

The Patient's Viewpoint of Cataract and Detached Retina Surgeries

ABSTRACT

Aims: The purpose of this paper is to (1) describe the details of a complex medical example allowing the reader to continually diagnose complications resulting from cataract and detached retina surgeries, (2) explain good and bad aspects of communications between patients, optometrists, ophthalmologists and systems engineers, and (3) show actual patient images during detaching retinas.

Methodology: This paper was written from the patient's point of view of the interactions between the patient, the optometrist and the ophthalmologists during a dozen eye surgeries for cataracts and detached retinæ. It was excerpted from the patient's notes (including test results, charts and images), hospital reports, and letters to the doctors and their referral reports. This paper was written in the first person singular and in chronological order: which should allow the reader to see changes in the interactions of the symptoms and treatments from ocular surgeries in a complex medical example.

Results: This paper has documented unsuccessful insertion of an intraocular lens (IOL), ignoring patient's complaints of pain, failure to warn the patient that a complicated IOL replacement would increase the probability of a detached retina (and failure to instruct him to detect such a detaching retina), lack of explanation of what the subject should expect after retinal detachment surgery (such as strabismus, diplopia, pain, wrinkled retina, and dynamic visual changes due to bubble changes), lack of explanation for the subject's visual acuity defects and color deficiencies, poor communication between patient care specialists about these defects, lack of knowledge of technicians using ophthalmological instruments, lack of documented processes for using these instruments (which means different technicians used the instruments differently), lack of proper medical care due to physician overload (i.e. scheduling more than 60 patients per day per physician), and ignoring the patient's complaints of pain. While reading this paper, the reader should accept or challenge each of these assertions.

Conclusions: The reader should judge the appropriateness of this conclusion, "The optometric and ophthalmologic medical community has done a disservice to this patient."

Keywords: cataract surgery; communication; complications; detached retina; detaching retina; ocular pain; quality of life; retina surgery; lessons learned;

12 1. INTRODUCTION

13 A. Terry Bahill (ATB) has had a dozen eye surgeries over the last half-dozen years. He has
 14 been examined and treated by an optometrist and ten ophthalmologists. The following report
 15 is his description of the interactions between these vision care specialists. This paper
 16 describes (1) cataract and detached retina surgeries and their after effects (including many
 17 images from the patient's viewpoint, which have never before been presented in the
 18 literature), and (2) quality of life measures.

19
 20 In 1977, Larry Stark et al. [1] described many nontraditional optometry tasks that
 21 professionals were performing in his Neuro-optometry Clinic at Berkeley (UC) and San
 22 Francisco (UCSF). This paper suggests another nontraditional task: assisting patients with
 23 detaching retinas. Detached retinas seem to be in the purview of ophthalmologists.
 24 However, this paper explains ways that an optometrist was involved in (1) diagnosing a
 25 detaching retina, (2) tracking the specialties and equipment of local ophthalmologists, (3)
 26 acting as a primary visual care provider (4) understanding and explaining to the patient what
 27 lies in store for him during and after the surgery, (5) diagnosing and perhaps solving
 28 postoperative complications {such as (a) postoperative diplopia, which (in this case) was
 29 ameliorated with prism spectacles, (b) the iris being trapped by the intraocular lens, which
 30 was solved by a lens replacement, (c) inflammation, in this case due to the suture securing
 31 the scleral buckle and (d) helping with pain diagnosis and remediation,} and (6) explaining
 32 the relationships between fundus photos, visual field diagrams and ocular coherence
 33 tomography images.

34 2. Methods/Results/History

35
 36 This section was written by ATB about his dozen eye surgeries. Different cases will have
 37 different numbers and details, but the overall processes should be about the same. This
 38 section is written from the patient's point of view of the interactions between the patient, the
 39 optometrist and the ophthalmologists during a dozen eye surgeries for cataracts and
 40 detached retina. Therefore, this section is written in the first person singular. It was
 41 excerpted from my notes, hospital reports, my letters to the doctors and their referral reports.
 42 Nothing was retrospectively edited. So it is possible that at one time I wrote something in my
 43 journal that was different than something that I had written at another time: I did not edit out
 44 these contradictions. Oscillations in my health and mood may be apparent. This case is
 45 multifaceted with many complications. The ten ophthalmologists are identified as
 46 "Ophthalmologist-1" to "Ophthalmologist-10."

47 May 24, 2007, First Cataract Operation

48 It all started on a beautiful May morning in Tucson. Ophthalmologist-1, his wife (the
 49 anesthesiologist) and a surgical nurse performed a cataract extraction and lens implant on
 50 my left eye. It was a quiet relaxed atmosphere where they were describing to the nurse their
 51 upcoming vacation to Italy. Ophthalmologist-1 was doing hydrodissection in the membrane
 52 capsule, when he suddenly said, "Whoops. What was that?" He wrote in his hospital report,
 53 "the posterior capsule had torn as a result of the hydrodissection... It was elected to insert
 54 an [available] MA60AC lens rather than the [selected] one-piece acrylic lens." That evening,
 55 the next morning and the next afternoon, I told his staff that I was in pain.

56 May 25, 2007, Follow-up Exam

57 The next morning, as Ophthalmologist-1 was examining the operated eye, he said that in
 58 order to compensate for the ruptured posterior capsule, he removed some of the vitreous,
 59 placed the lens (a square edged, 3-piece posterior chamber intraocular lens, Alcon model
 60 MA60AC) more anterior than planned (in the ciliary sulcus), and put a stitch in the cornea.
 61 Later he said that rupture of the posterior membrane capsule was a rare event, happening to

62 only one of his other patients 17 years ago. I told him that the eye hurt and that I was seeing
63 lots of floaters.

64 May 26, 2007, Pain in the Eye

65 My left eye hurt. It was tearing and bloodshot. Ophthalmologist-1 was on vacation in Italy. I
66 called a friend, Ophthalmologist-2, and told him that my eye hurt and I could not contact
67 Ophthalmologist-1 or his backup. He said that pain after a cataract operation most certainly
68 means infection. He advised me to go to the emergency room. Ophthalmologist-3 (who by
69 coincidence was the backup in Ophthalmologist-1's practice and also the ER
70 ophthalmologist on duty) gave me a prescription for Vicodin (hydrocodone). It did not relieve
71 the pain. I saw him another four times in the next two weeks. He said that he did not know
72 why there was severe pain. For the next four years at every medical exam with my ten
73 ophthalmologists, I complained about pain in the front of the eye. Table 1 shows that nothing
74 relived the pain.

Table 1. Since 2008, at various times, ATB has taken the following anti-pain drugs. None relieved the pain in the brain.			
Generic Name	Strength	Brand Name	Dosage
Ibuprofen	200 mg	Motrin®	16 pills per day
Hydrocodone/APAP	5/500 mg	Vicodin®	6 pills per day
Oxycodone/APAP	5/325 mg	Percocet®	6 pills per day
APAP is an abbreviation for acetaminophen.		Tylenol®	

75 May 8, 2008, One Year Later

76 I saw a static, 100-degree diameter¹, ¾ ring (two degrees thick) of bluish light for maybe a
77 half minute in left eye with the eye open. It looked like Figure 1 (top-left). That event was
78 probably caused by the vitreous (the jelly in the eyeball) detaching from the retina. At that
79 time, I did not know that a cataract operation, particularly one with complications, increased
80 the probability of a detached retina. The dark green (or gray) disk represents the subject's
81 field of view. Normally it would be filled with objects such as saguaro cacti, mesquite trees,
82 golden retrievers, palm trees, etc. as is shown in Figure 3 (left). Note: this is the visual
83 experience of one subject. The literature more often describes the detaching vitreous with
84 spider webs and lightning bolts

85 May 12, 2008, First Detached Retina Operation

86 The optometrist saw a half-dozen retinal tears (like tears in a fabric, not like tears when a
87 person is crying) and referred me to a retina specialist, Ophthalmologist-4. He scheduled an
88 operation for that evening. During that operation, he put a sclera buckle around the eyeball,
89 removed the vitreous humor (vitrectomy), repaired the retinal tears with freezing (cryopexy)
90 and with an endolaser, and inserted a bubble of perfluoropropane (C₃F₈) gas (pneumatic
91 retinoplexy). My double vision (diplopia) started after this surgery. The next day, and on
92 other visits, I complained about inflammation (bloodshotness), pain in the front of the eye
93 and now pain behind the eye.

94 This note was added in retrospect in 2013. The vitrectomy may have also pulled off some of
95 the ganglion cells and parts of the Inner Limiting Membrane around the optic disk.

96 Explanations of Technical Terms

97 I had a rhegmatogenous retinal detachment, which means tears (like tears in a fabric, not
98 like tears when a person is crying) in the retina allowed fluid to leak underneath the retina,

¹ In this paper, the size of the visual angle will be given in degrees of arc or angular size, because it is easy to estimate. For example, at arm's length, an average thumb is two degrees wide and a fist is a little less than ten degrees wide. For comparison, the sun and the moon are ½ degree in diameter.

99 thus detaching it from the choroid (the vascular layer of the eye lying between the retina and
 100 the sclera). The tears were probably caused by the detaching vitreous (the jelly in the
 101 eyeball). Ophthalmologist-4 decided to simultaneously use all common retinal repair
 102 techniques: scleral buckling, vitrectomy, laser photocoagulation and pneumatic retinoplexy.
 103 Simplistically, a scleral buckle is a band of silicone that is sutured around the eyeball under
 104 the extra ocular muscles. It buckles the eyeball pushing certain regions closer to the retina.
 105 In vitrectomy, the jelly-like vitreous humor is removed. Pars plana vitrectomy describes a
 106 particular pathway (pars plana) that the surgeon uses to remove the vitreous. In pneumatic
 107 retinoplexy the surgeon, inserts a bubble of about 15% perfluoropropane (C_3F_8) gas (the
 108 other 85% is just air) into the vitreous chamber of the eye (the big part of the eye between
 109 the lens in front and the retina in back). This bubble prevents fluid in the eye from passing
 110 through the tear and under the retina. This allows the choroid to pump the fluid out of the
 111 subretinal space allowing the retina to reattach to the choroid. You cannot fly in an airplane
 112 (or do anything else that will rapidly change the pressure around you) with a gas bubble in
 113 your eye.
 114 Typically, an ophthalmic laser for retina photocoagulation uses a diode-pumped solid-state
 115 green argon laser with a wavelength of 532 nm (a yellow 586 nm laser is another possibility),
 116 a power of 50 to 2000 mW, a pulse duration of 0.01 to 4.0 seconds with a 635 nm red laser
 117 aiming beam. The visual field comprises the images that the subject can see with the eye
 118 looking straight-ahead (primary position): typically, this is 90° temporal, 60° nasal, 60° up
 119 and 75° down.
 120 Concerning cataract operations, the human intraocular lens is enclosed in a capsule. This is
 121 sometimes referred to as the membrane capsule, a capsular bag, or a lens *capsule*. The
 122 front and backsides are referred to respectively as the anterior capsule and the posterior
 123 capsule.
 124 Throughout May and June, my vision was improving, although I did not expect the **phoria**:
 125 that the direction of gaze for the left eye, when at rest, was about ten degrees up and ten
 126 degrees left of the direction of the right eye.

127 June 29, 2008, Gas Bubble Disappears

128 Ophthalmologist-4 had told **us** to expect that if we lasted six weeks, or until the gas bubble
 129 disappeared, then we would be out of the woods for further complications. On this Sunday,
 130 we were in high spirits, because this was six weeks after the operation and the gas bubble
 131 was completely absorbed.

132 June 30, 2008, Retina Detaching

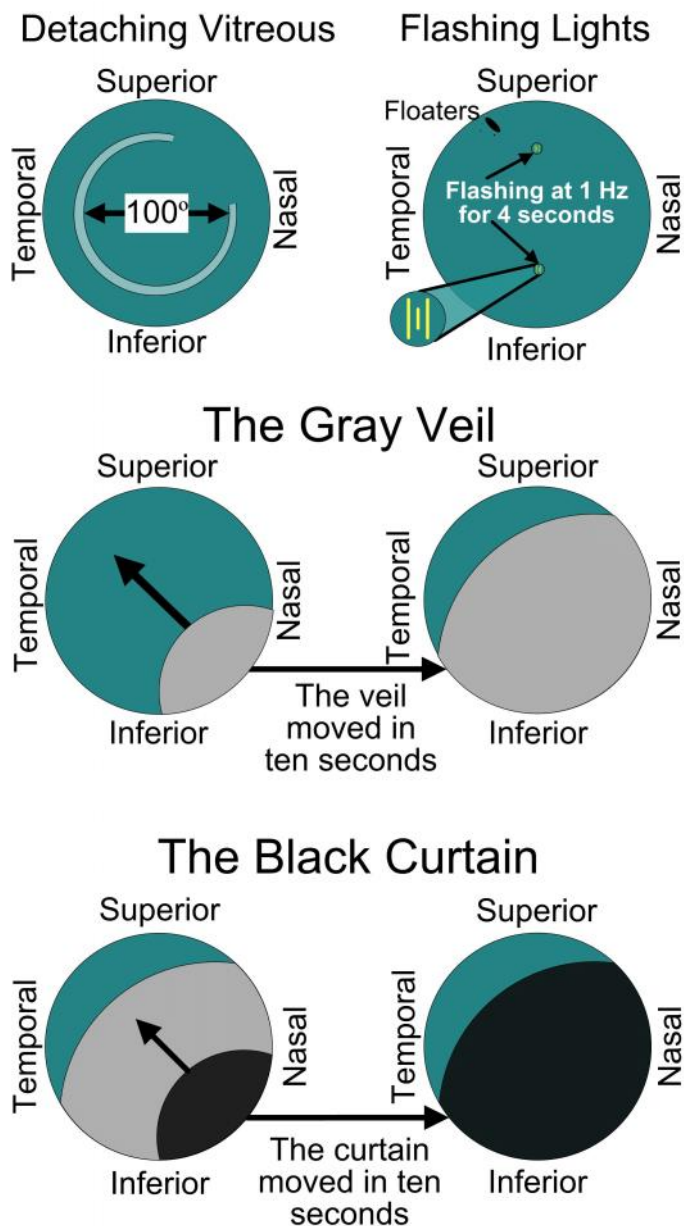


FIG 1. Temporal sequence from the patient's viewpoint of his left eye's retina detaching. Top-left: the vitreous detaching. The dark green (or gray) disk represents the subject's field of view. Top-right: floaters and flashing lights caused by the retina detaching. Middle: the gray veil started in the lower-right visual field and progressed to the upper-left. Bottom: the black curtain followed the same path as the gray veil.

At 10:00 AM, Ophthalmologist-4 saw a small hole in the retina, as well as a scab on the retina. He scheduled an operation for 3 PM the next day. Four hours later, I saw vertical yellow lines about two degrees long and one degree apart: three on top of my field of view and three on the bottom. See Figure 1 (top-right). They flashed at one hertz for a dozen

seconds. Later I saw big black floaters². Then a convex gray veil (with a radius of curvature of around 40°) moved from the lower-right to the upper-left across my field of vision: this took around ten seconds. Then, a few minutes later, a convex black curtain moved across my retina and eclipsed 80% of my field of vision. I called Ophthalmologist-4 and he confirmed that my macula of my retina had detached and we would do the operation the next day. I was not a happy puppy: since the operation, they would not let me drink beer, work on the computer for more than 15 minutes at a time, or go out of the house for more than an hour a day. I had to lie on my side for most of the day. My primary care physician had prescribed Sertraline for my depression.

Note: this is the visual experience of one subject. The literature most often describes the detaching retina with spider webs, flashing lights, lightning bolts, sparkling dots, fireflies, fireworks or sparks. I did not take measurements of the recovery from this first retinal detachment operation, because I had no idea of what to expect. So I could not plan an experiment.

July 1, 2008, Second Detached Retina Operation

Ophthalmologist-4 pushed the macula back into place, zapped the retina with his laser and inserted another gas bubble. A gas bubble occludes the retinal tear, permitting the choroid to remove subretinal fluid, and then the bubble presses the retina against the choroid, sheltering the edge of the tear until a choroid-retinal scar is formed, sealing the break. A bubble of perfluoropropane (C_3F_8) gas will gradually be absorbed into the blood stream and will be replaced by aqueous fluid, which is continually produced by the ciliary body. This process will take six to eight weeks depending on how big the bubble is and a bunch of other things. The first objects that I saw as the gas was absorbed were stars in the sky as shown in Figure 2. Obviously, I was outside looking straight ahead.

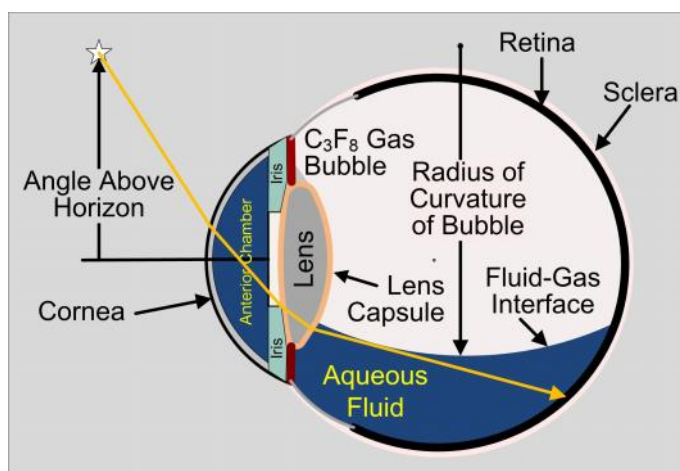


Fig. 2. Schematic drawing of the eye showing the path of the first light that the patient saw after the operation.

Because of the difference in the index of refraction of liquid and gas, light rays that go through the gas bubble diffuse before they reach the retina. Only rays going through the

² Floaters are small clumps of cells, pigment or gel that "float" inside the vitreous. They have a wide variety of sizes and shapes. For me they are often black circles tenths of a degree in diameter. Sometimes they move, seemingly like a house fly. Floaters may appear as small specks, hair-like objects, clouds, strings, streaks, dots, dust, or spider webs moving in front of a person's field of vision. They are especially apparent when looking at a plain white background or a blue sky.

aqueous fluid can reach the retina in focus, as shown in Figure 2. As a patient, this came as a surprise to me. Next, as the gas was being absorbed into the blood via the retina, choroid and aqueous fluid, the bubble changed its size and shape.

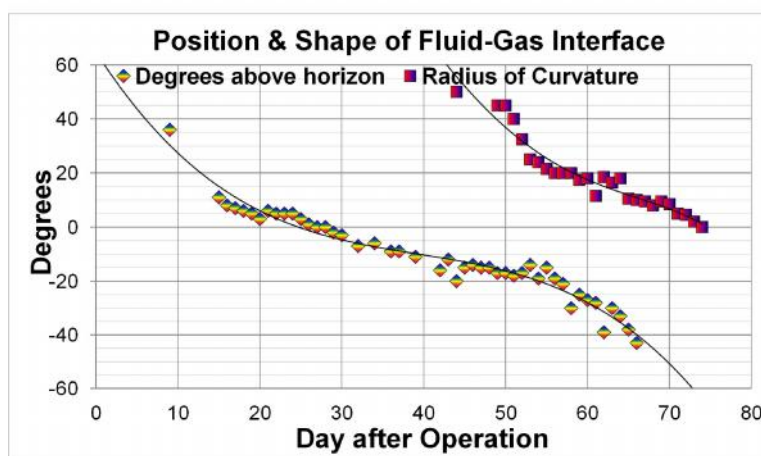
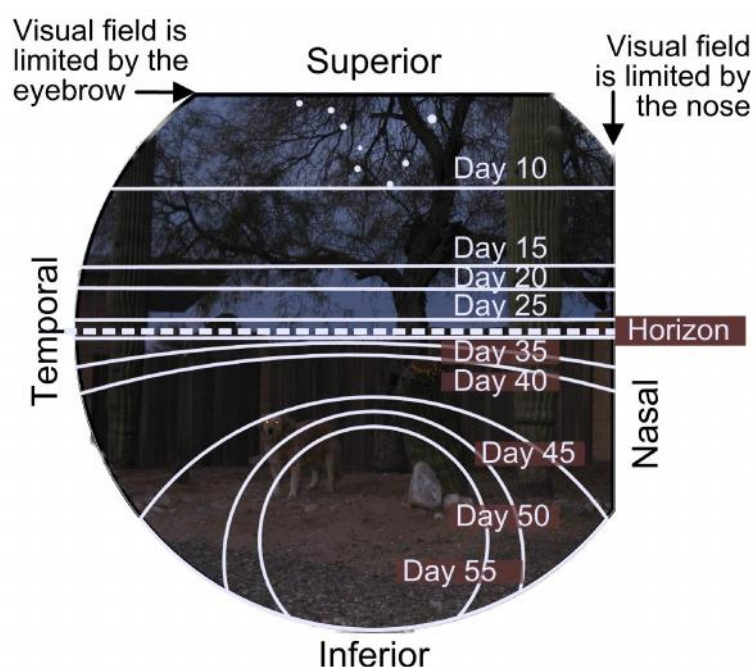


Fig. 3. The patient's viewpoint of the time sequence of the gas bubble being absorbed and replaced with aqueous fluid.

Figure 3 shows the patient's viewpoint of the time sequence of the gas bubble being absorbed and replaced with aqueous fluid. The patient can see only what is above the white (or grey) line for that day. For, example on day ten he can only see the stars. When the fluid-gas interface dropped below the horizon, it stopped being a straight line and seemed to have curvature, eventually turning into a circle. (Right) Quantitative data from the patient's viewpoint of the temporal disappearance of the C_3F_8 bubble. It seemed to disappear from the top down starting about the 10th day after the operation. On the 60th day, the bubble broke up into one big bubble and lots of little ones: the numbers in this figure are for the big bubble.

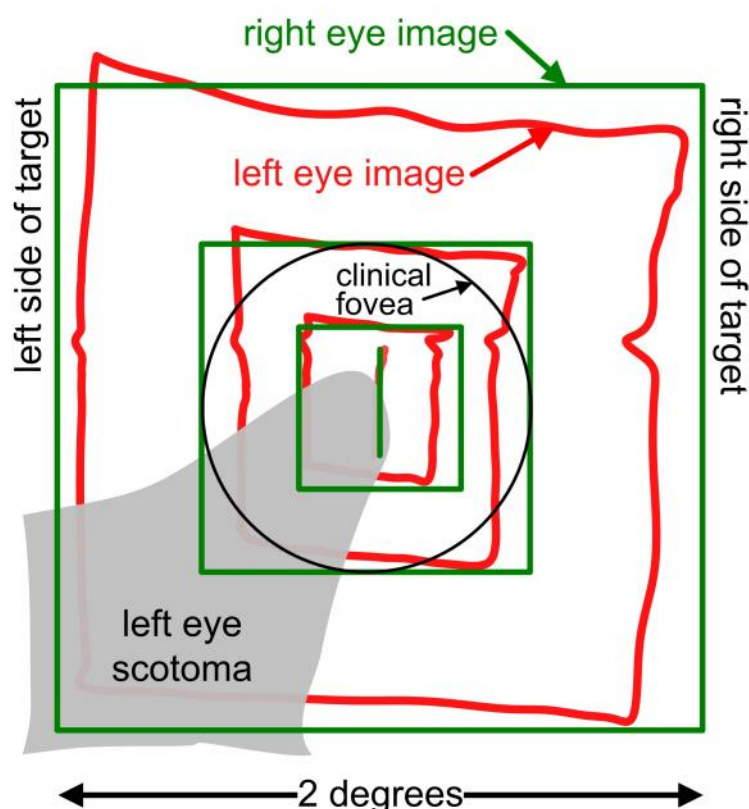


191 In the first few days after the operation, the bubble always increases in size, but I could not
 192 detect this. I could only see white with shadows and bright objects like windows. Around day
 193 10, I was surprised to see the bottom of the gas bubble. It was in my upper field of view
 194 (remember that the lens inverts the image before it is focused on the retina). In Figure 3, this
 195 gas-fluid interface looked horizontal, so I measured how far it was above the horizon. I saw
 196 lots of very strange reflections off of this gas-fluid interface. Later at about day 40 the bubble
 197 started to look more like a circle and less like a line. So I started measuring the radius of
 198 curvature of the bubble. The ophthalmological literature emphasizes the *volume* of the
 199 bubble Woon, et al. [2], which may be scientifically more relevant. But the patient does not
 200 care about volume. He cares about what is happening in his visual field. Figure 3 is for one
 201 patient only, with C_3F_8 gas only and in only one operation, although after the other two
 202 operations the bubble behaved the same way.

203 September 11, 2008, Distorted Vision

204 The gas bubble from the second detached retina operation was gone after 10 weeks. The
 205 left eye retinal image had become wrinkled. The width of the image of the left eye was
 206 around $\frac{3}{4}$ the size of the right eye. See Figure 4. With the left eye, everyone looked like a
 207 pinhead, or a person in an El Greco painting. The **phoria** had also changed.

208



209

210 **Fig. 4. The patient's viewpoint of binocular viewing of a small target. The right eye's**
 211 **image (green) is the same as the visual target. The left eye's image (red) shows the**
 212 **distortion due to a wrinkled retina or macular pucker. The scotoma in the lower-left**
 213 **quadrant resulted from peeling the ILM.**

214 September 12, 2008, Third Bubble

215 Ophthalmologist-4 found a new tear in my retina. He repaired it with 60 pulses of a head
 216 mounted laser. He inserted a cryopexy probe on top of the eyeball near the scleral buckle to

217 freeze (cryopexy) the area of the retina above the tear. He removed some fluid from the
218 eyeball and inserted a new bubble of C₃F₈. But he was doing these procedures while he was
219 seeing other regularly scheduled patients. So he finally gave up and asked **us** to come back
220 the next day.

221 September 13, 2008, Many Laser Pulses

222 Saturday morning we returned at 8 AM. Ophthalmologist-4 administered 567 laser pulses.
223 Ophthalmologist-4 said, "I know you want to ask, why? The answer is bad luck." Over the
224 next few months, there were varying degrees of vertical, horizontal and cyclorotational
225 disparities between the two eyes due to the misdirection (phoria) of the left eye. The pain on
226 the back of eye and the double vision (diplopia) started with the **first** surgery on May 12, 
227 2008. But the phoria might have been exacerbated by the cryopexy freezing on September
228 12, 2008. At this time, with the left eye, everyone looked like Don Quixote, tall and skinny.
229 At this time, my symptoms were (1) inflammation and pain in the front of the left eye, (2) pain
230 behind the left eye, (3) pain in the brain, (4) double vision, (5) lack of depth perception, (6)
231 poor visual acuity in the left eye due to a wrinkled retina, and (7) poor vision in the *right* eye
232 due to a cataract.

233 October 29, 2008, Macular Edema was Noticed

234 Using a Heidelberg Engineering OCT instrument, Ophthalmologist-4 noted cystoid edema in
235 the macular area. He also noted that the retina was reattached.

236 March 9, 2009, Attempts to Eliminate Edema

237 The image of the left eye was about ¾ the size of the image of the right eye. The left eye's
238 image was wrinkled. Ophthalmologist-4 had been recommending use of cortical steroids
239 (drops and injections) for five months trying to flatten the macula. There was fluid behind the
240 retina. At various times he called it inflammation, swelling, fluid, a cyst and cystoid macular
241 edema: for the rest of this paper I will refer to this as macular edema. Ophthalmologist-4
242 noted that the internal limiting membrane (ILM) was not thickened. He injected
243 corticosteroids (Kenalog) directly into my eyeball. I probably had a reaction to the carrier or
244 the preservative (benzyl alcohol), because the Kenalog turned into white crystals and I was
245 blind in that eye for a week. The intraocular pressure shot up to 30 mm Hg. Thirty-six drops
246 of three different eye medicines per day (spaced at least ten minutes apart) brought
247 everything back to "normal."

248 June 1, 2009, The Right Eye

249 A small inconvenience was caused by the cataract in my right eye. I had intended to have it
250 removed soon after the cataract in the left eye. But when the left retina started falling off, the
251 doctors suggested that nothing be done to the right eye until the left eye stabilized. For about
252 a year, I did not drive my car. Ophthalmologist-5 removed the cataract in the *right* eye and
253 replaced it with a 13 diopter artificial intraocular lens (IOL). Although the right eye was *her*
254 eye, she spent a good deal of time examining and tracking the progress of the left eye.

255 July 10, 2009, Kenalog

256 Ophthalmologist-4 injected *preservative-free* Kenalog into the left eyeball. It did not react
257 adversely. It did help with the fluid behind the retina.

258 September 4, 2009, Summary of Symptoms

259 The left eye's image was smaller than the right eye's image, it was wrinkled, it was about
260 eight degrees up, four degrees to the right and was rotated about three degrees clockwise. I
261 had a (possible) aniseikonia headache. I had no depth perception for near objects: therefore,
262 threading a needle, tying a hook on a fishing line or pounding in a nail was difficult, or near
263 impossible.
264 I wore a black patch over my left eye to see if that would reduce the pain in the brain. That
265 helped, but Ophthalmologist-4 asked me to stop doing that, because he was afraid the brain

266 would shut down that eye if I stopped using it. So for about six months, I wore a black patch
267 over my left eye when reading or working on the computer and I wore a black patch on my
268 right eye when I was teaching, riding in a car or watching television. This reduced the pain in
269 the brain.

270 October 16, 2009, Planning the Seventh Retinal Surgery

271 At a routine appointment, Ophthalmologist-4 worried about the macular edema and
272 scheduled surgery for October 20. He said that he will go in with his microscope, look, see
273 what is there and try to remove it. He said, "I *think* this will work."

274 October 20, 2009, Peeling the ILM

275 Ophthalmologist-4 peeled the internal limiting membrane (ILM) over the macula. The inner
276 limiting membrane is a diffusion barrier between the vitreous and the ganglion cells of the
277 retina. It is about two microns thick. He removed an area about one mm in diameter. He did
278 this manually, quite a feat! Then he injected Kenalog into the eyeball (fresh hospital Kenalog
279 is preservative free). The purpose of peeling the ILM was to reduce the edema, not to
280 improve visual acuity [3]; because visual acuity seldom improves after a macula-off
281 detachment [Nadal et al., 2012].

282 October 21, 2009, Follow-up Exam

283 The day after the surgery, he said, "That will be your last operation on that eye: that eye
284 can't take any more surgery: it was hard to get the membranes back together."
285 Ophthalmologist-4's practice schedules a patient every ten minutes. Well on that day he
286 said, "They're trying to kill me. Today they have scheduled 89 patients for me."

287 November 2, 2009, No Progress

288 I told Ophthalmologist-4 that peripheral vision in the left eye was good: but the left eye's
289 image was still smaller than the right eye's image. Since the operation, the left eye's image
290 had a two-degree diameter gray-brown cloud over the fovea. He looked and said that it was
291 a hemorrhage and that was not unusual: it will probably go away.
292 For the last year and a half I have reported to Ophthalmologist-4 that I have had the
293 following symptoms: (1) pain in the front of the left eye, (2) pain behind the left eye, (3) pain
294 in my brain, (4) double vision (diplopia) due to left eye phoria, (5) lack of depth perception
295 (stereopsis), and (6) poor visual acuity in the left eye due to a wrinkled retina and, since
296 peeling the ILM, a scotoma (an area in the field of vision where the subject sees nothing) in
297 the inferior temporal macula as shown in Figure 4.

298 June 23, 2010

299 I visited Ophthalmologist-4. Vision in the left eye has been about 20/60 for the last seven
300 months. I could obtain this only by scanning across the letters and recognizing them with
301 peripheral vision. There was tremendous variability in this measure. Peeling the internal
302 limiting membrane (ILM) over the macula has made the vision worse. At this time, we lost
303 confidence in Ophthalmologist-4 and switched to Ophthalmologist-6.

304 July 27, 2010, New Ophthalmologist

305 I asked if it would help if we removed the scleral buckle. Ophthalmologist-6 suggested *not*
306 removing the sclera buckle. His optical coherence tomography (OCT) confirmed fluid behind
307 the retina.

308 At this point my symptoms (and possible known causes) were (1) pain in the front of the left
309 eye and light sensitivity (perhaps caused by the haptics of the artificial lens interfering with
310 the iris), (2) inflammation and intermittent pain behind the left eye (perhaps caused by the
311 sclera buckle or damage **due** to the superior oblique and superior rectus muscles), (3) pain
312 in the brain. [Surely, this had many causes. It could be a continual retinally induced
313 aniseikonia headache (asthenopia). The MRI's did not reveal a cause. A neurologist found
314 no reason for them. They are not migraine or cluster headaches.] (4) left eye phoria [When



315 looking straight ahead, the left eye's image was rotated about three degrees right, two
316 degrees up and five degrees clockwise. (This may have been caused by the sclera buckle or
317 damage to the superior oblique and superior rectus muscles)], (5) diplopia and lack of
318 stereopsis (caused by the phoria and the wrinkled retina), (6) poor visual acuity (caused by a
319 wrinkled retina and a scotoma in the inferior temporal macula).

320 At this time, Optical Coherence Tomography (OCT) images were the cat's meow of
321 ophthalmology. The OCT instrument scans the retina with a laser beam. It stores this
322 information in a computer as a three dimensional model of the eye. The OCT images of my
323 eye showed fluid under the retina, so the doctors tried to get rid of that fluid. That fluid
324 caused an elevated thickness at two places in the retina. They were about five degrees left
325 and right of the fovea. Visual field analysis does not have the resolution to show such
326 defects. In fact, when I looked for evidence of such defects I could not find any. So the OCT
327 images showed a new type of pathology and my ophthalmological treatments over the last
328 two years were directed to reduce these fluids and those potential defects.

329 At most of my eye exams since May 2007, someone would measure the pupillary reflexes.
330 The right eye was always normal; the left eye was always non-circular and non-responsive
331 (tonic). I presumed that these test results were entered into my records and read by the
332 doctor: but no one ever told me about this anisocoria and no one did anything about it. From
333 my perspective as a patient, I think that, if a test or a measurement is being taken, then
334 standard office processes should ensure (not presume) that the results are analyzed by the
335 appropriate person or thing and explained to the patient.

336 November 5, 2010, Letter to Ophthalmologist-6

337 Visual acuity in the left eye is about 20/70. However, I note that viewing a Snellen chart is a
338 primitive indicator of vision. For example, it does not disclose important additional
339 information that the brain has shut down vision of my left eye by about 1.5 log units. That is,
340 if I want to see a target equally with both eyes in the same illumination, then I must put a 1.5
341 log unit neutral density filter in front of the right eye to equalize the perceptual disparity
342 between the eyes. It also fails to disclose retina wrinkles and scotomas as shown in Figure
343 4. It does not reveal lack of stereopsis or color vision deficiencies. Note added later: The one
344 hundred plus Snellen chart tests that were given to me over the last six years were a waste
345 of time and money.

346 December 3 and 8, 2010, MRIs

347 MRIs of the brain and left eye orbit showed no cause for the pain in the brain. This pain
348 seems to be localized in a cylinder two inches in diameter stretching between the temples.

349 December 10, 2010, Diagnosis of Phoria

350 The optometrist diagnosed the pain in the back of the eye and the vertical, horizontal and
351 cyclorotational disparities between the two eyes as being due to the sclera buckle and
352 effects of the surgery on the oblique muscles. He prescribed new spectacles with horizontal
353 and vertical prisms for both eyes. These spectacles got rid of some of the pain in the back of
354 the eye and attenuated the pain in the brain.

355 Over the last five years, when looking straight ahead (eyes in primary position), the self-
356 measured OS phoria was $5.7^\circ \pm 1.5^\circ$ right, $3.6^\circ \pm 2.3^\circ$ up and $4.5^\circ \pm 1^\circ$ clockwise. The
357 optometrist recommended spectacles with horizontal prisms of 1 Δ base-in for both eyes and
358 2 Δ base-down for the OD and base-up for the OS. Although it is only the left eye that is
359 misaligned, half of the needed prism correction is put in each spectacle lens.

360 December 29, 2010, Diagnosis of Tonic Pupil

361 The optometrist told me that the right eye pupillary response was normal, but the left pupil
362 was dilated, oblong shaped, with the pulling point at 11 o'clock, and was nonresponsive
363 (tonic). The optometrist wanted to run an experiment to see if the origin of the tonic pupil was
364 mechanical or neural. One possible neural cause of the tonic pupil was an injury (during the

365 surgeries) to the axons in the short ciliary nerve between the ciliary ganglion and the ciliary
366 muscles. So he called a retina specialist^s involved with my case, Ophthalmologist-8, and
367 they decided that pilocarpine (a pupil constrictor) might help and would not hurt. The
368 pilocarpine did not cause the pupil to constrict; therefore the tonic pupil was due to
369 mechanical not neural restraints. The pilocarpine was then discontinued. This experiment led
370 us to think that perhaps the haptics were hooked into the iris. However, we did not have an
371 instrument that could image the haptics. This situation eventually led to the lens replacement
372 surgery at the UCLA Medical School.

373 January 24, 2011, Confirmation of Tonic Pupil

374 Ophthalmologist-7 noted that the left pupil was an oblique oval with a diameter of 5 mm.
375 Prism cover testing showed 5 prism diopters.

376 January 31, 2011, Summary of Symptoms

377 I gave the optometrist the following summary of my symptoms: (1) inflammation and pain in
378 the front of the eyeball. I described it as a scratchy, blood-shot irritation of the eyeball. This
379 pain was intermittent. It came on a half-dozen times a day and lasted 10 or 20 minutes. The
380 left eye was light sensitive. After walking the dog in the sun for a half-hour, the eyelid was
381 almost closed and the eye hurt. (2) Pain in the back of the eyeball: an intermittent localized
382 pain, sometimes sharp, sometimes dull. It felt like a foreign body was trapped in the orbit. I
383 attributed it to the sclera buckle or to inflammation around the buckle. This pain had been
384 there for two years. (3) Pain in the brain. A continual periphery-induced aniseikonia
385 headache (asthenopia). My brain hurt when I got up in the morning: it got worse as the day
386 went on. I had put a black patch on the left eye for close vision like reading on a computer
387 screen and on the right eye for distance vision like when watching TV or being outside. That
388 helped, but Ophthalmologist-4 asked me to stop doing that. So I put a small (one degree) dot
389 on the left lens. This blocked the distorted left eye image and caused the left eye to use
390 peripheral not foveal vision. I had hoped that this would ameliorate the static aniseikonia.
391 The optometrist's prism spectacles did help with the pain. Roughly, the pain seemed to be
392 localized to a region between the temples. If I rubbed the temples, it helped. This pain got
393 worse a half-dozen times a day. These episodes lasted a half hour. However, the MRIs
394 found nothing and my neurologist found nothing wrong. (4) If I bent over and to pick up
395 something from the floor the left eye hurt. About once a day, I lose my balance and almost
396 fall.

397 I wrote that Ophthalmologist-7's report said that all four of these pains were consistent with
398 the eight operations that were done on that eye. He offered nothing to relieve the pains.

399 Spring 2011, Finding a Specialist

400 Now the biggest difficulty was finding an ophthalmologist who had the experience and
401 instruments to handle this one-in-a-million problem. Finally, Ophthalmologist-5
402 recommended Ophthalmologist-9, with whom she had done a fellowship, at the UCLA
403 Medical School. Ophthalmologist-9 was a professor of ophthalmology specializing in the
404 anterior chamber (cataracts and refractory surgery).

405 May 6, 2011, First visit to UCLA

406 At the UCLA medical center, Ophthalmologist-9 and two of his Fellows spent over an hour
407 examining me. He wrote in his report, "Ocular Motility... With Distance Fixation cc: 6 prism
408 diopter left exotropia and 4 prism diopter left hypertropia, Left incyclotortion persists after
409 horizontal and vertical deviations are neutralized.... The left pupil was 3×4 mm, oval, and
410 peaked at the 11 o'clock position... posterior synechiae [meaning places where the iris
411 adheres to lens] at the superonasal optic-haptic junction... A single posterior synechia is
412 noted at the 11 o'clock position. The iris is stuck to the optic-haptic junction at this location...
413 The quality of the central vision in his left eye is poor. He must scan over letters to read
414 them, and even when he does, his acuity is not very good."

415 June 17, 2011, Preoperative Visit

416 Ophthalmologist-9 noted, "2 permanent sutures that are attached to the scleral buckle tent
417 up, but do not pierce the conjunctiva."

418 July 21, 2011, Lens Exchange Operation

419 Professor Ophthalmologist-9 noted significant posterior synechia superonasally, an eccentric
420 pupil, and a chafe between the iris and the square edge of the intraocular lens. He removed
421 the artificial lens in the left eye and replaced it with a type of lens that was designed to be
422 placed in the ciliary sulcus (Starr Surgical AQ20110V). In two months the pain in the iris was
423 gone, but the pupil was still noncircular and nonresponsive (tonic).

424 Ophthalmologist-9's reports were excellent: they were clear, specific and detailed and he
425 made sure that copies were sent to all seven of my previous principal doctors. Evidentially
426 the optometrist and the eight ophthalmologists that had examined me before had never seen
427 this particular cluster of symptoms. So, I was a rare patient. I think that doctors in medical
428 schools are more experienced in dealing with rare cases. So, in retrospect, when I realized
429 that my case was so rare and I found Ophthalmologist-9 at the UCLA medical school that
430 solved my major problem, perhaps I should have stayed with him, even though it would have
431 meant frequent trips between Tucson and Los Angeles and a more expensive medical
432 insurance plan.

433 January 25, 2012, Revisiting Pain on Back of Eye

434 The optometrist notes inflammation of the sclera and of the anterior chamber. He prescribed
435 Bromday and Pred Forte. This prompted Ophthalmologist-6 to inspect the suture securing
436 the scleral buckle.

437 May 8, 2012, Ophthalmologist-6 is Optimistic

438 In his consultation report Ophthalmologist-6 wrote, "Bahill was in again with his remarkable
439 scientific knowledge and his scientific analysis of what is happening in his left eye. ...

440 Summary: The only treatable condition here is the macula edema."

441 June 4, 2012, Old Suture Removed

442 For four years, my sclera was inflamed, blood-shot and it hurt. Bromday seemed to be
443 helping. But on June 4, in an in-office operation, Ophthalmologist-6 removed an exposed
444 Dacron suture in the sclera from the original scleral buckle operation of May 12, 2008. The
445 pain dropped by 40%. But then he noted a 2 mm fistula in the sclera over the scleral buckle.
446 He consulted with his partner, Ophthalmologist-10, and then suggested an operation in the
447 hospital.



448 July 18, 2012, Fistula Sutured

449 Ophthalmologist-6 sutured a conjunctiva fistula in the sclera over the scleral buckle. The
450 operation went well, except that the area became infected. Ophthalmologist-6 and
451 Ophthalmologist-10 treated the infection with Ofloxacin and Neo/Poly/Gram.

452 November 6, 2012, Large Macular Edema

453 The optometrist noted that his OCT instrument showed an overall retinal thickening with a
454 maximum thickness near 500 microns in the area centered five degrees temporal of the
455 macula. The optometrist recommended that I accelerate my next visit with Ophthalmologist-6
456 and sent a consultation letter to him.

457 November 26, 2012, Treatment of Macular Edema

458 Ophthalmologist-6's OCT instrument replicated this macular edema with a thickness of 427
459 microns in the area centered five degrees temporal of the macula. He recommended
460 reapplication of cortical steroids (Durezol) four times a day. Table 3 summarizes the eye
461 drops that I have taken.

462

Table 3. Over the last six years, ATB has used the following eye drops.		
Category, Purpose	Generic Name	Brand Name
Corticosteroid, Anti-inflammatory	Difluprednate 0.05%	Durezol® emulsion
	Prednisolone acetate 1%	Omnipred®
	Prednisolone acetate 1%	Pred Forte®
	Triamcinolone acetonide	Kenalog® (by injection)
NSAID, Anti-inflammatory	Bromfenac 0.08%	Xibrom™
	Bromfenac 0.09%	Bromday™
	Ketorolac 0.4%	Acular®
Vasoconstrictor, Antihistamine, Anti-inflammatory	Naphazoline HCl, Pheiramine Maleate	Naphcon A®
Intra-ocular pressure reduction		
alpha agonist	Brimonidine tartrate 0.15%	Alphagan®
beta-adrenergic blocker	Levobunolol HCl 0.5%	Betagan®
cholinergic agonist	Pilocarpine HCl 1.0%	
Antibiotic	Gatifloxacin 0.3%	Zymar®
	Gatifloxacin 0.5%	Zymaxid™
	Moxifloxacin HCl 0.5%	Vigamox® Solution
	Neo/Poly/Gram	Neosporin®
	Ofloxacin 0.3%	Ocuflox®
Artificial Tears and Lubricants	Propylene glycol	Systane®
HCl means hydrochloride		

463

464 December 27, 2012, Miraculous Cure

465 The macular edema had started in 2008. It was detected and measured with OCT scans. It
 466 was treated with corticosteroid eye drops Omnipred® and Pred Forte®, injections of
 467 Kenalog® , peeling of the internal limiting membrane (ILM) over the macula, and eye drops
 468 of Xibrom™, Bromday™, Acular® and finally Durezol® four times a day. By Christmas, in
 469 one of the most successful treatments for my eye in four years, the swelling of the retina had
 470 nearly disappeared. The area of concern had thinned by 160 microns; it was now thinner
 471 than the right eye retina! Ophthalmologist-6 recommended continuing Durezol but only once
 472 a day. On March 9, 2013, the macular edema had returned. We increased Durezol to twice a
 473 day and by March 27 most of the macular edema went away. On July 11 the edema was
 474 mostly gone. Of course, this did not improve visual acuity.

475 December 29, 2012, More Mysteries

476 If there is only one object in my visual field and it is a small white light (as in non-contact
 477 tonometry), then it will appear white to the right eye and green to the left eye. I had
 478 mentioned this for two years, but I did not have an experiment to quantify it.

479 March 27, 2013, Color Blindness

480 The fovea of the left eye is color blind. When a small visual target, about one degree in
 481 diameter, is placed on the fovea, the left eye misperceives its color. A bright white dot on a
 482 white background appears green to the left eye. Conversely, a green laser dot on a white
 483 background appears white or bluish-white and a green dot on a red background appears
 484 white. These effects would be consistent with the destruction of ganglion cells [4] [Kolb, et
 485 al., 2013] during the ILM peeling of the left eye. The left eye shows no after image effects
 486 after staring at a primary color. With monocular viewing through a pin hole, the left eye fails
 487 the Ishihara Plates Test [5] [Flück, 2013] <http://www.colour-blindness.com/colour-blindness->

488 [tests/ishihara-colour-test-plates/](https://www.ishihara.com/tests/ishihara-colour-test-plates/). On the calibration plate, it can see the red number 12 on a
 489 blue background, but nothing on the other plates. On the X-Rite color IQ test (a simplified
 490 on-line version of a Farnsworth-Munsell 100 Hue Test,
 491 http://xritephoto.com/ph_toolframe.aspx?action=coloriq) his right eye scores 16 which is low
 492 and therefore good. The left eye scores 182, which is poor and in the 99th percentile. It is
 493 weak in the blue region. This is an unusual example of a color anomaly that is not based on
 494 rod and cone photoreceptor biochemical deficiencies. It could be based on destruction of
 495 color-opponent ganglion cells.

496 3. Discussion

497

Table 2. Summary of ATB's ocular status April 2013			
Description (name)	Probable cause	Primary solution	Present condition, 100% is best
Pain in front of the left eye	The iris was stuck to the square edge of the intraocular lens (IOL) or to the haptics, thereby immobilizing the iris.	Replacement of the IOL	95%, the pupil is still tonic
Pain behind the left eye	Sclera buckle and damage to oblique muscles	Removing exposed suture & suturing conjunctiva fistula over the scleral buckle	80%
General pain in the left eye	Inflammation of the sclera and in the anterior chamber	Corticosteroid eye drops	20%
Pain in the brain	Different images from the two eyes and something else	Reducing dynamic aniseikonia	60%
Poor visual acuity in left eye	Scotoma in the macula, macular edema, wrinkled retina	Corticosteroid eye drops	20%
Size and shape of the images are different in the left and right eyes (static aniseikonia)	Macula-off detached retina, peeling the ILM, subretinal edema and disruption of retinal pigment epithelium	Corticosteroid anti-inflammatory eye drops	10%
Double vision. In rest position, the left eye's image drifts up and to the right, compared to the right eye. (dynamic aniseikonia, phoria, diplopia)	Damage to or interference with oblique extra ocular muscles	Prisms in spectacles	70%
Lack of depth perception for objects within ten feet. (lack of stereopsis)	Static and dynamic aniseikonia	None	0%
Color blindness in left fovea	Peeling the ILM	None	10%
Poor vision in the <i>right</i> eye	Cataract	Replaced natural lens with an IOL	100%

498

499 Quality of Life

500 Because the images in my two eyes are of different sizes and shapes, it is difficult, error
 501 prone and time consuming to read homework (I often misperceive or skip words), grade
 502 exams, read textbooks, grade tests and read project reports. I do not recognize student
 503 faces as well as I used to. My ability to read lips is diminished, so my hearing impediment is
 504 exacerbated.
 505 The lack of stereopsis (depth perception for objects within 10 feet due to the difference in the
 506 images of the two eyes) makes it dangerous to climb stairs or even walk on a sidewalk. I
 507 lose my balance daily, but fortunately, I have only fallen few times, once I broke my fibula.
 508 This lack of depth perception makes it difficult to tighten a small screw, zip up a jacket,
 509 pound in a nail, put a nut on a bolt, or twist a wire around a receptacle screw terminal.
 510 When delivering a lecture, intermittent pain in the left eye breaks my concentration and I
 511 have to restart a derivation from the beginning. Because of the constant headaches, I cannot
 512 think quickly, this makes teaching ineffective.
 513 The scleral pain often interrupts me in mid-sentence. Sometimes I can resume my sentence
 514 and sometimes I cannot. Sometimes the pain interrupts me in the middle of the other
 515 person's sentence. All I can do is turn away, wait a while, apologize and then ask them to
 516 restart their train of thought. These pains occur a few dozen times a day: they last for about
 517 10 minutes.
 518 The pain in my brain varies (on a scale of 0 to 10) from 1 to 4. It spikes about a dozen times
 519 a day and these episodes last about 15 minutes, but sometimes they last for hours. This
 520 pain prevents me from working on a computer for extended periods. Sharp occurrences of
 521 pain make it impossible to maintain a continuous long chain of thought. Therefore, I cannot
 522 write papers or proposals. This pain peaks in the afternoon.
 523 After walking in the sun for a half-hour, working on a computer terminal for two hours, driving
 524 at night for one-quarter-hour or after 9 PM my left eye has closed itself.
 525 A few years ago when people asked me when I planned to retire, I would answer, "Between
 526 one and ten years from now: I'll work until some administer pisses me off." But my disability
 527 finally caused me to "voluntarily relinquish [my] employment, tenure, and/or continuing status
 528 at the university" in May 2011.

529 The Systems Approach

530 Starting in 2007, the subject continually complained of these symptoms (1) inflammation and
 531 pain in the front of the left eye, (2) pain behind the left eye, (3) pain in the brain, (4) left eye
 532 misalignment (phoria), (5) double vision (diplopia), (6) lack of depth perception (no
 533 stereopsis), (7) poor visual acuity, (8) foveal color blindness, (9) light sensitivity and (10) a
 534 non-circular and non-responsive (tonic) pupil. These ten complaints seemed like ten different
 535 problems. This is like the story of seven blind men describing an elephant: each saw a
 536 different aspect. But now we can see the relationships between these problems. We can
 537 understand this medical history as a system, instead of ten isolated events. As shown in
 538 table 4, it can be seen how treating one symptom affects other symptoms.

539

Table 4. Systems analysis of this case study

The event in this column	prompted the action in this column,	which produced the outcome in this column.	This later ameliorating action	produced this final outcome.
Cataract growth	original cataract operation	pain in the front of the eye	replacing the intraocular lens (IOL)	eliminated pain in the iris

	original cataract operation	light sensitivity and a non-circular, non-responsive (tonic) pupil	none is known	permanent damage to iris
Retinal detachment (probably precipitated by the above operation.)	many retina operations	macular edema	peeling the ILM	foveal scotoma, color blindness and poor visual acuity. Subsequent Durezol drops reduced edema.
	implanting a scleral buckle	inflammation and pain on the back of the eye	removing exposed sutures on the back of the eye	eliminated pain from the exposed sutures
	implanting a scleral buckle	pain on the front of the eye	removing the suture knot may help	unresolved pain
	implanting a scleral buckle	phoria, diplopia and pain in the brain	prescribing spectacles with prisms	reduced the brain pain
Second detachment	retina operation	wrinkled retina	none is known	permanent damage to retina

For years, we had a dozen doctors and a dozen symptoms: each doctor treated his most familiar symptoms, one at a time. This shows the need for face-to-face communication between the ophthalmologists and optometrists. If we had understood this *system* years ago, the treatment surely would have been different.

Lessons learned

Pain

Medical doctors have difficulty successfully treating pain, even if it is in their realm of study and experience. Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and the physician. If the cause is not visually obvious (either to the naked eye, in photos, CAT scans or MRIs), then many times it is not successfully treated. In this particular case, for the last five years most ophthalmologists did not think that they could resolve this patient's complaints about pain.

In fact, Ophthalmologist-6 wrote in his May 8, 2012 consultation report, "Bahill was in again with his remarkable scientific knowledge and his scientific analysis of what is happening in his left eye. He still complains of bi-temporal headaches, which I do not believe are related to his eye disease. If there is any connection it is purely stress or depression related as a result of his concern for his left eye. ... Summary: The only treatable condition here is the macula edema. Hopefully successful treatment will improve the acuity and bring him back to where he was." But on June 4, in an in-office operation, Ophthalmologist-6 removed an exposed Dacron suture in the sclera from the original scleral buckle operation. The pain that had bedeviled ATB for six years dropped by 40%. On July 18, in an in-hospital operation, he sutured a conjunctiva fistula in the sclera over the scleral buckle. The pain dropped by 20%. In summary, in May he said that the only improvement that could be made was reducing the macular edema: but in June and July he performed operations that substantially reduced the pain. It is hard to predict pain resolution.

565 Communications

566 From this study, we have learned about the medical profession. ATB was not simply jumping
567 around trying to find a doctor that could cure his problems. Instead, most of these doctors
568 were working together to help him. Certainly, they exchanged referral reports. One pair
569 talked on the telephone, and another pair talked in person about this case. Perhaps it would
570 have been better if there were more face-to-face communications, but that would have
571 required extra time, money and recourses.
572 Most of their communications were implemented by low quality FAX. Their referral reports
573 varied in quality: some were incomprehensible because the doctor used a canned report
574 generation program, some were superficial, some were mere boilerplate, but the reports of
575 one doctor were truly excellent. It is important that the patient and the doctors ensure that all
576 relevant parties (including the patient, when appropriate) get copies of the reports. In my
577 experiences, most of the times this link failed.



578 Selecting a doctor

579 I have found that searching the Internet and asking friends for recommendations about good
580 ophthalmologists was not useful. People tend to make recommendations based on only a
581 few data points. Searching the Internet to find specific procedures that I wanted the doctors
582 to use was futile. My best results came from asking doctors that I trusted for referrals and
583 then trusting the judgments of these doctors [although this process was also fallible]. In the
584 future, I will ask what the ophthalmologist's patient load is. I will shy away from the
585 ophthalmologists who schedule six patients per hour or from the cataract surgeons who
586 schedule four operations per hour, until someone mandates that this is unethical.
587 In the last five years, I have had ten eye operations and 130 doctor's visits. I estimate that,
588 on average, (a) the ophthalmologists scheduled a patient every 20 minutes with a standard
589 deviation (SD) of 10 and a range of 10 to 60, (b) on each visit, the ophthalmologists or their
590 staff spent 30 minutes with me with a SD of 15 and a range of 10 to 90, (c) Each operation
591 lasted 65 minutes with a SD of 15 and a range of 30 to 90.

592 Invisible gorilla

593 When people focus on a task that demands their attention, they often fail to notice
594 unexpected objects and events that occur in full view. This phenomenon is known as
595 *inattentional blindness*, because people typically do not consciously perceive aspects of their
596 world that fall outside of the focus of their attention [6] [Chabris and Simons, 2010]. Medical
597 doctors are just like the rest of us: they suffer from *inattentional blindness*; they only see
598 what they expect to see.

599 From the very first surgery until today, I have complained about pain in the eye. In retrospect
600 it seems that initially the pain was caused by the iris being trapped by the edge of the
601 original IOL: but it was difficult to figure this out, because people do not see what they do not
602 expect to see.

603 On December 29, 2010, the optometrist broke the mold and gave me a through exam lasting
604 1.5 hours. He looked for unusual things. Finally, he told me that the right-eye pupillary
605 response was normal, but the left pupil was dilated, oblong shaped with the pulling point at
606 11 o'clock, and was nonresponsive (tonic). This was the needed breakthrough. He had
607 looked at the iris, which no one else had done.

608 Ophthalmologist-1 was looking for evidence of the success of his surgery; therefore, he only
609 looked at visual acuity. He did not look at the iris. Ophthalmologist-3 was trained to look at
610 the cornea; therefore, he did not look at the iris. Ophthalmologist-4 was trained to look at the
611 retina; so he did not look at the iris or the sclera. Ophthalmologist-5 was trained to look at
612 the lens; so he did not look at the iris. Ophthalmologist-6 was trained to look at the retina; so
613 he did not look at the iris. Ophthalmologist-7 was a neuro-ophthalmologist trained to look for
614 neurological problems. He noted the tonic pupil, but wrote nothing about it. Ophthalmologist-
615 9 was trained to look at the anterior chamber; so he did not look at the sclera.



616 Process

617 In complicated procedures involving many physicians and many physical systems, it can be
 618 unclear who is in charge of the overall system. Some hospital rules force them to “work on
 619 only one body part at a time.” In addition, there is usually no patient’s advocate, who knows
 620 the system and is particularly interested in only the patients’ best interests. Perhaps both of
 621 these roles are played by the patient or a member of the patient’s family.
 622 For every visit, the patient should have a written letter listing symptoms and questions to ask
 623 the doctor. It is the patient’s responsibility to make sure that the doctor reads the letter. Often
 624 he/she does not. Also, I guess that it is the patient’s responsibility to make sure that tests
 625 and measurements (such as intraocular pressure, visual acuity and pupil reflexes) made by
 626 technicians are read by the doctor, because the process does not.
 627 The medical profession does not seem to have a strong culture of using feedback from the
 628 patients and other physicians. Often they do not checkup on their own work.

629 Miscellaneous

630 Be sure to shake eye drops before use, because some are suspensions, not solutions or
 631 emulsions. In suspensions, the solids will eventually fall to the bottom. Try to use
 632 preservative free eye drops.
 633 Professors in medical schools are probably more experienced in dealing with rare cases.
 634 When I realized that my case was rare and I found an ophthalmologist at UCLA medical
 635 school that solved my major problem, maybe I should have stayed with him, even though it
 636 would have meant frequent trips between Los Angeles and Tucson.
 637 Finally, do not accept an appointment for surgery right before the surgeon is scheduled for
 638 vacation! The surgeon may be distracted and you will miss out on follow-up care.
 639

640 4. Conclusion

641 Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the
 642 patient and the physician: in this case there were many causes of the pain, which caused
 643 confusion. There was no face-to-face communication between the dozen doctors that were
 644 involved in this case: furthermore, many times the written communications were not
 645 received, read or understood. In complicated procedures involving many physicians and
 646 many physical systems, there should be a patient’s advocate, who knows the system and is
 647 interested only in the patients’ best interests. I found the best metric for choosing a doctor
 648 was the amount of time that he or she scheduled for each appointment or operation. For the
 649 last six years this subject complained about ten specific symptoms, which were treated
 650 individually: treating this case as a system of interacting problems led to a better
 651 understanding and resolution.
 652

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661 Consent

662 The patient has given his informed consent for this report to be published.

663

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685

686 APPENDIX

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