

# **There Is Life After Macular Degeneration**

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## **Introduction**

What started out to be a journal of my experiences with macular degeneration for the benefit of my children has evolved into a detailed accounting of what a normal, middle class member of our society must contend with when MD starts to take its toll. Perhaps this relation of my experiences will be of some assistance to some other person who becomes afflicted, as I was, with this "untreatable" disease at a young age. My major objective in writing this story is to demonstrate to others who have been diagnosed with MD that "There is Life After Macular Degeneration."

What do you do when everything in your life evolves around what you can see, and somebody tells you that you have a condition that is not only going to take your central vision from you, but is also untreatable? I know what I did. I immediately felt like I was going to be sick to my stomach for the rest of my life. My world seemed to be caving in on me; and yes, the "poor me" syndrome really started to take hold. Even though I knew that I couldn't, and shouldn't, let that happen, it was still happening. Here was a real control freak losing all control of his future. My world, as I knew it, was falling apart, and I could not control what was happening.

The mere fact that I am committed to putting my experiences in writing should give you some indication that I did not let myself stay in that frame of mind. It took a while, as you will see, but my strong controlling personality took over and brought me out of the blue funk. If you will tolerate a controlled dose of rambling, I will try to relate my experience with MD with hope that it will be helpful--even if it is only for one person other than myself. Let's give it a shot and see what comes out of this.

## **Life In A Gray And Fuzzy World**

To better understand how this disease, whose origin and cure are not totally known at this time, can totally devastate a person's life, it is imperative that you have an understanding of the changes in vision that many of us with MD experience. In the early stages of the onset of the disease the changes are usually very subtle. In my case, I first noticed a small area in my right eye at about the five o'clock location that appeared to be a water spot on everything that I looked at. While I knew that it was there, it really was more of a nuisance than anything else. Once you are aware of this, it is rather easy to work around this area of your vision.

As the dry form of MD progresses, the water spot areas may enlarge, or there may be additional spots occurring in the field of vision. This form of MD usually will progress at a slow rate to the point where your central vision is blurred and cloudy. The fine detail of objects that you are trying to view (words, facial features, and shapes of objects) become distorted to the point of being unrecognizable. Straight lines appear to be wavy or squiggles in your vision. You can see the form of a

person across the room, but you can't see their face that would enable you to know who it is. If it is someone that you know, the minute they speak, their voice is recognizable to you, and you are instantly back in a comfortable area. If someone is not aware that you are a victim of this disease, they are baffled as to why you do not recognize them or greet them. This level of visual distortion normally will lead to high levels of frustration for the affected person and many times will result in the person not wanting to leave their familiar home environment.

Many victims of the dry form of MD will isolate themselves from the potential discomfort of not recognizing people and bumping into a person or object that is in this blurred area of vision. If this isolation from the rest of the world is allowed to continue, the person will begin to develop fears of crossing streets, maneuvering in traffic, and encountering many of the normal obstacles that life puts in their paths. The most effective way to combat this problem is to obtain the services of a low vision specialist who will train the MD person in the adaptation and mobility techniques that allow him to perform the tasks that he is used to. Some of the more common techniques are the use of other senses to compensate for loss of vision. The use of touch and hearing can compensate for the lack of vision in many of the normal daily tasks that are encountered.

Another effect of this disease is the distortion of colors. As my own condition progressed, I became aware that I was unable to distinguish the difference in colors such as gray, blue, and brown. They all appeared to be different shades of gray. I found that I was taking a pair of pants into the bathroom in the morning, so that I could try to determine the color of the slacks that I was planning on wearing that day by viewing them under the bright lights at the vanity. This distortion of colors progresses with the disease to the point that you cannot determine the color of a person's skin, either in person or on the television. I have often joked with some of my black friends that they are no different to me than any other person. In my vision, all faces take on the same yellowish white color, regardless of race.

A major complaint of many MD people is that the glare of bright sunlight and the glare of lights at night leaves them virtually unable to see anything. This is not only annoying, but it creates a real fear of navigation after daylight hours. When I am in bright sunlight, it is easy to add a pair of clip-on sunglasses to combat the glare; but in the evening it is difficult to reduce the glare without eliminating all objects from my field of vision. People with MD require a high concentration of light on objects that they are trying to view in order to obtain the contrast that they must have to detect them. This results in the MD person striving to find that fine balance between adequate lighting and non-glare lighting. I have learned to place the lighting that I require between me and the object that I am trying to view. This eliminates the glare of the lighting in my eyes.

Most people who are afflicted with MD try to regain the vision that they had before being diagnosed. This is an impossible task that will never be accomplished. As they try to use low vision aids, they are constantly experiencing the frustration of not being able to view things as they did before. The key to adjusting to this new world of gray and fuzzy objects in your central vision area, is to learn to utilize the healthy vision that you still have. The most effective tool for accomplishing this is

yourself. We all have peripheral vision that is virtually unaffected by this disease; however, we have been used to viewing objects with our central vision and only using our peripheral vision as a supplemental enhancement of whatever we are looking at.

The art of using the healthy peripheral vision is known as eccentric viewing. This is accomplished by concentrating your point of focus off center of whatever you are trying to view. If you are trying to see a face on the TV, it is necessary to look off to either side or above or below the face, so that you are capturing the person's face in your peripheral vision. Since each person has a different level of visual acuity in their peripheral vision, it is up to each person to determine where their best vision is located. While this method of viewing objects requires extensive practice, the rewards are extremely gratifying. As an MD person develops this ability, the area of vision being captured in the peripheral vision expands. I have been able to develop my own peripheral vision to the point where I now am able to see approximately 50% more in my peripheral vision than when I was first tested, following the major deterioration of the central vision in my good eye.

Approximately 85% of the people afflicted with MD suffer from the "dry" form of the disease. In my case, my right eye is dry and my left eye is "wet." This allows me to compare the differences between the two types of this disease on a first hand basis. While the occurrence of the wet form of MD is not as prevalent, the effects are much more severe. The major difference is that the central vision area is literally eliminated with wet MD. When trying to look at an object, the center of the object is just a gray or black void in the middle of the visual field. If I try to look at someone with my left or "wet" eye, I cannot see anything from their shoulders to the top of their head. This condition leaves the person with the only viewable area being their peripheral vision. It is easy to see why the wet form of MD is considered to be the most debilitating form of this disease. The only proven treatment for this form is the use of laser surgery to stop the leaking of blood vessels into the macula and the eye. While this procedure does stop the leaking, it also destroys the vision in any place where the laser ray hits the retina. After five laser surgery procedures on my left eye to stop the leaking of blood vessels, I have no central vision in that eye.

A very annoying effect of the disease is the transfer of images from one eye to the vision in the other eye. Essentially, the blind spot in my left eye will frequently appear in the center of the blurred vision of my right eye. There is no explanation for this occurrence, and most doctors just advise their patients to get used to it. Many people with MD also experience the appearance of a colored area in their field of vision. I have seen a rust-colored area approximately the size of a quarter each morning for the past year when I first awake. It will normally gradually fade to the light gray blur that I live with each day. The duration of the appearance of the colored spot varies from fifteen minutes to as much as an hour and a half; however, the most annoying effect of this disease is when I close my eyes at night to try to go to sleep. The blind spot in my left eye becomes a brilliant green spot that flashes with tracers running around the perimeter. While this is going on in my left eye, the right eye displays a faint red image of the blurred vision area in that eye. It is like having a laser light show going on when I am trying to go to sleep. One benefit of this is that I always have my own personal Christmas light display set up and

operational. I don't even have to get out in the cold to string up the lights. Unfortunately, nobody else is able to enjoy the display with me.

Now that I have given a brief overview of the types of distortion that MD afflicted people experience, I hope that it will lend some degree of understanding of the life that MD people face every day. One thing is for sure, our vision is constantly going through a myriad of changes that those with normal vision never experience. This condition certainly reinforces the saying that the only constant about change is change. Our world is changing every day for those of us battling this "life in the gray and fuzzy world."

### **When Did It Begin?**

In the fall of 1985, at the age of forty-five, I went in for my annual eye examination with my optometrist, not having any major complaints other than that my prescription glasses did not seem to be doing the job for me after a year. This was nothing new for me, as for the last few years I had to have a new prescription almost every twelve months. Once I had to cross that bridge into the world of bifocals, this seemed to be another part of entering middle age. Who said that these are the "best years of our lives?" It was probably all of the doctors that you now have to visit and support on a regular basis as we enter those gloriously-touted "golden years."

During the examination my optometrist noticed that I was having difficulty detecting numbers in a colored grid. I must admit that I really didn't pick up on this during the examination. Rather than alarm me during the examination, the optometrist conducted additional tests in such a manner as to not cause me to have any concern. I did notice that he seemed to be running more tests than usual, but it didn't really alarm me. There also seemed to be more questions than normal during this examination. I just assumed that this was a result of crossing into that "world of bifocals."

Once the examination was completed, the optometrist advised me that there had been a slight change in my eyes that would warrant a change in my lenses. Since I have always worked in engineering requiring extensive close detail work with drawings and specifications, this seemed to be par for the course for me. I usually had to have my lenses changed at least every other year and now it was becoming every year. Consequently, this did not seem to be anything unusual to me, and it didn't raise any red flags.

Then came the most devastating news that a healthy, middle aged man could ever anticipate in his wildest dreams. My optometrist said that he had found evidence of a condition that was known as "Senile MD." My first reaction to this was focused on the word "senile." I thought, "My God, I really am getting old!" There I was, a relatively young, active professional being told that I had a condition that was, by all association with the word "senile," a condition that should be coming into my life at least twenty years down the road.

The doctor went on to explain to me in great detail, that this was a deterioration

of the sight cones that make up the circumference of the macula. He very calmly showed me pictures of a healthy retina and macula along with a very explicit set of pictures that had been taken of an eye with MD. He went on to give me a detailed explanation of how MD would eventually impair my close central vision as it progressed, but it would not destroy my peripheral vision. I know that most of what he said seemed to go in one ear and out the other. I suppose that was the result of my denial that this was really happening to me.

He then took a series of photographs that he explained would permit him to have a permanent record of the condition of the retina in each of my eyes. These pictures would be the cornerstone used to develop a document base of the condition of my retina in both eyes at the time when the MD was originally discovered. This would enable him an opportunity to track my progress that normally had not been available in a younger person at that time. The good news was that I would not lose all of my vision. The only thought racing through my mind was that I wasn't going to be totally blind like my great grandfather. The explanation, while in hind sight was a very accurate accounting of MD, sounded like pure Greek to me at the time. Realizing this now has helped me to understand how other people and their families must feel when they are diagnosed with this "untreatable" condition. A major case of depression, confusion and helplessness all rolled up into one major crisis, and being explained in a foreign tongue to boot! What had I done to cause this? Or better yet, why was this happening to me?

As I left the doctor's office, I was trying to figure out how I was going to explain this to my family. How do you prepare your family for a bomb like this? I know that I thought about this for some time. Even though I lived less than five miles from the doctor's office, it took me a while to get home. To this day, I am not absolutely sure where I drove, but I know it took me almost an hour. When I finally did arrive that evening, I had decided to explain the situation to my wife and children in a way that would capitalize on the positive aspects of my individual condition which the optometrist had emphasized.

First, I tried to assure them that I would not be totally blind. I advised my family that it was my understanding that most cases of MD have been found in people who are in their senior years: seventy and eighty. I told them that the optometrist had made me aware that, through recent technical developments, the doctors were now able to detect this condition at an earlier state than had been possible before now. We should, therefore, see this as a warning which would allow me to maintain an active normal life while checking on my vision on a regular basis. This would afford me an opportunity to detect any change and get immediate attention. Hopefully, by the time my condition would effect my vision, there would be major progress in the treatment of MD.

### **My Initial Feelings Of Despair**

While I was trying to be positive for my family on the surface, I was scared to death inside. What could have possibly caused this condition? What could I have done differently in my life that would have prevented this from happening? Why was this happening to me? What was in the future for me? How much longer could

I look forward to working? How long would I be able to drive a car? How was I going to go through my life without being able to see? As I looked at each member of my family, I was thinking how terrible it would be to never see them again as I was able to at that minute. What kind of a life would I have without being able to see? Was I in store for a life as a blind man, like my paternal great grandfather? The stories of his dependence on other people kept running through my mind. I could feel the "negatives" taking control of my every thought. I had to find some way to stop thinking like this. This would surely wind up destroying me if I didn't get out of the doldrums.

Being an eternal optimist and an engineer by trade, my mind kept searching for some logical explanation for this condition. Surely, there had to be some treatment that would correct this, and everything would go back to normal--whatever that was. During the next few weeks, I tried to research every piece of information that I could get my hands on regarding MD. For openers, I went to the encyclopedia that we had at home. I checked every medical book that we had in the house and checked with my pharmacist and optometrist for any additional information that they could give me. Each piece of information that I read contained the same basic fact: there is no known treatment for this condition. This really wasn't giving me a chance to be optimistic. At that time, there really wasn't a wealth of information concerning MD like there is today. If only the Web had been available to me then, I am sure that it would have made a major difference in my mental and emotional outlook. In my frustration with all of the negative information and thoughts, I contacted my optometrist to make arrangements for an appointment with a retina specialist whom he had recommended during my examination.

### **Time For A Second Opinion**

Neither the retina specialist nor my optometrist prepared me for what was to come during this examination. Naively, I went into this assuming that the doctor would just take another set of pictures of my eyes as a check on the pictures taken a couple of weeks earlier by the optometrist. This was my first experience with fluorescein angiography. What an experience that was the first time! The light that the doctor shined in my eyes was brighter than anything I had ever seen. I could only imagine that this was how bright a welding flash was without safety goggles. Why would somebody be exposing my eyes to something like this? I had never had any test that left me unable to see anything but a huge blurred blue spot in my line of vision. I was convinced that this test was on the border line of being either illegal, immoral, or possibly some satanic ritual. The temporary loss of my central vision following the test was frightening at best. Was this the way I would see the world for the rest of my life? The severe headache that followed from the bright light and the flash bulb didn't do much to make me feel any better. What was I in store for? This couldn't possibly be the way I would spend the rest of my life.

The retina specialist confirmed the diagnosis of my optometrist, much to my chagrin. He was extremely optimistic though, and he tried to assure me that, since they had discovered this condition at such an early age, there was hope that the medical community may find some way of treating the condition. He explained that there was progress being made constantly toward the discovery of the cause of MD.

In fact, he shared a recent article with me that suggested that mega doses of vitamins (vitamin C, selenium, and zinc) had been successful in retarding the progress of MD. Allowing the eternal optimist in me to take over, I agreed to try this as a means of controlling the progress of my condition.

For the next two months, I faithfully took the vitamins along with my normal multivitamin daily dosage. Although I saw no appreciable change in my condition, I assumed that this would take a considerable time before there would be any noticeable change. After all, this did not come on all of a sudden, and whatever was causing this condition had to have taken time to deteriorate to this point. I reasoned that the vitamin treatment would have to take some degree of time before a buildup of the vitamins could start to show some sign of influence on my vision. The engineer again felt that he was on a path to controlling the condition.

### **The First Setback**

I had now been taking the mega doses of vitamins for about two and a half months. About this time, I was attending a four day business meeting for my job at my company's main office outside of Boston. Although I had advised my immediate supervisor of my recent discovery that I had MD, I was not ready to let everybody know about it. How could I possibly explain something like this to others, when I really didn't understand the why, what, how, and future of this untreatable monster that had entered my reasonably normal life? The evening of the third day, I attended a dinner meeting with my supervisor and about five of my coworkers from other regions of the country. About half way through the dinner, my vision in both eyes became blurred. Within a few minutes, I could not see anything in the top two thirds of my vision area. Panic set in immediately! This couldn't be happening to me now! My doctors had told me that this was a slowly-progressing condition that would not take all of my vision. This couldn't possibly be what they had meant by telling me that I would not lose all of my vision. My stomach started to do flip flops, and I thought that I was feeling the first signs of a heart attack coming on. Panic was controlling my every move. I had totally lost control of my very existence.

Fortunately, my supervisor's next door neighbor was an ophthalmologist associated with a major Boston hospital. A telephone call to him gave me an opportunity to talk to somebody that could give me some knowledgeable advise. His initial reaction was that this was, in all probability, a temporary condition that would clear up with some rest in a relatively short time period--within an hour or two. He told me to get back to the hotel and to try to relax and not allow the panic to control me. He suggested that I take some Tylenol or some similar over-the-counter medication that would help me calm down and get some sleep. He allowed that if the condition did not improve by morning, that I should contact him at the hospital, and that he would arrange to see me. Otherwise, he felt that the best thing that I could do was to catch the first flight back to Cleveland and see my retina specialist as soon as possible.

Needless to say, sleep did not come easy that night. I didn't want to call my wife in Ohio with this news late at night. I knew the moment she heard my voice,

she would hear the panic that I was experiencing. After an hour or two, I did drift off to sleep and was awakened by the telephone ringing in my hotel room at about 6:30 AM. It was my supervisor's neighbor checking to see how I was doing. Much to my surprise, my vision was almost totally restored to normal. I do not recall telling him the name of my retina specialist, but I must have told him the previous evening over the telephone. It turned out that they had both been students at the same university in Boston and were friends. He had contacted my doctor after talking to me and had made arrangements for me to see my doctor as soon as I could get back to the Cleveland area. To this day, I still do not know what that doctor's name was. He sure went beyond the norm in trying to accommodate a total stranger whom he had never seen before, either socially or professionally. Someday I would like to have the opportunity to express my gratitude to him personally.

Through all of this, I had not contacted my wife, as I did not want to worry her until I had an idea of what was going on. Now I knew that I must call her, as she would have to take me to Akron to see the retina specialist when I got back to the Cleveland area. I hated the thought of having to tell her something like this over the telephone, but I had to do it. Naturally, she was concerned; but, being the trooper that she always is, she was ready to do whatever was required to get me to the doctor's office.

Within an hour, I was on my way to the Providence, Rhode Island airport, thanks to one of my coworkers from Atlanta, who drove me there. When I got home, my wife was ready and waiting for me with open arms. The concern, fear, and worry could not be hidden in the expression in her eyes and on her face. What was happening? Why was this happening to us? If I could have possibly avoided putting her through this, I would have done it in a minute. Recently, she has let me know of the total frustration that she felt. There she was, standing on the sideline, watching her husband lose his sight and not being able to do a thing. Only now can I truly begin to understand how she felt at that time. I was so consumed with my own concerns, that I must admit that I really didn't consider completely how this was affecting my wife.

The retina specialist in Akron gave me a thorough examination and advised me that it appeared that a small blood clot may have passed through behind my eyes, causing this temporary condition. He had contacted some of his associates in the field of MD and had discovered that this had occurred in other patients who were taking the mega doses of vitamins that I had been taking. The cause of this appeared to be the fact that the vitamins were not soluble and therefore remained in a suspended state in my blood stream. He advised me to stop taking the vitamins and to just continue with a multiple vitamin that included a lower dosage of antioxidants. This has been maintained as a standard dosage for me ever since that episode.

Ironically, two or three weeks after my experience there was an article in the Cleveland Plain Dealer, our daily newspaper, concerning this very same side effect of taking mega doses of vitamins. What a way to find out about the side effects of a medical treatment or procedure! This turned out to be my first exposure to the realization that there is a multitude of information available to the average lay

person through many sources outside of the normal medical profession. Little did I realize at the time that this was the first of several unusual experiences that I would be subjected to in my battles with MD. Sometimes I feel like I have a much better appreciation for how a guinea pig must feel.

### **Remission. Life Returns To Normal**

The next ten years proved to be quite uneventful, as far as the progression of my MD. Being a parent to nine children, there has never been a time when I could really say that my life has been uneventful. I continued with my multiple vitamins on a daily basis, my annual eye examinations, and my daily check of my vision on the Amsler Grid. I chose a location in our bathroom where I could view the Amsler Grid the first thing every morning when I got out of bed. I became accustomed to not seeing any major change to the area of vision. There was only one small area in the lower right quadrant of my right eye that showed any signs of the MD creating a blurred island of vision. It appeared that the situation was under control, or at least in remission, and that my fears of losing my vision would not materialize for a considerable time. Maybe the original terminology of Senile MD had some validity after all. Once again I was in control of this situation. What a feeling of power!

Although my vision appeared to be stabilized, I was always keeping one ear open for any news or new developments about MD. The more time passed without any further developments, the more I was convincing myself that this would not have an adverse affect on my life style in the near future. It seemed that I was back to my own optimistic, invincible self again. This thing called "Senile MD" was **not** going to get me until I was well into my senior years.

### **Could MD Be Genetic?**

In 1993, my wife took my mother, who was 84 at the time, to our optometrist for her annual eye examination. My mother was a little woman who was determined to be independent and always hustled around whenever she went someplace. That day my wife waited for her while she went in for her examination. Mom didn't say anything when she came out, other than one of these days she would have to have an operation for cataracts, as they were getting worse in one eye. A couple of days later, while talking to my wife, she told her that the doctor had said something about MD. My mother was also diagnosed with MD, and had not even realized it. She had thought that the doctor was talking about a condition related to her cataracts. The worst part was, she had thought that her vision loss was because she had cataracts. Sadly, her MD had already progressed to the point that her central vision in one eye was totally gone. My mother lived two more years, and, after her cataract surgery, was able to see fine with one eye. This also gave me some hope that my MD may not really progress to the point where it would impair my central vision in both eyes.

Now, at least I had an idea where my MD had come from. Even though my mother was diagnosed eight years after me, it apparently was passed on to me from her. Since my father died in 1960 at the age of 52, there was no way to determine if it had been passed down from his side of the family. No matter who I talked to,

none of his relatives had any knowledge of anyone in the family having MD. In reality, they probably didn't even realize that they had it back then. Most people probably believed that this was just a result of aging. I know that my paternal great grandfather was blind at fifty or sixty years of age. However, I was always told that he lost his vision working at the fire end of a blast furnace in the steel mills in the Philadelphia area. In retrospect, this may or may not have been the cause of his blindness, even though, according to all of the information that I have heard, he was totally blind in both eyes.

### **The Onset Of Wet MD**

In June of 1994, I was requested to go to Saudi Arabia on a business trip to visit several facilities that we were bidding on as modernization projects. The timing on this trip was not the best for me in my personal life. We had just moved into our present home (a move that condensed a five bedroom home and a two bedroom condo into a three bedroom condo). This, in and by itself, was no small task. Just to make matters worse, I would be in Saudi over father's day. Being the father to nine children, Father's Day in our family has become an event to celebrate my survival and the kick off of a new summer season. The day that I left for Saudi Arabia, the news headlines were filled with the discovery of O.J. Simpson's wife and friend. Every time I turned a television on over there, the only thing that you could find was one of the CNN broadcasts covering the O.J. Simpson murders. During my ten day stay in Saudi I had come down with what I thought was an attack of food poisoning. Even though I tried to make sure that I did not drink anything that was not bottled or canned, I was experiencing severe stomach pains that were worse than anything I ever had. Since the medical facilities, although extensively equipped, had very few trained technical personnel that could speak English, I toughed it out on my own. All that I could remember was the story about one of our local men telling how his wife asked for something for pain when she was in the hospital having a baby. The nurse in the hospital brought her a pizza. Just a slight problem with the language. There was no way that I was going to let anyone take me to one of the Saudi hospitals. After a couple of days I seemed to be back to normal.

When I got back to the states, I still was not feeling up to par and went to my family doctor. He gave me some medication for my stomach pains and constant diarrhea. Within a week or so I was feeling better. Later that year, around November, I decided that I probably should get a doctor in our new area, so I made arrangements for a complete physical examination, the first one in five years. A month before this, I had been bringing our jet ski out of the water when I noticed that I was extremely short of breath after pushing the jet ski up a hill from the lake. This did not seem to be normal, but I was not overly concerned. During the physical and subsequent tests, I found out that I had not had food poisoning in Saudi Arabia, but had a heart attack, which had left a small area of permanent damage to the lower portion of my heart.

One of the tests that was performed, a cardiac catheterization, required that I take a blood thinning agent both before and after the procedure. For some reason, this concerned me, and I even discussed it with the cardiologist, emphasizing my MD. I suspect that my original episode with the blood clot behind my eye in 1985 stuck in

my mind. I was concerned that the blood thinner may have some adverse affect on the MD. My cardiologist, who happens to be a very direct person, advised me that if this medication was not taken, the risk of an additional heart attack was too great to ignore. He asked me what good it would be to worry about my vision if this could lead to a heart attack that may be fatal. Good point! Given this choice, I agreed to take the blood thinners. This really didn't require a whole lot of thought at that time.

This was the test that confirmed the heart attack that I had thought to be a case of food poisoning. Now I was starting a new experience: getting my body and system accustomed to taking heart medication everyday. Even though the doctors advised me that I was adjusting to this change, it was a constant series of tests and checkups for the next two months to insure that the medication was not having any adverse effect on me. It is surprising how medication to slow down the heart and reduce the blood pressure will totally change a very aggressive "Type A" personality. All of a sudden, things that seemed to be important before this had very low priority in my life. In retrospect, this was probably the best thing that ever happened to me. Not only was the medication preventing my heart from working harder than necessary, but I was starting to appreciate life with a different outlook. As they say, I had stopped and was starting to smell the roses.

About three weeks later, on an evening in February of 1995, I was watching television and noticed that the picture was curving inward on both sides of the screen. Within a few minutes, the center of the picture was becoming distorted and blurred. I had never seen anything like this before. Fortunately, my optometrist had given me a colored brochure that included very explicit detail drawings of how the effects of MD would distort the normal vision in both the wet and dry states. I dug out a copy of the brochure and very quickly realized that this sudden change in my vision was evidently being caused by what appeared to be wet MD. It took me a while, however, to realize that this was being caused by my left eye, not the eye that had shown signs of my MD. Here I was at almost eleven o'clock in the evening, losing part of my vision. Who could I call? Where could I go? It seemed senseless to consider calling anyone at that time of the evening.

So, once again, as when I was in the Boston area in 1985, I tried to get some sleep and decided to try to contact my optometrist first thing in the morning. Much to my displeasure, my optometrist could not see me, but an associate ophthalmologist would be able to see me early in the afternoon. The automobile trip from our house to the optometrist's office is about fifty miles. During this trip, I first discovered the true effects of wet MD as it is described in the pamphlets. We were following a semi tractor trailer truck down the highway. As I looked at the back of the trailer, it was caved in on each side, and the top of the trailer was bowed out. I knew then and there, without a doubt, that I was in trouble and truly experiencing the effects of wet MD.

The ophthalmologist's examination indicated that there was hemorrhaging or leaking in the left eye that should be treated immediately. He explained the condition to me and advised me that it was crucial to get it taken care of immediately. His first suggestion was to send me to another doctor either in Akron

or on the far east side of Cleveland, which would put us about an hour and a half to two hours from home at best. I asked him to try to locate a doctor on the west side of Cleveland, which would make it a little easier for us to travel back and forth. I was sure that this would not be a one time visit. Within approximately thirty minutes, an appointment was made with Retina Associates of Cleveland for that afternoon with their top retina specialist who treated MD.

### **Wet MD Diagnosis**

Following an extensive examination, and after the standard series of photographs were taken, the doctor came in and examined my eye at least three times. Then came the discussion that I had never anticipated. A blood vessel was leaking in my left eye, which means that it had suddenly become wet MD. The doctor went on to explain the difference between the two types. What a way to have to find out what the difference was and how it would affect me.

The only procedure that could possibly be performed was laser surgery to stop the blood vessel from leaking, which, if allowed to continue, would lead to my total loss of vision in the left eye. He told my wife and I that he would give us five minutes to think about it and discuss it, as the surgery would have to be performed immediately. The one negative aspect of the laser surgery was that it could possibly leave a permanent blind spot in my eye. He assured me, however, that, with my cooperation during the procedure, he would try everything in his power to make that spot as small as possible.

It was now approximately 5:30 in the afternoon. My wife had been fighting a migraine headache for the last three or four hours. I don't know what the expression on my face was at the time, but I do know the panic and fear that passed through me as the doctor told me what had to be done. I also know that the look on my wife's face was enough to make me realize that she was truly scared. It was the first time that I had ever seen her in a state where she appeared to be feeling that there was no hope for a positive ending. The tears swelled up in her eyes, and she came across the room and hugged me. It was impossible for either of us to say anything at first. Finally, we both mustered up the courage and strength to talk about it. We both knew that I really didn't have a choice in this decision. It had to be done. I can remember saying aloud to my wife that I could not believe that this was really happening to me. Within the last two months, we had gone through learning that I had a heart attack during the summer, I had a heart catheterization after being taken by ambulance to the hospital, and now this! Why?

Once we had made the decision to proceed with the laser surgery, it seemed like an hour had passed before the doctor came back into the room. In reality, it probably was not more than the original five minutes that he had said he would give us. As soon as I told him of our decision, the doctor prepared to give me a shot in the eye to numb it for surgery. The syringe looked like something a veterinarian would use for a horse. One look at that syringe and my wife had to get out of the room. She later told me that she could not possibly have sat there while they gave me that shot. She also later told me that when the doctor said that I would have to have the laser surgery performed immediately, her migraine headache vanished

instantly. What a way to cure a headache! I told her that I would not like to make that a steady practice for getting rid of her headaches.

After the doctor gave me the novocain injection, he told the male nurse to take me to the laser room and prepare me for the procedure. As the nurse started to walk out of the examination room, he looked back over his shoulder and asked me to follow him. By then, the novocaine had started to take effect, and I could not see him. I told him that I would follow if I could see him. He commented that at least I had not lost my sense of humor during this. What he didn't realize, was that I was not trying to be humorous, just truthful. Although that syringe appeared to be about eight or ten inches long, I did not feel anything when they inserted it just below my eye. I think they had used some drops to numb the eye prior to inserting the syringe.

Getting ready for the laser surgery procedure was an experience in itself. They put a jacket over my shirt that almost reminded me of a straight jacket. Not that I have had any experience wearing a straight jacket, though there are probably some people that would willingly assert that I had. Then it was time to set my head in the laser head rest and to strap me into that so that there was no chance of moving even a fraction of an inch. The doctor and the nurse then took great pains to explain how important it was for me to remain perfectly still during the procedure. Even the slightest movement of a finger would result in movement of my eye, which could be extremely dangerous. The slightest eye movement would result in loss of all vision in my left eye. After telling me this, the doctor advised me that it was critical that I remain totally relaxed during the procedure. How do you stay totally relaxed after being told that even a slight movement of your finger could result in the loss of vision? Not an easy task, to say the least.

Throughout the laser surgical procedure, which took about fifteen or twenty minutes, the nurse stood behind me applying pressure on my head to ensure that I did not move. She later told me that this procedure required her to call upon all of the strength in her arms and hands to make sure that I did not even twitch a muscle. By the end of the procedure, she was shaking her arms and massaging them to relieve the tension and cramping.

The laser procedure was interesting to me as an instrumentation engineer. The doctor explained the types of laser that he was planning on using and the frequency of each of the types of laser beams. Since I had an elementary knowledge of lasers, it was interesting to know what level was being employed in this procedure on something as delicate and fragile as a human eye. As the laser frequency increased and the type was changed, the color of the laser beam also changed. There was some discomfort, but not as much as I had anticipated. During the procedure, the doctor held a shrouded lens in my left eye, which eliminated the possibility of blinking. Each time I thought that I would not be able to sit there without moving my eye any longer, the doctor assured me that it was almost over and that I had to hang in there just a little longer. When the procedure was finished, the nurse placed a patch over my left eye so that I would not run the risk of getting something in it, since the novocain left me with the inability to blink or to move my eye for about four or five hours following the procedure.

By the time the procedure was complete, it was a major task just to walk out to our car in the parking garage adjacent to the medical building. By this time, two doctors had given me at least ten or twelve sets of drops in my eyes, a shot of novocain, and numerous flashes of light. What vision I was able to use in my right eye was so blurred and distorted that I had to hold my wife's shoulder to guide me through the doorways and hall ways. To make matters worse, we had to take an elevator up to the next floor where there is a walkway into the parking garage. My equilibrium was not very good, considering the patch on one eye and everything else that I had been through that day. All I wanted to do was get home by then, and we still had an hour's ride from the doctor's office to our home.

By the time we hit our town, I was developing a headache that was worse than any hangover I had ever had in my fifty-plus years. As the novocain wore off, my headache got worse. With all of the heart medication that I take, I had very few choices as to what I could take for the pain. Extra-Strength Tylenol was the strongest thing that I was allowed to take. Fortunately, after finally getting something to eat (a delivered pizza that was every bit as tasty as a filet mignon at that point) and a couple hours of rest, my headache disappeared. The most annoying after effect was a continuous bright green light in my left eye for the rest of the evening and throughout the night. Have you ever tried to sleep with a bright green light shining in your eye, even when it is closed and under a thick gauze patch? Not an easy task to accomplish!

As they say, timing is everything. Fortunately, I was off work at this time recovering from my cardiac catheterization and getting adjusted to the heart medication that I had been given. I was also on a fairly regimented exercise program and was kept quite active during this time. This probably helped me to recover from the laser procedure in a very short time.

The morning after the laser surgery I awoke to a blind spot that was about a quarter of an inch in diameter. The doctor had advised me that the initial blind spot would be at least two or three times the size that I would be left with once the swelling went down. Surprisingly, there was little or no discomfort the next day, and I was able to be as mobile as I had been prior to the procedure. This was great. It appeared that things had turned out better than I had expected.

### **Laser Surgery Follow-up**

Two months later, I went back for a follow-up visit to the retina specialist and discovered that there was further leakage in my left eye. This required a second of what would be four additional laser surgeries on that eye. It turned out that each time I went back for a check up through August of 1995, I had another leaking vessel. The final result after five laser surgical procedures left me with the loss of most of my central vision in the left eye. Following the laser surgical procedures, I was unable to see anything other than the four corners of the Amsler Grid. Everything else was just a large blind area in my central vision. This sure was not what I or my optometrist had expected as a "slowly progressing condition". During that time, in July of 1995, I also had a cardiac stent implanted in my heart that I am sure contributed to the continued leakage in the left eye. As in the original cardiac

catherization, I had to take blood thinners both before and after the cardiac procedure. Although no doctors have ever agreed that this is a contributing factor, I believe that the blood thinners definitely contributed to my left eye changing from the dry state to wet MD.

As a side note, the last laser procedure was performed in August of 1995 under different conditions than the first four procedures. Due to the time of my appointment that day, it was almost 6:00 pm when the retina specialist decided that I would require yet another laser procedure. He was running late and had a patient waiting for him to perform surgery at one of the area hospitals when he left the office. Since this procedure was to be performed on a much smaller area, he recommended that we go ahead with this procedure without the novocain. In hind site, I now realize that he was also trying to speed up the process, as there was normally a fifteen or twenty minute wait for the novocain to take effect. While I can understand his attempts to take care of all of his patients as expeditiously as possible, I surely wish that he had not taken this short cut on me. Each time he pulled the trigger on the laser gun, it felt like the laser beam was burning right through my skull and out through the back of my head. The pain was worse than all of the discomfort from the previous procedures put together. I would never want to go through that again.

### **Learning To Use My Peripheral Vision**

The loss of all central vision in my left eye proved to be quite a challenge to my normal daily activities. Initially, I learned how to compensate for this loss with the central vision in my right eye. Along with turning my head slightly to the left, my central vision in my right eye seemed to be taking over so that I really did not notice much influence of the left eye after a couple of months. This started to be a real inconvenience when I was driving. By turning my head to view the side mirror on the car, I was moving my center of vision away from the road in front of me. There had to be a better way to do this.

Since I drove quite a bit each week, between 500 and 1,000 miles, I had a lot of time on the highway by myself. I had read in several sources that when your vision becomes impaired, your brain is capable of using other areas and enhancing other functions that were secondary functions prior to the disability. If this was true, I should be able to do something to improve or at least capitalize on the vision that I still had. I decided to experiment with how much I was still able to see with my left eye, even though I had little to no central vision left. As I was trying to pick up objects in the peripheral vision, I noticed that by looking straight ahead in the same manner that I would with normal central vision, I could start to detect objects in my peripheral vision. As I practiced viewing objects with my left eye, I found that, if I moved my normal central viewing point up and down or left to right slowly, I was able to recognize objects almost as clearly as I used to with my central vision. This was great. As a result of these exercises, the peripheral vision in my left eye had developed to an improved state that made it possible for me to see almost as much as I had before. I could even look in the side view mirror of the car without moving my head to view the mirror with my right eye. I found that I was now able to view objects in my peripheral vision in everything that I encountered in my normal daily

activities. Later on, I was advised that I was practicing eccentric viewing. While I was not aware that this was a recommended way to retain some vision, I was just trying to see as much as I possibly could without pivoting my head all of the time. Most people with whom I associated or worked were not even aware that I had no central vision in my left eye. It appeared on the surface that I would be able to work right up to my normal retirement age. I did not have many instances where the loss of the central vision in my left eye created a problem. I was convinced that this was the point that I had been striving for. I had this MD under control--again!

### **In Control Again**

Here I was at fifty-five years old, my heart condition was under control (thanks to two coronary stents), and my MD was also now under control. I had it made. My wife and I had a beautiful condo on the shore of Lake Erie. I owned a twenty-seven foot power cruiser that allowed me to enjoy the lake. We had a wave runner that would top end at about 48 MPH. Everything was going great. We had weathered the rough spot, and I could look forward to retiring to a life of fishing and cruising. Who could ask for anything more? The next two years seemed to be going almost too well. For the most part, our family was doing fine with a few exceptions (to be expected with nine children and seventeen grandchildren.) As long as I used some common sense, my life could be pretty normal by most standards. Basically, as long as I recognized my limitations and did not exceed them, I could lead a normal life.

There had been some major changes in my job during that time. I went from coordinating all quotations for my division of the company for the entire U.S. to being a project manager in the north central region of the country. It was easier in many ways to handle the business in fifteen states instead of all fifty states plus Saudi Arabia. My job responsibilities seemed to have lessened, but , in reality, the pressures of my job became greater than they had been in the past. My new supervisor did not seem to have any understanding of the limitations that had been put on me physically as a result of my heart condition and my MD. Each time I had to go for a checkup, either for my condition or for my semi-annual cardiology examination, there were sarcastic comments about the amount of time that I had to take off. This manifested into heated arguments at each performance review.

By June of 1997, I was engrossed in two major projects that were growing on a daily basis. Needless to say, the pressure was growing at an equal pace. It seemed that I was either hopping a plane to northern Minnesota or driving to the panhandle of West Virginia every other day. This travel was starting to show its toll on me both physically and emotionally. With all of my stress control techniques in place, I was still not able to continually protect myself from the effects of high stress. Some days I felt like I was a string under extreme pressure that was going to snap at any second. It seemed that, no matter what I did, or how many hours I put into my job, it was never enough. Even the people that worked for me on the various projects would comment that they could not understand how the company could expect me to continue at this pace. It was becoming impossible for me to sit down and have a discussion with anyone during the normal work day. I might add that the normal work day was becoming a standard ten to twelve hours at the office, with an additional two or three hours in the evening at home or in a motel room. In spite of

my repeated requests for assistance, there was never any indication that there was any hope of getting requisitions approved for additional personnel.

### **MD Marches On**

The last week of June had been scheduled as a week-long meeting with my client in northern Minnesota to review the scope of work for the project and to investigate some open design issues. By Wednesday evening of that week, the vision in my right eye was beginning to blur. That evening after dinner, my first reaction was that I had probably pushed myself too far beyond my limits. I decided to exclude myself from the project team's normal "after dinner get together" to review what had been accomplished during the day. I felt that a good night's rest would do me a world of good. Even though I was not sitting in a meeting with my project team, I spent the evening composing meeting minutes for the first three days of our meeting. I did, however, get a good night's sleep once this task was completed.

When I awoke Thursday morning, about half of my central vision in my right eye was a gray blur. After taking a shower, it still did not go away. I contacted the travel agent and made arrangements to get an earlier flight back to Cleveland later that morning. Once these arrangements were made, I called my project team and advised them that I would be going back to Cleveland that morning. We met for breakfast and I brought them up to speed on what I needed them to accomplish in my absence. Since I still had partial vision in my good eye, I drove myself the fifty five miles to the Duluth airport. After all, there isn't a lot of traffic between Eveleth and Duluth, Minnesota. This is not what you would call a megatropolis of the world.

Upon arriving at the airport, I discovered that the flights from Duluth to Minneapolis-St. Paul had been canceled due to fog in Minneapolis. With partial vision in one eye and no central vision in the other, there was no way that I would attempt the three hour drive to the airport. Since I knew that I was going to be stuck at the Duluth airport, I called my wife in Huron, Ohio to let her know what was going on. She gave me the doctor's phone number so that I could make an appointment for the next day. I was able to set up an appointment for the next morning at one of the retina specialist's offices on the east side of Cleveland. I finally got out of Duluth at about 2:00 pm and arrived in Cleveland at approximately 7:00 pm. By the time I arrived home, the combined frustration of the long day of travel and the loss of part of my vision was really showing it's toll on me. Needless to say, I was not a happy camper by then. It did, however, feel good to be back home on familiar turf. The comfort of familiar surroundings always eases the apprehension and the fear.

The next morning, Friday, my wife drove me to the retina specialist's office for an examination. This examination included two different types of angiography tests to ensure that there was no hemorrhaging in my right eye. The tests proved to be negative, and the doctor felt that the problem was being caused by a build up of drusen. My eye appeared to still be in the dry state, which meant that I would not need to undergo laser surgery. Neither that, nor any other treatment, could correct this condition. Approximately one third of my central vision in my good eye had been impaired by this latest flare up.

Many of the fears and negative thoughts concerning MD were once again surfacing in my mind. Was this the beginning of the end of my career as a wage earner? What was I going to do now? What kind of changes were my wife and I facing? Would we be able to continue to live in our condo on the lake? As in the beginning of this adventure with MD, the questions came much faster than did the answers. When they did come, they were no different than before. There is still no cure for this condition. Keep checking the Amsler grid every day in order to detect any changes. And then what?

One morning approximately two weeks later, I noticed a change in my vision on the way to the office. For a change, it was an improvement. The spot that had covered almost a third of my central vision in the right eye was now about half the size it had been since the last week of June. I contacted my doctor that morning and he advised me that this had probably been the result of a reduction in the swelling behind the retina. Most of the central vision in the upper left quadrant of my good eye was distorted now, but I could still see pretty good with the rest of my central vision in that eye. I was tickled to death that my worst fears had been proven to be false. It truly seemed that this was going to be a case in which the central vision in my right eye would be on a steady path of improvement, and I was going to be able to continue working.

### **Short-Lived Euphoria**

By August, I was rolling along again in my standard mode of operation and feeling that my vision had arrived at a stable state. In spite of a small blurred vision area in my good eye, I was able to do almost everything that I had been able to before the previous setback. My life was becoming normal again, and I felt generally quite optimistic. This MD was not interfering with my ability to work, to boat, or to enjoy the many important things in my life.

With my personal life and my work life both appearing to be back to normal, the travel was also returning. By the middle of August, I was back in Minnesota for a week-long project meeting with my customer and part of my project team. As normal, the work days were being stretched out to twelve- and fourteen-hour days at the job site, followed by at least two or three hours of meetings and paper work in the evening. We had traveled to Minnesota on Sunday so that we could get started first thing Monday morning. Much to my surprise, Wednesday evening I noticed that the vision in my right eye was again getting blurry. What was it with my trips to northern Minnesota? This appeared to be a repeat of the last trip in June, and my comfort zone was being penetrated again. My euphoric feelings of being able to lead the normal life of a person with normal vision were being torn away, and I didn't seem to be able to stop or to control this anymore.

As in June, my project team jumped in and took over the balance of the week-long meeting so that I could get my eye checked as soon as I could get back to the Cleveland area. Again, as in June, when I got to the airport in Duluth, I found that my flight was canceled, and I could not get out of Duluth until 4:00 pm at the earliest. Oh, joy, another day of sitting in an airport for six hours with very limited vision again and nothing to do. My luck sure seemed to be in a rut lately.

Fortunately, I had my retina specialist's telephone number with me this time. I made a telephone call to his office, and set up an appointment for the following morning. Since my wife was not expecting me until Friday evening, I knew that I would have to call her and once again give her the news that my good eye had acted up again. This was beginning to become a too familiar situation, and I hated to be putting her through this. It just didn't seem fair to put someone that you love through this kind of emotional roller coaster ride.

When I called her, she responded just as I expected. Her first concern was to get me to the doctor and have my good eye checked to make sure that there was no additional growth of blood vessels. Even though she was trying to handle this setback as sensibly as she had in the past, there was an underlying air of concern and frustration in her voice. She later told me that it was getting through to her in that she was helpless and frustrated with having to sit on the side lines and watch me losing my eyesight. After I had talked to my wife, I thought about how she must feel. I knew how I would feel if the roles were reversed, and it was putting me on a major guilt trip. It wasn't fair to her, and it was my fault that she was going through this.

With plenty of time on my hands, I had more than enough opportunity to think about the situation. I was feeling guilty, but I had to find some way to continue with my normal optimistic, positive outlook on life. There had to be something that I could do to retain some degree of control over what my life style was going to certainly become. What? Why? Where? How? Somewhere out there, there was an answer, and I was determined to find it. The guilt and "poor me" feelings were starting to lessen, and the positive Dave was trying to find some way to get his life under control again!

It was almost 10:00 pm when I finally got home that night. What a day it had been. I had left my hotel at about 8:30 this morning, 7:30 our time, and it was now almost 10:00 pm. Fourteen and a half hours of traveling under exceptional stress. What a life this was becoming. I guess the strain of the day was very evident when I walked into the house, because my wife threw her arms around my neck and just hugged me. Wow, that was the best that I had felt all day. Instantly I knew that we would get through this together.

The next morning, we repeated the same routine that we had executed just about six weeks earlier. The ride to the other side of Cleveland, the preliminary examination, the angiograph and flashing lights for the pictures, and the wait for the diagnosis from the retina specialist. This time, however, my normal doctor was not available, and his associate was going to see me. The nurse and technician had both advised me that this doctor had taken over for my original ophthalmologist and was now heading up all of the research on MD. This helped, because I assumed that he would be more familiar with the way my vision appeared to be deteriorating. He appeared to be quite knowledgeable about MD, but his people skills left a whole lot to be desired. After examining my eyes and reviewing my file photographs, he advised me that the drusen had created this recent loss of vision and that there wasn't anything that he could do.

He then sat there and dictated a letter into a recorder as though my wife and I were not even in the room. I could tell from the dictation that there had been a measurable decrease in my vision, but really could not determine anything else from his mumbling into the recorder. As he started to leave the office, I asked what I should do now. He turned his head toward me and in an almost inaudible tone said, "Call Doctor Novak if it gets worse," and walked out of the office. Had this been happening thirty years ago, I probably would have blown my stack and told this sorry excuse for a human being what I thought of him and his professionalism. There is a good chance that I may have even become physical with anyone who would treat me this way. But, being a little older and perhaps a bit wiser, I just sat there in shock, stewing inside. How could a well-educated professional be this uncaring and oblivious to another human being? When we checked out through the reception area, I found that the doctor had not even scheduled me for a follow up visit. When I discovered this, my first reaction was, "Well, you will probably never see me again!"

In spite of having spent over three hours in the doctor's office, my wife and I were both so upset that we could not eat at that immediate time. We decided to drive part way home and stop someplace for something to eat. The longer we drove, the more I ranted and raved about the doctor and how he didn't have any interest in me as a person. I felt that, as long as I was not a candidate for laser surgery, where he could make some money, he wasn't interested, and he just wanted to get me out of the office so that he could get a more financially-lucrative patient in there. He gave no advice or recommendations for anything that may help me in any way.

In hindsight, this doctor may have done me a favor in the long run. As I was stewing and venting my spleen to my wife, I realized that, with my central vision down to about 50% in my good eye now, the only way I could actually read was with the bifocal in my glasses. The light bulb flashed. Why not get a pair of glasses made the same as the bifocal strength that would be the normal size of a full lens? This was bound to give a larger viewing area that would utilize all of the central vision that I still had. Why hadn't that MD specialist thought of this? Both my wife and I were convinced that this had to be a way for me to see better with the vision that I was still able to use.

Once we stopped for something to eat, we headed for the optician at our local mall. When I discussed this with the woman who had been handling me for the past couple of years, she advised me that she had already done this for other patients with MD. Since her grandmother and aunt both have MD, she is quite familiar with the trials and tribulations that I was going through. I picked up my new reading glasses the next afternoon and I was able to read more than I had been able to in the last two months. Unknowingly, I had come up with what low vision specialist now call computer glasses. I, the patient, had self-prescribed the best tool yet for me. This was a real boost to me. The glass was approaching the half full mark again: no longer half empty.

## **The Information Bank Opens**

The next day was Saturday, and what would turn out to be a beautiful August weekend on the shores of Lake Erie. I happened to look out through the windows on our enclosed porch that faces the lake. About twenty feet from our porch is the condo swimming pool. As I perused the people in the pool and sitting around it, I noticed that my wife was talking to one of our neighbors who works for the Cleveland Sight Center. As I was getting ready to go to the pool, the thought crossed my mind that this now would be the time to start investigating what was available for people with impaired vision. I certainly qualified as visually impaired now, and there was no indication that this situation was going to improve or clear up of its own accord.

When I got out to the pool, I went over to talk to our neighbor. I started to tell her what had happened to me in the last two months, and she informed me that my wife had already given her a report on my condition. I then asked her if there were any programs sponsored by the Sight Center that were structured for people with MD. Much to my surprise, she started to tell me about a litany of programs offered through the Sight Center and other various agencies. She told me that she would get me some literature so that I would be aware of what was available. One of the services that she was telling me about hit a harmonious chord. She told me that the State of Ohio has a Bureau of Services for the visually impaired that is a department within the Rehabilitation Commission. Their primary goal is to either get people back to work after a visual disability or to help the visually impaired to continue working. I did not feel that I was really in either of those categories yet, but it seemed like a smart move to become informed about what services would be available when I reached that point in my deteriorating vision. Just hearing about the services was a tremendous lift, and my mental attitude began an upswing. It sounded like there really was some hope for this untreatable, incurable monster called "macular degeneration."

Within four or five days, I had several pieces of information about the services that were available from the Sight Center and the Bureau of Services for the Visually Impaired. The more I read about the services from the state, it appeared that this was the best set of services that I would eventually be able to use. As I read on, I began to realize that some of the services required some extensive paperwork and pre-qualification prior to receiving any of the applicable equipment or services offered. It seemed to make sense to try and investigate this further. Our neighbor was familiar with many of the services generically, but she admitted that the administrative implementation was not in her normal area of expertise. In spite of this, she was able to get me some telephone numbers and addresses of state people that would be able to advise me on the required application procedures. After thinking about this for a week or so, I decided that it would be in my best interest to get the ball rolling immediately. The engineer and control freak was once again taking control of my life. So I made the first call to the State Department of Rehabilitation.

That call put me right in the middle of what I would soon learn were the typical bureaucratic procedures to be encountered when dealing with a government

agency: slow, slow, and slower! Probably the most difficult part of making that call was admitting to myself that I was now going to be considered as a disabled person. It seems that we all have a fear of admitting defeat and asking for help. I know that I did and have found that it was an unwarranted fear.

After about two weeks, I still had not received the application form that was supposed to be sent to me the day after my telephone call. When I made a follow-up call, I discovered that somehow my request had fallen between the cracks. What a shock! How could that have happened? Enough sarcasm! Within about two hours of my follow-up, I received a call from a counselor who would be my primary contact for the Rehabilitation Services. He advised me to gather my medical records, and anything else pertaining to my job performance and work experience, and to meet him in two days at his office. Being a project manager who has to control cost, schedule and documentation, it was an easy task for me to put my hands on everything he would need and more.

After reviewing the documents that I had taken to the meeting, he told me that the first step was to have a low vision evaluation performed by an accredited vision center. Much to my surprise, I would have to go to Columbus for this evaluation--approximately 130 miles from my home. The Cleveland Sight Center was only about half that distance, and that was where I had received all of my preliminary information. I was advised that they had recently reorganized the coverage areas for the various state offices, and that my home area was now covered through Columbus. In a weird way, that made sense to me, because I had been through numerous organizational changes on my own job during the last ten years. What was one more?

The low vision personal evaluation could not be performed until the middle of October at the earliest, due to their extensive patient load and the fact that I would be covered under the new fiscal budget which took effect on October first. More of that infamous government red tape and bureaucracy. How does the government ever get anything accomplished?

### **The Benefits Of Low Vision Specialists**

The low vision evaluation started with an extensive eye examination without the use of drops. Since they already had copies of my examinations performed by both the retina specialist and my optometrist, they did not feel that the drops would be necessary. The doctor also advised me that she wanted to get an accurate diagnosis of both my uncorrected and my corrected acuity. She advised me that if she were to dilate my eyes, it would be at least four to six hours before she would be able to obtain accurate data.

The examination and review of my previous record took almost two hours. When it was over, the doctor informed me that the vision in my right eye had deteriorated to the point of being legally blind. She felt, however, that with a new prescription and some low vision aids, she would be able to help to keep me working.

After looking at the reading glasses that I had made in August, she recommended that I change to the half-lens style, which would allow me to use the prescription area for reading and my natural vision for distance. To this day I still use this style of glasses for reading and working on the computer. Since the computer was such a major portion of my job, the doctor prescribed the reading lenses so that I could see the computer monitor and the keyboard.

The next two or more hours was dedicated to exposure to, and trial of, a multitude of low vision aids and equipment. This was a world totally foreign to me. The first aid to be discussed was proper lighting. By using a fold-up fluorescent light, known as an Ott Light, I was able to read print that I was having trouble with in the past. Of course, the new reading lenses also had a tremendously positive effect on this.

Next came a reading table that, along with the light, eliminated the glare and allowed me to view written materials at the most comfortable distance for me. Each piece of equipment was making the previously-difficult tasks much easier for me. I was really getting excited. I could see light (hope) at the end of the tunnel, and it wasn't a freight train coming at me.

The magnification devices proved to be even more encouraging than the other low vision aids. I was seeing more types and styles of magnifiers than I ever thought possible. Trying those was a real challenge. Some of them helped, and some did nothing at all for me. It became a game to find which seemed to be the best for my individual needs. By the time we finished, I had selected five different types of magnifiers that would make it possible for me to continue working. Each style gave me a means to accomplish vision tasks that had been getting more difficult each day.

After lunch, I was given an opportunity to try out some of the computer software that would magnify any text or software that I had on the computer. This was extremely encouraging and gave me hope that I would be able to continue many of the tasks required in the performance of my position as a Senior Project Manager.

Along with this, I also had an opportunity to try several different types of closed-circuit television (CCTV) units. For those who are not familiar with this equipment, they are devices which project any text or material (a book, a magazine, a letter, a checkbook, etc.) onto a monitor with adjustable degrees of magnification. The newer devices are set up so that you can write a letter or write out a check on the slide tray under the monitor. It was determined that, for the time being, this was more than what I would require.

After we had finished that, we were all ready for a break. The doctor then summarized the recommendations that we had come up with throughout the day, and she performed the final sizing and measurements for my new glasses. By the time we were finished, I had spent six and a half hours at the low vision center. I was bushed, but I was so excited about what was being recommended to the state as low vision aids for me. My life with impaired vision was going to be much better

than I had thought. Throughout all of this, my wife had been waiting patiently for me to finish. We were in an area of Columbus on the south end of the Ohio State University main campus. Neither of us was familiar with it, and she was apprehensive about wandering too far from the center. She told me that, although it was a long day, she was happy that I was able to get some help and assistance. As you can well imagine, the trip home to "Our Paradise On The Lake" was much more upbeat. Now we both had some hope.

About two weeks later, my state counselor arranged for an industrial low vision consultant to meet with me at my place of employment. When he arrived at my office, he surveyed the physical work area environment and the equipment (computer, printer, desk, telephone and lighting) that I used everyday. He subsequently recommended the furnishing of the Zoom Text computer magnification software, a computer monitor glare screen, speakers for the computer, a scanner and a work stand for my desk. He advised both me and my supervisor that the State of Ohio would furnish all of the equipment, and the only contribution required of my employer would be the services of someone to install the equipment. Naturally, my supervisor readily agreed to this.

By the week before Christmas, all of the equipment furnished by the State of Ohio through the Vision Center and the Industrial Consultant arrived at my home. It was just like having an early Christmas present. Regardless of my being on vacation until the first of the year, I was able to inspect all of the equipment and start using the low vision devices at home. In November, about a month earlier, I had purchased a new IBM Aptiva computer for my personal use, and I had just about completed the set-up and transfer of files from my old Packard Bell 486 Computer over to the IBM. Now I was anxious to try out some of the new low vision toys on my own computer. Between the glasses and the magnification software, I was able to see things on the computer screen that I had not been able to view before. I was really excited about how much better things would be at work when I returned after the holidays. I just knew that things were going to be better now. I would be able to see documents easier and would be able to get back to the speed that I used to be able to maintain.

This year, I was actually anxious for the holidays to come and go. There was something positive about this fight to overcome MD that I could truly look forward to. Once again, my hopes were aroused, and I was feeling good about the future.

### **The Bottom Falls Out**

The holidays were very enjoyable for us and our family. Everyone was healthy and appeared to be doing well. We had our usual New Year's Eve open house at our condo with about twenty people from the condo development. This was the third year for the event, and everybody started looking forward to it before Christmas. Our friends all like the idea of being able to get together and not have to worry about being out on the highways with all of the amateur drunks.

There was one minor problem that caused a certain level of discomfort during the holidays. The day before Christmas, I developed a kidney stone and wound up

passing it late that evening. I had tried to call my family doctor and was unable to get in touch with him on Christmas Eve. The Monday after Christmas, I finally was able to contact him, and we set an appointment for an examination to make sure that there were no major complications from passing the stone.

As I got ready to drive to the doctor appointment, I noticed that there were no cars on the road outside of our condominium at 2:30 in the afternoon. This seemed unusual, as the road is a state highway that runs along the shore of Lake Erie and normally has a fair amount of traffic. I decided to pull over to the side of the road and take a closer look at this situation. As I put a pair of clip-on sunglasses on, I noticed that all of a sudden there were other cars on the road. Allowing that this was not a good sign, I decided that, in the future, I would use my sunglasses whenever I was driving during the daylight hours. This should have been my first indication that something was going on with my good eye.

Early in the morning of January 2, about three o'clock, I woke up to a severe pain in my good right eye. When I got out of bed, I noticed that I had a blind spot approximately the size of a half dollar in that eye. It was a gray spot that appeared to be made up of bubbles. What now? What could possibly have been causing this to happen to my good eye? It wasn't like the left eye when it went from dry to wet.

It was the day after New Year's Day, and I just knew that almost every doctor had taken a long weekend. I knew that I could not call anyone at three in the morning, so I took some Tylenol and went back to bed, with the hope that the pain would subside. By the time I awoke, the pain was gone, but the blind spot was still there. It had faded slightly, but I still could not see anything through my good eye's central vision. My heart was in my throat, and I just knew that the end of my central vision had come.

When I called the office of the retina specialist, they advised me that they could not possibly get me in today, even with an emergency. They did, however, make arrangements for me to see my doctor at a closer office the following morning, Saturday.

The next morning proved to be a repeat of the standard routine with the angiogram and examinations of my retina by the doctor. After the examination and review of the angiogram pictures, the doctor advised me that there was a major buildup of fluid behind the retina in my right eye and there was nothing that could be done to evacuate it. The swelling caused by the buildup of fluid had created the blind spot, and there was no way of predicting what the permanent effect would be on my vision. He said that the eye was still dry and would not require any additional laser surgery.

After a rather lengthy discussion about what might cause this, the consensus was that he could not explain why it had happened, and he did not know if it would dissipate or not. If it were to dissipate, he was unsure of how long it would take for that to happen. Not a very comforting prognosis.

As we were ready to leave the examining room, I asked the doctor what I should do next. His response was to plan on coming back to see him in six months. That was just wonderful! Another example of intelligent comments that doctors have a tendency to make. Needless to say, I left the office in a state of total frustration, coupled with a major case of devastation. I had a feeling that my life was on the verge of some major changes that I just knew that I was not going to like.

The next couple of days were not among the best of my life. Not only was my central vision just about totally gone, but my insight into life was not very clear right then either. I had to face the reality that my driving was definitely curtailed for the time being. If I could not drive, how was I ever going to get back and forth to the office? The trip was forty-five miles and I knew that there was no way for me to accomplish this on a daily basis. What was I going to do to earn a living now? I found myself on a major downer. My excitement about using the new low vision aids on the job had been replaced with total despair, and I was experiencing every negative feeling that I could possibly imagine. I was vacillating between, fear, pity, anger, inadequacy, failure, and downright disgust with this whole battle to overcome MD. I had lost the battle and felt like I had also lost the war. There was no light at the end of the tunnel, and I was sure that I could hear that freight train coming towards my back.

I did not know where to turn. I could not even find a way to discuss this with my wife this time. In the past, I had always been able to sit down with her, and we could both freely discuss anything that either one of us was facing. But this time was different. I had lost, and I did not know how to push my ego aside and talk about it. This was the first time that I had ever felt so abandoned by all hope, and the first time that I had felt alone in a world that appeared to me to be filled with darkness.

When I went to bed that Saturday evening, I could only think of one source to turn to. I prayed to God for the understanding and guidance to get through this, and I asked for his love and protection. The only answer that kept running through my mind was the one line of the Serenity Prayer that says "accept the things that you cannot change." By morning, I awoke with a feeling that God was telling me to get back on track with my positive attitude and that He would guide me down that path--no matter how dark it was going to be.

Later that day, I was able to start talking to my wife about how I felt and what we were looking at in the future. We were both able to let our thoughts and feelings out and assure each other that we would overcome this. Together, we have faced some major crises in our twenty years of marriage, and we both knew that this could also be handled. This has turned out to be another test for our strong relationship that began as a friendship and has grown to be an example to our children of what a truly loving marriage should be. Being best friends as well as lovers makes it possible for you to turn to each other in any situation. You always know that your best friend will be there for you. This time, we were there for each other.

## **The Second Shoe Falls**

On Sunday evening, I called my supervisor to inform him what had happened to my vision. We both agreed that a major portion of my responsibilities could be handled through my home with the use of my computer on the Internet. I planned to have my wife take me to the office on Tuesday so that I could bring home my project files and laptop computer. That appeared to be an acceptable means of allowing me to continue to work while I was waiting to see how permanent the vision loss was going to be.

The first week of working in this alternate mode started off with me receiving a telephone call. They asked that I not come into the office that Monday, but wait till Tuesday so that some of the paperwork could be pulled together. Since that Monday was the first day back after the holidays, it seemed to be a logical request. In retrospect, I should have raised my antennae at that point.

My wife took me to the office on Tuesday, and I picked up the paper work that they had for me, plus some of the files that I felt would be required. The rest of the project information was on diskette and on my laptop computer at home. The week started off with me not being able to access the company network with my laptop or my own computer. I was told that there was a problem with the card in my laptop, and that I could not set up a second connection through my own computer. The system was not designed for more than one access address per person.

During the first week, I processed over 125 e-mail messages and answered numerous telephone calls all day long. Many of those messages were being transmitted at all hours of the day and night. One supervisor would come into the office normally at 3:00 AM and the other supervisor that I reported to came in around 9:00 AM and stayed until 10:00 or 11:00 pm. So I was getting requests for immediate reply over a twenty hour period out of the standard twenty-four hour day. My work days at home were averaging sixteen hours a day during that first week. Even with it being a short four day week, due to the request to hold up on picking up the paper work on Monday, I felt that was not a poor showing for somebody with limited vision.

The following Monday, I was bombarded with e-mail messages pertaining to information that I did not have at home. While I tried my best to meet the requests that were being made, it was impossible to address everything without the information at hand. On top of this, the messages that did come through on my laptop were all printing out in a six- or eight-point font which was impossible for me to read. As a result, I had to copy all of the messages to a diskette and then convert them in my computer so that I could read them. Still, I did not put two and two together and realize that they were making it as difficult as possible for me to work at home.

By five o'clock that afternoon, I was totally swamped and could not see any way to get the work completed that had been requested for that day. I placed a call to my supervisor to see if there were any items that could slip until the next day. At that time, he advised me that, in his opinion, I was not able to keep up with the

work load, and that he was going to request that I be put on short term disability. He explained that the company felt that it would be better for me to concentrate on doing whatever I could to get my vision back.

The next morning, I received a telephone call from the personnel department at our main office in Massachusetts advising me that the paperwork had been started for my short term disability leave effective the previous Monday. When I complained that I had worked the entire week at home in accordance with my verbal agreement with my supervisor, they changed it to the Saturday of the week that I worked from my home. I finally realized what was going on, and I knew that I would never be able to go back to my previous employment with the company that I had worked for the past fifteen years. This generated more anger in me than anything else at this point. It wasn't until later that the hurt crept into my feelings for being treated this way after fifteen years of dedicated service and always putting the job first. During the next two weeks, I worked each day to summarize the status of my projects and to develop a list of tasks that needed to be completed on each project in chronological order. When I had my wife take me to the office, the supervisors were mysteriously unavailable to meet with me and review this information, even though I had made an appointment to be there at their convenience.

While I was reviewing the information with two of the engineers that had worked for me, one of my supervisors walked past my wife and stopped to inquire how I was doing. She was astounded at the total ignorance of the one question that he asked her. He asked her if she thought that I was going to make it! By the time I got out of my meeting and was ready to come home, she was on the verge of going ballistic. She told me that it sounded to her that they were asking if I was terminal. It really took her off guard, or she probably would have really laid into him.

When I heard this, my blood pressure probably went off the chart. I was ready to go back in the office and tell him off in no uncertain terms. Once I calmed down, I realized that he was not worth getting into it with him at his level of conduct. It appears that he went to the same university as many of the doctors that make ignorant statements to their patients.

Since this episode with my former employer, I have come to realize that they inadvertently did me a favor by pushing things for me to go on disability. Thanks to their treatment of me as an employee and as a human being, I now will never have to deal with them again. That, in itself, was a real benefit for me.

On the first of March, I received a call from my supervisor advising me that they had hired two engineers to replace me in the job that I had been doing. I realized for sure that my days as an employee there were over. Since it did not appear to them that I would be able to return to full-time employment, they asked me to come into the office that week and empty out my office, as they were short on office space. While it did hurt me to have to empty out my office, I did it with a certain feeling of relief. It was quite demeaning to think that fifteen years of work as a major contributor to a company that I had admired could be reduced to three boxes of miscellaneous papers. Not even a thank you from the management or a

farewell luncheon. That probably hurt me more than anything else that had happened. When I walked out the door that last day, I made up my mind that this was the closing of that chapter in my life. My life would go on, in spite of their thoughts or actions. I was not going to do anything to jeopardize the long-term disability benefits that I had paid for all of those years and had coming to me.

### **Adjusting To Vision Impairment**

While I was going through all of the rejection by my employer, I was working with the Ohio State Bureau of Services for the Visually Impaired to make sure that they were apprised of what was happening, both with my vision and my employment status. They were most cooperative, and they worked with me to get an appointment with the low vision specialist so that I could be reevaluated based on my change in vision impairment. They determined that I was now qualified for some additional low vision tools that were not appropriate when I first was evaluated. I was examined and fitted for telescopic glasses that appeared to be a solution for me to be able to drive again. This gave me some encouragement that I may be able to return to work on a part-time basis someplace in the future. There did appear to be hope arising in my outlook on life again.

By the end of March, I had been informed that I was approved for long-term disability under the insurance policy that I had carried for years at my place of employment. This was a lift to my morale, as I then knew that this coverage would carry through until my normal retirement age of 65. Although the benefits awarded would be a reduction in net earnings of about 25%, the benefits were not taxable. Thanks to that, we would not be hurt too severely and could maintain our present life style--a concern of mine that I had not even mentioned to my wife. Being the only wage earner and the bread winner of the family, it was disconcerting to not know what our income would be at the end of the thirteen week full-salary short-term disability benefit period. Put the "For Sale" signs away, and don't worry about standing in the food stamp line. We're going to be okay. Although that is a bit of an exaggeration, the point is made that we did not have to be concerned about that aspect of our lives.

As part of the long term disability benefit, it was my responsibility to apply for Social Security Disability Benefits within thirty days of being advised of my insurance award. As I prepared to submit my application for the Social Security benefits, I was hearing horror stories of people not being approved for up to two years after their application and following numerous appeals to Social Security. By the time I was set for my interview, I had gathered all of the requested information, plus any other piece of supporting information that I could find. The interviewer advised me that the normal time for processing a request for disability benefits was at least six months, and that I should not be surprised if I had to go through at least one appeal. Much to my surprise, my approval notification arrived three months to the day from my initial interview. This reinforced my belief that if you tell the truth and furnish the information requested, you will receive whatever is due to you. Much of my skepticism about the Social Security system had been put to rest.

By the middle of March, I was working with other people on the Internet that were victims of MD. Before I knew it, I was spending from four to five hours a day on the Internet sharing information with others and trying to give them some level of hope. Much to my surprise, this became a tremendous healing agent for me. The more I worked with others that were battling this disease, the better I was adjusting to the life of a visually impaired person. It dawned on me one day that I had finally accepted the fact that I was visually impaired and that I was never going to have the same level of vision that I had before. All of the low vision tools that I could get would never bring my vision back to normal again. I was learning how to use the vision that I still had, and I was not doing too badly. I even had the prospect of driving my car again within my sights--no pun intended.

With the acceptance of my own visual condition came a desire to share this with others who were battling the same monster that I had just conquered. As I pursued this through the Internet, I found that I was feeling better about myself and my current life. This really wasn't a bad hand that I had been dealt. Now, I was able to help others start their healing process, and they were feeling better about themselves, as well. Boy, this thing was getting contagious, and I liked the feelings that I was experiencing. I had found a level of self-satisfaction that I had never experienced in thirty-four years of working in engineering. Could this be what God had in store for me when I asked for His help? If it wasn't, someone sure was pulling my chain. I now could see a purpose and a challenge for me to help others to resume their lives. When I started to type a message to a stranger that was going through the denial of becoming visually impaired, the words seemed to be coming from an unknown source. I was being helped by someone or some force that I had never experienced before. I had found a purpose for my own life.

### **A New Challenge And Opportunity**

During the summer months, I continued on the path of helping others through the Internet and had expanded my efforts to a site that was dedicated to support for people with MD. My time on the Internet kept increasing, and before I knew it, I was talking to people all over the world that were battling MD. I was sharing experiences and learning more about this disease everyday.

By the end of July, I had received my telescopic glasses and found that I could see objects and people that I had not seen in the last year or so. I was elated that these glasses could make it possible to use my peripheral vision to replace my lost central vision. The day I received them, my vision tested better than my low vision specialist ever anticipated. The corrected acuity in my good eye had improved from 20/125 to 20/15 with the telescopic lens, and I could drive a car without having to get a special license in the Bioptic Driving program. I now knew that I was legally able to drive with the telescopic glasses, but I also knew that I would never be able to drive at night again. With oncoming headlights appearing to be three feet in diameter, I knew that I was not a safe driver at night. I could live with that, because I was the one that stopped driving in January when I knew that I could not see other cars on the road and did not want to cause an injury to some innocent driver. But now I could see the real possibility of me being able to work part time. This would be a real boost to my ego and my feeling of self worth.

My friend, who works for the Cleveland Sight Center, approached me to inquire if I would be willing to consider working for the Sight Center as a counselor for people with MD. The idea was quite appealing, but I was concerned about having to drive to the Sight Center, which is fifty-four miles from my home. After several meetings with the staff, it appeared that they were undecided as to how they would work this out. They seemed to be pushing for me to go into their offices each week, and I was more interested in working with people in our area where there was very little being offered for the visually impaired.

I was discussing the situation over the phone one day with my counselor from the Bureau of Services for the Visually Impaired. After listening to my concerns and frustration about not being able to get the possible employment opportunity off of dead center, she asked me if I would be interested in working in a similar capacity with the State of Ohio. My first thoughts were that I would wind up being one of those state employee bureaucrats that I had so often complained about. How could I handle that? After a meeting with one of the regional Vocational Rehabilitation people, I learned that they were interested in having me work for an independent employment agency that they contract to find jobs for disabled people. By the end of October, I was setting up meeting with ten different agencies in the area to interview for a position as a job developer for the visually impaired.

After meeting with six of the ten agencies, I was offered a position with an agency that is just ten miles from my home as a job developer responsible for setting up a separate group that deals strictly with the visually impaired. I have accepted the offer and will be starting to work twenty hours a week in this capacity. I don't honestly know when I have ever been so excited about a new job. I find myself planning things that I would like to include in the effort to find employment for the visually impaired and preparing interviewing guides for employers and clients. This opportunity to help other visually impaired people back into the work force has given me a chance to help the more than 80% unemployed visually impaired people. I will do everything within my power to help others and to strive to make them feel good about themselves again.

### **Is There Life After Macular Degeneration?**

Yes, there is a wonderful life after you have been diagnosed with macular degeneration. First, you must accept the fact that you are now one of the almost two million people in the U.S. alone that are afflicted with this disease. Then, you must make up your mind that you are going to learn how the vision that you still have can be utilized to remain independent and a productive member of our society. Don't give up and wait for some miracle to come your way. Life does not work that way.

If you have access to a computer, get on it, and search for information. One source of computer access that many of us overlook is the public library. Also, if you have a friend or family member who has a computer, ask them to help you look up information on this disease that is about to change your life. Visit every site that you can find, and don't rest until you have found the answers that you are searching for.

If you have not visited a low vision specialist yet, by all means, find a qualified one who will take an interest in you and will help you to make a life for yourself. If you don't feel comfortable with the first person you encounter, get a second opinion. Some of the best low vision specialists are right in your own area. They are the local optometrist that have already worked with people that have MD. Don't stop searching for the medical help that will address your own individual vision problems. Each one of us is a unique model, since we do not come from an assembly line or a mold, so each person will have a different set of visual effects and symptoms from this disease. There are many doctors out there that do truly dedicate their lives to help those afflicted with this disease. It is up to you to find the one doctor that can meet your individual needs and desires.

After you have found all of the information that you can on MD, and you have found a good low vision specialist and followed his or her recommendations, you have one more job to do. Work harder than you have ever worked in your life to apply everything that you have learned and heard. Give this job more effort than you have ever put into anything. It is the most important task that you have to accomplish in your life. It will mean your life as you want it to be.

Yes, there were many times during my own battle with MD that I was down in the dumps and ready to give up. Every time I felt that way, I would give myself a kick in the butt and get on with my own battle to not let this disease get the best of me. I also tried to be aware of how others were dealing with this same disease. Invariably, I would find that others that I came in contact with had it a lot worse than I did. This would bring me back to reality and make me realize that, if someone else could deal with their problems, I could certainly handle my own. That usually pulled me out of the pity party.

Another excellent source of help was my Internet group, MD Support, at [www.mdsupport.org](http://www.mdsupport.org). My wife and I have an excellent relationship that always allowed us to share our feelings with each other, but it is difficult to explain your visual experiences with someone that does not have MD. This is where my "cyber family" has been a constant source of comfort and understanding. It does help to share your experiences with others who are going through the same thing or have gone through it already. You wind up realizing that you are not all alone in this battle. I have learned that having a support network of family and friends is the secret to overcoming the obstacles encountered with this miserable disease. As the owner of our web site says, use these obstacles as stepping stones to a better life. Try it. It works!

Finally, I truly hope that this tale of my battle with MD will help at least one more person to find that yes, there **is** life after macular degeneration. Whether it is you or a loved one that is battling this disease, you are not alone in this war against MD.

Well, we made it through this task, and I must admit that I feel much better now that I have shared my experiences and feelings with someone else. I hope that you have enjoyed reading my story as much as I have enjoyed writing it.