

Progress

Progress is a difficult concept for macular degeneration patients. They are told that the best they can expect is for the disease to advance slowly and thus their eyes might serve them for activities such as dressing and walking for some time. Progress in a negative direction is monitored by high-tech scans, photos and self-administered tests of the eyes by having patients look at an Amsler grid daily.

The “Hope” chapter of this book (page 10) told of changes in Mark’s vision that occurred during his first two months of weekly IVs. Because only negative change is expected, he had difficulty believing that his vision could possibly be improving. “I must be looking at things more closely and that’s why I’m seeing this color,” he often said. However, when some yellow objects such as traffic lights and lines down the center of roads began to appear orangish-yellow to him, he suddenly remembered a school-bus yellow truck he had spent hours playing with before he was kindergarten age. The realization that orangish-yellow *was* and still *is* the color that warns us “Be careful!” made the improvement in his vision seem more real.

Five months after he received the diagnosis of macular degeneration, we attended a concert. He decided to wear his old glasses because he was wearing dress clothes. His new glasses, made using the prescription he got at the eye exam where he first heard “You have macular degeneration,” have safety side shields which he did not want to remove to make them suitable to wear to the concert.

Wearing the old glasses was “a shock,” he said. He had been attributing improved ease of seeing his computer monitor at work to having a new prescription in his glasses. The evening of the concert, he was amazed that he could see very well with his old glasses. The change in his vision was not due to the new prescription: it was his eyes that had improved.

At that time, he had taken twelve IVs. He also had just had an appointment with a holistic eye doctor recommended by our dentist. The new eye doctor had a special camera to photograph the retina. She took photographs of his retinas and compared them to photographs taken by the retina specialist over four months previously.

“No change,” she said, which is usually the best news possible for a macular degeneration patient. She also told us that she had been looking at retina photos for over thirty years.

The allergy doctor who many years previously told my mother about the macular degeneration IV protocol “stopping it in its tracks” was very pleased to hear about the improvements in vision Mark had noticed and that the retina photos showed no change. He recommended that Mark take the IVs every other week until his six-month appointment with the retina specialist. After that, if the report was also positive, he said Mark could take the IVs at monthly or longer intervals, but he should be taking zinc, selenium and taurine supplements daily. (See page 27 for more about these supplements including dosages). He also recommended

that Mark have a self-test¹ that would detect the beginning of possible deterioration in his vision. He said a self-test would reveal any deterioration in vision before the scans, photographs and examinations by eye doctors could detect the change.

As the six-month appointment with the retina specialist grew near, we both began to dread it because the first appointment had been so depressing. Mark's goal was to remain on good terms with the doctor so if he ever experienced a crisis and needed an anti-VEGF injection, she would take care of him quickly. Since she seemed very conventional, he decided not to tell her about taking IVs, etc.

On the day of the appointment, he first saw the same young assistant as on the previous visit. As part of taking Mark's recent history, he asked, "Have you noticed any changes in your vision?" Mark replied that he was seeing blue and yellow better and that he could see his computer monitor at work more easily. "But I did have a refraction before I first came here in December and got new glasses in January," he explained. However, Mark had disproved the "new glasses made the difference" theory to himself when he wore his old glasses to drive to the concert a month previously.

Our next stop was the mid-office waiting area. I whispered to Mark that I was surprised that he had mentioned seeing blue and yellow better and asked, "What are you going to tell the doctor if she asks you about why the improvement happened?" Before he could reply, a technician summoned him for eye scans and photographs.

When the tests were finished, we were ushered into the room where the doctor would examine his eyes and discuss the test results and her findings with us. After the examination, she looked at his test results on a computer monitor. Her back was to me and I could see the monitor. She studied the OCT (Optical Coherence Tomography) scan quietly. She asked Mark if he had ever smoked. He replied, "No, but my parents did and I got plenty of second-hand smoke growing up."

Then she examined a set of four color photos of Mark's retinas, each of which was a composite of photos taken from several different angles. She began making "Hmmm... hmm... hmmm... hmm... hmm" sounds as she clicked with her computer mouse. What was she seeing? The "hmm" sounds drove me to the verge of panic. I looked closely at the photos to try to determine what she saw. They all looked very similar aside from slight variations in color. The two upper images on the monitor were bright red with a small yellow spot in the middle of the cloud of orbs. The two lower images also contained a yellow spot (the macula) in the center and but were duller red and even grayish-red in some places.

She turned her chair to face him squarely and said, "Your macular degeneration is *definitely* stable. Whatever you're doing, *keep doing it!*" Then she replied to Mark's comment about his parents smoking and she told us about her childhood

¹ Mark's self-test is paying attention to how easily he can see and work at his computer monitor at work. Before he began taking the IVs, he had to take his glasses off and put his nose close to the monitor, put them on, take them off, put them on, etc. all the time. If he ever cannot keep his eyes at a set distance from his monitor and work comfortably with his glasses on, he will know it is time to return to weekly IV treatments until his vision again improves. The doctor thought this sounded like a good self-test.

experiences with smoking. She described growing up on a farm in Iowa, her father smoking, giving her a puff of his cigarette when she was about ten years old, and how that experience “cured” her of smoking for life. However, her three siblings, who did not take a puff at an early age, all smoke now. She told us she’d recently found her bronzed baby shoes in her basement. They were part of an ashtray set and she had dropped the ashtray. Mark later said she was like a totally different person than she had been on our first visit. She seemed human instead of an aloof authority figure.

The next day, as I was mentally processing what had transpired at the appointment, I remembered having read that the color of a normal, healthy retina is bright red. However, with macular degeneration the color dulls and can become mottled.² Perhaps a change to a more normal retina color was what she had seen! I also realized that it must be very difficult for a doctor to have to tell patients terribly depressing news for most of the day every weekday. When she saw better-than-usual retina photos, she might have been so surprised that she lost her inhibitions and opened up to us. As we shared baby shoe and other stories, she became a real person under her white coat. By the end of our visit, we felt that we had begun to know her personally and she was learning about us. Without knowing why she saw what she saw, she gave us comfort.

Although she did not know what we had been doing, much of the “doing” happened in the kitchen where the next several chapters will take us. These chapters will make cooking easier than you may expect. Time in the kitchen will improve your nutritional status which is the most effective factor for improving outcomes with macular degeneration.

² This information is on page 22.