

Descent into Darkness Dawn!

One man's journey through vision loss & recovery

Diary begins on next page ...



Rich Hoeg (365DaysOfBirds.Com)

(Pre Dawn at the Mouth of Lester River on Lake Superior ... 800 yards from my house)

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Note: Individuals are granted a non-commercial license to utilize this diary in as such as those efforts help other patients or family members learn how to deal with the medical condition known as Blepharospasm. Contact me, Rich Hoeg, if you desire to use this diary in some other manner. Thank you.

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Introduction

My name is Richard Hoeg. I live in Duluth, Minnesota on the edge of the Boreal Forest. I live for the outdoors which in my case includes 1,000+ mile bicycle tours, hiking the evergreen forests with my camera, and Nordic skiing. While on a bicycle tour of the Norwegian Arctic during the August of 2019, I crashed due to poor eyesight. This event was the culmination of slowly deteriorating eyesight, but now I could not fool myself anymore. As my wife, Molly, of 37 years, said: "Rich, you need help". Over the preceding two years I had learned "tricks" to deal with vision which was getting steadily worse. This magician (i.e. me) did not have any rabbits to pull out of his hat anymore.

Upon returning home to the United States from Norway I began a series of doctor's appointments in an attempt to determine what was happening to my eyesight. The first doctors I saw told me my problem was dry eyes, but this did not jive with what I was experiencing. While I certainly had days with dry eyes, I felt my problem was worse. At times in addition to squinting, I would not be able to prevent my eyelids from closing involuntarily. Once closed, I often could not reopen my eyes for long periods of time.

After three months of getting nowhere fast, I researched who were the top eye doctors in Minnesota. The Monday after Thanksgiving I saw [Dr. John Berestka](#) in Minneapolis (180 miles south of my Duluth home). He correctly diagnosed my condition as Blepharospasm. This rare disorder occurs when the brain and the eye miscommunicate via the nerves. Although my vision is perfect, my brain sends a signal to my eyelids telling them to slam shut. Sometimes it could be over 20 minutes before I was able to reopen my eyes. The condition was always significantly worse when outside. I eventually learned that dry eye, stress and bright light made my Blepharospasm much worse. By the time I was diagnosed with this disorder, rather than taking long bicycle tours or cross-country skiing, I had to give up both trail running and hiking. Prior to Thanksgiving while I was trail running I ran into a tree at full speed, knocking myself over. Aside from getting a sore head, I knew running was now dangerous. Thus I decided to give up running in favor of short hikes. After all, I reasoned ... how much trouble can one get into during a slow walk? I learned otherwise. Just before Christmas during a short walk near my house, Blepharospasm continuously forced my eyelids shut. I then proceeded to walk into snow banks four times, stumbling and falling every time. I knew I was in deep trouble. I had lost the freedom to be outside without someone leading me around by the elbow.

Although I had been diagnosed with Blepharospasm at the end of November, I needed to wait till early January for my first treatment. Apparently there is an end of year rush for medical appointments as individuals try to have treatments before a given insurance year ends. I had been informed that when given a series of Botox injections, the poison (Botox) would paralyze my eyelid nerves and prevent my uncontrolled blinking. Thus, I started my five week wait till early January to see my next doctor, [Dr. Nichols Schmitt](#) (a surgeon who specializes in eyelids).

I had been advised by [Dr. Berestka](#) to keep a diary for [Dr. Schmitt](#). **Originally this diary was just for my doctors, my wife and me.** Shortly before Christmas I gave my children and their spouses' access to this diary. I wanted them to understand both my medical condition and emotions. Although I had been a happy individual, my loss of vision had brought me so low that I had Googled "Blepharospasm and Suicide". While I don't believe I ever seriously considered taking my own life, I was very interested in learning how other individuals had dealt with the combination of my medical conditions and depression..

During my wait for the initial treatment (five weeks) I tried to remind myself that I had been informed that Botox injections for Blepharospasm were effective for over 95% of patients. While intellectually this gave me hope, being functionally blind most of the time prior to my first series of injections terrified me and made me doubt the Botox injections would work in my case. Given my Blepharospasm would kick in almost always whenever I went outside, It was darned difficult learning to accept I was functionally blind whenever outside.

Here are two short videos I had Molly take of me of Blepharospasm flare-ups. It is not pretty, but reality is often messy.

- [Video #1](#)
- [Video #2](#)

Thankfully the treatments are working, and I have returned to a "new normal" life. My vision will never return to the pre Blepharospasm period, but it is darn good. I am able to do anything and everything I used to do prior to my loss of vision.

About half way through this diary, I decided to make my words available to the world at large. This journey was terrifying, and if I am able to help other individuals who are diagnosed with Blepharospasm (and their family members) experience a slightly less stressful journey than mine, I will be happy.

There are two basic parts to this diary ... The Pre Treatment Period and the Post Initial Treatment Period. I decided to continue writing occasional entries until I

had successfully transited the period between the first two injections. With Botox, the efficacy of the injections wears off in 3 to 4 months. I wanted to insure I was able to keep up a normal life throughout the entire three month period between treatments #1 and #2. In my case I had 50 units of Botox injected. My side effects were minimal ... just some poor reading vision for the initial two weeks and a brief episode of double vision.

All of the entries are “original”. I did not change anything except for minor grammatical and punctuation edits. My diary covers a period of approximately four months ending on April 7, 2020. As one of my joys in life (and still is given my successful treatment), I have occasionally added photographs I took during this journey.

This image was taken before Blepharospasm took me down my dark path. I am holding “Silver”, an injured Snowy Owl which I discovered and rescued during a hike in the Boreal forest. It was a unique experience “hand capturing” a large owl.



A conclusion follows the final diary entry.

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Pre Treatment Period

- **December 1, 2019:** Received 18+ inches of snow in the Blizzard. Started shoveling at 7 am in the dark and I could see fine (wearing scleral lenses and goggles to stop snow from getting in my eyes). However by 9:00 am after an hour spent trying to repair a broken snowblower, I needed sunglasses and a baseball cap. The bright white snow was bothering my left eye. Weather conditions were still cloudy. Finished clearing the walk and driveway shortly before noon ... now back inside and not wearing scleral lenses. Vision is fine using my normal glasses.



(My world ... post blizzard ... across the street from my house)

- **December 2, 2019:** Took a walk starting at 8:15 am. It's beautiful outside today ... bright, sunny, clear and cold (5F). I was wearing my scleral contacts lenses and wraparound sunglasses. Whether it was because of the cold weather or the bright reflective light off all our new snow (19 inches in yesterday's blizzard), I had to keep my eyes closed 70% of the time. Essentially I was walking blind, with brief periods having my eyes open to get my bearings. Depressing.

- **December 2, 2019:** Went cross-country skiing around 1:30 pm. Was wearing my sclera lens and dark smoke goggles. While I could not see perfectly, my vision was decent enough (not good). Weather conditions were 22F and bright sun. Ski Trails were partially shaded most of the time.
- **December 2, 2019:** Wearing my prescription glasses inside post sundown. Am able to see perfectly indoors, and just fine outside (BBQ'ing dinner)
- **December 3, 2019:** Sun just came out at 10 am. Given the new snow from the blizzard, it is very, very bright. I am wearing glasses inside the house and my left eye wants to close given the bright light. My left eye does not feel dry. Changed to wearing wraparound sunglasses inside the house. Sun is also behind some clouds now. Much better.
- **December 4, 2019:** We were finally plowed out this morning. I took the opportunity to run errands and go birding. When the sun came out, the reflective glare while driving was intense and I was almost blinded. I cut short my birding and drove carefully to Relf Eye Care where I both scheduled an appointment with Dr. Strom tomorrow and purchased a pair of wrap around FL-41 sunglasses. These helped, but I am still very light sensitive. I was wearing my Scleral lenses. Now home just after sunset (4:30 pm). Wearing my normal glasses inside ... significantly less light inside home and given time of day ... vision is perfect.
 - *Side note #1:* Remembered that about one month ago I went out to photograph the Northern Lights at 1 am. I wore my normal eyeglasses, and had no trouble driving (normal dry conditions within car) or seeing. I had to drive 35 minutes to Boulder Lake. While outside during the middle of the night, I could see perfectly between 2 am and 4 am.
 - *Side note #2:* Just prior to Thanksgiving I was down in Milwaukee to meet our new grandchild. One day I went birding and drove 1.75 hours to a waterfront area where a number of Snowy Owls had been seen. There was no snow on the ground, and I left before sunrise. Prior to sunrise, during the low light time of the morning I could see fine (wearing Sclera Lenses). My vision while driving became more difficult as the sun rose, but when I reached Lake Michigan and actually got out of the car to look for owls, I could see fine ... even though it was extremely windy and I was next to Lake Michigan. I have noticed if my brain is distracted while I am outside (i.e. intense

concentration upon some task), I may have better vision. If I am just walking (or driving the car) I am much more bothered by light.

- **December 6 and 7, 2019:** I went birding Sax Zim Bog both days, leaving before sunrise. My brain now tells me if I leave during low light, all is good. I stayed out for five hours each day with a significant amount of driving. All went well. My vision was decent and always good after I got out of the car to hike.



(A Great Gray Owl I photographed during this birding excursion)

- **December 8, 2019:** I thought the FL-41 tinted sunglasses may had been a real winner in my battle against dry eyes and its effects, including light sensitivity, but today is presented me with experiences which force me to reconsider that view. The weather today is gloomy ... 32F with dark clouds as we await another winter storm tonight. This morning while reading around the house wearing my normal prescription eyeglasses, my vision was fine, but the moment we stepped outside to go to church I had an anxiety attack. I was wearing my Scleral contact lenses and the FL-41

sunglasses (even though it was dark). My vision sucked both during the drive to church and during service (inside). Once we got home and I could relax, life was good again. Stress obviously makes my vision worse.

- **December 8, 2019:** Same gloomy day in the afternoon. I went cross country skiing ... great snow conditions and a good fast ski ... lousy vision. I was wearing my Scleral contact lenses and some smoke ski goggles. I managed to avoid anxiety attacks ... I kind of figured it would be hard to get into trouble walking over to the trails ... and if I fell while skiing it was a non issue. I could really only see the trail while skiing about 60% of the time, but given I know these trails by heart, skiing them was not a too much of a challenge.
- **December 8, 2019:** I just realized that my problems this morning could have been made worse by my time on my tablet. I awoke at 5:10 and was on my tablet nonstop till we left for church at 9:45 am. It is a new tablet, and I was working on its configuration. My problems today reminded me I have heard how screen time can worsen dry eyes. Research on the web yielded dry eyes may be worsened by the blue light screens emit. This new tablet runs Android 9 which has both a night mode and blue light filter. I activated both and maxed out the blue light filter. Given how much I like my tablet, and the amount of time I tend to spend reading on the device, it will be an interesting test. When weather permits and I head out birding in the early morning, I have almost zero screen time.
- **December 10, 2019:** Managed to go up to Sax Zim Bog birding today. Wore the FL-41 glasses. Not perfect, but helps. I also read it helps to distract the brain and sing or hum. Believe it or not, when I started to have trouble seeing today, I started singing theme songs from 1960's sitcoms (my childhood). It helped.
- **December 11, 2019:** I tried going cross country skiing this afternoon at 2 pm. It is a beautiful, super bright sunny day. As an experiment I wore my prescription sunglasses and clear ski goggles over my glasses. The moment I stepped outside and was in the bright sun my left eye slammed shut hard. I tried skiing but I was essentially blind. After 3 kilometers which included a fall on an easy flat section of the trail (I am an expert skier), I gave up and walked home. Once indoors and in dimmer light with no direct sunlight, I am able to see fine. Did some research on Amazon and just ordered some category 4 mountaineering sunglasses. They arrive Monday.

- **December 12, 2019:** Molly likes me to use the word "roadblocks", not "failures". Thus, I experienced another roadblock today. Once again I went skiing. Weather conditions were cloudy and 22F. Initially I could see okay on the 8km ski, but my vision progressively worsened till I was skiing with very little eyesight. The only saving grace is I have these trails memorized. Even so I was painfully whipped by a pine branch I never saw (classic tracks are on the outside next to the trees), and towards the end of my ski I slowly skied off the trail (not on purpose) into a tree. End result, I am giving up Nordic skiing till I conquer my vision problem. Hopefully one of the six pairs of eyeglasses I have on order which deal with various spectrum of lights will help. It's hard to give up my favorite two forms of outdoor exercise ... bicycling and cross-country skiing.
- **December 12, 2019:** Molly and I had a telecom today with our financial advisor. During the one hour meeting, we were viewing PDF reports on my PC. I was wearing prescription computer glasses. By the end of the meeting my bad eye ... the left one ... was on fire. After the meeting I inserted some drops in the left eye and relaxed. My eye recovered pretty well.
- **December 13, 2019:** I am depressed and scared with life. Molly is loving and fantastic, but losing the outside world and my independence is horrifying. Apparently the play Molly saw last night at the Duluth Playhouse was a visual treat, The Wizard of Oz. However it was depressing to hear about the play this morning from her because I knew I would not have been able to watch. Yesterday was a horrible day for my left eye. My life now revolves around shoveling snow and reading. The six new pair of glasses arrive starting tomorrow. Please, God, let one of them help. I was not prepared psychologically for the huge effect bright snow would have on my vision. I was stumbling through life two weeks ago and surviving before the snows came, but now I am in prison. I need to make adjustments on how I spend my day, but it's hard. I want to cry.
- **December 14, 2019:** Wearing my scleral lenses and some goggles my vision was perfect before sunrise, and I was easily able to shovel the 4 inches of new snow from the driveway and walk. However, during the drive down to Minneapolis starting at 11:30 am, for the first hour in bright sunny conditions, I was able to drive. After an hour I let Molly take over the driving. After an additional hour of bright sunny conditions, the reflection off the snow became too much for my eyes, and for the rest of the drive I had to keep my eyes 100% closed. I was wearing my Scleral contact lenses and FL41 wraparound sunglasses. We stopped briefly at the Maple Grove

REI store. The fluorescent lights in REI were painful. I am now in my son's house. Inside I can see fine. During this entire process my eyes never felt dry ... which is often true. My eyes don't feel all that dry, but oh man am I light sensitive.



(Christmas Luminaria light up a foot bridge near my house. Low light = vision for me)

- **December 16, 2019:** Tried to take a walk around noon. I was wearing scleral contact lenses, FL41 sunglasses and full goggles. Within minutes of getting outside my left eye insisted on closing. Weather conditions were mild ... 20F, calm winds and clouds.
- **December 20, 2019:** Molly and I spent the entire day out and about. The weather was mild ... approaching 32F in the afternoon with clouds to sunny conditions. I tried working out at YMCA. The end result was not pretty. While I did get some exercise I stressed out trying to find my way around a new building. Stress equals no vision. We then went over to some friends for a Christmas lunch. As we sat around the table and the sun came out ... reflecting off the snow I lost my vision. By the time we left, I was only able to sit in the car with my eyes closed. We are now home after dark, and my eyesight is perfect.. I need to learn how to handle stress, as it sets off the Blepharospasm.

- **December 21, 2019:** I'm a prisoner. I can no longer drive. If I even walk outside, my eyes slam shut. If Molly is not available to drive me somewhere, I just sit at home. I have gone from a person who spent his time bicycling thousands of miles on bike tours and spending hours bird hiking the forests of NE Minnesota to a shut-in who worries he is going blind. Help.
- **December 22, 2019:** Conflicting experiences ... this morning just as the sun came up and as I started to load the car, I had a major anxiety attack. This was immediately followed by a Blepharospasm attack. I was totally stressed out. However, now that I have been a passenger in the car for four hours, my vision has been good. Normally my eyes slam shut as I sit in a car. The day is bright and sunny but the extreme light is not an issue. The temperature is mild ... starting 32F to 46F. During the drive I have been reading an eBook, Intertwined by Joaquin Farias. The book is about dystopia and how people retrain their brain after significant events. The theme of the book is that when one's brain is focused upon something other than a common task like driving, vision is much better. During the long drive from Duluth to Milwaukee (7 hours), in addition to reading I have used the ePen to write using my left hand (I am right handed) on my tablet. When I glance up from my tablet and look outside the car at the passing scenery, I am able to sightsee ... which is unusual. Normally my eyes are involuntarily closed during our entire time in the car. I will have to research in more depth how to retrain my brain and avoid anxiety attacks. My eyes should not be able to handle being in the car for this long a period of time.
- **December 27, 2019:** Milwaukee was a challenge ... not because of Carl and Chelsea who provided a great loving environment, but because my vision continues to worsen, and any movement outside of a home brings on anxiety which just reinforces my Blepharospasm. Today is sunny and warm (28F). Normally I would be cross-country skiing birding. None of that is possible. I am a shut-in. I tried taking a walk in the woods before the sun came out this morning. My eyes insisted on closing 70% of the time. It's good I know the trails around here or I would have quickly become disoriented and gotten lost.
- **December 31, 2019:** On this final day of the year, I will note observations which are consistent in terms of my Blepharospasm.

- Stress sets off violent episodes. Today I start actively working to manage how my body deals with stress and I am starting Qigong classes.
- Dry eyes make my episodes much worse. Just a few minutes ago I stepped outside to fill the birdfeeders. It is 8 am on a cold, clear day. My eyes immediately wanted to slam shut, but upon coming back inside into a warmer, more humid environment, my episode subsided
- The moist, humid warm environment of the YMCA pool is fantastic. I have started swimming ½ mile a few times per week. While in the pool, I have perfect vision. However, immediately upon exiting the pool area I experience severe Blepharospasm episodes ... not sure if it is due to being stressed or dehydrated... possibly both??
- Today is the first bright sunny day in a long while ... we'll see how it goes
- Normally while at home I am able to see fine except for TV (no real loss). However the moment I walk out the front door, my Blepharospasm kicks in with a vengeance.

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- **December 31, 2019: (continued)**

- An update on the sunny day. Molly took me to look for Snowy Owls. We left home about 90 minutes before sunset. The bright light forced me to shut my eyes while we were driving, and I could not open them. When we arrived in the area where we looked for owls, when I was in the shade I was fine, but in the sun ... uff dah, horrible. Once the sun set I was able to see again and keep my eyes open.



(Snowy Owl on New Year's Eve ... low light for my eyes at sunset)

- **January 2, 2020:** Tried a walk this morning. We live on 7 Bridges Road, and I hiked up to the 3rd bridge and back. The weather was overcast skies, light wind, and 28F. I was out for only 30 minutes, and handled the stress portion of being out on my own fine. The road does not have much traffic, and I am able to "hear" cars long before they get close. For the first 10 minutes my vision was fair, and then went downhill from that point. During the final half of my walk, my eyelids were locked shut ... not spasming, but I also could not open them. I stumbled three times because I could not see ... walking into the snowbanks. The third time I fell ... no harm done, but

frustrating. I would be extremely upset if not for the fact my first Botox treatment is on Monday. If it does not work, I will fall into deep depression.

- **January 5, 2020:** Perhaps if my Botox treatments are successful I will have to edit / publish this short diary. A title might be: A Descent Into Darkness ... Dawn! I have never known such deep depression. Blepharospasm robbed me of my independence ... not able to do any of the outdoor activities I love ... even drive a car. I am 100% dependent on others. Yesterday was a good example. While my sight was still acceptable, Molly and I pitched the idea of covering the Breezy Point Pond Hockey Tournament for Lake Country Journal. By the time the event arrived (yesterday) my vision was horrible. After only a few minutes outside my sight descended into darkness. My eyelids slammed shut, which makes it very difficult for a photographer to take photos of hockey games (my job). Even walking from the frozen rinks to our car became an extremely difficult Olympic sport. I could not see to walk. The weather was mild ... mid 20's, overcast and little wind. However after the sun went down and darkness reigned supreme, I was not only able to watch the fireworks, but also take great photographs. Generally if I am active at a hobby and using my hands, I am able to easily keep my eyelids open. Tomorrow is my first Botox treatment. I hope dawn will be beautiful

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Post Treatment Period

- **January 6, 2020:** My first Botox treatment was today. The doctor seems to be confident it will help significantly. I have been warned to expect a seven day wait to feel results. However, let's step back to yesterday. My vision was horrible during the drive to Minneapolis. The weather was bright and sunny, which as we were travelling south meant we were facing the sun and all its reflective glory. My eyes were closed for the entire trip. However, when we arrived at my youngest son's house, I was surprisingly relaxed. It is so good to be moving forward with treatment, that my psyche was in good shape. Surprisingly, I had a good sleep, but woke up terrified. Our eye appointment was at 7:45 am and all I could think of was that the Botox would fail. The actual treatment only took about 10 minutes, about 12 to 14 injections around my eyes ... a tiny bit of pain but not bad at all. When we arrived home in Duluth I was starting to feel confident (no Botox results yet). However, using special eyeglasses that filter out light I took my first successful hike in the forest since Thanksgiving. I left the house at 3 pm and hiked in the woods using deer trails for 70 minutes. I was able to see the path, deadfall, and scan the trees for owls. Life is good.
- **January 9, 2020:** After the dark of night comes dawn. I can see! The Botox seems to be working. Over the past few days I have taken three hikes in the deep forest, following deer paths in bright sunny conditions. No problem! My vision was perfect and I was able to see all the deadfall (stepping over same). One Godsend is the rollup glasses I just acquired. These are the same inexpensive glasses that the eye doctor gives you after dilating your eyes. These rollups insert between my prescription glasses and my face ... easily stay in place, and man do they block the light! In addition, I drove over to my owling grounds yesterday afternoon. I was able to easily keep my eyes open, and had perfect vision. Better yet, I found and saw two Snowy Owls. My vision is coming back. When the snow and ski conditions are better, I intend to try cross country skiing.
- **January 9, 2020:** Had an excellent appointment with Dr. Fuchs this morning. He is a doctor who has dry eye himself. We are starting a series of tests to research if there are underlying reasons which have caused my Blepharospasm ... Lyme Disease, Diabetes, or Thyroid problems. In addition, apparently I forget to blink which is weird. I always thought

blinking was automatic. As noted in my first entry today, this will be an ongoing journey... at times a battle and at times a research project.

- **January 15, 2020:** Not as much to say when all is going "normal". My blood work all came back negative, which is good. Did another cross-country ski today and saw the trails fine. No problem with driving and am going out birding in the morning regularly. My main side effect from the Botox seems to be less than perfect "close-up" vision, but by making the font size larger on my tablet all is fine.
- **January 17, 2020:** The last two days have been most excellent. Everything started with photographing the American Spirit (ship) steaming past Splitrock Lighthouse in the Sea Smoke (-18F), spending an hour that same evening watching and photographing two Snowy Owls, and finally taking a perfect Nordic ski this afternoon. During each of these experiences I never once thought about Blepharospasm; I lived in the moment with perfect sight. Having written that, I am very worried about what the future holds. When will the Botox wear off and will each treatment be as successful as the first injections? However, for the moment life is good. I do not plan on many entries to this diary now unless something significant occurs ... positive or negative. My next treatment is scheduled for April 6th.



Rich Hoeg (365DaysOfBirds.Com)

(Last ship of the season sails past Split Rock Lighthouse on Lake Superior)

- **January 22, 2020:** Although it has been two weeks since my initial Botox treatment, my eyesight continues to be excellent, and I have had zero episodes of my eyelids involuntarily slamming shut. Still, my self confidence is low. Life is good, but I have constant worries about what the future may hold. We leave for Fort Myers, Florida early tomorrow morning, and I am stressing out while packing. Let me be clear that there is no apparent reason for my stress other than my own fear. As FDR so famously said at the beginning of WW2, "we have nothing to fear but fear but fear itself". While intellectually I know my fear is irrational, leaving home on our first trip since I crashed my bike while touring in Norway last summer is frightening for me. I realize I need to get through a few cycles of Botox to regain my confidence. My doctor believes all will be good, but our brains have a great propensity to worry. Somewhat related I continue to attend Qigong twice per week. It is a great means of mediating and relaxing.
- **February 14, 2020:** Life has been good, and I have not felt the need to update this diary, but it is time for some more information. Almost six weeks have passed since my initial injections, and my vision is still very good. Although I live in a very dry winter climate (northern Minnesota), I have been able to drive, snowshoe in the woods for birding, cross-country ski and even take a bicycle ride when we had a rare day with temperatures in the low 40's (it's minus 23F this morning). I have had a few issues that have resulted from my treatment. Apparently the Botox has caused me to not blink often enough ... thus the doctor has me taking actions to help keep my eyes lubricated. I also have blinking exercises. Finally, my near vision for reading is worse than before my treatment, but I am able to overcome this problem by increasing the font size on my tablet. My primary question right now is whether the effectiveness of the treatment will last till my next round of injections at 3 months ... early April.
- **February 27, 2020:** All by myself ... Molly is on a ski trip with Susan. I am very worried that my Botox treatment is starting to become less effective. Today is very bright, and my eyes are very light sensitive. I drove up to Sax-Zim Bog before sunrise, and while watching an owl after sunrise I had to give up. I was standing outside with the sun at my back, and the brightness even with my sunglasses was too difficult to handle. I was able to drive home fine by using the super light blocking optical rollup glasses. Now while using my tablet I experience a blinking / spasm episode while inside the house. This is scary. I have five weeks till my second treatment. With respect to my vision at this point, my reading or near vision has suffered due to Botox, and while driving my eyes feel heavy.

- **February 28, 2020:** Well, yesterday may have been a false alarm. However, I am convinced the effect of the first treatment is beginning to wear off. The last few days when I head out somewhere I immediately stress out which is bad news because it is a trigger for Blepharospasm. Once I drive the car and "settle my mind down and relax", life is much better. I think the effect of the first treatment is wearing off, but I am making things worse by getting scared.
- **March 10, 2020:** While I am now convinced the effect of my first treatment has worn off a bit, I am also convinced I was scaring myself over the prospect of having a period of "blindness" prior to my second treatment. I am still able to easily drive, cross-country ski, and bicycle, but I have learned that my sensitivity to light is now my biggest problem right. The glare of the sun off melting snow is hard to handle. I wear sunglasses or the optical rollups (given when your eyes are dilated by the doctor) at all times when it is bright. In addition, I am focusing on relaxation exercises learned via Qigong. Both of these items help immensely. Four weeks to go (less one day)
- **March 16, 2020:** The effect of my first treatment is definitely wearing off. I am still able to see perfectly inside and outdoors, but driving has become tiring. I really have to concentrate to keep my vision 100%. The key is to relax, which has become difficult due to Coronavirus. Perhaps the stress of the disease is making my vision worse. I need to work on my relaxation more including the use of Qigong. It's a crazy world. I'm lucky to live in northern Minnesota ... a bit less crazy up here.
- **March 24, 2020:** Yesterday was my 64th birthday, and also the end of our first week of "stay at home" to protect against Coronavirus. To put it bluntly, it was a strange birthday which did not involve any friends or family (not safe to visit), and I am also continuing to feel the positive effects of my first Botox treatment wearing off. Light is increasingly difficult to handle, and the glistening melting snow does not help matters. My second treatment is scheduled for two weeks from yesterday, but my eye doctor's office is starting to cancel some appointments and all surgeries due to Coronavirus. Thus, I now have the double stress of wondering how fast my Botox will wear off, and whether I will be able to receive my next treatment on time. Uff dah.
- **April 1, 2020:** Great news! My eye doctor's office considers my Botox treatment essential, and even though they are cancelling most

appointments due to Coronavirus concerns, I will still get my second treatment on Monday. Molly and I will drive down to Minneapolis and back on one tank of gas. Our only stop will be the doctor's office. Given the effect of my first treatment is definitely wearing off, I am so relieved. Only four days to go. While driving has become quite difficult, I am still able to bike, ski and hike. My vision isn't perfect particularly on bright sunny days, but I am surviving. Yea!



(Painted Bunting at the Audubon Corkscrew Swamp)

Once I knew the Botox injections were working, Molly and I treated ourselves to a trip south to Fort Myers. Friends had invited us down to visit and escape the sub zero temperatures in northern Minnesota for sunny, warm Florida. Thankfully our trip was in late January before the Coronavirus crisis. I learned not only could I bicycle once more in perfect safety, but also do any outdoor activity. The bright sun did not bother me! Albeit I was careful and wore dark sunglasses 100% of the time.

- **April 7, 2020:** This will be my last entry in this diary. Yesterday was my second treatment of Botox for Blepharospasm. For me it is a life saving, vision enabling treatment. It is significant that I have survived the first period between treatments. I now know what the future holds. Botox enables, and I understand how quickly it wears off over the three months between treatments. While everyone who gets treated with Botox is different, my path sounds somewhat normal according to my doctor. My first injection was 50 units, and by 2.5 months the efficacy was wearing off. The last week leading up to my second treatment, the final week of the three month period was hard. Although I was still able to maintain an active outdoors life (run, bicycle, hike, bird), those activities have once again become a challenge. Bright light is harder to handle, and the reflection of sunlight off melting snow is painful. I can still drive a car if I restrict my trips to smaller distances.

Continued on next page ...

- **April 7th (continued):** I had a great conversation with my Botox injection doctor yesterday. This diary was helpful as I could explain my exact experiences. Apparently my side effects were mild. The best result of our conversation is he will allow me to get injections every two months. I know that I can easily live a normal life for over two months given Botox. Dr. Schmidt did not want to increase my dosage in an attempt to help me make it the full three months. This might have led to increased side effects. I asked if a two month treatment cycle was acceptable, and the answer was yes. Thankfully I am lucky enough to have the financial resources to pay for the shorter treatment cycle. Over the course of the year, my insurance will pay for three treatments, and I will pay for three treatments. It is money well spent. One closing comment, I had a major stress attack on the drive down to Minneapolis from Duluth. The combination of the Coronavirus crisis, my worry about the second treatment (one had to be tested by a nurse before being admitted to the eye doctor), my eyes slammed shut. Stress! I need to continue my fight to be calm. However, these are not normal times. Getting home to Duluth I took a hike over to my Great Horned Owl's nest. I took this photograph. It is great to be alive and living life to the fullest. Peace!



(Mom and one of the triplets)

Descent into Darkness ... Dawn!

One man's journey through vision loss & recovery

Conclusion

Everyone's Blepharospasm journey is different. I hope that by revealing the deep fear and depression I experienced, you will better understand your own emotions are normal. Reach out to family and friends to explain your condition. If my eyes were open, everyone just assumed all was good. One of my jokes with friends who we had over for dinner was ... if my eyes were closed, their conversation was NOT boring unless they also noticed my chin drooping to my chest (i.e. for a snooze!).

In addition to not closing yourself off from others, make sure you research. The web is a great resource. After years of working as a "techie" for Honeywell, I understand the value of reputable sources. I tended to restrict my Google searches to academic and foundation web sites. Content posted on most commercial web sites I tended to ignore. Here are two great places to learn more about Blepharospasm:

- [Blepharospasm Foundation](#)
- [Living with Blepharospasm Private Facebook Group](#)

One word of caution relative to this Facebook group (and other online forums), be aware that members posting to these forums tend to be individuals having trouble with their condition. Folks who have succeeded in battling Blepharospasm do not tend to post as often. Recently I learned about another individual in northern Minnesota who has Blepharospasm. It was great support for me to meet and talk with her. Her Botox injections have worked for over 20 years!

Once again, research ... and then do more research. I went through many doctors before I was correctly diagnosed. It was horrible experience to break down in tears in one doctor's office. I told this doctor I was going blind, but I received little help except a recommendation to be examined again in two weeks. As the seriousness of my condition became apparent, my wife started coming to each and every doctor's visit. We had questions written down in advance, and she would write down the answers. Given my stress, although I heard everything doctor's stated, I often did not remember 100% just a few hours later.

Finally, be aware insurance companies, not doctors, tend to drive treatment cycles (i.e. 3 to 4 months between injections). If your financial resources allow

you to occasionally pay for your own treatments, discuss the option of shorter periods between injections with your medical professional. Dr. Schmitt who gives me injections was hesitant to increase my injection dosages (I receive 50 units of Botox) for fear of increased side effects. However, when he understood I would happily pay (i.e. I was not concerned about insurance reimbursement) for a shorter time period between treatments, he was very willing to put me on a two month cycle. The net effect of a two month period between treatments is:

- I pay out of pocket for 3 of 6 treatments per year
- I know my treatments do not start to wear off till part way through the 3rd month
- Thus ... I keep my vision optimized.

God Bless! You can conquer this Blepharospasm. Don't let it overwhelm you. By no means is my vision perfect, but I have my life back. I am able to safely drive a car, and experience the glory of nature in the Northwoods.

I welcome being contacted. You are not alone.

Finally ... all my love to Molly, my wife for over 36 years. I would not have survived this journey without her love and support.

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Note: Individuals are granted a non-commercial license to utilize this diary in as such as those efforts help other patients or family members learn how to deal with the medical condition known as Blepharospasm. Contact me, Rich Hoeg, if you desire to use this diary in some other manner. Thank you.