



MYASTHENIA GRAVIS

FOUNDATION OF AMERICA, INC.®



This letter was originally sent to MGFA in Oct. 2007 and was updated by Annette Nov. 2008

Dear Myasthenia Gravis Foundation of America,

Please allow me to introduce myself, my name is Annette Kennedy-Bowman, I am a busy wife, mother and a corporate accounts sales manager for the Hilton hotel in my area. In addition, I am an interior designer, working hard to acquire clients for my design business. I also have myasthenia gravis. I was diagnosed in the fall of 2005 after a long string of visits to doctor upon doctor and more medical testing than most people go through in a lifetime. I thought you may be interested in reading how I learned about MG.

This story begins in the fall of 2004, I had just turned 39. I began to feel a general sense of fatigue, but brushed it off, due the fact that I was a busy wife, mother and part-time art student, finishing my last year of design school. By February of 2005, I began experiencing what I referred to as "ghosting," kind of like double vision. I described it as seeing a shadow behind whatever I was looking at. It would be the same exact image of what I was actually seeing, but with a lighter, shadowy version just above or behind the real image. I first noticed this while watching television, Law and Order to be exact, with the white text on the black background that is displayed between scenes.

Within the following weeks this "ghosting" was happening more frequently, along with the feeling that I was looking through a veil at times. Because these symptoms were not constant, I would blame them on being tired. Unfortunately, they kept returning, and so I went to the eye doctor. The physician told me that I was just getting older, after all I was approaching 40 (like I needed to be reminded), and that my eyes were just having trouble focusing. A slight adjustment to my reading glasses prescription should do the trick. It didn't. In March, a very strange thing happened. It was a very important night for me—my portfolio exhibit at art school. I was extremely excited and a bit nervous. As I walked across the parking lot carrying my portfolio bag by the handles, as I had done a million times before, my fingers let go of the handles. This really frightened me, but since I was able to regain the strength in my hand almost immediately, I continued across the parking lot, went up to the gallery, and set up my portfolio pieces. I don't think anyone noticed me flexing my fingers throughout the show. In the back of my mind I was thinking, "Did I just have a stroke or TIA?" I was thinking of my grandmother, who had suffered several TIAs prior to a major stroke that left her paralyzed and in a wheelchair over 10 years before. Now she was fighting for her life, congestive heart failure was getting the best of her, and my family had just met with Hospice earlier in the week. Although this incident rattled me, I quickly returned to normal, and attributed it to being overly stressed. After all, it was a big night and I was only a few weeks from graduation.

On April 2, 2005, I graduated with honors from art school. My family threw a party and everyone was so proud of me, but mostly I was proud of myself for what I had accomplished. It wasn't easy to go back to school at my age, with the responsibilities of a family. Not to mention I was a "non-traditional" student, which basically meant I was not 18 anymore. Anyway, I was proud, but mostly felt very blessed to have the love and support of my family. They believed in my ability and encouraged me throughout the last 3 years, and now that the schooling was over, I was an Interior Designer. The world was my oyster; I only wished I felt better. My symptoms were persisting; I knew something was not right with my eyes. So I made another appointment, with my long time ophthalmologist, not the optometrist. Much to my surprise, the ophthalmologist told me the same thing; I was getting older and my eyes were too. The physician said that my eyes were healthy, and when I reiterated my eye symptoms, she made another joke about 40 being around the corner, smiled and sent me on my way. I left the office feeling very frustrated. In the doctor's defense, I never mentioned the muscle weakness or fatigue to her; it just never occurred to me that those symptoms may be connected to my vision issues.

The next few weeks were a whirlwind. My grandmother passed away, and so I put everything else aside and dealt with her death. I read at the funeral, through my tears; everything went double on me for just a moment. I regained my composure and finished the reading. Later that day everyone gathered at our home. As I sat around with family members, telling stories and reliving our time spent with our grandmother, I looked around the room at my extended family thinking how lucky we were to have each other. I also remember wishing that I had the energy that I saw in my cousins and thinking to myself, "What is

happening to me?" And so it goes...on April 28 while driving my son to the dentist, I began having visual disturbances. At first, I thought I was getting a migraine, since I have suffered from classic migraine since I was eight years old. Visual disturbances at the onset of a migraine attack were nothing new to me. This, however, was different from anything I had ever experienced, instead of "blind spots" and "shattered images," objects seemed to be coming toward me in 3-D double vision. The episode lasted only a few minutes and then my vision cleared, only to repeat itself 30 minutes later. My husband came to the dentist immediately. He called our family physician's office from the car. We were told to come right in, and so we did. My physician was unavailable, so I met with someone else in the practice. Of course I had never met her before, and so she didn't know me from Adam...I was very upset and frightened. She immediately ordered a STAT MRI. The MRI was negative (great, no signs of stroke) and so the conclusion was drawn that this episode was some sort of "strange migraine," although I never got a headache, nausea, numbness or confusion, as I normally do with a migraine attack. Keep in mind, at this point, I was telling whomever I saw about ALL of my symptoms, but no one was tying them together. I wanted to believe this migraine conclusion, even though it just didn't seem to fit. I guess in my heart I knew better, but I just hoped and prayed that it would never happen again...wishful thinking.

By the time May rolled around, I was still experiencing fatigue that would come and go, along with the vision "ghosting" and periodic episodes of double vision. I also began to experience a different visual; I would see two images of an object, but not clearly separate images, more like an overlapping. Since the MRI was negative and my ophthalmologist said my eyes were fine, I really didn't know what to do. I also noticed some muscle weakness. For example, there were times I couldn't turn the key in the ignition of my car the first time I tried. Or when I went to turn up a tube of lipstick with a quick twist, I needed two hands to turn the tube. I felt fatigued more often and so I thought I should see a neurologist. I was scared to drive at night, due to the visual disturbances. Daytime driving was at times challenging enough, but at night with the glare of the lights, it was becoming frightening. Definitely time to see the neurologist. Herein lies the irony, since I was a teenager I had a neurologist that I saw twice a year for my migraine management. Fortunately, my migraines have remained the same and I usually only get 3-5 a year. My neurologist had retired six years earlier, and since my migraines were under control at that time, I opted to just see my family doctor for treatment. Anyway, the point is that now, when I needed a neurologist, I couldn't just call and make an appointment myself. I had to see my family physician first, and get a referral from him. The neurologist's office would not schedule an office visit unless it was requested by my family doctor. This is because I was a "new patient," even though it was the same group I had seen for 20 years! So... I saw my family physician in early June and told him about every symptom I had been experiencing. He recommended that I see a neuro-ophthalmologist and a neurologist just to be thorough. With my family physician's referral, I could now schedule the appointments. The neuro-ophthalmologist couldn't see me for 4 weeks and the neurologist for 8 weeks. In retrospect, I should have asked my family doctor to speak to the physicians and try to get me in sooner, but I didn't. Live and learn.

July, finally it was time to see the neuro-ophthalmologist. When I met him, I felt hopeful that my vision problems would be diagnosed and corrected. He first focused on my corneas, due to the fact that my brother has Degenerative Corneal Disease and has had a transplant. Fortunately, my corneas were fine, so he continued testing. Sometime in July, I began to have an additional symptom, the feeling that something was stuck in my throat. I could swallow, but I had to swallow hard sometimes, and even then, I had the sensation that food or even a baby aspirin was just "hanging" in my throat. Some days I would be extremely aware of this feeling and other days I wouldn't even notice it. This sensation could occur even if I had not eaten anything. By this time, I was not sleeping well. I would fall asleep, but awake around 3:30 a.m. every morning. Things were taking a toll on me. August 2005: With all my symptoms persisting, I went back to my family doctor's office. Since my physician was on vacation, my appointment was with yet another doctor in the practice. I told her about the swallowing issue, not sleeping well, as well as exhausted. I also informed her that I was under the care of a neuro-ophthalmologist for my eyes. She ordered a barium swallow and an ultrasound of the thyroid. The barium swallow was negative, but the ultrasound showed that my thyroid was very slightly enlarged and appeared multi-nodular. This prompted her to order a TSH and T4 blood work and a radioactive iodine uptake test. The blood work for my thyroid came back within a normal range, but my uptake was high. During the uptake test, the doctor who reads the test told me that my scan was definitely looking like Graves Disease, which is a hyper active thyroid. I thought okay, maybe we are getting somewhere now. When I read up on the thyroid, every symptom you could think of could be caused by your thyroid acting improperly. But after all the results were in, we had no definitive answers, since the levels were not as high as they thought. They decided that my thyroid blood levels should be monitored every 4 months for the next year. So again, another dead-end to resolving my symptoms; this just threw us off course for a bit. I reiterated to the physician my sleeping difficulties and how tired I was still feeling in addition to my visual problems. I explained to her that I had just seen the neuro-ophthalmologist and was waiting eight weeks to see the neurologist. I felt confident that the neuro-ophthalmologist would get to the root of the problem. I really felt like he was listening to me (he was) and running every test that he thought may be relevant. I informed her that he had just ordered an MRI of the orbits of my eyes to check the muscles around the eye. She wrote me a prescription for a sleeping pill, (which I never got filled) and chalked up difficulty sleeping to stress, since I had mentioned to her that our son had just gotten his driver's permit. This of course was not the problem—the problem now was not the constant worry of not knowing what was going on, but knowing that there was surely something wrong, and it was beginning to get the better of me. I also began noticing more motor skill issues. For example, I couldn't push the pump of a liquid soap bottle down with two fingers anymore; I had to use the palm of my hand to work the dispenser. Also, while eating I remember a time when I felt like I couldn't hold the fork between my fingers and I put it down for a few minutes and then resumed holding it as usual. And there was another incident, while peeling potatoes: after I had peeled a few, I remember feeling like I just couldn't grip another one; my fingers

wouldn't stay around it. These are just a few examples. Something else was that, from time to time, my speech was just a bit slurred—only a word or two and not to the point that anyone would think anything of it, but I noticed. Remember, these symptoms were not constant, and I continued with my everyday activities, but when they occurred, I KNEW something was wrong.

September 2005: I expressed concern about these additional symptoms to the neuro-ophthalmologist; and so he ordered blood work to test for antibodies to things I'd never heard of, MG being one of them, as well as an echocardiogram to test for mitral valve prolapse, stroke and a hole in the heart. He also had my MRI's reread to double check for weakness in the eye muscles and again to rule out TIA or stroke. On September 30, 2005, the neuro-ophthalmologist told me in a phone conversation that the rereading of the MRI's showed nothing, but the echo showed that I did have a hole in my heart. He expressed to me in that same telephone conversation that I also tested positive for myasthenia gravis. He continued on, saying that I had to have a CT scan of the chest to rule out a thymoma, or tumor (sometimes cancerous, he informed me) of the thymus gland. My head was spinning as the doctor transferred me to the secretary to set up these tests. I never thought I could be so frightened by information that I didn't even truly understand, but I was very, very frightened. I had the CT done in the morning and went directly to see the cardiologist regarding the hole in my heart. He said not to be concerned, it had been there since birth and was extremely tiny. We would only revisit that issue if the neurologist felt that my symptoms were related to TIA or stroke, which the cardiologist felt was highly unlikely, due to my symptoms and testing positive for myasthenia gravis. He said we needed a positive diagnosis of MG from the neurologist. He told us that the CT could not confirm or rule out a tumor but the thymus gland was enlarged and the radiologist felt it was most likely residual thymus tissue. This cardiologist was so concerned with my symptoms and test results, he said I needed to see a neurologist ASAP (my previously scheduled appointment was still weeks away). He insisted on calling to speak with the neurologist directly, as we waited in the exam room. A new appointment with the neurologist was scheduled for the following Friday, Oct. 7. "Finally" I thought, "we might be getting somewhere." October 2005: On Monday, Oct. 3, 2005, I received another call from my neuro-ophthalmologist telling me that I needed to see a pulmonologist, because the CT of the chest showed 3 very small nodules on my lungs. This phone call sent me into a panic; I had had about enough of this scary news as I could take. I don't know how I got through the next week, but I did. An appointment was scheduled with the pulmonologist, for Tuesday Oct. 11. At this point, I still have all my symptoms and the swallowing issue is getting worse. At times, when I try to eat I begin to cough and feel as if I may choke. This is extremely frightening and so I become afraid to eat much at all. Needless to say, I'd lost a considerable amount of weight, probably about 15 pounds at this point. I, like every other woman I know, don't mind losing a few pounds. This however, was not the way I wanted to lose them. Out of fear of aspirating, I ate very little.

Friday Oct. 7 I met the neurologist. During my neurological exam, I was stunned at how weak I was. You must understand that twice a year, for about 18 years, I visited my former neurologist, for my migraine checkups. I always kind of laughed to myself at the exam, I NEVER had any difficulties keeping my balance, squeezing her fingers or pushing her away, but this time the exam was very different and it brought me to tears. The neurologist confirmed the MG diagnoses and he was extremely concerned about my swallowing difficulties. He said that I must now see a neuromuscular specialist and he highly recommended physicians at two different hospitals. In his opinion, he told me that I must have my thymus gland removed. This would increase my chances of going into remission. Once the thymus tissue was removed, I wouldn't have to be concerned about it turning cancerous. He stressed that I should not have it removed by transcervical thymectomy, a small incision in the throat and removal of thymus, because all of the tissue must be removed so that it does not regenerate. He felt that a sternotomy, cracking the sternum and removing the thymus tissue underneath, was a much better option. Although I understood his point, that by opening up my chest cavity the surgeon would have a much better view of the thymus gland and be able to see and remove any remaining bits of thymus tissue, that was not what I wanted to hear. Needless to say, this was quickly becoming the worst day of my life. Upon checking out, my medical records were faxed to both hospitals. Thankfully, I had the support of my husband and my mom at that appointment. Although it was very difficult for them to see me so weak and to hear what the doctor had to say, I don't think I could have made it through that day without them. The neurologist started me on medication, Mestinon. I noticed a change in my swallowing after just a few doses. On Tuesday Oct. 11, the pulmonologist, reviewed the CT scan and told me that the nodules were old calcifications caused by exposure to some lung disease or infection, and we will never know exactly what caused them. He also remarked on the thymus gland, saying he felt that it should be removed too. He said that my lungs were in great shape and that unless I had breathing difficulties, I didn't need to see him again. Wow, finally some good news! Oct. 27: I met with the neuromuscular specialist at the first hospital. I am very fortunate that he took me on as a patient because his case load was already very high. He adjusted my dose of Mestinon. He also agreed that at some point, I should have a thymectomy, done by full sternotomy. He was aware, and thought it was a good idea, that I was going for a second opinion. I felt that after all this time I owed it to myself to make sure I sought out the best medical treatment possible.

So the "Three Musketeers," my husband, my mom and I, headed for the next medical center. I jokingly referred to this as the "Medical Tour." At least I saw some humor in these turn of events. November 7, 2005: We met with the specialist at the second hospital. My appointment was Nov.7, (the day after my 40th birthday, let's just say it wasn't my best birthday and turning 40 had nothing to do with it.) He is one of the foremost authorities on MG in our country, perhaps the world, and I was very fortunate to be evaluated by him. After a thorough exam, he also expressed that a thymectomy by full sternotomy was the proper course of action to take sometime in the future. Well, at least the two physicians were in agreement, and I trusted both of their opinions; now someone just had to convince me that cracking open my chest and removing a gland was the right

thing to do. Anyway, I was responding well to the medication, so both physicians said to wait until after the New Year to revisit the thymectomy issue. I would decide which physician I was going to stick with after I decided on a surgeon. So, that's what I did, the Three Musketeers took off again to interview Cardio Thoracic Surgeons at both hospitals. The first surgeon was very comfortable performing the full sternotomy. The second surgeon wanted to do the surgery using the da Vinci robot, but he could not guarantee that he would be able to remove all the thymus tissue. I decided to go on the advice of both neuromuscular specialists and so I had a thymectomy by full sternotomy. February 15, 2006, was the date of my surgery. Everything went well, other than the fact that I learned I'm allergic to painkillers. I had never had major surgery before, so this was new information to me. I went home with Tylenol and Advil for the pain. The first week was the roughest. Breathing and moving hurt and coughing was almost unbearable, but then things starting looking up quickly. It took about 10 weeks until I was able to resume all of my normal activities. It really is amazing how fast you begin to recover. I was very fortunate to have family and friends to support me through this time. I know that I am a very lucky girl.

Three years after my diagnosis, I am happy to report that I am doing extremely well in regard to my MG. I have not needed any additional treatment or surgeries. I continue to take Mestinon three times a day, and it does a great job of controlling my symptoms. I sometimes still experience double vision if I wake up after falling asleep in front of the television late at night. I rarely have difficulty swallowing, and I do very well at my neurological exams. I do have to pace myself and keep in mind that I am living with a chronic illness. I feel extremely lucky that my body has responded so well to the medication and the surgery, and I live my life to the fullest. It takes years to know if the thymectomy plays any part in reducing the symptoms. Over the past two years, I have had my share of medical issues that are completely unrelated to my MG. I'm told by my physicians that the fact that these conditions have not affected the myasthenia gravis is a very good sign that I may one day go into remission.

So, that's just a glimpse (yes, really I left so much out, I could write a book) of my life over the past few years. What prompted me to write this letter is that we need to get the word out to the masses, especially to young women, who may think that their symptoms are just part of their overworked, overstressed everyday lives. I know there are other people walking around saying to themselves, "What is wrong with me and why can't anyone find the answers?" I would like to help them find the answers, and so I personally will be writing to politicians, magazines, news programs and talk shows. Knowledge is power; we must provide this information to everyone, so that they can have a stronger hand in their own health care. There is help, but first you have to know what's wrong. Every one of the physicians I visited was doing their best to make a proper diagnosis. Unfortunately because myasthenia gravis is such a rare condition, most people have never heard of it and it is not one of the first things that doctors think to test for. This fact makes it all the more frightening when you or someone you love is diagnosed with MG. I found the Myasthenia Gravis Foundation of America on the Internet. I know that the Foundation works tirelessly to spread awareness and education about MG. I look forward to helping you with this effort, and as the website says, "Strive for a world without MG."

Sincerely,

Annette Kennedy-Bowman

***this letter was originally sent to MGFA in Oct. 2007 and was updated by Annette Nov. 2008**