

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16

A Patient's Viewpoint of Cataract and Detached Retina Surgeries

A. Terry Bahill^{a*} PhD, Patrick J. Barry^b OD

^aSystems Engineering
University of Arizona
1622 W. Montenegro
Tucson AZ USA 85704-1822

^bEnvision Eye Care Center
Tucson Arizona, USA
envisioneyecarecenter@gmail.com

ABSTRACT

Aims: The purpose of this paper is to (1) describe the changing details of a complex medical case study allowing the reader to continually diagnose complications resulting from cataract and retinal detachment surgeries, (2) explain good and bad aspects of communications between patients, optometrists, ophthalmologists and systems engineers and (3) show a patient's view of a detaching retina.

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 retinal detachments. It was excerpted from the patient's notes (including test results, charts and images), surgical reports, letters to the doctors and their referral reports. This paper was written in the first person singular and in chronological order. This should help 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 malposition of an intraocular lens, ignoring patient's complaints of pain, 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 potential 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: Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and the physician: in this case, there were many causes of the pain, which caused confusion. For the last six years, this patient complained about ten specific symptoms, which were treated individually: treating this case as a system of interacting problems led to a better understanding and resolution.

Keywords: cataract surgery; scleral buckle, communication; complications; retinal detachment; detaching retina; ocular pain; quality of life; retina surgery; lessons learned;

* Tel.: (520) 742-5469; E-mail address: terry@sie.arizona.edu

19 **ACRONYMS**

20	<i>ILM</i>	<i>Inner Limiting Membrane</i>
21	<i>IOL</i>	<i>Intraocular Lens</i>
22	<i>MRI</i>	<i>Magnetic Resonance Imaging</i>
23	<i>OCT</i>	<i>Optical Coherence Tomography</i>
24	<i>OS</i>	<i>Left eye</i>
25	<i>OD</i>	<i>Right eye</i>
26	<i>RD</i>	<i>Retinal Detachment</i>
27	<i>RPE</i>	<i>Retinal Pigment Epithelium</i>
28		

29 **1. INTRODUCTION**

30 **1.1 Who Should Read This Paper And Why Should They Read It?**

31 **1.1.1 Ophthalmologists**

32 Ophthalmologists can read this paper and diagnose the patient's medical problems. The
33 patient's symptoms and the interactions of people have been laid out in chronological order.
34 These are the facts that were thought to be true at the time, but some of them might prove to
35 be wrong in the end. The appendix provides useful but possibly irrelevant statistics that he or
36 she might want to consider. Hopefully, the ophthalmologist can learn a little about the
37 patient's viewpoint of ocular surgeries. The ophthalmologist could learn about the types of
38 pain that can result from ocular surgeries. Then he or she could write brochures that
39 describe potential postoperative pain and explain treatments that could be used to resolve
40 those pains. Finally, the ophthalmologist can decide what he/she would have done differently
41 than these ophthalmologists did.

42 **1.1.2 Optometrists**

43 Optometrists can expand their horizons and find their place in ocular surgeries. In 1977,
44 Larry Stark et al. [1] described many nontraditional optometry tasks that professionals were
45 performing in his Neuro-optometry Clinic at Berkeley (UC) and San Francisco (UCSF). This
46 paper suggests another nontraditional task: assisting patients with detaching retinas.
47 Detached retinas seem to be in the purview of ophthalmologists. However, this paper
48 explains ways that an optometrist was involved in (1) diagnosing a detaching retina, (2)
49 tracking the specialties and equipment of local ophthalmologists, (3) acting as a primary
50 visual care provider, (4) understanding and explaining to the patient what lies in store for him
51 during and after the surgery, (5) diagnosing and perhaps solving postoperative complications
52 {such as (a) postoperative diplopia, which (in this case) was ameliorated with prism
53 spectacles, (b) the iris being trapped by the intraocular lens, which was solved by a lens
54 replacement, (c) inflammation, in this case due to the suture securing the scleral buckle and
55 (d) helping with pain diagnosis and remediation,} and (6) explaining the relationships
56 between fundus photos, visual field diagrams and ocular coherence tomography images.
57 The American Optometric Association also has an extensive set of recommendations for
58 optometrists dealing with retinal detachments [2].

59 **1.1.3 Students of Ophthalmology and Optometry**

60 Students of Ophthalmology and Optometry can augment their diagnostic skills by practicing
61 on this real-life case study. In addition, they can learn about a topic that does not get much
62 attention in the curriculum, namely pain.

63 1.1.4 Patient Advocates

64 Intelligent laymen, patient advocates and patient advisors can learn about complications and
65 interactions between cataract and retinal detachment surgeries, such as the following. Pain
66 is hard to diagnose, measure, quantify and treat, making it frustrating for both the patient and
67 the physician: in this case, there were many causes of the pain, which caused confusion.
68 There was no face-to-face communication between the dozen doctors that were involved in
69 this case: furthermore, many times the written communications were not received, read or
70 understood. In complicated procedures involving many physicians and many physical
71 systems, perhaps there should be a patient's advocate, who knows the system and is
72 interested only in the patients' best interests. A useful metric for choosing a doctor is the
73 amount of time that he or she schedules for each appointment or operation. A better
74 understanding and resolution for a medical problem may be treating the symptoms, the
75 doctors, the patients and the procedures as a whole system instead of a group of specific
76 entities to be treated individually.

77 1.1.5 Families and friends

78 Families and friends of patients who have or will undergo ocular surgeries can understand
79 what the patient is experiencing and what signs and symptoms should be reported to the
80 ophthalmologist. When a new clue surfaces, this group has to answer difficult questions
81 such as, Should we call the doctor? Should we call the doctor? Should we go to the
82 emergency room? Should we take more narcotic pain pills? Reading this paper should help
83 with these decisions.

84 2. HISTORY/METHODS/RESULTS

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

91 This section was written by ATB about his eye surgeries. Other patients will have different
92 numbers and details, but the overall processes should be about the same. This section is
93 written from the patient's point of view of the interactions between the patient, the
94 optometrist and the ophthalmologists during eye surgeries for cataracts and retinal
95 detachment. Therefore, this section is written in the first person singular. It was excerpted
96 from my notes, surgical reports, my letters to the doctors and their referral reports. Nothing
97 was retrospectively edited. So it is possible that at one time I wrote something in my journal
98 that was different from something that I had written at another time: I did not edit out these
99 contradictions. Oscillations in my health and mood may be apparent. This case is
100 multifaceted with many complications. The ten ophthalmologists are identified as
101 "Ophthalmologist-1" to "Ophthalmologist-10."

102 May 24, 2007, First Cataract Operation

103 It all started on a beautiful May morning in Tucson. Ophthalmologist-1, (assisted by his wife
104 (the anesthesiologist) and a surgical nurse) performed a cataract extraction and lens implant
105 on my left eye. It was a quiet relaxed atmosphere where they were describing to the nurse
106 their upcoming vacation to Italy. Ophthalmologist-1 was doing hydrodissection in the
107 membrane capsule, when he suddenly said, "Whoops. What was that?" He wrote in his
108 surgical report, "the posterior capsule had torn as a result of the hydrodissection... It was
109 elected to insert an [available] MA60AC lens rather than the [selected] one-piece acrylic
110 lens." Kenalog was not used to assist the partial anterior vitrectomy. That evening, the next
111 morning and the next afternoon, I told his staff that I was in pain.

112 May 25, 2007, Follow-up Exam

113 The next morning I told Ophthalmologist-1 that the eye hurt and that I was seeing many
114 floaters. As he was examining the operated eye, he said that in order to compensate for the
115 ruptured posterior capsule, he removed some of the vitreous (which pulled on the retina),
116 placed the lens (a square edged, 3-piece posterior chamber intraocular lens (IOL), Alcon
117 model MA60AC) more anterior than planned (in the ciliary sulcus), and put a suture in the
118 cornea. Later he said that rupture of the posterior membrane capsule was a rare event,
119 happening to only one of his other patients 17 years ago. See the appendix for statistics
120 from the literature.

121 May 26, 2007, Pain in the Eye

122 My left eye hurt. It was tearing and bloodshot. Ophthalmologist-1 was on vacation in Italy. I
123 called a friend, Ophthalmologist-2, and told him that my eye hurt and I could not contact
124 Ophthalmologist-1 or his backup. He said that pain after a cataract operation most certainly
125 means infection. He advised me to go to the emergency room. Ophthalmologist-3 (who by
126 coincidence was the backup in Ophthalmologist-1's practice and also the ER
127 ophthalmologist on duty) gave me a prescription for Vicodin (hydrocodone). It did not relieve
128 the pain. I saw him another four times in the next two weeks. With his slit lamp, he never
129 saw inflammation within the eye (endophthalmitis): so he said that he did not know why there
130 was severe pain. For the next four years at every medical exam with my ten
131 ophthalmologists, I complained about pain in the front of the eye. Table 1 shows that nothing
132 relived this pain.

133 **Table 1. Since 2008, at various times, ATB has taken the following anti-pain drugs.**
134 **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®	

135 May 8, 2008, One Year Later

136 I saw a static, 100-degree diameter¹, ¾ ring (two degrees thick) of bluish light for maybe a
137 half minute in left eye with the eye open. It looked like Figure 1 (top-left). The dark green (or
138 gray) disk represents the subject's field of view. That event was probably caused by the
139 vitreous (the jelly in the eyeball) detaching from the retina. Please note that this is the visual
140 experience of one subject. The literature more often describes the detaching vitreous with
141 spider webs and lightning bolts.

142 Note added in 2013: Both moving the lens forward and removing some of the vitreous gel
143 would move the vitreous forward, and pull on the retina. This sequence can lead to a retinal
144 tear and a detachment, especially during the first year after surgery. "if the cataract surgery
145 is complicated with a capsular rupture, the risk increase for RD [retinal detachment] is ten-
146 folded." It is a shame that I did not know that in 2007.

147 May 12, 2008, First Detached Retina Operation

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, the clinical fovea (one degree in diameter) is the width of the fingernail on the little finger at arm's length and a fist is a little less than ten degrees wide. For comparison, the sun and the moon are ½ degree in diameter.

148 The optometrist saw a half-dozen retinal tears (like tears in a fabric, not like tears when a
149 person is crying) and referred me to a retina specialist, Ophthalmologist-4. He told me that
150 the operation had a 92% chance of success and if it did fail, there was a second operation
151 that he could do that had a 50% chance for success. For more statistics like these, the
152 reader should go to the appendix. He scheduled an operation for that evening. During that
153 operation, he put a scleral buckle around the eyeball, removed the vitreous humor
154 (vitrectomy), repaired the retinal tears with freezing (cryopexy) and with an endolaser, and
155 inserted a bubble of perfluoropropane (C_3F_8) gas (also called octafluoropropane), a
156 procedure known as pneumatic retinoplexy. My double vision (diplopia) started after this
157 surgery. The next day, and on other visits, I complained about inflammation, a blood shot
158 eye, foreign body sensation (like an eyelash trapped under the eyelid), pain in the front of
159 the eye and now pain behind the eye.

160 Explanations of Technical Terms

161 I had a rhegmatogenous (rhegma = rent or rupture) retinal detachment, which means tears
162 (like tears in a fabric, not like tears when a person is crying) in my retina allowed fluid to leak
163 underneath the retina, thus detaching it from the choroid (the vascular layer of the eye lying
164 between the retina and the sclera). The tears were probably caused by the detaching
165 vitreous (the jelly in the eyeball). Ophthalmologist-4 decided to simultaneously use all
166 common retinal repair techniques: scleral buckling, vitrectomy, laser photocoagulation and
167 pneumatic retinoplexy. Simplistically, a scleral buckle is a band of silicone that is sutured
168 around the eyeball under the extra ocular muscles. It buckles the eyeball pushing certain
169 regions closer to the retina. In vitrectomy, the jelly-like vitreous humor is removed. Pars
170 plana vitrectomy describes a particular pathway (through the pars plana) that the surgeon
171 uses to remove the vitreous. In pneumatic retinoplexy the surgeon, inserts a bubble of about
172 15% perfluoropropane (C_3F_8) gas (the other 85% is just air) into the vitreous chamber of the
173 eye (the big part of the eye between the lens in front and the retina in back). This bubble
174 prevents fluid in the eye from passing through the tear and under the retina. This allows the
175 choroid to pump the fluid out of the subretinal space allowing the retina to reattach to the
176 choroid. You cannot fly in an airplane (or do anything else that will rapidly change the
177 pressure around you) with a gas bubble in your eye.

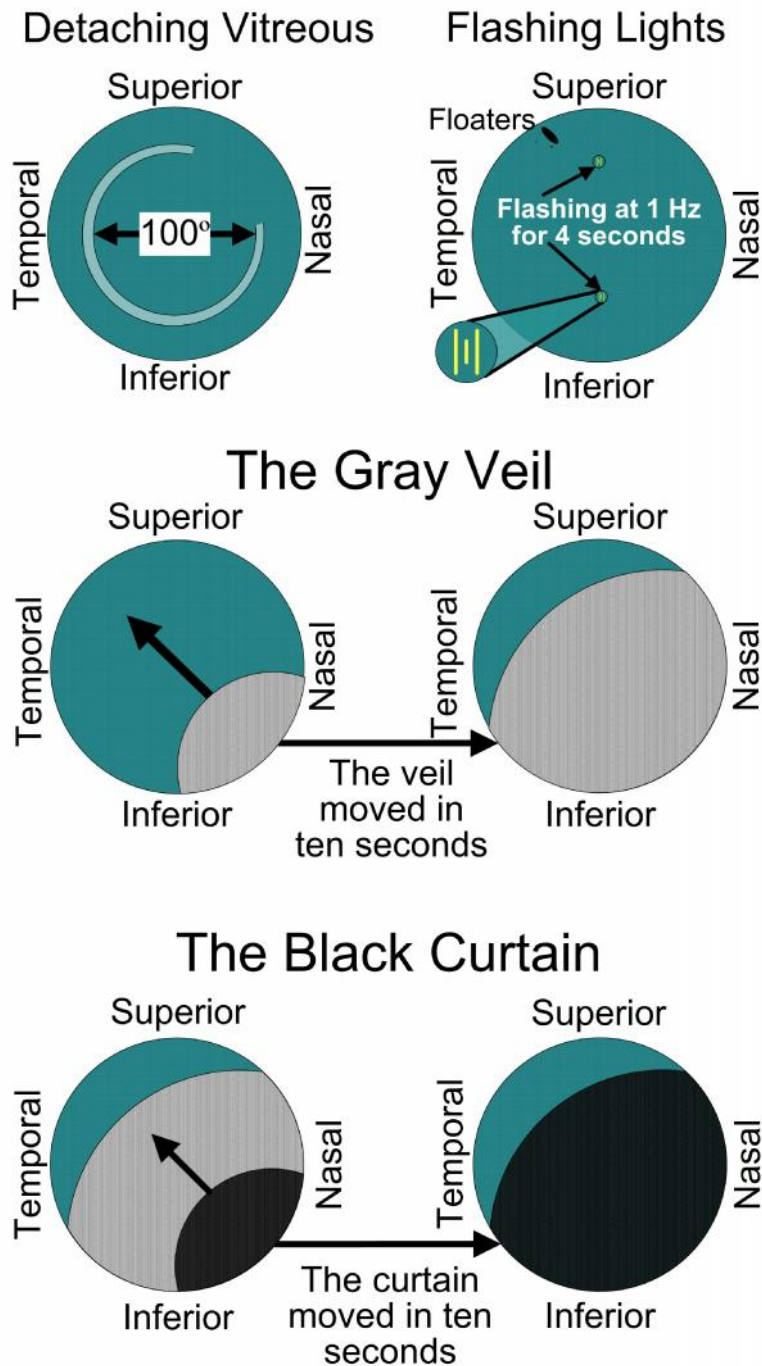
178 Typically, an ophthalmic laser for retina photocoagulation uses a diode-pumped solid-state
179 green argon laser with a wavelength of 532 nm (a yellow 586 nm laser is another possibility),
180 a power of 50 to 2000 mW, a pulse duration of 0.01 to 4.0 seconds with a 635 nm red laser
181 aiming beam. The visual field comprises the images that the subject can see with the eye
182 looking straight-ahead (primary position): typically, this is 90° temporal, 60° nasal, 60° up
183 and 75° down.

184 Concerning cataract operations, the human crystalline lens is enclosed in a capsule. This is
185 sometimes referred to as the membrane capsule, a capsular bag, or a lens *capsule*. The
186 front and backsides are referred to respectively as the anterior capsule and the posterior
187 capsule.

188 Throughout May and June, my vision was improving. However, I was surprised by the tropia:
189 when at rest, my left-eye images were about ten degrees up and ten degrees to the left of
190 the right-eye images and I could not fuse the right and left eye images. Ophthalmologist-4
191 did not prepare me for this.

192 June 29, 2008, Gas Bubble Disappears

193 Ophthalmologist-4 had told my wife and me to be patient for six weeks, or until the gas
194 bubble disappeared, then we would be out of the woods for further complications. Therefore,
195 on this Sunday, we were in high spirits, because this was six weeks after the operation and
196 the gas bubble was finally completely absorbed.



198

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

204 At 10:00 AM, Ophthalmologist-4 saw a small hole in the retina, as well as a scab on the
205 retina. He scheduled an operation for 3 PM the next day. Four hours later, I saw vertical
206 yellow lines about two degrees long and one degree apart: three on top of my field of view
207 and three on the bottom. See Figure 1 (top-right). They flashed at one hertz for about ten
208 seconds. Later I saw big black floaters². Then a convex gray veil (with a radius of curvature
209 of around 40°) moved from the lower-right to the upper-left across my field of vision as
210 shown in Figure 1 (middle row): this took around ten seconds. Then, a few minutes later, a
211 convex black curtain moved across my retina and eclipsed 80% of my field of vision, Figure
212 1 (bottom row). I called Ophthalmologist-4, told him my symptoms and he confirmed that the
213 macula of my retina had detached and we would do the operation the next day, as
214 scheduled. I was not a happy puppy: since the retinal detachment operation, they would not
215 let me drink beer, work on the computer for more than 15 minutes at a time, or go out of the
216 house for more than an hour a day. I had to lie on my side for most of the day. My primary
217 care physician had prescribed Sertraline for my depression.

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

223 July 1, 2008, Second Detached Retina Operation

224 Ophthalmologist-4 pushed the macula back into place, zapped the retina with his laser and
225 inserted another gas bubble. A gas bubble occludes the retinal tear, permitting the choroid to
226 remove subretinal fluid, and then the bubble presses the retina against the choroid,
227 sheltering the edge of the tear until a choroid-retinal scar is formed, sealing the break. A
228 bubble of perfluoropropane (C₃F₈) gas will gradually be absorbed into the blood stream and
229 will be replaced by aqueous fluid, which is continually produced by the ciliary body. This
230 process will take six to eight weeks, depending on how big the bubble is and a bunch of
231 other things. The first objects that I saw as the gas was absorbed were stars in the sky as
232 shown in Figure 2. Obviously, I was outdoors looking straight ahead.

233

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.

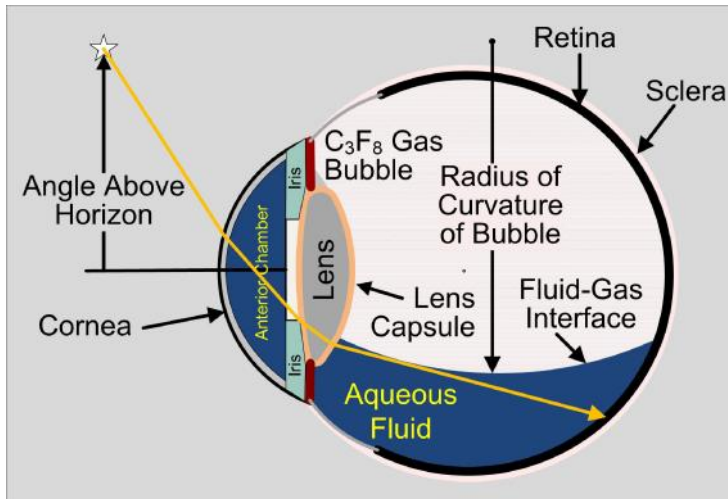
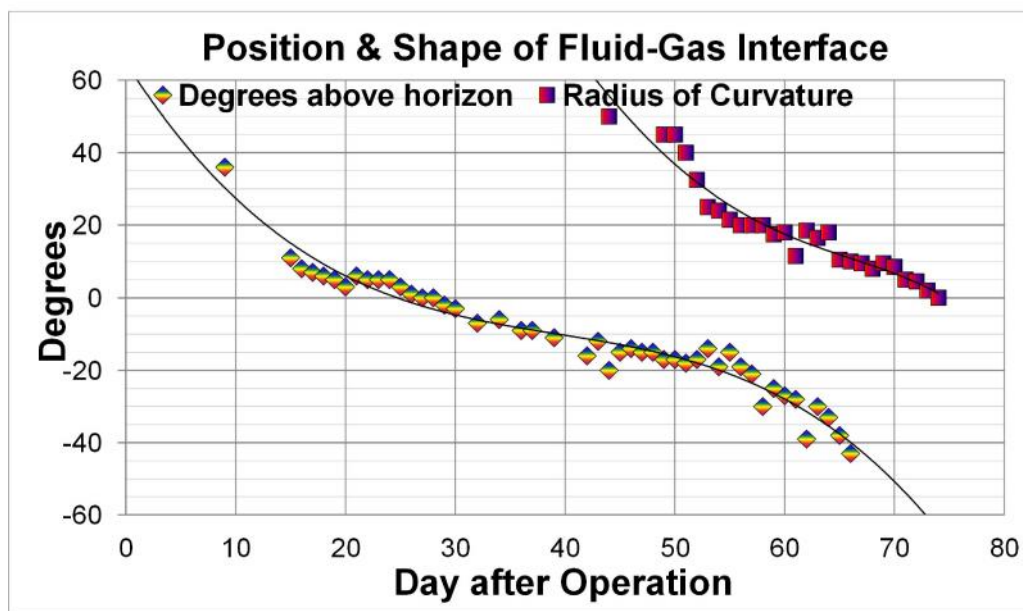
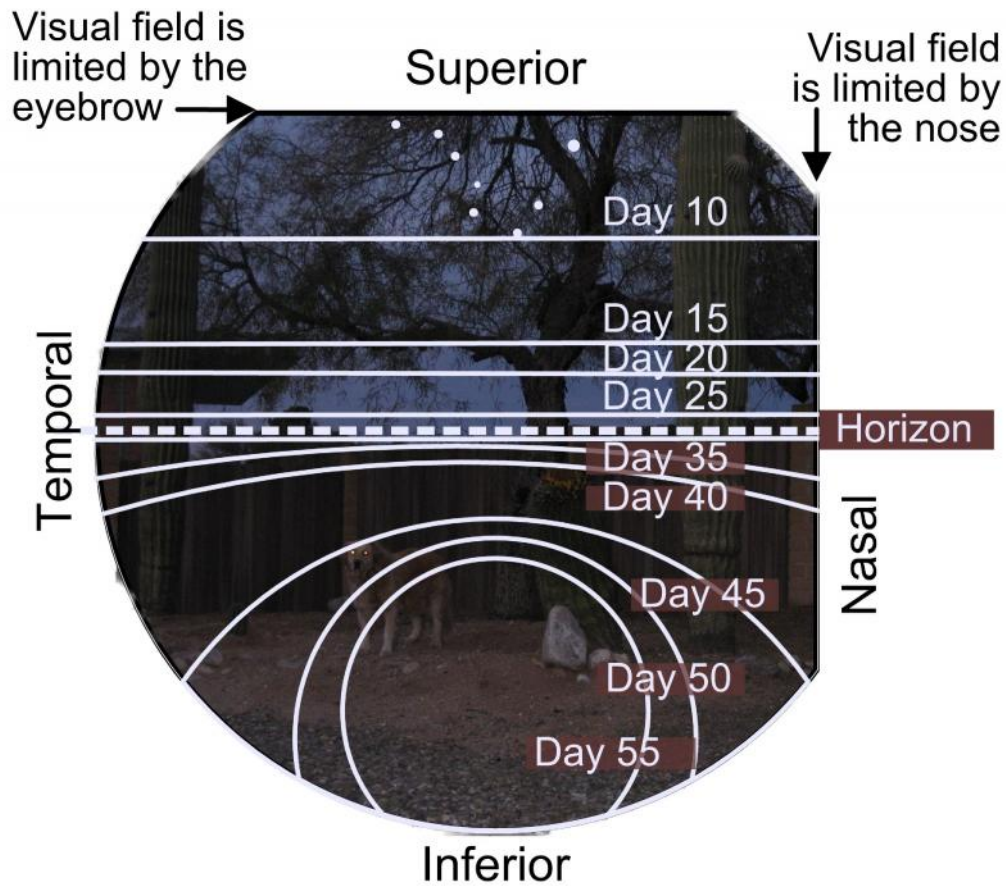


Fig. 2. Schematic drawing of the eye showing the path of the first light that the patient saw after the retinal detachment operations that used perfluoropropane gas.

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 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.



243

244

245

Fig. 3. The patient's viewpoint of the time sequence of the gas bubble being absorbed and replaced with aqueous fluid. The two curves are just two views of the same event.

246 Figure 3, which is unique, shows my viewpoint of the time sequence of the gas bubble being
247 absorbed and replaced with aqueous fluid. I could only see what was above the white line for
248 that day. For, example, on day ten I could only see the stars. The surface of the bubble
249 looked like a straight line about 25 degrees above the horizon. When the fluid-gas interface
250 dropped below the horizon, it stopped being a straight line and seemed to have curvature,
251 eventually turning into a circle. For example on day 55 it looked like a circle with a radius of
252 curvature of 25 degrees, whose top was 20 degrees below the horizon. The bottom of Figure
253 3 shows quantitative data from my viewpoint of the temporal disappearance of the C_3F_8
254 bubble. It seemed to disappear from the top down starting about the 10th day after the
255 operation. On the 60th day, the bubble broke up into one big bubble and many little ones: the
256 numbers in this figure are for the big bubble.

257 In the first few days after the operation, the bubble always increases in size, but I could not
258 detect this. I could only see white with shadows and bright objects like windows. Around day
259 10, I was surprised to see the bottom of the gas bubble. It was in my upper field of view
260 (remember that the lens inverts the image before it is focused on the retina). In Figure 3, this
261 gas-fluid interface looked horizontal, so I measured how far it was above the horizon. I saw
262 many very strange reflections off this gas-fluid interface. Later at about day 40 the bubble
263 started to look more like a circle and less like a line. So I started measuring the radius of
264 curvature of the bubble. The ophthalmological literature emphasizes the *volume* of the
265 bubble [3], which may be scientifically more relevant. But as the patient, I did not care about
266 the volume. I only cared about what was happening in my visual field. Figure 3 is for one
267 patient only, with C_3F_8 gas only and in only one operation, although after the other two RD
268 operations the bubble behaved the same way.

269 August 3, 2008

270 Since the implant of the scleral buckle, my eyes were misaligned (strabismus and diplopia)
271 by as much as twenty degrees. On this date I was finally able to align the left and right eye
272 images, albeit with difficulty and not for long.

273 September 11, 2008, Distorted Vision

274 The gas bubble from the second retinal detachment operation was gone after 10 weeks. The
275 left eye retinal image had become wrinkled, because of the macula-off detachment. The
276 width of the image of the left eye was around $\frac{3}{4}$ the size of the right eye. See Figure 4. With
277 the left eye, everyone looked like a pinhead, or a person in an El Greco painting. There was
278 some improvement in that the misalignment (tropia) of the left eye had become smaller and I
279 was able to roughly align the two eyes.

280 The ophthalmologists' have no instruments that could produce a figure showing as much
281 detail as in figure 4. Their closest tool would be an Amsler grid.

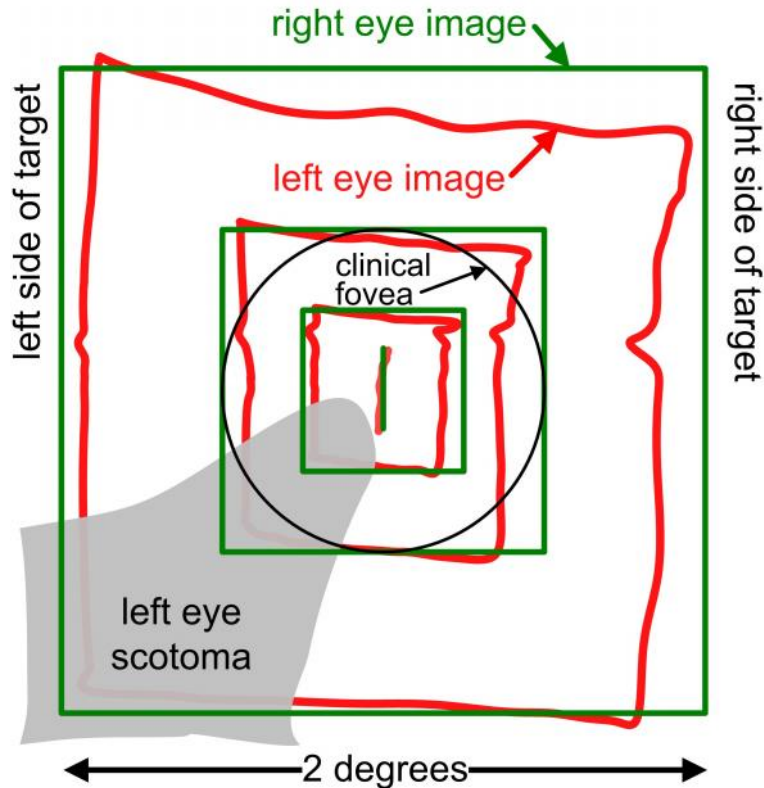


Fig. 4. The patient's viewpoint of binocular viewing of a small target. The right eye's image (green) is the same as the visual target. The left eye's image (red) shows the distortion due to a wrinkled retina or macular pucker. (However, the left eye scotoma did not appear for another year, around October 20, 2009.)

September 12, 2008, Third Bubble

During a routine office visit, Ophthalmologist-4 found a new tear in my retina. He repaired it with 60 pulses of a head mounted laser. He inserted a cryopexy probe on top of the eyeball near the scleral buckle to freeze (cryopexy) the area of the retina above the tear. He removed some fluid from the eyeball and inserted a new bubble of C_3F_8 . But he was doing these procedures while he was seeing other regularly scheduled patients in his office. So he finally gave up and asked me to come back the next day.

September 13, 2008, Many Laser Pulses

Saturday morning we returned at 8 AM. Ophthalmologist-4 administered 567 laser pulses. He said, "I know you want to ask, why? The answer is bad luck." Over the next few months, there were varying degrees of vertical, horizontal and cyclorotational disparities between the two eyes due to the misdirection (phoria) of the left eye. The pain on the back of eye and the double vision (diplopia) started with the first surgery on May 12, 2008. But the phoria might have been exacerbated by the cryopexy freezing on September 12, 2008. At this time, with the left eye, everyone looked like Don Quixote, tall and skinny.

At this time, my symptoms were (1) inflammation and pain in the front of the left eye, (2) pain behind the left eye, (3) pain in the brain, (4) double vision, (5) lack of depth perception, (6) poor visual acuity in the left eye due to a wrinkled retina, and (7) poor vision in the *right* eye due to a cataract. Intraocular pressures were always normal.

October 29, 2008, Macular Edema was Noticed

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

309 March 9, 2009, Attempts to Eliminate Edema

310 The image of the left eye was about $\frac{3}{4}$ the size of the image of the right eye and the left
311 eye's image was wrinkled. Ophthalmologist-4 had been recommending use of cortical
312 steroids (drops and injections) for five months trying to flatten the macula. There was fluid
313 behind the retina. At various times he called it inflammation, swelling, fluid, a cyst and
314 cystoid macular edema: for the rest of this paper I will refer to this as macular edema.
315 Ophthalmologist-4 noted that the inner limiting membrane (ILM) was not thickened. He
316 injected corticosteroids (Kenalog®) directly into my eyeball. I probably had a reaction to the
317 carrier or the preservative (benzyl alcohol), because the Kenalog turned into white crystals
318 and I was blind in that eye for a week. The intraocular pressure increased to 30 mm Hg.
319 Thirty-six eye drops per day of three different types (spaced at least ten minutes apart)
320 brought everything back to "normal."

321 June 1, 2009, The Right Eye

322 A small inconvenience was caused by the cataract in my right eye. I had intended to have it
323 removed soon after the cataract in the left eye. But when the left retina started falling off, the
324 doctors suggested that nothing be done to the right eye until the left eye stabilized. For about
325 a year, I did not drive my car. Ophthalmologist-5 removed the cataract in the *right* eye and
326 replaced it with a 13 diopter artificial IOL. Although the right eye was *his* eye, he spent a
327 good deal of time examining and tracking the progress of the left eye.

328 July 10, 2009, Additional Intra-ocular injection

329 Ophthalmologist-4 injected *preservative-free* triamcinolone acetonide (generic Kenalog) into
330 the left eyeball. It did not react adversely and it did help with the fluid behind the retina.

331 September 4, 2009, Summary of Symptoms

332 The left eye's image was smaller than the right eye's image, it was wrinkled, it was about
333 eight degrees up, four degrees to the right and was rotated about three degrees clockwise. I
334 had a (possible) aniseikonia headache. I had no depth perception for near objects: therefore,
335 threading a needle, tying a hook on a fishing line or pounding in a nail was difficult, or near
336 impossible.

337 For about six months, I wore a black patch over my left eye when reading or working on the
338 computer and I wore the black patch on my right eye when I was teaching, riding in a car or
339 watching television. This reduced the pain in the brain. However, Ophthalmologist-4 asked
340 me to stop doing that, because he was afraid the brain would shut down the left eye if I
341 stopped using it.

342 October 16, 2009, Planning the Seventh Retinal Surgery

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

346 October 20, 2009, Peeling the ILM

347 Ophthalmologist-4 peeled the inner limiting membrane (ILM) over the macula. The inner
348 limiting membrane is a diffusion barrier between the vitreous and the ganglion cells of the
349 retina. It is about two microns thick. He removed an area about one mm in diameter. He did
350 this manually, quite a feat! Then he injected Kenalog into the eyeball (fresh hospital Kenalog
351 is preservative free). Note added in 2013: The purpose of peeling the ILM was to reduce the
352 edema, not to improve visual acuity [4], because visual acuity seldom improves after a
353 macula-off detachment. Peeling of the ILM is used to repair macular holes. However, it has

side effects. Tadayoni et al., [5] wrote "ILM peeling may reduce retinal sensitivity, and significantly increase the incidence of microscotomas.... We found that mean retinal sensitivity was significantly lower ... in eyes that underwent peeling than in those that did not. Postoperative microscotomas were also significantly more frequent in eyes that had undergone peeling..." The scotoma that resulted from peeling my ILM is shown in Figure 4.

October 21, 2009, Follow-up Exam

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

November 2, 2009, No Progress

I told Ophthalmologist-4 that peripheral vision in the left eye was good: but the left eye's image was still smaller than the right eye's image. Since the operation, the left eye's image had a two-degree diameter gray-brown cloud over the fovea. He looked and said that it was a hemorrhage and that was not unusual: it will probably go away.

For the last year and a half I have reported to Ophthalmologist-4 that I have had the following symptoms: (1) pain in the front of the left eye, (2) pain behind the left eye, (3) pain in my brain, (4) double vision (diplopia) due to left eye phoria, (5) lack of depth perception (no stereopsis), and (6) poor visual acuity in the left eye due to a wrinkled retina and, since peeling the ILM, a scotoma (an area in the field of vision where the subject sees nothing) in the inferior temporal macula as shown in Figure 4.

June 23, 2010

I visited Ophthalmologist-4. Vision in the left eye has been about 20/60 to 20/70 for the last half year. I could obtain this only by scanning across the letters and recognizing them with peripheral vision. There was tremendous variability in this measure. Peeling the inner limiting membrane (ILM) over the macula has made the vision worse. Ophthalmologist-4 wrote, "Andrew's main problem now is buckle associated discomfort. I am going to put him on a trial of high dose Motrin [sixteen 200 mg pills per day] and consider biofeedback therapy prior to the removal of the scleral buckle." At this time, we lost confidence in Ophthalmologist-4 and switched to Ophthalmologist-6.

July 27, 2010, New Ophthalmologist

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

At this point my symptoms (and possible known causes) were (1) pain in the front of the left eye and light sensitivity (perhaps caused by the haptics of the artificial lens interfering with the iris), (2) inflammation and intermittent pain behind the left eye (perhaps caused by the scleral buckle or damage to the superior rectus and superior oblique muscles), (3) pain in the brain, [Surely, this had many causes. It could be a continual retinally induced aniseikonia headache (asthenopia). The MRI's did not reveal a cause. A neurologist found no reason for them. They are not migraine or cluster headaches.] (4) left eye phoria [When looking straight ahead, the left eye's image was rotated about three degrees right, two degrees up and five degrees clockwise. (This may have been caused by the scleral buckle, damage to superior oblique muscle or interference with the inferior rectus muscle.)], (5) diplopia and lack of stereopsis (caused by the phoria and the wrinkled retina) and (6) poor visual acuity (caused by a wrinkled retina and a scotoma in the inferior temporal macula).

At this time, Optical Coherence Tomography (OCT) images were the cat's meow of ophthalmology. The OCT instrument scans the retina with a laser beam. It stores this

402 information in a computer as a three dimensional model of the eye. The OCT images of my
403 eye showed fluid under the retina, so the doctors tried to get rid of that fluid. That fluid
404 caused an elevated thickness at two places in the retina. They were about five degrees left
405 and right of the fovea. Visual field analysis does not have the resolution to show such
406 defects. In fact, when I looked for evidence of such defects I could not find any. So the OCT
407 images showed a new type of pathology and my ophthalmological treatments over the last
408 two years were directed to reduce these fluids and those potential defects.

409 At most of my eye exams since May 2007, before dilation, a technician would measure the
410 pupillary reflexes. The right eye was normal; the left eye was irregular and non-reactive
411 (tonic). I presumed that these test results were entered into my records and read by the
412 doctor: but no ophthalmologist ever commented on this anisocoria.

413 November 5, 2010, Letter to Ophthalmologist-6

414 Visual acuity in the left eye is about 20/70. However, viewing a Snellen chart is a primitive
415 indicator of vision. For example, it does not disclose the important additional information that
416 the brain has shut down vision of the left eye by about 1.5 log units. That is, if I want to see a
417 target equally with both eyes in the same illumination, then I must put a 1.5 log unit neutral
418 density filter in front of the right eye to equalize the perceptual disparity between the eyes. It
419 also fails to disclose retina wrinkles and scotomas as shown in Figure 4. It does not reveal
420 lack of stereopsis or color vision deficiencies. If I were given enough time and
421 encouragement, I would saccade across the letters of the Snellen chart and recognize the
422 proper letter with off-foveal vision.

423 December 3 and 8, 2010, MRIs

424 Magnetic Resonance Imaging (MRI) of the brain and left eye orbit showed no cause for the
425 pain in the brain. This pain seems to be localized in a cylinder two inches in diameter
426 stretching between the temples.

427 December 10, 2010, Diagnosis of Phoria

428 The optometrist measured the misalignment of the eyes. This was the first time that anyone
429 had measured it. He suggested that the pain in the back of the eye and the vertical,
430 horizontal and cyclorotational disparities between the two eyes were due to the scleral
431 buckle and the effects of the surgery on the superior rectus and perhaps the superior oblique
432 muscles. He prescribed new spectacles with horizontal and vertical prisms for both eyes.
433 These spectacles got rid of some of the pain in the back of the eye and attenuated the pain
434 in the brain. Since the first retina operation, when looking straight ahead (eyes in primary
435 position), my left-eye image 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
436 optometrist recommended spectacles with horizontal prisms of 1 Δ base-in for both eyes,
437 and 2 Δ base-down for the OD and 2 Δ base-up for the OS. Although it is only the left eye
438 that is misaligned, half of the needed prism correction is put into each spectacle lens. *Note*
439 *added in 2013*: alternative words that describe my eye position at rest are that the left eye
440 was abducted 5.7° , depressed 3.6° and excyclorotated 4.5° . One degree is roughly two prism
441 diopters, Δ .

442 December 29, 2010, Diagnosis of Tonic Pupil

443 The optometrist told me that the right eye pupillary response was normal, but the left pupil
444 was dilated, oblong shaped, with the pulling point at 11 o'clock, and was nonresponsive
445 (tonic). The optometrist wanted to run an experiment to see if the origin of the tonic pupil was
446 mechanical or neural. One possible neural cause of the tonic pupil was an injury (during the
447 surgeries) to the axons in the short ciliary nerve between the ciliary ganglion and the ciliary
448 muscles. So he called a retina specialist distantly involved with my case, Ophthalmologist-8.
449 Together they decided that pilocarpine (a pupil constrictor) might help and would not hurt.
450 The pilocarpine did not cause the pupil to constrict; therefore, the tonic pupil was due to

451 mechanical not neural restraints. The pilocarpine was then discontinued. This experiment led
452 us to think that perhaps the haptics were hooked into the iris. However, we did not have an
453 instrument that could image the haptics. Note added later: This situation led to the lens
454 replacement surgery of July 21, 2011.

455 January 24, 2011, Confirmation of Tonic Pupil

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

458 January 31, 2011, Summary of Symptoms

459 I gave the optometrist the following summary of my symptoms: (1) inflammation and pain in
460 the front of the eyeball. I described it as a scratchy, blood-shot irritation of the eyeball. This
461 pain was intermittent. It came on a half-dozen times a day and lasted 10 or 20 minutes. The
462 left eye was light sensitive. After walking the dog in the sun for a half-hour, the eyelid was
463 almost closed and the eye hurt. (2) Pain in the back of the eyeball: an intermittent localized
464 pain, sometimes sharp, sometimes dull. It felt like a foreign body was trapped in the orbit. I
465 attributed it to the scleral buckle or to inflammation around the buckle. This pain had been
466 there for two years. (3) Pain in the brain, a continual periphery-induced aniseikonia
467 headache (asthenopia). My brain hurt when I got up in the morning: it got worse as the day
468 went on. I had put a black patch on the left eye for close vision like reading on a computer
469 screen and on the right eye for distance vision like when watching TV or being outside. That
470 helped, but Ophthalmologist-4 and the Optometrist asked me to stop doing that, because
471 they were afraid that the brain would shut down that eye. So I put a small (one degree) dot in
472 the center of the left lens. This blocked the distorted left eye image and caused the left eye
473 to use peripheral not foveal vision. I had hoped that this would ameliorate the static
474 aniseikonia. The optometrist's prism spectacles did help with the pain. Roughly, the pain
475 seemed to be localized to a region between the temples. If I rubbed the temples hard, it
476 helped to alleviate the pain. This pain got worse five or ten times a day. These episodes
477 lasted a half hour. However, the MRIs found nothing and my neurologist found nothing
478 wrong. (4) If I bent over to pick up something from the floor, the left eye hurt. About once a
479 day, I would lose my balance and almost fall.

480 My notes state that Ophthalmologist-7 wrote in his report that all four of these pains were
481 consistent with the eight operations that were done on that eye. He also offered nothing to
482 relieve the pains.

483 Spring 2011, Finding a Specialist

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

489 May 6, 2011, First visit to Ophthalmologist-9

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

499 June 17, 2011, Preoperative Visit

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

502 July 21, 2011, Lens Exchange Operation

503 Ophthalmologist-9 noted significant posterior synechia superonasally, an eccentric pupil and
504 a chafe between the iris and the square edge of the IOL. He performed refractive cataract
505 surgery with peripheral corneal relaxing incisions. He removed the IOL in the left eye and
506 replaced it with a type of lens that was designed to be placed in the ciliary sulcus (Starr
507 Surgical AQ20110V). In two months the pain in the iris was gone, but the pupil was still
508 noncircular and nonresponsive (tonic).

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

518 January 25, 2012, Revisiting the Pain Behind the Eye

519 The optometrist noted inflammation of the sclera and of the anterior chamber. He prescribed
520 Bromday and Pred Forte. This prompted Ophthalmologist-6 to inspect the suture securing
521 the scleral buckle.

522 May 8, 2012, Ophthalmologist-6 is Optimistic

523 In his consultation report Ophthalmologist-6 wrote, "Bahill was in again with his remarkable
524 scientific knowledge and his scientific analysis of what is happening in his left eye. ...
525 Summary: The only treatable condition here is the macula edema."

526 June 4, 2012, Old Suture Removed

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

533 July 18, 2012, Fistula Sutured

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

537 November 6, 2012, Large Macular Edema

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

542 November 26, 2012, Treatment of Macular Edema

Ophthalmologist-6's OCT instrument replicated this macular edema with a thickness of 427 microns in the area centered five degrees temporal of the macula. He recommended reapplication of cortical steroids (Durezol) four times a day. Table 2 summarizes the eye drops that I have taken.

Table 2. 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		

December 27, 2012, Miraculous Cure

The macular edema had started in 2008. It was detected and measured with OCT scans. It was treated with corticosteroid eye drops Omnipred® and Pred Forte®, injections of Kenalog®, peeling of the inner limiting membrane (ILM) over the macula, and eye drops of Xibrom™, Bromday™, Acular® and finally Durezol® four times a day. By Christmas, in one of the most successful treatments (or coincidences) for my eye in four years, the swelling of the retina had nearly disappeared. The area of concern had thinned by 160 microns; it was now thinner than the right eye retina! Ophthalmologist-6 recommended continuing Durezol but only once a day. On March 9, 2013, a small amount of macular edema had returned. We increased Durezol to twice a day and by March 27, most of the macular edema had gone away. On July 11, the edema was almost completely gone. Unfortunately, this did not cure the visual acuity deficit.

December 29, 2012, More Mysteries

If there were only one object in my visual field and it was a small green dot of light, then it appeared green to my right eye and white to my left eye. This was repeatable in intraocular pressure tests (glaucoma air-puff test, Reichert AT555 non-contact tonometer). Several times, a white dot in a Humphrey visual fields test appeared green. Also, the left eye did not show negative color afterimages. I had mentioned these peculiarities for two years, but I did not have experiments to explain them, nor did anyone else.

March 27, 2013, Color Blindness

568 The fovea of the left eye is color vision deficient. When a small (0.07 degree diameter) green
569 dot of laser light was positioned on my fovea, it appeared green to the right eye and white to
570 the left eye. This was repeatable in intraocular pressure tests and with lasers in my
571 laboratory. These effects would be consistent with destruction of retinal ganglion cells [6]
572 while peeling the inner limiting membrane (ILM) of my left eye. It might also be consistent
573 with the brain shutting down vision in the left eye by one or two log units. The Ishihara test
574 for color blindness [7] indicated that I perceived two of the 22 test plates correctly, indicating
575 color blindness.
576 <http://www.colour-blindness.com/colour-blindness-tests/ishihara-colour-test-plates/>. On the
577 X-Rite color IQ test, a simplified on-line version of a Farnsworth-Munsell 100 Hue Test,
578 http://xritephoto.com/ph_toolframe.aspx?action=coloriq,
579 my right eye scored 16, which is low and therefore good. My left eye scored 182, which is
580 poor and in the 99th percentile. This is an unusual example of a color anomaly that is not
581 based a defective gene responsible for producing the green photo-pigment (deuteranopia). It
582 could be based on destruction of retinal ganglion cells.

583 October 17, 2013

584 My intraocular pressures (IOP) were 13 mm Hg, as they have been for the last year. With
585 the exception of the incidence with the preservative in Kenalog in March 2009, my IOPs
586 seldom went above 20 mm Hg.

587 3. DISCUSSION

588 Table 3. Summary of ATB's ocular status October 2013

Description	Determined to be	Primary treatment	Present condition 100% is best
OS = the left eye, OD = the right eye, IOL = the intraocular lens, ILM = inner limiting membrane			
Poor vision in the <i>right</i> eye (OD)	Cataract	Replaced natural lens with IOL	100%
Pain on front of OS and light sensitivity	The iris was stuck to the square edge of IOL or to the haptics, thereby immobilizing the iris	Replaced IOL	90%, the pupil is still tonic
Pain behind OS	Scleral buckle, its sutures and damage to or obstruction of the superior rectus and superior oblique muscles	Removed exposed suture & sutured conjunctiva fistula over the scleral buckle	80%, the muscles are still damaged
Poor visual acuity in OS macula	Wrinkled retina, macular edema	Durezol twice a day is keeping the macular edema down	70%
Different size and shape of eye images and one or two log difference in the luminance threshold of OS and OD	Macula-off detached retina, peeling the ILM, subretinal edema and disruption of retinal pigment epithelium	Corticosteroid anti-inflammatory eye drops	10%
At rest, OS image drifts up and to the right of OD image causing double vision.	Damage to or interference with the superior rectus and superior oblique extra ocular muscles	Prisms in spectacles	60%

Lack of depth perception for objects within ten feet (lack of stereopsis)	Different size and shape of eye images and misalignment of the left eye particularly cyclorotation	None	0%
Color deficiency in OS fovea	Peeling the ILM	Ishihara test for color blindness, and Farnsworth-Munsell 100 Hue Test	0%
Poor visual acuity in OS fovea	Macular scotoma due to peeling the ILM	Maybe a macular 10-2 threshold visual fields test could quantify it.	0%
General pain in OS	Inflammation of the sclera	OS is blood shot and it hurts for about 15 minutes a few times a day, a drop of Systane or Refresh helps	60%
Pain in the brain	Different images from the two eyes particularly due to cyclorotation	Headaches, five times a day, 30 minute duration	40%

589 3.1 Quality of Life

590 Because the images in my two eyes are of different sizes and shapes, it is difficult, error
591 prone and time consuming to read. My ability to read lips is diminished, so my hearing
592 impediment is exacerbated. The lack of stereopsis (depth perception for objects within 10
593 feet due to the difference in the images of the two eyes) makes it dangerous to climb stairs
594 or even walk on a sidewalk. I lose my balance daily, but fortunately, I have only fallen few
595 times, once I broke my fibula. This lack of depth perception makes it difficult to tighten a
596 small screw, zip up a jacket, pound in a nail, put a nut on a bolt or twist a wire around a
597 receptacle screw terminal.

598 The pain in my brain varies (on a scale of 0 to 10) from one to four. It spikes about a dozen
599 times a day and these episodes last about 15 minutes, but sometimes they last for hours.
600 This pain prevents me from working on a computer for extended periods. Sharp occurrences
601 of pain make it impossible to maintain a continuous long chain of thought. Therefore, writing
602 papers or proposals is difficult.

603 3.2 The Systems Thinking Approach

604 The next sentence should be read rapidly. For the last six years I have complained that my
605 left eye had pain, floaters, pain on front of the eye, light sensitivity, poor visual acuity,
606 inflammation, blood shotness, foreign body sensation (like an eyelash trapped under the
607 eyelid), pain behind the eye, no vision due to the C₃F₈ bubble, no vision due to the Kenalog
608 injection, strange visual effects due to absorption of C₃F₈ bubble, phoria or double vision,
609 headaches, pain on front of the eye, pain behind the eye, poor visual acuity in the macula,
610 poor visual acuity in the fovea, color deficiency in the fovea, general pain, different
611 luminance thresholds for the two eyes, different primary positions of the two eyes (the left
612 eye image drifted up and to the right causing double vision), lack of depth perception, lack of
613 stereopsis, pain in the brain, lack of explanation of expectations, ophthalmological
614 instruments used differently by different technicians, and physician overload.

615 I have abridged these complaints into the following symptoms (1) inflammation and pain on
616 the front of OS, (2) pain behind OS, (3) pain in the brain, (4) OS misalignment (phoria), (5)
617 double vision (diplopia), (6) lack of depth perception (no stereopsis), (7) poor visual acuity in

OS, (8) OS foveal color blindness, (9) OS light sensitivity and (10) OS non-circular and non-responsive pupil. This sounds like many disassociated symptoms. I am sure that the ophthalmologists felt overwhelmed as they treated one symptom at a time.

These ten symptoms seemed like ten different problems. This is like the story of seven blind men describing an elephant: each saw a different aspect. But now we can see the relationships between these problems. We can understand this medical history as a system, instead of ten isolated events. As shown in figure 5, it can be seen how treating one symptom affected other symptoms.

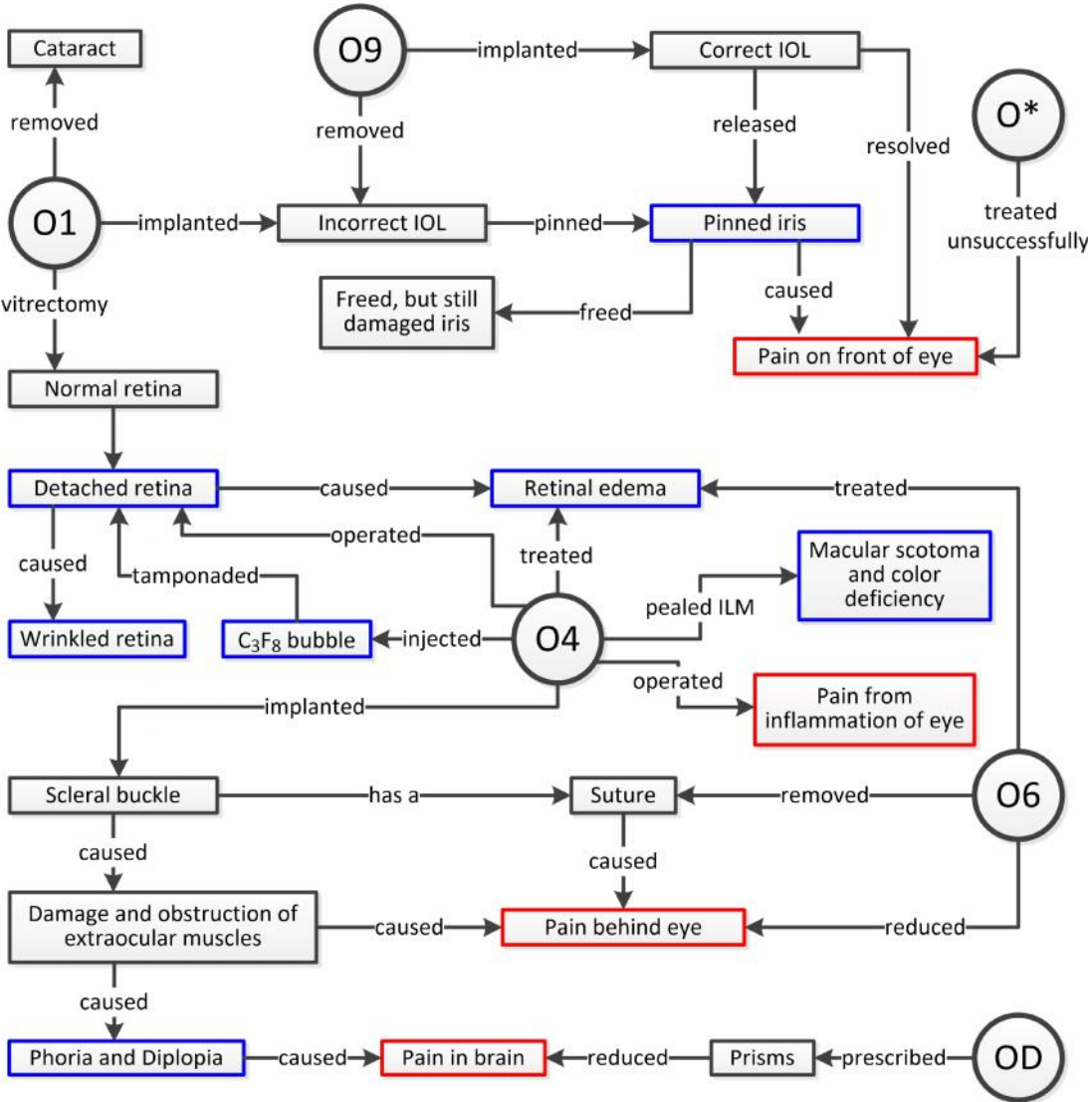


Fig. 5. Ocular history of ATB's left eye represented with objects and their relationships. O1 to O10 represent the ten Ophthalmologists, with O* meaning many. OD represents the Optometrist. IOL stands for intraocular lens. ILM means inner limiting membrane. Boxes with thick blue borders are states with reduced quality of vision. Boxes with thick red borders are states associated with pain.

For years, I 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

634 between the ophthalmologists and optometrists. If we had understood this *system* years ago,
635 my treatment surely would have been different.

636 **4. LESSONS LEARNED**

637 **4.1 Pain**

638 Medical doctors have difficulty successfully treating pain, even if it is in their realm of study
639 and experience. Pain is hard to diagnose, measure, quantify and treat. And most
640 importantly, pain is often an important clue as to what is wrong. If the cause is not visually
641 obvious (either to the naked eye, in photos, CAT scans or MRIs), then many times it is not
642 successfully treated. In this particular case, for the last six years most ophthalmologists
643 failed to resolve my complaints about pain.

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

657 Before each of my operations, the ophthalmologist discussed likely outcomes and some
658 risks of the operation. However, none of them mentioned the risk of potential postoperative
659 pain. We believe that the ophthalmologist should know about the types of pain that could
660 result from each type of ocular surgery. Perhaps they could describe in a brochure what the
661 pain could be like. They could tell the patient what to do if such pain occurs. And then they
662 could explain what they would do to alleviate the pain and correct the operation. However,
663 this would require uncompensated time.

664 **4.2 Communications**

665 From this case, we have learned a little bit about the medical profession. I was not simply
666 jumping around trying to find a doctor that could cure my problems. Instead, most of these
667 doctors were working together to help me. Certainly, they exchanged referral reports. One
668 pair talked on the telephone, and another pair talked in person about this case. Perhaps it
669 would have been better if there were more face-to-face communications, but that would have
670 required extra time, money and resources.

671 Most of their communications were implemented by FAX. Their referral reports varied in
672 quality: some were incomprehensible because the doctor used a canned report generation
673 program, some were superficial, some were merely boilerplate, but the reports of one doctor
674 were truly excellent. So we know what excellence is. It is important that the patient and the
675 doctors ensure that all relevant parties (including the patient, when appropriate) get copies of
676 the reports. In my experiences, most of the time this link failed.

677 Often referral reports were written by inclusion of standard common phrases. Sometimes
678 they started with partially filled out forms with default values checked. Two of my doctors
679 wrote in their reports that they had administered the Ishihara color blindness test, but they
680 actually had not. However, abandoning such forms and short cuts would cost time.

681 **4.3 Selecting a Doctor**

682 I have found that searching the Internet and asking friends for recommendations about good
683 ophthalmologists was not useful. People tend to make recommendations based on only a
684 few data points. Searching the Internet to find specific procedures that I wanted the doctors
685 to use was futile. My best results came from asking doctors that I trusted for referrals and
686 then trusting the judgments of these doctors [although this process was also fallible]. In the
687 future, I will ask what the ophthalmologist's patient load is. I will not recommend
688 ophthalmologists who schedule more than six patients per hour nor the cataract surgeons
689 who schedule more than four operations per hour. The average ophthalmologist can perform
690 a cataract surgery in less than ten minutes. However, scheduling patients at this rate would
691 not allow breaks or time to fix minor complications.

692 An anonymous reviewer of this paper wrote, "a retina surgeon seeing 6 patients per hour is
693 the norm and most in private practice see up to 10 per hour. That's the reality of being a
694 small businessman.... Likewise face-to-face communication for each patient is impossible
695 with physicians seeing 500+ patients per week and none in the same location."

696 In the last six years, I have had 12 eye operations and 150 doctor's visits. I estimate that, on
697 average, (a) the ophthalmologists scheduled a patient every 20 minutes with a standard
698 deviation (SD) of 10 and a range of 10 to 60, (b) on each visit, the ophthalmologists or their
699 staff spent 30 minutes with me with a SD of 15 and a range of 10 to 90, (c) Each operation
700 lasted 65 minutes with a SD of 15 and a range of 30 to 90.

701 **4.4 Invisible Gorilla**

702 When people focus on a task that demands their attention, they usually fail to notice
703 unexpected objects and events that occur in full view. This phenomenon is known as
704 *inattention blindness*, because people typically do not consciously perceive aspects of their
705 world that fall outside of the focus of their attention [8]. Medical doctors are just like the rest
706 of us: they suffer from *inattention blindness*; they only see what they expect to see.

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

711 On December 29, 2010, the optometrist broke the mold and gave me a through exam lasting
712 1.5 hours. He looked for unusual things. Finally, he told me that the right-eye pupillary
713 response was normal, but the left pupil was dilated, oblong-shaped with the pulling point at
714 11 o'clock, and was nonresponsive (tonic). This was the needed breakthrough. He had
715 looked at the iris, which no one else had done.

716 Ophthalmologist-1 was looking for evidence of the success of his surgery; therefore, he only
717 looked at visual acuity: he did not look at the iris. Ophthalmologist-3 was using his slit lamp
718 to look for inflammation; therefore, he did not look at the iris. Ophthalmologist-4 was trained
719 to look at the retina; so he did not look at the iris. Ophthalmologist-5 was trained to look at
720 the lens; so he did not look at the iris. Ophthalmologist-6 was trained to look at the retina; so
721 he did not look at the iris. Ophthalmologist-7 was a neuro-ophthalmologist trained to look for
722 neurological problems: he noted the tonic pupil, but said nothing about it.

723 At the beginning of each exam, a technician measured intraocular pressures, Snellen acuity
724 and pupillary reflexes. The ophthalmologists often commented about the pressures and the
725 acuity, but none mentioned the abnormal pupil.

726 It would be prohibitively expensive for each ophthalmologist to look at all measurements that
727 were taken, read all of the information presented by the patient, and examine all aspects of
728 the eye. They focus on their specialty and leave tangents for others to deal with.

729 **4.5 Process**

730 In complicated procedures involving many physicians and many physical systems, it can be
731 unclear who is in charge of the overall system. Some hospital rules force them to “work on
732 only one body part at a time.” In addition, there is usually no patient’s advocate, who knows
733 the system and is particularly interested in only the patients’ best interests. Perhaps both of
734 these roles are played by the patient or a member of the patient’s family.

735 For every visit, the patient should have a written letter listing symptoms and questions to ask
736 the doctor. It is the patient’s responsibility to make sure that the doctor reads the letter. Often
737 he/she does not. Also, I guess that it is the patient’s responsibility to make sure that tests
738 and measurements (such as intraocular pressure, visual acuity and pupil reflexes) made by
739 technicians are read by the doctor, because the process does not.

740 The medical profession does not seem to have a strong culture of using feedback from the
741 patients and other physicians. Often they do not even checkup on their own work. For
742 example, ophthalmologist-1 never looked for possible complications of cataract surgery such
743 as a trapped iris, cystoid macular edema, intraocular infection or signs of potential retinal
744 detachment. Ophthalmologist-4 did not look for possible complications of retina surgery such
745 as strabismus and diplopia and he did not look for possible complications of peeling the
746 inner limiting membrane such as central scotomas.

747 It seems that the purpose of the present process is to deliver the most cost-effective medical
748 treatment, requiring the least amount of physician time, to the largest possible number of
749 people. Other goals must be the responsibility of the patient.

750 **4.6 Miscellaneous**

751 Be sure to shake eye drops before use, because some are suspensions, not solutions or
752 emulsions. In suspensions, the solids will eventually fall to the bottom. Try to use
753 preservative free eye drops.

754 There is a journal article that might have a patient’s description of his visual images during
755 the first month after a retinal detachment operation [14]. However, it is in French and I could
756 not obtain a copy.

757 Professors in medical schools are probably more experienced in dealing with rare cases.
758 When I realized that my case was rare and I found an ophthalmologist at a medical school
759 that solved my major problem, maybe I should have stayed with him, even though it would
760 have meant frequent trips between Los Angeles and Tucson.

761 My final advice is, do not accept an appointment for surgery right before the surgeon is
762 scheduled for vacation! The surgeon may be distracted and you will miss follow-up care.

763 **5. CONCLUSION**

764 (1) Pain is hard to diagnose, measure, quantify and treat, making it frustrating for both the
765 patient and the physician: in my case, there were many causes of pain and this produced
766 confusion. (2) There was no face-to-face communication between the dozen doctors that
767 were involved in this case: furthermore, many times the written communications were not
768 received, read or understood. (3) In complicated procedures involving many physicians and
769 many physical systems, perhaps there should be a patient’s advocate, who knows the
770 system and is interested only in the patients’ best interests. (4) I found the best metric for
771 choosing a doctor was the amount of time that he or she scheduled for each appointment or
772 operation. (5) For the last six years, I complained about ten specific symptoms, which were
773 treated individually: treating this case as a system of interacting problems led to a better
774 understanding and resolution.

775 **ACKNOWLEDGEMENTS**

776 For helpful comments on the manuscript, we thank members of the Systems Engineering
777 Brain Trust: Bruce Gissing, George Dolan, Jerry Swain, Bob Sklar and Brad Sowers. We
778 thank Lawrence Jones Esq. for legal advice.

779 **COMPETING INTERESTS**

780 Neither author has any conflicts of interest with regards to this paper: furthermore, we
781 believe that there is nothing that could be construed as a conflict of interest. This research
782 was not funded by any organization.

783 **AUTHORS' CONTRIBUTIONS**

784 Bahill designed the study, performed the statistical analysis, wrote the protocol and wrote the
785 first draft of the manuscript. Barry provided the medical instruments, measurements, clinical
786 images and medical expertise.

787 **CONSENT**

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

789 **REFERENCES**

- 790 1. Stark L, Bahill AT, Ciuffreda KJ, Kenyon RV, Phillips S. Neuro-optometry: an
791 evolving specialty clinic, *American Journal of Optometry and Physiological Optics*,
792 1977;**54**:85-96.
- 793 2. Jones WL (editor), *Optometric clinical practice guideline care of the patient with*
794 *retinal detachment and related peripheral vitreoretinal disease reference guide for*
795 *clinicians*, American Optometric Association, St. Louis, MO, 2004.
- 796 3. Woon WH, Greig D, Savage MD, Spokes D, Skorski S. Thompson GL, Murphy B,
797 Taylor S. Evidence for the aqueous absorption of gas from the eye following
798 vitreoretinal surgery, *Phys. Med. Biol.* 2008;**53**:3309–3316 doi:10.1088/0031-
799 9155/53/12/016
- 800 4. Nadal J, Verdaguer P, Canut MI. Treatment of Retinal Detachment Secondary to
801 Macular Hole in High Myopia: Vitrectomy with Dissection of the Inner Limiting
802 Membrane to the Edge of the Staphyloma and Long-term Tamponade. *Retina*.
803 2012;**32**(8):1525-1530.
- 804 5. Tadayoni R, Svorenova I, Erginay A, Gaudric A, Massin P. Decreased retinal
805 sensitivity after internal limiting membrane peeling for macular hole surgery, *British J*
806 *Ophthalmol* 2012;0:1–4. doi:10.1136/bjophthalmol-2012-302035.
- 807 6. Kolb H, Nelson R, Fernandez E, Jones BW (editors). Webvision: The Organization
808 of the Retina and Visual System, <http://webvision.med.utah.edu/book/> accessed
809 November 2, 2013.
- 810 7. Flück D. *Colblindor*, <http://www.colblindor.com/color-arrangement-test/> , accessed
811 November 2, 2013.
- 812 8. Chabris C, Simons D. *The Invisible Gorilla: and Other Ways our Intuitions Deceive*
813 *us*, New York, Crown Publishers, 2010. Available at:
814 <http://www.theinvisiblegorilla.com/videos.html> Accessed November 2, 2013.

9. Lee RM, Foot B, Eke T. Posterior capsule rupture rate with akinetic and kinetic block anesthetic techniques, *J Cataract Refract Surg.* 2013 Jan;**39**(1):128-31. doi: 10.1016/j.jcrs.2012.11.002.
10. Haug S, Bhisitkul RB. Risk factors for retinal detachment following cataract surgery. *Current Opinion in Ophthalmology* 2012;**23**(1):7–11.
11. Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. Risk for retinal detachment after phacoemulsification: a whole-population study of cataract surgery outcomes, *Arch Ophthalmol.* 2012;**130**(7):882-888.
12. Benson SE, Schlottmann PG, Bunce C, Xing W, Charteris DG. Optical Coherence Tomography Analysis of the Macula after Scleral Buckle Surgery for Retinal Detachment, *Ophthalmology* 2007;**114**:108–112
13. Beutel J, Dahmen G, Ziegler A, Hoerauf H. Internal limiting membrane peeling with indocyanine green or trypan blue in macular hole surgery a randomized trial, *Arch Ophthalmol.* 2007;**125**(3):326-332. Doi:10.1001/archophth.125.3.326.
14. Bertin S, Chauvaud D. Simple retinal detachment: computer reconstruction of visual perception during the first month after surgery. *J Fr Ophtalmol*; 2000 Dec;**23**(10):1026-1028.

APPENDIX: SUCCESS RATE

What is the likelihood of success for a medical procedure? That is a hard question to answer, because it depends on the type of operation, the patient, the surgeon, the staff, the year, the operating equipment and the definition of success. This appendix will examine published success rate examples for cataract and retinal detachment operations. The percentages do not total to 100% because the studies had different definitions for the outcomes, which were not mutually exclusive. There is a lot of variability in these numbers as is demonstrated by the large standard deviations.

A.1 Cataract Surgery Success Rate

For simplicity, let us define cataract surgery success as an operation where the biological lens was removed and an artificial IOL was inserted without serious complications. With this definition, papers published in the last decade have documented that 97% of cataract operations are successful ($\bar{x} = 96.7$, $\sigma = 3.6$, $n = 11$) the numbers in parenthesis are (average, standard deviation, number of reports), while 0.8% had posterior capsule rupture [9], 1.4% caused cystoid macular edema that produced visual acuity less than 20/40 ($\bar{x} = 1.4$, $\sigma = 0.6$, $n = 8$), 0.7% caused intraocular infection ($\bar{x} = 0.7$, $\sigma = 0.4$, $n = 11$), which is called endophthalmitis, and 1% were followed by retinal detachment within a year [10] and [11]. The percentages do not total to 100% because the outcomes are not mutually exclusive.

A.2 Retinal Detachment Surgery Success Rate

Of retinal detachment surgeries, about 90% are successfully repaired with a single operation. In the remaining cases, the retina detaches again and needs another operation that has a 50% success rate, which yields an overall success rate of 95% http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Retinal_detachment.

857 If the retina is successfully reattached, another possible failure is ocular misalignment after
858 surgery. Among 821 patients who underwent scleral buckle surgery 1.5% of the patients
859 developed strabismus and diplopia
860 <http://www.ncbi.nlm.nih.gov/pubmed/17978674>. Another study reported that among of 1030
861 patients who underwent scleral buckle surgery 3.8% developed strabismus and diplopia
862 <http://www.ncbi.nlm.nih.gov/pubmed/22466475>. A third study reported that among of 750
863 patients who underwent scleral buckle surgery 3.3% developed strabismus and diplopia
864 [http://80.36.73.149/almacen/medicina/ofthalmologia/enciclopedias/duane/pages/v6/v6c059.ht](http://80.36.73.149/almacen/medicina/ofthalmologia/enciclopedias/duane/pages/v6/v6c059.html)
865 [ml](http://80.36.73.149/almacen/medicina/ofthalmologia/enciclopedias/duane/pages/v6/v6c059.html)
866 The average misalignment percentage for these three reviews is $(\bar{x} = 2.9, \sigma = 1.2, n = 3)$.
867 Another possible failure mode is macular edema. A recent paper [12] stated that 55% of their
868 patients who had scleral buckles implanted had cystoid macular edema a. k. a. subretinal
869 fluid $(\bar{x} = 42, \sigma = 37, n = 9)$. Less than 1% of retinal detachment operations produced
870 intraocular infection $(\bar{x} = 0.7, \sigma = 0.4, n = 11)$.

871 **A.3 Interlimiting Membrane Peeling Success Rate**

872 Macular holes in the retina are commonly treated by peeling off the inner limiting membrane.
873 This operation is effective in closing macular holes. However, ILM peeling has complications:
874 39% caused central scotomas [13 et al.] $(\bar{x} = 39, \sigma = 15, n = 5)$, 0.1% resulted with
875 infection, 1% produced retinal detachment and 75% created a need for cataract removal
876 within one year.