

MEDICAL MYSTERY:

Preparation for surgery revealed cause of deteriorating eyesight

By Sandra G. Boodman, Special to The Washington Post / Tuesday, December 20, 2011

SILVIA BACOT HAD DEVISED A STRATEGY for coping with her steadily worsening eyesight.

As she walked down the hall of the suburban Maryland federal building where she works as a medical researcher, Bacot would say, "Hi, how are you?" to everyone she passed, worried that if she didn't she might inadvertently snub someone she knew but couldn't see. She always sat in the front row at lectures and close to the screen in movies. At crowded scientific meetings she tried to seem unwaveringly approachable, peering and squinting at name tags when their wearers got close enough.

*A fearful vision —
Her blurry, worsening
eyesight wasn't just due to
nearsightedness*

"I would feel like an idiot," she said, referring to her practice of universal greeting. "At scientific conferences you want to make connections, and if you can't see people, it's bad." Luckily her work was unaffected by her inability to see at a distance because as a bench scientist she focused on objects at close range.

Bacot was frustrated that her ophthalmologist had been unable to correct her severe nearsightedness and the distortion known as astigmatism that often accompanies it. She assumed that her deteriorating eyesight was an inevitable result of aging; her eye doctor offered no other explanation.

It wasn't until the summer of 2010, while undergoing a work-up for laser eye surgery, that Bacot, now 38, learned that her visual problems were not caused by the normal progression of myopia, but in fact indicated something far more serious.

"I turned white as a sheet of paper," Bacot recalled, after corneal specialist **Roy Rubinfeld** told her that lasik was out of the question. "I didn't even know I had anything wrong with me."

Beware of lasik

The first time her eyesight caused problems, Bacot was 6 and had just started school in her native Costa Rica. She could not see the blackboard and began suffering from severe headaches, which her grandmother dismissed as fiction, saying that "children do not get headaches." But



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after the pain persisted, Bacot was taken to a doctor, who determined she was nearsighted and prescribed her first pair of eyeglasses. The headaches disappeared, and for years she saw well with glasses.

In 2004, Bacot noticed that the vision in her left eye seemed unaccountably blurry. Her eye doctor strengthened her prescription, but she soon noticed that her vision was fuzzy again.

"I figured it was the best they can do," she said, noting that the pattern of visits to the eye doctor occurred every six months or so for six years, as her vision deteriorated and her prescription got progressively stronger. "I settled for it because of my own ignorance."

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She tried wearing contact lenses, but they were uncomfortable and her vision was poorer than with glasses. Driving, especially at night, became more difficult. At times her eyes felt swollen, and Bacot developed headaches, just as she had as a child.

Fed up, Bacot thought laser eye surgery might be the answer. She was impressed by the experience of co-workers who had undergone lasik, which uses a laser to reshape the cornea, sharpening vision. In July 2010, midway through the preoperative evaluation in Rubinfeld's Chevy Chase office, she met with the corneal surgeon.

"He told me, 'I have good news and bad news,'" Bacot recalled. The bad news, she remembers him saying, was that she would not be having lasik. "If I do it," he told her, "you could lose your eyesight." The good news, he continued, was that her problem had a name — keratoconus — and Rubinfeld had a treatment, although it was experimental and therefore not covered by insurance.

'No wonder you can't see'

Keratoconus, a progressive thinning of the cornea caused by a defect in the collagen, affects about one in every 2,000 Americans, according to the National Eye Institute. The cause of the disorder is unknown, but the condition can be hereditary. In some cases keratoconus, which causes normally rounded corneas to become cone-shaped, progressively distorting vision, results from years of wearing hard contact lenses or excessive eye rubbing.

One of the tests performed prior to lasik is corneal topography, which creates a topographical map of the surface of the cornea. "Keratoconus is one of the things you're looking for," said Rubinfeld, because it is a red flag for lasik candidates. But corneal topography machines are expensive and not all ophthalmologists or optometrists own them; this can make diagnosing keratoconus more difficult.

"When I looked at her topography, I said, 'No wonder you can't see,'" Rubinfeld recalled. The test revealed severe kerato-

conus in her left eye. Although her right eye is so far unaffected, the disparity made it hard for her to see because keratoconus in one eye, particularly the dominant one, can cause a patient to feel that her vision in general is poor.

Standard treatments for keratoconus are glasses or rigid, gas-permeable contact lenses, but neither of these approaches arrests the progression of the disease and both are inadequate in cases where the condition has become advanced. In such cases, which involve about 10 to 20 percent of keratoconus patients, a corneal transplant is necessary to restore sight.

"It used to be we'd say to patients, 'Boy, I hope you don't get worse,'" Rubinfeld said, noting that corneal transplants have a long and sometimes difficult recovery period. "There really wasn't much we could do."

For the past three years, however, eye surgeons in the United States, Rubinfeld among them, have been conducting clinical trials of a procedure widely used in Europe called corneal crosslinking. The procedure halts keratoconus and in some cases produces modest improvements in vision.

The treatment, developed in Germany and first performed in 1998, takes about 90 minutes for both eyes and is performed under sedation in a doctor's office. It combines the use of special riboflavin eyedrops applied to the anesthetized cornea combined with exposure to ultraviolet light. The process strengthens the cornea, permitting it to form new crosslinks or bonds within the collagen fibers and reducing its curvature.

Most studies of crosslinking have found a low rate of complications. A report last year in the American Journal of Ophthalmology by Italian surgeons found "long term stability ... without relevant side effects" in patients assessed four years after crosslinking was performed.

"I immediately decided to do it," Bacot said, adding that she felt she had no other



Silvia Bacot attributed her failing eyesight to the routine effects of aging.

options and had been prepared to spend the same amount of money on lasik, which many insurance policies do not cover. Bacot paid \$3,200 for the procedure, which was performed in August 2010 on her left eye; Rubinfeld is monitoring her right eye in case it develops keratoconus, which usually affects both eyes.

Bacot was back at work the following day; she said both procedure and recovery were painless. In the past 16 months, she said, her vision has markedly improved. "I can see so much more clearly with my glasses, including who I'm actually talking to," she said. Her headaches have dissipated.

Bacot shudders when she thinks about what might have happened had her eyesight gotten worse. "If I can't see, I can't do my job, which I love," she said. "In that case, I'm done."



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