disease will be recruited from patient spouses and the community at large.

Study participants will have their brain activity recorded during four fMRI scans while they lie comfortably with their eyes open and gaze on a fixation point. During all for fMRI scan, spontaneous blinks in all participants and eye muscle spasms in patients will be recorded using electrodes attached to the skin around the eye that can detect the

electrical activity in the underlying muscles. During two of the four scans, reflexive blinks will be elicited using air puffs delivered to an eye. The occurrence of all blinks and spasms will be verified by comparing muscle electrode recordings to video recordings that are made with an eye-tracker system inside the MRI scanner.

By characterizing the abnormal brain signals associated with the spontaneous and reflexive blinking, a better understand of how blinking mechanisms are affected in BSP will be gained. This knowledge in turn could lead to an imaging biomarker that can improve our ability to diagnose BSP and monitor brain responses to treatment interventions. Identifying the brain mechanisms associated with dystonic spasms in BSP could help improve emerging therapies that alter circuit function. For example, it might help direct the selection of the best target brain region for transcranial magnetic stimulation, which has shown some potential to improve symptoms in BSP. Further investigations will be needed, however, to try and link abnormal brain activity and circuit dysfunction to the underlying molecular or cellular disturbances that may be present in BSP.

Injection Techniques with Botulinum Toxin in the Treatment of Blepharospasm

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The development of Botulinum Toxin (BoNT), a muscle paralyzing agent from the bacteria, *Clostridium botulinum*, has produced major advances in the treatment of dystonia (such as blepharospasm or torticollis), hemifacial spasm, tremor, tic disorders, and a number of other conditions - including those annoying crow's feet! In 2000, because of the wide variety of injection techniques in treating blepharospasm, a group of ophthalmologists and neurologists recognized as "experts" by the BEBRF were surveyed for injection locations and amount of toxin injected on initial and average visits. Each of the respondents indicated dosages, dilutions, and number of injections for a typical patient. Although there were some differences in the sites for injection between injectors with ophthalmology and neurology training, these differences have declined. The five sites per eye identified in the figure are the most common locations for toxin injection. Other sites will vary with the presentation, and the experience of the physician. The purpose of this handout is to assist patients and physicians with discussion points to tailor future toxin therapy.

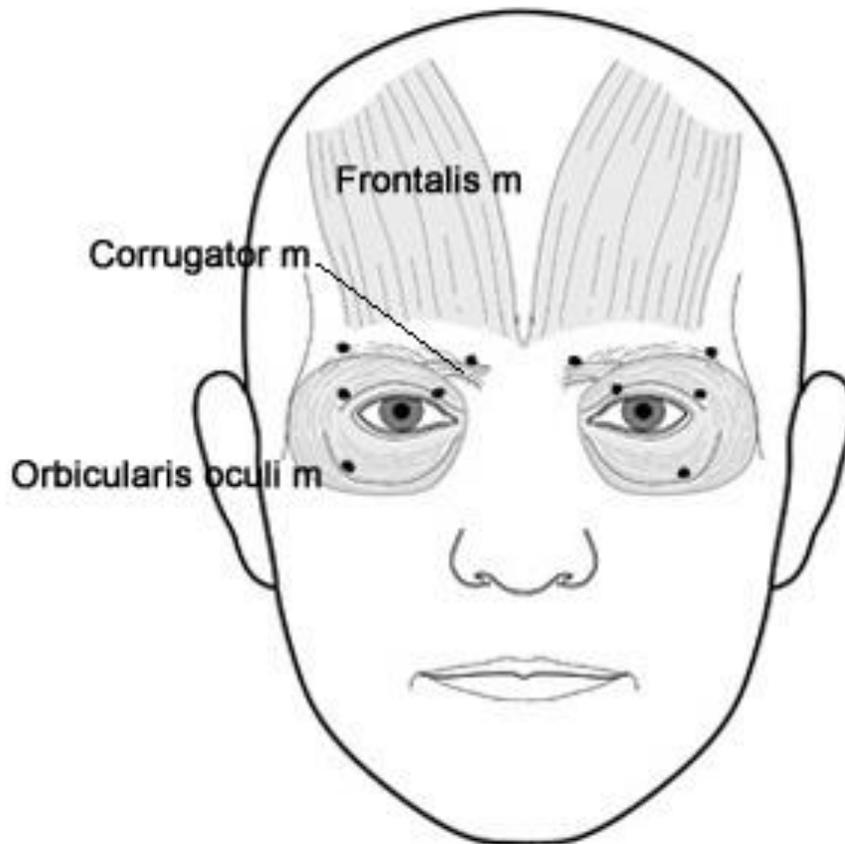
Toxin Dosage:

Toxin dosage varies from patient to patient, and units vary from toxin to toxin. Currently, there are four commercially available toxins. The three BoNT-A include Botox®, Dysport® and Xeomin®; Myobloc®/Neurobloc® is the only available a B-type toxin. While the injection techniques will not change with these toxins, dosages will differ. It is therefore important to know the brand name, not just A or B, of toxin used at each injection session.

Initial dosage range for each toxin is listed in the table. Further dosage adjustment may be made for size of the patient, severity of the symptoms, and prior response to therapy. Ideal dosing should produce a benefit within one week of the session, and a total duration of benefit of approximately twelve weeks. In instances where side effects, such as lid drooping (ptosis), double vision (diplopia), or tearing occurs, injection with less toxin or in a slightly different location may allow more effective response.

Each of the A-type toxins requires reconstitution with preservative free, normal saline. Most experienced injectors reconstitute with 1 cc of solution, thus with Botox® and Xeomin®, 0.01 cc = 1 unit, and Dysport®, 0.01 cc = 5 units. Myobloc®/Neurobloc® may offer some convenience of use, because this preparation does not require reconstitution and may be stored in the refrigerator. The dilution for this toxin is 0.01 cc = 50 units. It is difficult to convert from one toxin to another on the basis of dosage ratio, and each compound should be treated as a unique toxin.

Injection Diagram for Treating Blepharospasm



The 10 most recommended injection sites are marked on the diagram. Injection of the corrugator supercilii m is often helpful in patients with furrowing around the eyebrows. Injection under the skin of the upper lids is more effective than injections higher in the orbit (off the lid margin). Injections to the lower lids may be off the lower lid margin, and usually just to the lateral site to avoid tearing.

Other injection sites include the lateral orbicularis oculi m. - particularly if deep furrows in the skin indicate spasm in this area. With midline brow furrowing, injection of the procerus may be helpful. Nasal movements may respond to levator labii superioris nasi m., but this injection may cause tearing and lip weakness.

Relative dosages for Botulinum Toxin^a

Toxin	Frontalis		Upper Lid		Lower Lid	Other	Recommended Dosage/eye ^b
	Site	Total	Site	Total	Site	Site	
BoNT -Type A							
Botox®	5	10	5	10	8	5	30-50
Dysport®	15	30	15	30	25	15	100-120
Xeomin®	5	10	5	10	10	5	35
BoNT -Type B							
Myobloc®	150	300	150	300	200	200	1,000-2,500

^a This table is adapted from Stacy M, Handbook of Dystonia. Informa Press 2006.

^b Recommended dosages are obtained from the Package Insert from countries that have approved the toxin. They are listed as a per eye dosage. Product approvals vary from country to country.

This article originally appeared in the Benign Essential Blepharospasm Research Foundation Newsletter, Volume 26, Number 3, page 13 (2007). Note that the paragraph beginning, "Each of the A-type toxins..." has been revised from that appearing in the newsletter to correct numerical errors.

ESSENTIAL BLEPHAROSPASM

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Essential blepharospasm is a chronic bilateral upper facial dystonia of unknown etiology. It has been postulated that the condition is caused by either a central monoamine overactivity or a relative cholinergic deficiency, but neither of these mechanisms has been proved. Some physicians consider this condition to be purely psychogenic. Although this may be the case in rare patients, and although the condition worsens during periods of stress, most patients have no underlying psychiatric disease nor appear in need of psychologic counseling.

Essential blepharospasm affects both the orbital and palpebral portions of the orbicularis oculi muscles, resulting in involuntary closure of the eyelids. The frontalis muscle, corrugator supercilii, and procerus muscles may also be affected, producing significant spasms of the forehead and nasal regions. The condition usually begins in the 4th-6th decades of life; however, I have observed it in several children in their early teens, and I also have examined in several elderly patients in whom the disorder began when they were over seventy years old. It occurs with equal frequency in men and women.

The onset of essential blepharospasm is insidious, beginning as an increased frequency of blinking that often is exacerbated by certain stimuli, such as sunlight, reading, wind, or stress. It gradually progresses over months to

years until there is prolonged spasmodic eye-lid closure that occurs without obvious external provocation. Although both eyes usually are affected simultaneously, one eye may be affected weeks or months before the other. The spasms are mild at first, but eventually they may become so severe that they prevent reading, driving, and other normal daily activities. Indeed, essential blepharospasm may become sufficiently severe that affected individuals are functionally blind. In addition, patients with essential blepharospasm thus become socially and occupationally disabled. Such patients may quit their jobs, shun social contacts, and become severely depressed. Most patients who develop essential blepharospasm have the condition through the rest of their lives; however, a small percentage, about 10%, experience spontaneous and permanent relief of symptoms.

There are three main types of treatment for essential blepharospasm: oral medication, surgery, and botulinum toxin. In addition, various miscellaneous treatments may be of benefit in selected patients.

Oral Medication. Oral medication is not the optimum treatment for essential blepharospasm, partly because most of the anticholinergic agents and other drugs used have limited effectiveness in this condition and partly because most of these drugs have unwanted side effects, such as confusion, sedation, and light-

headedness. I usually use oral drugs for those patients who have severe essential blepharospasm but who do not wish to undergo injections of botulinum toxin or who cannot undergo the injections for other reasons. Drugs that may benefit patients with essential blepharospasm include clonazepam (Clonopin), trihexyphenidyl (Artane), and cyproheptadine.

Surgery. Numerous surgical techniques have been used to treat essential blepharospasm. These procedures are designed to reduce the innervation of the orbicularis oculi muscles by selectively avulsing branches of the seventh cranial (facial) nerve or to remove portions of the muscles themselves. The most successful surgical procedures for the relief of essential blepharospasm are the partial myectomy, in which portions of the orbicularis oculi are excised and the full myectomy, in which as much as possible of the orbicularis oculi, corrugator supercilii, and procerus muscles are excised. Because many patients with essential blepharospasm have redundant skin or dropping of the eyelids from constant manual elevation of the eyelids in order to see, the partial myectomy often is combined with other procedures on the eyelids, such as blepharoplasty, repair of dehiscence of the levator aponeurosis, and repair of a lax lateral canthal tendon. These procedures may take several hours to perform and are usually performed under general anesthesia. Full myectomies are

often performed on one side first and on the other side at a later date. Bleeding or infection can complicate any surgery, but the main risk of this surgery is excessive weakness of eyelid closure, resulting in partial facial paralysis, inability to close the eyelids completely, and exposure keratopathy. In addition, the surgery renders the skin of the eyelids and eyebrows hypersensitive, resulting in increased discomfort should the patient subsequently require injections of botulinum toxin.

WE RESERVE THE RIGHT TO EDIT ANY & ALL ARTICLES.

Blepharospasm and Tardive Dyskinesia

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Blepharospasm is a focal dystonia. Dystonia is a disease affecting the motor system of the brain that leads to involuntary movements and postures. In its focal forms, it affects only one part of the body. In blepharospasm, the dystonia affects the eyelid closing muscles. Blepharospasm is characterized by frequent blinking or sustained closure of the eyelids. In its purest form, involvement of the eyelid closing muscles is the only symptom. Some patients with blepharospasm will have other focal dystonias involving nearby or distant muscles. Commonly, other muscles of the face will be involved, giving rise to abnormal movements of the eyebrows, forehead, or lips. The dystonia can even spread to involve muscles that open and close the jaw and the tongue muscles. When the dystonia affects more widespread facial muscles, then the disorder is known as cranial dystonia or Meige syndrome.

Tardive dyskinesia is a movement disorder that results from taking certain drugs, particularly a class of drugs called neuroleptics. These drugs influence the chemicals in the brain. One of the chemicals affected is dopamine, which seems to play an important role in control of movement. The prolonged use of these drugs may result in some alteration in the motor system that leads to the production of involuntary movement. Since these movements are produced as a late effect of taking these drugs, the dyskinesia is called tardive, which means late. Once these movements occur, they can be quite long-lasting and possibly permanent. Tardive dyskinesias can affect any muscle in the body, but they very commonly affect cranial nerve muscles. The muscles affected tend to be the tongue, the jaw closing muscles, and the muscles around the mouth, but eyelid closing muscles can also be affected. When eyelid closing muscles are affected, there can be blinking or sustained closure of the eyelids, which could have the appearance of blepharospasm. Movements of the tongue and lips are particularly prominent in tardive dyskinesia. These movements can also occur in rhythmic repetitive trains.

Because both blepharospasm and tardive dyskinesia can cause blinking or sustained closure of the eyelids, their appearance can be similar. However, tardive dyskinesia would only infrequently involve the muscles of eye closure. Therefore, unless the focal dystonia in the patient with blepharospasm has spread to involve the rest of the face, it ordinarily would not be difficult on clinical grounds to separate patients with blepharospasm and tardive dyskinesia.

The etiologies of blepharospasm (or dystonia) and tardive dyskinesia are unknown. There are increasing hints of important genetic factors in blepharospasm. Certainly, familial generalized dystonia has a genetic origin. Evidence is accumulating that there is a higher than expected incidence of focal dystonias in some families, which indicates a genetic basis. An additional factor that seems important in the production of dystonia is trauma. Many patients have a history of irritation of the eye that precedes the development of blepharospasm. Neither genetic factors nor trauma seem to play a role in tardive dyskinesia as far as can be determined at the present time. By definition, tardive dyskinesia is caused by drug therapy. Since both movement disorders have some similarities of appearance, and the causes of both are unknown, it is possible that they are physiologically similar in some ways, but this would have to be considered speculation.

Lastly, both blepharospasm and tardive dyskinesia are difficult to treat. There is no systemic medication that works well for either condition. If patients with tardive dyskinesia have prolonged eyelid closure that makes it difficult for them to see, then it might well be appropriate to treat them with botulinum toxin, just as it is in patients who have blepharospasm.

Blepharospasm: ORAL MEDICATIONS

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Rush University Medical Center
Chicago, Illinois

The most effective treatment for blepharospasm is botulinum toxin injections. Oral medications have not been adequately evaluated in clinical trials for safety and efficacy in blepharospasm, and are not frequently used as a primary treatment. Anticholinergic drugs, including trihexyphenidyl, benzotropine, biperiden, atropine, procyclidine, orphenadrine, scopolamine, and ethopropazine have been used for the treatment of dystonia, and are most frequently administered to children with generalized dystonia. These agents have limited benefit in patients with blepharospasm because of side effects which frequently limit the dose, and lack of proven efficacy. The most frequent side effects associated with anticholinergic agents include blurred vision, dry mouth, sedation, confusion, and memory problems. Additional side effects can include urinary retention, agitation, and anxiety. Anticholinergic agents should not be used in patients with glaucoma.

If anticholinergic drugs are used, it is important to initiate treatment at the lowest possible dose of a given agent and to escalate the dose slowly over a period of weeks to months. Anticholinergic dosing should be divided into 3 or 4 daily doses. Improvement is often delayed thus dose adjustments should be made slowly, allowing a week or two at a dose level. Adults are usually unable to tolerate high doses because of side effects. Ethopropazine appears to have fewer peripheral side effects than most other anticholinergic agents, but it is not available in the United States. If side effects occur in the absence of benefit, anticholinergic treatment should be discontinued. Discontinuation of anticholinergic agents should be done gradually, as withdrawal effects may occur.

Dopaminergic drugs are most frequently used for the treatment of Parkinson's disease. Although dystonia is clearly different from Parkinson's disease, carbidopa/levodopa and other dopamine agonist drugs are sometimes administered to patients with focal dystonia, including blepharospasm. There are insufficient studies to understand whether there is a beneficial effect. Some patients may improve, especially those with a dystonic disorder called dopa responsive dystonia (DRD), a dystonic syndrome arising from mutations in GTP cyclohyrolase 1 gene that shows a marked, sustained response to low doses of levodopa and usually presents in children. Although adult onset focal dystonia would be a rare manifestation of DRD, given the expanding clinical features described, an empiric trial of levodopa could be considered.

Dopamine receptor antagonists (antipsychotic agents, some antiemetic agents) have been suggested as a treatment for dystonia, although not adequately evaluated. The side effects of these types of medications include reversible drug induced parkinsonism and potentially permanent tardive dyskinesia. Because of the nature of these side effects, these agents are not suggested for use in blepharospasm. Although the atypical antipsychotics, including clozapine and quetiapine, may have a lower frequency of tardive dyskinesia, both agents have important side effects, including sedation, orthostatic hypotension, lowered seizure threshold, and metabolic syndrome (diabetes, dyslipidemia, and hypertension, with associated obesity).

Tetrabenazine is a medication that depletes monoamines, including dopamine, and has

dopamine blocking properties. Tetrabenazine is FDA approved for treatment of chorea associated with Huntington's disease. It is not approved for dystonia. Although controlled studies have not been done, open label studies suggest improvement in dystonia in up to 25% to 60% of patients. Side effects from tetrabenazine are common and include sedation, depression, parkinsonism, akathisia, nervousness and insomnia. In the United States, the cost of tetrabenazine treatment may be prohibitive.

Clonazepam is a benzodiazepine that is used frequently for dystonia but has not been evaluated in controlled studies. Small case series have described benefit in blepharospasm patients, especially those patients in whom anxiety is a major exacerbating factor. Clonazepam is gradually escalated to avoid side effects. The adverse effects include sedation, depression, confusion and dependence. Patients should not suddenly stop clonazepam, but should be slowly tapered from the medication under a physician's guidance.

Baclofen is a GABA receptor agonist that has been reported to be of some benefit in dystonia, although controlled studies are lacking. Baclofen may be particularly useful for generalized dystonia in children, but adults seldom tolerate the drug at doses sufficient to provide benefit. Baclofen is started at low doses and slowly increased until benefit or side effects occur. The most common side effects from baclofen are dizziness, sedation, nausea, and urinary symptoms. Confusion, hallucinations and paranoia have been reported, but are rare. Patients should not suddenly stop baclofen as this may cause psychosis, seizures or dramatic increase in dystonia.

There are many other oral medications that have been suggested as treatment for dystonia. At this time, however, for the treatment of blepharospasm, botulinum toxin remains the first line.

SSDI APPLICATION CHECKLIST

- Name(s) on all issued Social Security cards
- Original or certified copy of birth certificate
- Marriage license(s) and divorce papers and/or spousal death certificates
- SS #s, birthdates, of yourself, spouse, children, etc
- Medical information including dates you had/will have appointments, all current medications
- Evidence of your medical disability:
- Medical Source Statement
- Letters from doctors
- Letters from your prime caregiver, spouse/partner, your driver, yourself, explaining how your life has changed
- Pictures of bruises from falls, if applicable
- Proof of US Citizenship or legal residency
- Proof of military service: bring the original or certified copy of your military discharge papers for all periods of active duty
- Evidence of any workman's compensation, public disability, or black lung benefits
- Evidence of disability compensation from your employer if you have received it
- Date you became disabled and your last day of work
- Previously filed application for SSDI or information that you wish to file now
- Decide if you will file for SSI, too
- Details about future pensions or annuities based in whole or part on work after 1956 not covered by Social Security
- Explain how blepharospasm has changed your daily living and makes you disabled (See questions and answers for more details)
- Explain how blepharospasm actually keeps you from doing your job/employment. Give examples of work situations. Include accommodations you have made to adjust but have not worked. State clearly that blepharospasm has no known cure. (See questions and answers for more details)
- Work history to include beginning dates, ending dates, title, and responsibilities for the last fifteen years
- Your last W-2 or Federal Income Tax Return
- You may be asked for a bank account number in which to make deposits

What is “functionally blind”

Some medical people who are unacquainted with blepharospasm, may have difficulty grasping the concept that people who cannot voluntarily open their eyes are just as sightless as those who are blind from actual disease of the visual system. This problem is even more confounding to the outsider because many people with blepharospasm experience some periods when their eyelids behave normally. When the eyes are open, the vision may be normal. But when the eyelids are forcibly closed because of involuntary, uncontrollable, bilateral spasms of the orbicularis oculi muscles (“blepharospasm”), the patients can’t see. They are “functionally blind” (sightless) until the eyelids open. Patients suffering from blepharospasm are unable to “sustain visual fields and acuity” because their eyes close involuntarily. The forced eyelid closure results from hyperexcitability of the nerves controlling the muscles of eyelid closure. Thus, an eye examination may show "normal vision," whereas a few minutes earlier or later, the patient's eyelids can be forcibly held shut by the spasms.

Blepharospasm can be an isolated abnormality (benign essential blepharospasm), or it can co-exist with movement disorders involving the lower face and neck (segmental dystonia or Meige syndrome).

In blepharospasm, whatever the cause, the person afflicted can be functionally blind and, if so, should be accorded the same disability considerations as individuals with primary abnormalities of the visual system.

What do I need to know before applying for SSDI

(Guide written for BEBRF patients, 2014)

1. *What is SSDI and when does one apply?*

Social Security Disability Insurance

SSDI are monthly monetary benefits dependent on 1) disability approval and 2) based on your own/personal prior work earnings record under Social Security taxes previously paid throughout your lifetime. One applies for SSDI if working is no longer an option due to a disability.

If you are of retirement age (62+) or older, you are eligible to receive regular Social Security benefits based on your previous earnings. However there are certain circumstances in which you may apply for disability. Please contact the Social Security Administration to learn more.

If working is no longer an option due to your disability then you might consider applying for SSDI.

2. *What is SSI and when does one apply?*

Supplemental Security Income

SSI has nothing to do with disability; rather, it is solely based on financial need (limited income and resources). It is not dependent on previous taxes paid into Social Security. If you cannot monetarily sustain yourself, have no family financial support, and find you have a financial need, then you might qualify to receive SSI also. If needed, this can be approved before SSDI to fill in the gap while waiting for approval.

3. *Can I apply for both?*

Yes

A person who is not disabled can apply for SSI.

A person who is disabled can apply for SSDI and not SSI. Or...

A person can apply for both if both disabled and in financial need.

4. *Can you receive partial or short term disability with Social Security?*

No - according to Social Security you are either disabled or not. Period!

5. *What additional information should I request from the Social Security Administration?*

Ask for a pamphlet titled, "If You Are Blind or Have Low Vision - How We Can Help."

6. *What are the main factors in being approved for SSDI?*

The initial step is to learn if you qualify. The premise of SSDI is that you cannot work. If you are currently employed, even part time, you cannot apply for disability. Your application will not be accepted if you are still working.

Question #1: Will your disabling medical condition last at least one year?

Answer #1: Yes, blepharospasm has no known cure and in some cases gets progressively worse

Question #2: Can your skills set be transferred to other employment?

Answer #2: A Social Security vocational counselor will recognize ANY job in which you can be productive. Explain that your weeks, days, and sometimes hours in the day can be inconsistent. There are times when you are functionally blind. Your everyday functional abilities are not predictable nor consistent. There is no way to control the spasms when they happen. **You must prove to the SSA that you cannot work in any capacity.**

7. Is Meige Syndrome / Oromandibular Dystonia or Hemifacial Spasm considered an acceptable reason to apply for SSDI?

Meige Syndrome, also known as cranial dystonia, is a combination of blepharospasm and oromandibular dystonia. Patients with Meige also have blepharospasm. Only blepharospasm (BEB) is on the SSDI impairment list as "functional blindness." Therefore, the reason given for SSDI application is blepharospasm and not Meige since Meige might affect your appearance but does not affect your ability to work.

Hemifacial spasm (HFS) is a neuromuscular disorder characterized by frequent involuntary contractions (*spasms*) of the muscles on one side (*hemi-*) of the face (*facial*). It usually begins with twitching/spasming near the eye and spreads down the face. Sometimes micro vascular decompression surgery relieves the symptoms, but there are risks. For others, Botulinum Toxin-A injections help. Once again, refer to the above statement. Of these disorders only blepharospasm is on the approved SSDI impairment list.

8. How is disability determined by the Social Security Administration (SSA)?

Social Security Administration regulations provide for disability evaluation under a procedure known as the "sequential evaluation process." For adults this process requires review of the claimant's current work activity, the severity of impairment, the claimant's "residual function capacity," past work, age, education, and work experience. In sequence, Social Security evaluates the following:

- a. Are you currently working? If yes, you will be automatically denied.
- b. Do you have a severe impairment?
- c. Are you disabled according to Social Security's Impairments list? (See attached) Do your doctor's medical records and letters support your claim?
- d. Can you continue to do your past relevant work?
- e. Can your skills transfer to another field? Are you employable?
- f. Given your age, education, work experience and residual function capacity, are there jobs that exist in the national economy that match your skill set that you can perform? {This is often the basis for denial.}

9. What is Residual Functional Capacity (RFC)?

The code of SSDI federal regulations describes "residual functional capacity" as follows: an evaluation of your remaining ability to work after taking into account all of the limitations of your severe medical conditions. This means, how much can you do and for how long can you do it? SSA will look at your ability to see, hear, and speak; maintain concentration and attention; understand, remember and carry out instructions; respond appropriately to supervisors, co-workers, and usual work situations; cope with changes in the work setting; exert yourself physically for various work-related activities; do manipulative and postural activities; and tolerate certain environmental conditions.

10. What if I stop working, and with less stress and schedules, my severe blepharospasm symptoms improve?

It is not uncommon that when you remove yourself from the stress and schedules of work and make daily life-style modifications there is a chance that your symptoms might not be as prominent. Should you then return to work? You must consider that should you go back to work, you may put yourself into the same downward spiraling situation.

If you feel that work responsibilities, schedules, reading, driving, etc. cause your symptoms/condition to worsen, then you should consider going forward with your application. Time-wise, this is a long process (several months up to 2 years). If finance is an issue, apply for SSI. *Considerations:*

If you go back to work, you are no longer eligible for SSDI.

If you apply for benefits and then decide to go back to work, your claim will not be accepted. In that case you can apply again at another time when you have stopped working.

11. How severe is your impairment?

Blepharospasm affects each individual differently. In addition, your symptoms can change and may not always be the same or the same severity. Symptoms can come on unexpectedly, vary, and be inconsistent. It is up to you and your doctor to determine the severity.

12. Does being older work in my favor to be approved?

Being closer to retirement age can be a positive factor in determining your case. There are no guarantees.

13. Before applying, how do I learn about the benefits (how much \$\$\$) I am entitled to if approved?

The Social Security Administration no longer prints and distributes annual statements explaining your future benefits. These statements are now available online. Go to www.socialsecurity.gov/myaccount and set up an account or contact your Social Security office.

14. How do I move forward to apply for SSDI?

1) Online at www.socialsecurity.gov OR

2) Schedule an appointment at your local Social Security office. Your assigned representative will explain the application process, ask you questions, and complete all forms on the computer for you.

15. What information must I have available to complete this application process?

- Name(s) on all issued Social Security cards
- Date of birth (original or certified copy of birth certificate)
- Are you married? More than once? To whom? On what date? Who married you? In what state? Did the marriage end? How? (original or certified copies of marriage license and divorce papers/death certificate if appropriate)
- You will be asked about your children
- Provide Social Security numbers , birthdates, and ages for yourself, spouse, children, etc.
- Medical information from all doctors aware of your blepharospasm, dates you had/will have appointments, all medications currently taking, etc.
- Provide evidence of your medical disability with:
 - Letters from doctors - you can bring them with you or Social Security will send a form to your doctor. Ask Social Security to send for updates if your condition changes or worsens. (See included samples)
 - A letter from your prime caregiver, spouse/partner, your driver, etc. explaining how your life has changed
 - Pictures of bruises from falls, if applicable
- Are you a citizen of the USA? If born in another country, bring proof of U.S. citizenship or legal residency.
- Have you been in military service? Bring the original or certified copy of your military discharge papers for all periods of active duty.
- Have you or do you intend to file for worker's compensation, public disability, or black lung benefits?
- Have you received disability compensation from your employer? Have proof available if asked.
- On what date did you become disabled? What was your last date of work?
- Have you previously filed an application for SSDI?
- Do you want to file for SSI, too?
- Are you or do you expect to be entitled to a pension or annuity based in whole or part on work after 1956 not covered by Social Security?
- Explain how blepharospasm has changed your daily living and makes you disabled. If you have this written down and in front of you during your initial interview, you might be less nervous and it will keep you on track. Examples: I cannot maintain eye contact; I cannot look upward for a reasonable amount of time; I cannot sustain reading; I experience blurriness; I need to focus to keep my eyes open and sometimes lose peripheral vision; lights can trigger spasms and eyelid closing; I have difficulty adjusting from light to dark and dark to light; my eyes tire easily; my activities are dictated by where I am in my injection cycle and

how well my eyes respond to the medication each time; eyelid spasming can prevent me from performing some everyday activities. This is consistent 365 days a year / 7 days a week / 24 hours a day. *Don't* rely on limited or inability to drive unless your job is a driver. SSDI does not compensate you for inability to get to work - only for inability to work. They will tell you to take public transportation.

- Explain in detail how blepharospasm actually keeps you from doing your specific job; give examples of work situations. Identify accommodations you have made to adjust and try to continue employment. Show you tried to keep your job.
- Make it clear that blepharospasm can get worse with time. There is no known cure; and treatments are not working well for you. Include in your claim packet the attached page about "functional blindness" (Emphasize you can't see because your eyes close involuntarily). See question #16c for more information about functional blindness.
- They will ask for résumé-type information about all jobs you've worked: beginning dates, end dates, title, and responsibilities in the last 15 years.
- Your last W-2 or Federal Income Tax Return; If self-employed, have your federal tax return.
- You may be asked for a bank account number in which to make deposits.

16. *What information should I discuss with my doctor previous to the Social Security application interview? And what involvement should I have in regards to the letters my doctors submit to SSA?*

A. If possible, prior to your final application, personally deliver the Social Security medical form to your doctor when requesting completion. If unable, telephone or email the office. Be sure your doctor knows exactly what Social Security needs to read/understand in this letter. Offer sample letters as a guideline.

B. *Therefore it is imperative to have conversations with your doctor* about your daily living limitations, changes, accommodations, etc. Talk about what aggravates your symptoms the most, what you feel when you cannot function, or things you can no longer do. It is essential for your doctor to include objective medical evidence such as but not limited to: visual acuity tests, visual range tests, comments about photophobia (light sensitivity) and dry eyes, obvious and commonly occurring facial spasms and grimacing, what may precipitate or aggravate the symptoms, how symptoms are manifested, specific medications and treatments current and past, daily accommodations that affect your pattern of living and employment [you can sometimes be "functionally blind"], falls/trips and resulting bruises due to functional blindness, and necessity to move slower.

C. Collect letters from ALL your doctors. The more support and facts you submit, the better. Consider your neuro-ophthalmologist, your ophthalmologist, your neurologist, your therapist, your primary care/internist, even your optometrist. You are welcome to use the enclosed sample letters to share with your doctor, so he/she may use them as guidelines in documenting your condition.

D. Ask your doctor(s) for a copy of the letter sent to Social Security for your own files. (This is good to have if at a later date you need to employ a lawyer.)

E. Many patients have suggested that you request the phrase "functional blindness" be included. *Some medical professionals are unacquainted with blepharospasm and therefore may have difficulty grasping the concept of functional blindness which is identified in patients who cannot voluntarily open their eyes and are just as sightless as those who are blind from actual disease of the visual system. This problem is even more confounding to those unfamiliar with blepharospasm because many patients experience some periods when their eyelids behave normally. One is "functionally blind" when unexpectedly she/he is unable to sustain visual acuity (see) because his/her eyes close involuntarily. This vision loss results in difficulty performing daily activities of living that require sight.* Please see separate print out for more information on the definition of being "functionally blind." This printout might be included with your SSDI application.

17. *The possibility exists that Social Security might ask you to be examined by one of their own physicians at no cost to you. What if you refuse?*

Understand that the state disability determination services may request a medical consultation exam at the expense of Social Security. If you don't go, your claim will probably be denied.

Sometimes doctors are unfamiliar with blepharospasm, so it is important to take documentation such as brochures from the BEBRF with you to any such consultation.

If you ask nicely for permission to see your own specialist at your own cost, without refusing to see theirs, this might be approved.

18. *What else do I need to collect in order to complete the SSDI application form (online or with appointment at the Social Security office)? [These suggestions were made by blepharospasm patients who have previously applied and been approved]*

- a. Include a letter from your spouse or primary family member/care giver explaining how your life and his/her life has changed
- b. Include letters from friends who have helped you do things (ex: drive) that you could previously do alone
- c. Include photos of bruises from falls/accidents as a result of your eye condition
- d. Include everything and anything related to your health; don't leave anything out
- e. Include literature from BEBRF (booklets)
- f. Social Security will want to see certified copies of: your birth certificate, all marriage licenses (especially if your name changed), and divorce papers.
- g. All employment details: Have a written list of all employment, duties, year began and stopped. Detail at least the last 15 years. (Consider bringing a resume.)
- h. Base your answers on your disability only, not what you think/wish you can/cannot do. Be realistic.
- i. Social Security will look more favorably on an approval if you explain what real accommodations / adaptations you made at work, getting to and from work, and

why / how you are unable to work at full capacity in order to maintain your employment. How long did you try these new methods? List all adaptations no matter how small including simple things such as wearing sunglasses indoors, rearranging your work place furniture, changing lighting, or enlarging the font on the computer screen. In other words, how hard did you try to continue working? You might consider putting this in writing so you can leave it with them.

j. At the end, you will be asked if there is anything you wish to add. Be prepared!

19. What are some Social Security procedures I should be aware of?

- a) Social Security wants to see only original documents whenever possible. Sometimes they just want to see them and other times they will keep them.
- b) Always keep a copy of everything before submitting to the Social Security office.
- c) Social Security will scan all papers into the computer and then shred them. You will not be able to get anything back.
- d) Never agree to sign any blank forms; but if you must, write that you are signing a blank form.
- e) You will be asked to sign medical authorization forms so Social Security can obtain medical records from your physicians.

20. What are some additional helpful hints suggested by other patients who have already been approved?

- Applying for SSDI takes a commitment to gathering information, organization, patience, perseverance, and a positive attitude. You need to act on your own behalf to follow through, and follow up.
- Include information about "functional blindness" (see additional information sheet).
- Index your papers so they are organized/ordered and easily found.
- Whenever given forms to complete, make a blank copy first and practice on those before copying your answers to the final form.
- If you receive papers to complete, always look for the due date. Sometimes you only have a few days turn-around.
- Don't try to complete all the papers in one day.
- Yes, someone else may help complete the forms if he/she signs his/her name at the end.
- Stay focused; don't give up; expect this to take time!

21. What else should I share with Social Security?

It is important to tell Social Security examiners if you have developed depression, anxiety, or other issues as a result of your ophthalmological or neurological condition. Social Security is required to consider you as a total person.

22. After this, am I done with the paperwork?

No way! You will be sent an 8 page Functional Report about your daily life to complete in a limited time. Make a copy and practice on it before filling in the final version. Add as many extra paragraphs as needed on separate papers and mark them accordingly to the question number. Keep a copy of the final before returning it.

At the same time, you will receive a 12 page Work History report to complete. This is not only about where you have worked in the past, but also about your job skills and what other jobs to which you might be able to adapt.

Be sure to return them by the due date.

If you are unsuccessful in your initial filing (as is often the case) and you choose appeal, you will be asked to complete these identical papers again.

23. The SSDI approval procedure takes a while (months or even couple of years). When do disability benefits start? Are SSDI payments retroactive?

Yes. The law provides that if approved, count 5 months after your last day of employment, then SSDI payments start. Back benefits are received in one lump sum. Federal and State taxes are not taken out and you will need to adjust your withholding accordingly or possibly pay a tax penalty.

24. What is the SSDI approval based on?

Some of the factors reviewed are: medical documentation and the answers to the following questions:

- Is your impairment found in the Social Security Disability Impairment listing (sometimes known as the "blue book")?
- Can you do past relevant work or are your skills transferable?
- Given your age, education, work experience and "**residual functional capacity**" do jobs exist in the national economy that you can do?

Note: see the attached Social Security impairment list.

25. After I apply, how can I check the status of my claim?

At the end of your application you will be given a contact person to telephone with questions and a claim number that can be used to go online to check your status.

26. How long does it take?

You will hear in approximately 120 days.

27. What if I am approved?

Your mail from the Social Security office will be thick - many pages.

READ CAREFULLY: It might say you have been approved but ask if you want to appeal (if you don't agree with your approval). Or if you applied for both SSI and SSDI, note what is being approved.

28. If approved will I receive Medicare? How does that work?

According to the current guidelines, you will be automatically eligible for Medicare parts A and B exactly 29 months after your last day of work due to your disability. That

includes a 5 month waiting period plus 24 months actually receiving Social Security Disability payments (back pay benefits are included). If approved, Social Security will automatically send you your Medicare card with Parts A and B.

29. What if my application is denied?

If you are unsuccessful and denied (which happens to many people) you have 60 days to appeal. An "appeal" is often called a "Request for Reconsideration." This form is 8 pages. You can be denied and appeal TWICE! Also, see the Social Security pamphlet titled: The Right to Question the Decision Made on Your Claim.

30. Do I need to employ an attorney?

You can be denied twice and appeal twice. The next review step is to apply for a hearing date to go before an administrative law judge. The rule of thumb seems to be that on first application, try it yourself. You may choose to retain a lawyer for your second go-round. But you are required to hire a lawyer for a hearing when going before the judge.

You need to complete the forms to apply for a hearing before an administrative law judge. This judge has the right to review and reverse earlier determinations.

31. What is a Social Security hearing like?

The administrative law judge does not work for Social Security. He/she is fair and impartial, but you and your lawyer must prove your case. He/she may be present in the room or on a two-way video screen.

A court stenographer is in the room writing down every word to be reviewed later.

A vocational counselor who is employed by Social Security is in the room. His/her job is to find you employment that exists in the national economy that you can do. This has nothing to do with your transportation to or from work.

If you retained a lawyer, he/she is in the room.

Some places will allow your companion to be in the room; some won't.

You are your best advocate. You will be asked questions by the judge and do the most talking. Be prepared to answer questions about all aspects of your blepharospasm. If you do not understand it, how can you explain it to others? Bring pamphlets from BEBRF to leave with the judge.

Please note: The judge might not be in the room with you; he/She could be in anywhere including another state. You might see the judge by audio/video, but all other persons involved will be in the room with you.

32. What if my appeal is denied?

You may file an appeal to the Appeals Council. For the most part, this appeal usually results in a denial. If so, you may pursue your case through the Federal Court System. An attorney is required at these levels of the court system.

33. Where do I find an attorney who specializes in Social Security appeals?

If you choose to employ an attorney, you most definitely want to find one who specializes in Social Security cases. Not all lawyers are alike - find one who will talk to you personally.

- National Organization of Social Security Claimants' Representatives
19 East Central Avenue, Pearl River, New York 10965, (800) 431-2804.
- Or telephone or email BEBRF patients on the list of those who have already been approved for SSDI. (Listed separately)

[34. What does a Social Security lawyer charge?](#)

Approximately 25% of your back pay benefits received upon approval. But no matter what the fee, the maximum limit is \$6000. If your case drags on, your back pay is well beyond that, and it is pay that you would not have received otherwise. Social Security will pay your lawyer directly out of your benefits, before writing you a check for back pay benefits. It is possible that your tax accountant might be able to deduct this fee when completing your taxes.

[35. What is the CAI, "Compassionate Allowance Initiative?"](#)

The Compassionate Allowance Initiative allows severe medical conditions to be moved to the "head-of-the-line" to expedite a decision in Social Security. Currently there are 200 conditions on this list (most are cancer related or fatal). Blepharospasm is not on this list.

[36. What do I need to know about COBRA?](#)

If you are under the age of 62, leave your job and file for SSDI - please be aware... Under the U.S. government plan named COBRA, people who leave a job may retain their group medical insurance for 18 months after they leave the employer. Although you pay 100% of your premiums out of pocket, this allows you to remain insured. It is very important to remain insured while applying for SSDI since qualifying can take a number of months or longer. Even after approval of disability status, you must wait 2 years until you are automatically enrolled in Medicare. The COBRA program then allows for an 11 month extension totaling 29 months, but you must notify COBRA of your intention to extend coverage within 60 days of receiving your Disability Award Settlement. If you fail to do this, you will have no health insurance for 2 years or until you turn age 62, whichever comes first.

A question arose concerning COBRA and the Affordable Care Act. Concerning this, you must check with your individual state and its policies.

[Please note this information about Long Term Care Insurance...](#)

If you are considering the purchase of Long Term Care Insurance (LTC), please be aware that being on SSDI may affect your ability to purchase LTC. You might look into purchasing it **before** applying for SSDI and learn if it will stay in effect.

You are your own best advocate. Be well informed!

Benign Essential Blepharospasm is a rare disorder. Some doctors have not heard of nor encountered a single case. So it is not unreasonable that SSDI evaluators, judges, and others need to be walked through what it is and how it affects daily life. You may be asked where on the web they find more information. Refer them to www.blepharospasm.org. Be informed yourself so you can answer questions, explain, and educate others. Be patient. Good Luck!

BEBRF Patients who have been Approved for Social Security Disability

(You have their permission to contact to ask questions)

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Medical Glossary

Apraxia of the eyelid - difficulty in opening the eyes in the absence of spasms; thus eyelid closure

Basal ganglia - gray matter in the brain that coordinates movement (such as eye movement)

Benign - does not kill; is not malignant

Blepharo - a Greek word meaning eyelid

Blepharoplasty - aesthetic or reconstructive surgery which removes excess skin, fat and muscle from the eyelids to help keep eyes open to improve appearance and increase vision

Blepharospasm, also named

Benign Essential Blepharospasm (BEB) - sustained, involuntary, forceful, and repetitive closure of the eyelids; a focal dystonia

Botulinum (neuro) toxin (BoNT) - a biologic protein and nerve toxin derived from bacteria which, when injected into muscles, temporarily weakens the muscle fibers. Used to decrease eyelid spasming

Chemodenervation - "Denervation" of muscles implies blockage of nerve stimulation to muscles, resulting in paralysis or decreased action. "Chemodenervation" implies using a substance to cause the blockage. Botulinum toxin (BoNT) injections is such a substance.

Dry Eye Syndrome - an ocular surface condition in which there is a decrease in quantity of tears and change in tear quality, resulting in drying out of the ocular surface causing discomfort, visual disturbance, and/or foreign body sensation

Dystonia - a neurological movement disorder in which involuntary, sustained and repetitive muscular contractions result in abnormal movements

Essential / Idiopathic - of unknown cause

Focal dystonia - a single body part or muscle group is dystonic or affected with contractions

Functional blindness - vision loss resulting in difficulty to perform daily activities of living that require sight. For BEB patients this is due to eyelids being forcibly closed due to spasms of the orbicular oculi muscles.

Genetic - hereditary

Hemifacial spasm - a neuromuscular disorder characterized by spasming seen on only one side/half of the face; not a dystonia; thought to be caused by compression of the facial nerve. Differs from BEB; treatment is sometimes similar.

Levator muscle - main muscle in the upper eyelid responsible for eyelid elevation

Orbicularis oculi muscle - main closing muscle of the eye; shaped like an ellipse encircling the whole eye

Oromandibular (OMD) - pertaining to the mouth and jaw

Meige Syndrome (oromandibular dystonia) - a form of oral facial dystonia named after Henri Meige. Patient has along with BEB. Symptoms might include chin thrusting.

Myectomy (*limited or radical*) - surgical procedure to remove some or all of the muscles that spasm around the eyelids; sometimes performed on patients for whom BoNT is ineffective

Photophobia - extreme sensitivity to light; **not** the fear of light

Ptosis - drooping/falling of the eyelid(s) with limited eye opening which can result in the decrease in visual fields (the P is silent)

Residual Functional Capacity - remaining ability to work after taking into account all physical and mental limitations

Spasm - sudden and involuntary, convulsive contraction of muscles

Synapse - structure that allows a nerve cell (neuron) to transmit electrical or chemical signals to another neuron or muscle

Tardive Dyskinesia (TD)- Tardive means delayed onset. Dyskinesia refers to abnormal muscle movements or difficulty initiating voluntary movements.

Thalamus - midline part of the brain that acts as a relay of sensory and motor impulses passing to higher levels of the brain;

Personal SSDI Experience (2013)

By: Anonymous

No one wants to say, "I am disabled." No one looks forward to retiring due to a disability. However, I have benign essential blepharospasm (BEB) and it affects my daily quality of living.

I am a teacher. My eyes seemed functional in the morning with minor hiccups: I strained to keep them open in the afternoon potentially compromising the children's safety; it was impossible to complete paperwork after school; and my eyes crashed by evening. When this scenario repeated daily with no improvement, my eyes were telling me something ... it was definitely time to stop teaching/working.

Wow! No demanding schedule and much less stress definitely improved my daily eye function and comfort. It was time to apply for Social Security Disability Insurance (SSDI) - Do not confuse SSDI with SSI for those with low income. Although it is encouraged to complete the application online, I had too many questions and it wasn't easy on my eyes, so I made an appointment at my local Social Security office. Having started this application online, I had a good idea of what to bring with me for my interview: 1) Information about your condition; 2) Treatments you have received and whether they have been successful; 3) ALL your ailments; 4) ALL medications you are taking; 5) Your educational background; 6) Details about your past work history; 7) Notes from your doctors about your condition saying BEB is a permanent condition and will last one year or longer / Explain your limitations; and 8) Agreement to give SS permission to request your medical records. [I had four physicians' reports: neuro-ophthalmologist, neurologist, ophthalmologist, and internist.]

Of course I was nervous. The interviewer's job is to gather facts and complete the SS forms through questions and answers with the same forms used for all disabilities. The main follow up question was, "What changes did you make at work to be able to stay." I made a point to mention all the things I can no longer do that I used to take for granted: work under fluorescent lighting, keep socially acceptable eye contact, look upward, watch training videos, sustain reading, and on and on. To keep the job I carpooled, asked for bigger print, wore sunglasses inside, took breaks when possible, and my spouse helped with paperwork at home. I was sure to state that I had to stop working from a job that I love because my symptoms were so severe, treatments were temporary, and there is no known cure. I also brought with me a written narrative (to leave there) explaining how blepharospasm affects my daily life.

At the end of this session lasting more than an hour, I was given the name of a caseworker if I had future questions, and told I would hear the result within 120 days. I heard from a reliable source that after you leave, your interviewer writes down his/her impression of you, and all of the papers you leave behind are scanned into their computer and then shredded. This is the end of the application forms until the next step... *more small print FORMS!* You receive forms in the mail with a deadline to return: Function Report - eight pages. 2. Work History Report - twelve pages.

After three months of waiting, I was DENIED. Therefore, I reapplied with a "REQUEST FOR RECONSIDERATION and needed to complete the same forms again and get updated doctor reports. After five months of waiting, I was DENIED again. I was advised by a knowledgeable retired SS worker that it is worthwhile to apply for Social Security benefits yourself, before hiring an attorney. However, after two denials, the next step would be an "APPEAL" before a judge, and one should not go before a judge without a lawyer.

I returned to my main doctor for a long conversation about what I can no longer do, accommodations I make daily, and how my life has changed. He took notes and wrote a new letter for SS stating these limitations and why. This letter was weighted heavily in my appeal.

I waited more than a year for my APPEAL before a judge. Once this date is assigned, you MUST be there or your case is lost. What is important to note is that the Administrative Law Judge

who is assigned to and hears your case does NOT work for Social Security. However the vocational trainer is an employee of Social Security. He/she sits in on your appeal hearing and tries to determine functional jobs you might still be able to perform.

My case was heard via video by a judge in another state. A court stenographer was present and wrote down every word. I was told the appeal process might take fifteen minutes; my appeal took almost 50 minutes. The judge spent time asking questions to learn about my blepharospasm since he had never heard of it. These questions included why I wasn't looking at him (I was facing an open window and the room had fluorescent lights), why the botulinum toxin A treatments/injections need to be repeated, and would my responses be backed if he searched for this information on the internet. My lawyer pointed out to the judge some very important points previously written in my files. I therefore believe my lawyer was the key player in my appeal success. At the end I was told I would hear a ruling in four to six weeks.

Almost twelve weeks later I received in the mail my DECISION LETTER - favorable. But at first this was confusing because the first few pages explained how I can appeal this favorable decision if I disagree! I received my AWARDS NOTIFICATION explaining how SS arrived at the amount I received in back benefits and what I would receive in future payments. I also automatically received a "Welcome to Medicare" letter and a Medicare card with a future beginning date.

My DECISION LETTER was quite informative. For the first time I received an explanation of why I was denied the first two times based on the opinions of the SS consultants - "environmental limitations but no visual limitations." It explained the weight given to the letters submitted by my doctors with the most weight on the explanation of my daily limitations. It explained how the judge arrived at a final decision. Interestingly, I was not approved for having blepharospasm itself as listed in the SS Blue Book under Special Senses and Speech section 8(b). Instead I was approved under sections 216(i) and 223(d) - which indicates the inability to maintain skillful employment due to technical blindness.

Before Medicare begins, I need to learn much to make an informed decision about new insurance coverage. It requires time to be on the telephone, asking the right questions, and completing and returning forms. This is where I currently am in my journey.

Note: Although my SS benefits were approved retroactive to the day I retired, there is a five month waiting period to be sure you are permanently disabled. My back pay therefore began from five months after date of retirement. Once you are on SSDI for two years, you automatically receive Medicare. Your lawyer's fee, which cannot exceed \$6,000, is sent directly to him/her by SS before you receive your claim. Taxes are not taken out and will need to be paid in the future.

My total process applying for SS disability took twenty-seven months from beginning to approval. I encountered many obstacles. My best advice: BE PREPARED - Go into your SS office/appeal knowledgeable! If you don't know the details of your own ailment, why should a judge understand it? PERSEVERE - don't give up! Don't stress out completing the paperwork. If you are denied, try again. If denied again, then appeal. Get an experienced SSDI lawyer for the appeal; he/she knows the system. Be confident and patient; this is a slow process.

If you want to learn how much SSDI you would receive should you apply and be approved, go to www.socialsecurity.gov/myaccount , set up an account, and you will have access to your records.

My Experience Filing for Social Security Disability (2011)

Heidi Vasquez-Cruz, Puerto Rico

Going through the “Social Security Disability Experience” (SSDI) is a tedious process, but the reward comes by being tenacious. SSDI initially sees a paper, not a person; therefore, the presentation has to grab their attention, hopefully, in the first attempt. Unfortunately, this was not the case with me. I filed for SSDI in April 2008, and did not make it through the first step. I filed online and answered every question they asked for, taking breaks in between. I never imagined I would cut my career short because of my “disorder” blepharospasm (cranial dystonia). My life changed within months. I worked in the public-school system in Florida as an occupational therapist. My classroom was literally in my trunk as I drove to seven different schools to provide my services to students with physical and mental impairments.

I began to notice a change in my eyes as far back as March 2007. My eyes felt gritty, sensitive to light, and reacted to any air movement, even air conditioning. In September 2007, I went to an optometrist who told me that I had severe dry eyes and should see an ophthalmologist. This is when my journey began. I felt liable as a driver because my eyes would shut tight and not open unless I did it manually and held them open. I drove with my finger on my temple which helped my driving and my time in the classroom. As an occupational therapist, it was my responsibility to work on fine motor skills with my students, and attend team meetings to discuss progress. I wore dark sun glasses with my fingers on my temples to keep my eyes open. I constantly apologized to the parents and staff for not being able to make eye contact with them. Someone always made a joke about it, and I just went along with it.

I began to see an ophthalmologist who diagnosed me with dry eye syndrome. The doctor prescribed Restasis®, Lacriset®, put plugs in my lacrimal ducts, which eventually came out and became infected, then the lacrimal ducts were cauterized. My initial doctor used humor to make symptoms go away, but I didn't find this to be any laughing matter. I went to another ophthalmologist, who was highly recommended. Again, same diagnosis, and told me that just as the deaf learn to live with their deafness, there was nothing else he could do, and I should learn to live with dry eyes. He sent me to a cornea specialist. Every time I went to a new physician, I cried. It actually felt good to cry because it moistened my eyes. The cornea specialist came up with an inconclusive diagnosis. They all reported “remarkable” because I was able to see the letters on the chart.

At this point, I took off two weeks in December 2007, with winter break following. I gave myself a month to feel better and then go back to work in January 2008. I called the Mayo Clinic which refused to give me an appointment because “dry eyes” is curable and any ophthalmologist can treat it. My supervisor suggested I apply for disability because I could hurt myself driving, and to consider how I could work with my students with my eyes closed. It was getting worse quickly, and I wanted answers quickly. I took my supervisor's advice, requested my medical records, and was denied employment disability because “dry eyes” is not a cause for disability, and all my records stated my vision was “remarkable.” So, I was told to take drops and that would solve my problems. I spoke to an attorney, and he said my case had no weight.

As my condition worsened, I decided to apply for SSDI in March 2008, hoping I was a candidate. I applied, but my case wasn't evaluated because I was ONE credit short, therefore, I was denied. I heard over and over that everyone is denied the first time, and I should hire a lawyer with experience filing SSDI claims. When the lawyer saw my letter, I was told it was a “very bad” letter because SSDI would not look at my application regardless of my condition.

A domino effect followed. I lost my job, had no health insurance, no income, and lost my house. I moved to Puerto Rico with my parents. I was losing my independence and needed to be with them. The first thing I did was apply for medical insurance which I did qualify for.

I did research and learned about the Boston Foundation for Sight and the wonderful work they were doing with Scleral lenses. I went to Boston in April 2009. For the first time, someone was asking me the right questions. Someone understood how I was feeling. I couldn't help but be filled with emotion. I've previously had cancer twice, but this has been more taxing than anything else. For the first time, I heard the words "blepharospasm/Meige Syndrome." I began to educate myself, and I realized I wasn't the only one. I shared all the information I learned with my doctors in Puerto Rico because they didn't know what they were dealing with. I left Boston wearing Scleral lenses with my eyes moist, but still photophobic and clenching my eyelids. But most important, I left with a true diagnosis.

Deep inside, I felt that there had to be an exception to the "credit" rule. I decided to walk into the Social Security office to inquire. When I spoke to the officer after my long wait, he realized, I was still there. By this time, my eyes, and the rest of my face, down to my neck were in spasms. He asked the infamous question, "Are you okay?" I still haven't gotten used to the question.

Finally, I went into the supervisor's office. She asked about my visit, and I asked, "I'm short a credit since I last applied in April, 2008. Are there any exceptions?" I was persistent. When asked what my problem was, I was informed that the only exception was for visual impairments. I was given an appointment for an interview to file for SSDI in October 2010.

I found that it was important to have a system of organization, because I was asked about all my previous jobs with dates, how my condition affected my work, a description of the condition, a list with addresses, and telephone numbers of all the doctors I saw, the outcome of my treatment, all the medication I've been on, what they were for and side effects. This disability report form is online. I found it was best to do it before the appointment, because I was able to concentrate. Otherwise, my nervousness and anxiety would have prevented me to speak everything on my mind. The report was discussed, and it was no longer just on paper. I was now a person with a condition.

Needless to say, after all this work, I was denied in February 2011, four months after I reapplied. This time, I appealed, with the help of a savvy lawyer who knew the "ins and outs" of the Social Security system. A completed "Request for Reconsideration" and an "Adult Function Form" allowed me to write about all the limitations, changes, adaptations, intensity of pain, psychological effects, difficulties with activities of daily living, socialization, independence/dependency, chore management, mobility, and how this condition affects my overall life. All medical records were requested by my lawyer and scanned by March 17, 2011.

On February 22, 2012, I received a Notice of Decision stating, "Fully Favorable," followed by my "Awards Letter" and a breakdown of future payments and backpay.

Prior to starting the filing process, I obtained a "Disability Packet" from BEBRF which I found beneficial. I also prepared an information packet for the SSDI representative who was going to interview me.

It is imperative that somewhere in your medical records, the term "functionally blind" be included. The following is a paragraph of the terminology that held weight to the decision making:

The medical evidence shows that the claimant was diagnosed with sever blepharospasm and in the year 2007, associated to this disease, she developed dry eyes, marked corneal hyperalgesia, pain

and photophobia. She was prescribed Lacriset® treatment without improvement of symptoms. She also was recommended Boston Scleral Lenses with improvement of pain; however, without improvement of her blepharospasm that has been progressive. She has a visual acuity of 25/25 in both eyes when she is able to open her eyes. However, the high frequency spasms of her lid closure are uncontrollable and she is “functionally blind” as indicated by her ophthalmologist at the Boston Foundation for Sight in the US.

Much time, energy, and many phone calls were made by both my lawyer, whom I highly recommend, and respect, and by myself. I learned that the key to a less stressful experience is organization. Following up with the doctors who don't understand the importance of meeting deadlines is also necessary. After reapplying in Puerto Rico, the process took eleven months. My experience did not differ much from that of others' experiences. I recommend bringing information about blepharospasm whenever meeting with a new doctor. I was surprised how many doctors misdiagnosed me. We need to increase awareness.

Thank you for caring for people who suffer every day with a condition that we hope has a cure someday.

Perhaps the most important part of your application for Social Security Disability is getting clear, understandable letters from your doctors about blepharospasm and how it affects you. Sometimes the Social Security people may require you to be evaluated by a doctor who is totally unacquainted with the malady. We include here a sample of several reprinted physician letters to aid the doctor.

Social Security Disability Physician Sample Letter 1

RE:

To Whom It May Concern:

_____ has been known to me and in my care since _____, suffering from **Essential Blepharospasm** (Blue Book Section 2.00, subsection 8b), a well recognized neurologic condition characterized by episodic, spontaneous, involuntary closure of the eyes, rendering this individual bilaterally blind with the equivalence of no light perception vision during these unpredictable periods of variable duration and frequency. Unfortunately, even with regular treatments, this patient continues to suffer from statutory blindness (visual acuity worse than or equal to 20/200 in both eyes and/or profound visual field loss to within 5° of central fixation) approximately _____ percent of the time.

In evaluating the visual compromise in this individual who suffers from severe Essential Blepharospasm, “best” visual acuity, “best” visual field, and “best” visual efficiency (as defined in Blue Book Sections 2.02, 2.03, and 2.04, respectively) must be appropriately interpreted in the context of this devastating, unique neurologic disorder.

Four additional circumstances make this an even more compromising disorder:

1. The most significant vision impairment in Essential Blepharospasm occurs instantly and unpredictably, making such activities as walking in public spaces and driving generally unsafe.
2. Since this patient is infrequently fully sighted; partially sighted at other times due to “squinted,” constricted visual fields; and completely blind at others, most of the compensatory mechanisms usually well-developed in many partially sighted individuals are lacking, thus causing an even greater functional impairment.
3. By attempting to maintain eyelid opening by physical means, such as chronic brow elevation and manual separation of the eyelids, this patient often develops dry eyes and poor quality tear films, causing glare and dazzle from even low power light which further impairs vision.
4. Essential Blepharospasm is incurable.

In short, it is my professional opinion that this individual meets Social Security criteria for _____ % disability based upon vision compromise. If I can provide any further information, please do not hesitate to contact our office.

Sincerely,

Charles N. S. Soparkar, M.D., PhD
Plastic Eye Surgery Associates
3730 Kirby Drive, Suite 900
Houston, TX 77098

Social Security Disability Physician Sample Letter 2

To Whom It May Concern;

My patient, xxx, has a disabling impairment of visual function Benign Essential Blepharospasm. Blepharospasm is a neurological condition characterized by abnormal, involuntary, prolonged closure of the eyelids and/or impaired eyelid opening in the absence of spasm. This disabling condition may be present when the patient is seated and at rest (for example, when driving a motor vehicle, engaging in social activities such as conversation across a desk or table, watching television or reading). The condition also may be present when the patient is walking. Thus, to avoid a collision, this patient is forced to attempt to hold her/his eyelids open with one hand while driving with the other or to stop the vehicle completely. To avoid falling, she/he must stop walking until the spasm stops. Indeed, when xxx's eyes are involuntarily closed, she/he has no vision, or visual acuity in the better eye after best correction may be 20/200 or less. In addition, she/he may have loss or contraction of the peripheral visual fields in the better eye such as to have a visual field that extends less than ten degrees, thus producing a visual efficiency of less than twenty degrees. Although these losses are intermittent and episodic, they nevertheless prevent her/him from functioning continuously in order to drive, walk or read.

Essential blepharospasm is usually idiopathic, although it can be secondary to other neurological syndromes such as a stroke, neuro-degenerative diseases, or drug toxicity. Very few patients have familial involvement. The condition has not been able to be eliminated by medical means (ex. Botox – botulinum toxin A) and is expected to persist for the rest of xxx's life. Further medical improvement is not expected at this time, although there is always hope. Indeed, she/he may require other therapy, possibly even surgery, but even then, there is no cure for the condition at the present time. Thus, because of problems in daily activities, it is my opinion that this person is totally and permanently disabled.

Please let me know if you require any additional information.

Respectfully submitted,

Dr. XXX
Doctor's Title

Social Security Disability Physician Sample Letter 3

To Whom It May Concern:

My patient, xxx, has a disabling impairment of visual functioning due to Essential Blepharospasm. This neurological condition causes involuntary, prolonged eyelid closure and/or interferes with eyelid opening. It may be present at rest or when active, and interferes with driving a car, walking, reading, writing, social activities and conversing. During periods of involuntary lid closure, the visual acuity and field are extremely limited, to less than 20/200 in either eye and less than a ten degree field in either eye regardless of correction, making it impossible to drive, walk, or read during episodes of visual loss. The episodes increase with increasing fatigue and as the day goes by.

XXX is being treated with botulinum toxin A for her/his blepharospasm but it is only partially effective, leaving her/him intermittently and episodically disabled. Further treatment, including surgery, may be needed in the future, but further improvement is not expected, and the condition is expected to persist the rest of her/his life. XXX is still able to hear and reason normally. However, her/his visual impairment leaves her/him permanently disabled.

Please let me know if you require any additional information.

Respectfully submitted,

Dr. XXX
Doctor's Title

Social Security Disability Physician Sample Letter 4

RE: Patient's Name

Dear Social Security:

Patient X is a 53-year-old woman with a history of blepharospasm. Her problems began in 2008. Because her eyelids were involuntarily closing, she was unable to see well enough to perform her necessary functions at work as a (profession).

She sought medical assistance from Dr. ABC on (date) who recommended that she also try the drug 123 and noted that she should receive botulinum toxin injections. Drug 123 was not helpful and she was started on drug 456 which also did not improve the blepharospasm symptoms. On (dates) I injected her with X units of botulinum toxin around both eyes. Although this medication was somewhat helpful, Patient X experience side effects: ptosis and blurry vision which resolved once the botulinum toxin wore off. We tried the BOnT treatments three times and none offered the relief she needed to from the blepharospasm symptoms. She sought the necessary care and BOnT treatment of choice but has not improved.

Blepharospasm is a chronic condition which worsens with stress, and for which there is no known cure. Recovery is not anticipated. Patient X's visual abilities and daily functions are impaired by her blepharospasm and she now seeks disability coverage.

Sincerely,

Doctor's Name

Doctor's Title

Explanation of Percentages

Qualification for SS disability has changed in the past and may change again in the future, although changes are more dependent upon clearer definition these days rather than changes in absolute numbers. To see if you qualify for disability, you add up all the organ systems involved, say you have one leg, kidney trouble, and poor vision, each of which gives you a specific score obtained from published tables. If your number is high enough, then you qualify for some degree of disability. The degree of disability that you are awarded (e.g. 50% or 100% or some other percentage) is based upon your total score.

Visual loss is based upon a calculated Visual Efficiency which is determined by plugging visual acuity and visual field into a table. The degree of Visual Efficiency that you have can then award you some degree of visual impairment which goes into your total score for disability. Currently, if you have best corrected visual acuity of less than 20/200 in both eyes or visual fields subtending 5 degrees or less from central fixation in both eyes, or some combination of better vision with worse visual field, etc., then you qualify for 100 % visual impairment which awards you 100% disability.

Although the numbers should speak for themselves, final determination of whether or not a person gets awarded disability often goes before a judge who may require the patient to appear in person. If a person with BEB shows up in court and appears able to walk by themselves or able to read, the judge may dismiss the case out of hand, because there are currently no guidelines for intermittent dysfunction of any organ system. When the system was set up, they figured you either had an amputated leg or you didn't. There were no intermittent amputees.

Also, when physicians fill out the letter we've written, they may be uncomfortable saying a patient is "totally blind" or even "legally blind" when visual acuity and visual field are sometimes quite good or normal, especially if they have documented visions in their chart during spectacle prescription. So, I've given both the physician and the judge a way to accept that the patient may sometimes have "useful" vision by allowing physicians to enter a number into the percent time that they feel the patient is dysfunctional, or blind. If I were filling this out, I would write "> 90 %" of the time.

I put in the section describing why BEB is particularly problematic, so that if a physician writes a smaller number than > 90 % that they feel comfortable writing, such as say "50 %" of the time, the patient (or a lawyer on behalf of the patient) can make the argument to the judge that the problem is no one knows what 50% of the time the vision will be good, and then when the vision is suddenly bad, the patient has none of the usual coping mechanisms that most visually impaired people develop. So, their "functional" blindness is far greater than one might expect.

The final blank for the percent of disability the patient has is so that a physician can extrapolate for the judge what impact this functional blindness truly has. So, a doctor who only feels comfortable writing the patient has total blindness 50% of the time might also appreciate that this means they are 100% disabled.

In summary, in the first blank, I would generally write >90% and in the second blank I would write 100%.

Here is the example I gave the SS lawyers to present to the judges:

A sighted person putting on his shoes sits on the bed, quickly glances about the room, finds his shoes and puts them on. A blind person has learned to always put his shoes next to the leg of the bed and quickly finds them by feel and puts them on. The person with BEB in a good minute may quickly spot his shoes, but most times he will sit on the bed struggling to force his eyes open with his fingers for ten minutes, trying to scan the room to find his shoes, before he then attempts to cross the room to get them and return to the bed before putting them on, so he never knows how long it will take him to dress or whether he will ever find his shoes that morning or not.

Social Security BLUE BOOK Approved Impairments for Receiving Social Security Disability Insurance (SSDI)

Just as the automobile industry has a Blue Book to show old car values and the BEBRF has a Blue Book that tells who we are, the Social Security Administration has a Blue Book too – “Disability Evaluation Under Social Security.” It includes a list of impairments that assists to Social Security employees in determining whether applicants may qualify and be approved to receive Social Security Disability Insurance (SSDI).

<https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>

Here are listed reasons under which blepharospasm patients have been previously approved for SSDI.

2.00 Special Senses and Speech – Adult

1. How do we evaluate specific visual problems?

(a) Statutory Blindness

(b) Blepharospasm – This movement disorder is characterized by repetitive, bilateral, involuntary closure of the eyelids. If you have this disorder, you may have measurable visual acuities and visual fields that do not satisfy the criteria of 2.02 or 2.03. Blepharospasm generally responds to therapy. However, if therapy is not effective, we will consider how the involuntary closure of your eyelids affects your ability to maintain visual function over time.

216(i) The term “disability” means (A) inability to engage in any substantial gainful activity by reason of any medical determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than twelve months, or (B) blindness; and the term “blindness” means central visual acuity of 20/200 or less in the better eye with the use of a correcting lens.

223(d) The term “disability” means (A) inability to engage in any substantial gainful activity by reason of any medical determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than twelve months, or (B) in the case of an individual who has attained the age of 55 and is blind (within the meaning of “blindness” as defined in section 216(i), inability by reason of such blindness to engage in substantial gainful activity requiring skills or abilities comparable to those of any gainful activity in which he has previously engaged with some regularity and over a substantial period of time.

Benign Essential Blepharospasm is a rare disorder. Some doctors have not heard of nor encountered a single case. So, it is not unreasonable that SSDI evaluators, judges, and others need to be walked through what it is and how it affects daily life. You may be asked where on the web they find more information. Refer them to www.blepharospasm.org Be informed yourself so you can answer questions, explain, and educate others. Be patient. Good Luck!