



# The Story of My Eyes

Gustavo Pérez Firmat



*Photo courtesy of the author*

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*For Leon Herndon*

During my teenage years, when I heard things go bump in the night, it was usually my grandmother running into the furniture on the way to the bathroom. Some nights she didn't make it in time.

Years after her death, my mother remarked casually that her mother's blindness was caused by cataracts but that she refused to see doctors because the only one she trusted was her father, who had died when she was eleven years old. I was puzzled that my mother and her three siblings did not insist that their mother consult an *oculista*, an eye specialist, but in their world—Cuba in the middle decades of the last century—people accepted afflictions like blindness as fate. That Abuela Martínez couldn't see was a given, like her recurrent dyspepsia. I have no idea whether my mother's informal diagnosis was correct.

In Cuba, Abuela Martínez's eyesight was already failing, but she saw well enough to lead an independent life. The only times I rode a bus as a child were with her. That's how she got around Havana, unlike the rest of the family. She and my mother were close, and I saw my grandmother almost every week. Her eyesight was too weak for reading, but she was able to play canasta with her grandchildren. To see the hand she was holding, she closed her left eye and placed the cards up against her right eye, "the good one." To my credit, it never occurred to me to take advantage of her impairment.

She never owned eyeglasses but some years later, in Miami, had a magnifying glass that she used to write to her youngest son, Tío Richard, who lived in New York City. Using a blunt pencil, she filled a page with three or four slanted sentences. By the middle 1960s, the magnifying glass didn't magnify enough, and I began taking dictation for her letters. After we finished, I'd put a pencil in her hand and guide it to the bottom of the sheet, where she'd blind-sign, "Mamá." Then she'd root around in a little pouch inside her purse. She'd take out some coins, and I'd pick a quarter, which she called a peseta, a Cuban coin worth twenty cents. It was my payment for something I shouldn't have been paid for.

Tío Richard, who had issues of his own, hardly ever answered her letters. After the first couple of years in Miami, my mother began faking his letters, which I would read to my grandmother. The proof of their authenticity was the closing. Tío Richard always ended with an odd valediction: "Perfectamente, Ricardo." My mother made sure to close the same way. But in truth, Tío Richard, an alcoholic who had

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attempted suicide several times, wasn't doing "perfectly." The last letter I ever saw from him, after his mother had passed away, contained only one sentence: "Billita, who am I?" Billita was the name by which he and his siblings knew their grandmother.

By the time I was an undergraduate at the University of Miami, Abuela Martínez was no longer living with us. Her failing memory turned out to be an incipient case of dementia, a second blindness. After waiting longer than they should have, her children put her in a retirement facility (I resist calling it a "home"). She lived on for several years, but I never saw her again. I didn't realize why until much later. Already I was afraid that the darkness in her life would become part of mine.

As one sightless grandmother disappeared from my life, my other grandmother, who also had vision problems, entered it. In Cuba, my only regular contact with Abuela Constantina, who worked in the *almacén*, a food-wholesaling business that she and my grandfather had built after emigrating from Spain, had occurred on Fridays. At lunchtime, I would go over to her house, which was next to ours, and show her my weekly *boletín*, or report card. If my grades were good, which they usually were, she'd give me a peso that I put in a metal piggy bank. There was no chitchat. No grandmotherly warmth or fuzziness. Ours was a business transaction, like the ones she negotiated at the *almacén*. After I got the peso, I gave her a kiss on a rouge-smearred cheek and left her to a plate of *fabada* or *caldo gallego*.

When I was a student at the University of Miami, Abuela Constantina was diagnosed with glaucoma. By then, we had become much closer. Unlike my other grandmother, she liked men better than boys. As a near-adult, I was someone with whom she could talk about family or politics and tell me stories illustrating her business savvy. Constantina lived in the upstairs apartment of my family's duplex. I'd come home from my morning classes and go upstairs. While we listened to Cuban-exile talk radio, I'd enjoy the Spanish dishes that she cooked wonderfully. In the evening, I'd go back upstairs. We'd drink Cuban coffee and watch a Latin American telenovela. Before leaving, I'd put drops in both her eyes, which she wiped immediately with a hankie fastened with a safety pin to her sleeveless housedress. She had no idea about the nature of her disease. All she knew was that her doctor said to make sure she put *goticas* in her eyes in the evening. When she passed away a decade later, she could still see well enough to spend her days reading the exile tabloids.

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It was during these years that my eye pressure (technically “intraocular pressure,” or IOP) was checked for the first time. The optometrist used a pneumatic tonometer, which releases a puff of air against your pupil and gauges the pressure by the resistance. I don’t remember exactly how old I was at the time, probably around twenty-one, but I do remember the numbers: 23 millimeters of mercury (mmHg) in my right eye, 24 in my left. Individual thresholds vary, but readings above the teens are considered too high, a possible indicator of glaucoma. Shaken, I concluded that my fear of blindness was becoming a reality.

The optometrist suggested that I consult an eye specialist. I went to see a Cuban *oculista* who dilated my pupils, examined the backs of my eyes, said everything looked normal, and suggested that I rub my eyes vigorously every morning. His reasoning, though I wasn’t aware of it at the time, was that the morning rub would squeeze out some of the fluid in the eye, thereby lowering the pressure. A couple of years later, upon hearing this doctor’s suggestion, an ophthalmologist at the University of Michigan, where I had gone for graduate work, replied: “That’s a good idea if you want a detached retina.”

I stopped rubbing my eyes but continued to engage in other quirks (in Spanish, such things are called *manías*). I got into the habit of perusing specialized journals in the current serials section of the University of Miami library. I didn’t understand much, but I did learn that glaucoma involved damage to the optic nerve from too much aqueous fluid. Going on the surmise—my own surmise—that the less liquid in my body, the lower my eye pressure, I went around dehydrated like a box of raisins, which may explain why, years later, I developed kidney stones.

I also learned that IOP fluctuates, that it’s highest in the morning and decreases gradually during the day (which induced me to schedule checkups in the afternoon), and that the pressure is higher when it’s cold, lower when it’s hot. And so I sequenced appointments to fall in the summer. Terrified of following in Abuela Martínez’s uncertain footsteps, I deceived myself into believing that if the glaucoma wasn’t diagnosed, it wasn’t there. In the game I was playing, I won by losing. If I succeeded in camouflaging the disease, I increased the likelihood of the outcome I feared.

To heighten my anxiety, my father was also diagnosed with glaucoma. Like his mother, he didn’t know much about the disease; he fussed with my mother about the nightly drops and joked crudely about his deteriorating eyesight, which ended his driving days. He once told me: “Si sigo

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así, voy a tener que empezar a ver por el ojo del culo." If his sight kept getting worse, he was going to have to start seeing the world through his asshole (in Spanish, *el ojo del culo*). Rather than as glaucoma, he spoke of it as *carcoma* (woodworm), a word in the Cuban idiom for a run of bad luck: "me cayó carcoma" (I got woodworm). I figured I was next: the bookworm with woodworm.

At Michigan, I was seen by an ophthalmologist with a bright last name: Lichter. Once I graduated and took a teaching position at Duke University, he referred me to Bruce Shields, a respected glaucoma specialist at Duke Eye Center whose name was also a metaphor: he was impenetrable. When Shields left Duke for northern pastures, his patients were inherited by a tall young man not long out of medical school, whom I'll call Dr. E (E for eyesight). Unlike Shields, Dr. E was affable and warm. While he examined me, he'd make small talk about sports, mention the colorful socks I was wearing or his honeymoon in Barcelona. A couple of times, when I've been alarmed about something (a swollen eyelid, unusual redness), I've written to his personal email rather than using the online medical portal. Every time, he's answered me within minutes, even on a Friday evening. In my experience, this doesn't happen often. Next to a cure, access is what a patient is most grateful for.

When I began seeing Dr. E, the pressure was what it always had been, somewhere between 20 and 24 mmHg, with the left eye's usually higher, but the visual field remained normal. For twenty years, I saw him once a year. He'd come in, look in my eyes, put the anesthetic drops in them,

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and take the pressure. I'd go home and write it down using the medical lingo: OD and OS, Latin for right eye (*oculus dextrus*) and left eye (*oculus sinister*). It made sense to me that my left eye was the sinister one, since it had never corrected to 20/20, the result of a wrinkled retina probably caused by a childhood infection. I don't notice it unless I take a sheet of graph paper and hold it up to my sinister eye. The squares look like squiggles.

As I got older, the visits to Dr. E, which had always been stressful, became nerve-racking. The onset of glaucoma tends to be age-related. In my forties and fifties, I comforted myself by thinking that I was probably a few years away, but as I entered my sixties, the margin of safety began to shrink. As the next appointment approached, a dark cloud would envelop me. I turned into a zombie, going about my usual business but thinking only about the upcoming evaluation. I realized that the anticipation of trouble is trouble, but common sense had nothing to do with it. My two grandmothers did. My father did.

When the day finally arrives, my wife, Mary Anne, takes the wheel so that the tension of driving doesn't hike my IOP (another *manía*). Doing breathing exercises in the passenger seat (still another), I wonder whether this is my future: being driven everywhere. After too brief a trip from our house in Chapel Hill to the Duke Eye Center, I check in. Always the same questions: name, date of birth, address, insurance coverage, and have I fallen in the last thirty days. Not even in love, I reply. The lady at the counter is not amused.

We take a seat in the windowless waiting room, whose soft lighting strikes me as lugubrious. All around, men and women are reading their phones, doing crossword puzzles, or knitting (at the glaucoma clinic, it's always senior day). Sitting next to me, another of Dr. E's patients tells me that she's had glaucoma for fifteen years. She's calm, unperturbed by the upcoming eye check. I would like to share her equanimity, but I can't. Already I'm imagining myself with a high-tech cane and José Feliciano eyeglasses. Were someone to take my blood pressure, the numbers would be scaling the Pico Turquino, Cuba's highest mountain.

Maybe the people around me are as agitated as I am, except that they hide it better. I don't think so. I suppose all glaucoma patients, only a fraction of whom are in real danger of losing functional vision, are apprehensive about their condition. But there is a difference between apprehension and panic, which is what I'm feeling. I try to distract myself by going to the restroom, recalling the movie we watched last night,

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deciding what I'd like for dinner, daydreaming about our beach vacation. None of it works. I talk to Mary Anne, make an effort to read, look around for a pretty stranger to admire while I can still see her face, but that doesn't work either. In my mind's eye, a pink neon sign flashes in big block letters: GLAUCOMA! GLAUCOMA!

I remember that after he lost his eyesight, Borges wrote a wonderful poem titled "Elogio de la sombra" ("In Praise of Darkness"). I'm no Borges, and a blind seer still can't see. I'd rather be a sighted dunce.

For nearly twenty years, I remained what the medical establishment dubs a "glaucoma suspect." After I had seen Dr. E a few times, curious that my long-running elevated pressure had not affected the nerve, he measured the thickness of my corneas. The technical name for this measurement is pachymetry (the one good thing about disease: it increases your vocabulary). If the cornea is too thick, it can artificially inflate pressure readings; too thin, and it makes them appear lower than they are. (These misreadings are called "artifacts.") It turned out that my corneas are thicker than normal, which meant that the nonartifactual pressure was two or three points lower than the tonometer reading. I remember saying to him: "So this means I may never get glaucoma?" He didn't say yes, and he didn't say no. He said: "It's possible."

I held on to the thickness of the cornea as a miraculous exemption from the family fate. All those years of worry for nothing. All those silly

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*manías*. All those excruciating hours in the gloomy waiting room. But the miracle was not granted.

The bane of glaucoma suspects and sufferers is the visual field test. Everybody hates it because it's not a passive test, the kind where you stand or sit or lie down while a machine peers at your insides. You have to collaborate, which makes you feel like an accomplice in your undoing. The apparatus is a concave dish, somewhat like a miniature version of the firmament on the ceiling of a planetarium. You place your chin on a pad and wait for points of light—the stars—to appear. In the old days, a technician sat behind the dish, Wizard of Oz-like, and worked the machine, but years ago, computers took over the *fiat lux*.

Sitting in a darkened cubicle, you know that you must see stars. They can appear anywhere in the miniature sky. The flashes are spaced at different intervals so that it's impossible to trick the test. When you see a speck of light in one area, you press the clicker in your sweaty palm; when you see another somewhere else, you click again. Then it happens that for a few seconds, the sky is dark. And you think: A star twinkled, and I didn't see it! It must mean I have glaucoma, or if I already had it, it's gotten worse.

At this point, it's hard to avoid clicking at star-ghosts or looking around, desperately hunting for points of light, both of which defeat the purpose of the test. Since what is being measured is your peripheral vision, you have to stay focused on a bright central light—a motionless moon—while the shower of stars pops up in every far and near corner of the firmament. At times, I've let my eyes wander so much that the technician had to stop the machine to let me take a breather and start over. Normally the test should take no more than five or ten minutes. Some of mine have taken half an hour.

I'm sixty-seven years old, and I'm about to see Dr. E again. I anticipate that I'll have to submit to another visual field test. The night before the appointment, in our bedroom, I perform my own version of perimetry. I keep my right eye closed and check the other one for blind spots. I notice something like a gray cirrus cloud in the upper-right corner, but I'm not sure what to make of it. Maybe it's always been there. Maybe not.

The next day, my pressure falls within the usual range: OD 20, OS 21. Glowing, I go back to the waiting room, where I tell Mary Anne that everything is fine because the pressure hasn't risen. I've dodged the *carcoma* bullet once again, maybe forever. Now it's time for the visual field.

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Ten or fifteen minutes after the exam, Dr. E comes into the examining room. “Well, Gustavo, it looks like you have glaucoma.” I’ve spent most of my life expecting to hear these words, and yet when I do, I’m in shock, dumbfounded, as if all my books suddenly disappeared from their shelves. My heart starts thumping. I glance at the screen that pictures my visual field. The right eye is fine, no dark areas other than the blind spot everyone has, but the sinister eye is a mess, gray and black patches everywhere, like a Rorschach chart gone haywire. I think of those harrowing nights with Abuela Martínez. I think of my father’s unfunny jokes. I mumble: “Am I going to go blind?” Dr. E replies in a tone that laces kindness with irritation: “No, you’re not going to go blind.” “Are you sure?” “Yes.”

Of course, I don’t believe him.

As I evoke that afternoon, I begin to feel what I felt then and for many months, when my waking life was taken over by a pathological fear of blindness (the word is *scotomaphobia*). To check my vision, I’d shut one eye and then the other many times a day. Before going to sleep, I’d repeat my unscientific visual field exam. The only time I didn’t worry was when I was teaching. The concentration required by the classes took my mind off my eyes. Years earlier, I had been diagnosed with prostate cancer, another legacy from my ancestors. The malignancy in the mutinous gland, which could have killed me, didn’t scare me half as much as a spotty visual field.

Subsequent tests confirmed that I did have a loss of vision, but not as extensive as it had first seemed. Apparently I was so nervous that I ended up cooking the results of that earlier test. The loss, though significant, was limited to an area in the upper-right quadrant of my visual field, right where the cirrus cloud hovered.

The first time I had my vision checked, I was a senior at La Salle High School in Miami. Halfway through the year, in my first-period class, Religion, I had been moved to a corner seat in the back row because I had become too argumentative, principally the result of having read Will Durant’s *Story of Philosophy* over the summer vacation. From my seat, I couldn’t make out what Brother Austin wrote on the blackboard. A few days later, when he saw me walk into class wearing glasses, he gave me the side-eye, probably thinking that I wore them to draw attention to myself. Not so. Like my father and my brothers, I was short-sighted.

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My first pair—oval lenses inside plain gray plastic frames—got lost along the way, but I’ve kept all the others, sixteen in total, inside an old cigar humidor. Mary Anne thinks this is very strange—and just like me.

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For a few years, I used the glasses sparingly. By my early twenties, the myopia had progressed, and I had to wear them all the time. I still do, though now I need help only to read. You may think this is another *manía*, yet it’s only vanity: my nose appears smaller with glasses. My first pair—oval lenses inside plain gray plastic frames—got lost along the way, but I’ve kept all the others, sixteen in total, inside an old cigar humidor. Mary Anne thinks this is very strange—and just like me.

I took them out recently and arranged them chronologically: my life in lenses. *Veni, vidi, vita*. The oldest, which I was wearing when I got married for the first time, have large and heavy brown plastic frames. In graduate school, I moved on to gold frames of various shapes. In the 1990s, I switched to tortoiseshell glasses, a pair of which I was wearing when I married Mary Anne. Then I opted for a pewter frame and, about ten years ago, for rimless. Were you to peek inside the humidor, you’d notice that my collection doesn’t include a single pair of shades. It spooks me to see through a glass darkly. I’m bothered by the dimming effect, which I’ve always interpreted as foreshadowing.

I have open-angle glaucoma, which means that I’m not susceptible to the sudden spikes in pressure characteristic of acute-angle glaucoma, the other most common form of the disease. In Spanish, these spikes are called *la punzada del clavo*, the stabbing pain (*punzada*) of having a nail (*clavo*) driven through your pupil. In this respect, I’m fortunate. After the first abnormal visual field, Dr. E prescribed drops, which lowered the pressure, but not quite enough. A year later, he performed a trabeculectomy, or “trab” for short, which opens a small canal under the upper

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eyelid so that the aqueous fluid can drain more efficiently. At the same time, he removed the cataract in that eye.

I had to wear an eye patch for about a week. Predictably, during that week, I lived in fear that when the patch came off, I'd be totally blind in that eye. When it did come off, I was relieved to be able to see, but my vision was so blurry that I couldn't read the top line in the letter chart. Inflammation from the procedure. A few weeks of steroid drops took care of it. At my first checkup after the surgery, the pressure in the formerly sinister eye had plunged to nine. I was elated. A couple of months later, Dr. E removed the cataract from my right eye. For the first time since I was a kid, I could read street signs without glasses.

The story of my eyes doesn't end here, however. Once someone enters what Spanish elegantly calls *la tercera edad* (old age), victories give way to holding actions. As appointment followed appointment, three months apart, the pressure in my left eye started creeping up. Eventually it reached the upper teens, nearly what it had been before the trab. The scarring from the incision had blocked the canal. Nonetheless, my visual field remained unchanged, so rather than perform another procedure, Dr. E prescribed a drop that recently had come on the market. It dipped the pressure back to the midteens.

After the detection of blotches in my visual field, I began to understand the challenge of managing glaucoma, for both the physician and the patient. When I was told that I had prostate cancer (I was wearing the glasses with the pewter frames at the time), choosing the treatment was left up to me: surgery, radiation, hormone therapy, cryotherapy. After research and consultation, I opted for surgery. It was a good decision. I've been cancer-free for more than twenty years. With glaucoma, the course of treatment is out of my hands. There's nothing I can do to help myself, and helplessness is nearly as unsettling as disease. Every once in a while, I ask Dr. E whether there's anything I can do. Basically the answer is no. Some studies suggest that exercise and meditation may reduce ocular pressure, but it's nothing as definitive as the way diet and lifestyle influence blood pressure. All I can do is to use the drops "UD," as directed. This is termed "compliance."

Of course I comply, but I'd also like to contribute. Since I can't, I have to trust, which I find difficult to do, and not only with physicians. In the nearly two decades before the diagnosis, I trusted Dr. E because of his demeanor and position, but the trust wasn't tested. He told me what I

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wanted to hear, and that was good enough. It was not until I made the unwelcome transition from suspect to sufferer that I needed to trust him in a concrete, consequential way. It didn't happen all at once. When the trab didn't work as well as it does with most patients, my scepticism surfaced. Before the surgery, I had asked Dr. E whether a trab had an expiration date. He smiled at the way I framed the question. "Ten percent fail per year. And so in five years, about half of them have failed." Mine kept the pressure down for only a few months. A confident man, he had expected a better outcome.

In the years since, I've been on the verge of having more surgery several times. Other tests, in particular the OCT (ocular coherence tomography), may indicate further damage to the nerve. But the visual field has remained "stable" (Dr. E's favorite word), and for now, he's decided to wait and see, or rather, wait and see how well I see. I know that sooner or later, I'll need something else done to my left eye, just as I know that it's nearly certain that I'll also develop glaucoma in my "good eye."

Oddly, perhaps, I learned to trust Dr. E because of his occasional hesitation about what path to pursue with me. I'm sitting in the exam chair, and he's going through my chart. He stops and looks away. I can see the wheels turning in his head. He's considering this option (another trab), that option (a stent), or a third option (whatever that may be). Even for a top specialist like him, what to do when isn't obvious. The treatment of glaucoma involves one judgment call after another. Trusting his judgment, I've been able to shed Abuela Martínez's misgivings about doctors, or at least about my eye doctor. When I did, I felt that a burden had been lifted from me. My eyes are in his hands. I'm fine with that.

At the same time, our relationship has evolved. In the beginning, he'd show me graphs and images of my tests and explain what they meant. On one occasion, he turned the computer screen toward me so that I could see a picture of the back of my eye. I blurted out that I'd rather not see it, a reaction he didn't expect. My blunt refusal surprised even me. When I was told I had prostate cancer, I read as much as I could about the disease. Not so with glaucoma. My research on it ended half a century ago with those medical journals at the University of Miami library. My behavior may seem strange, since cancer dominates our imagination like no other disease, but every one of us has dark corners in our psyche. The dread of blindness is the darkest of mine. I suspect I'm not alone in this.

My reaction made Dr. E aware that I'm the kind of patient who's rattled rather than reassured by detail. Since then, he tells me what I need

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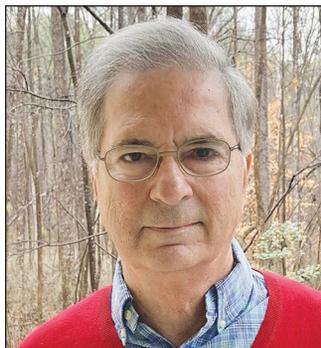
to know. I ask him a question or two, and he answers in a few sentences. Our version of “don’t ask, don’t tell” may not work for everybody, but it works for me. These days, when Mary Anne and I get back into the car, I don’t have to adjust the driver’s seat, because I’m the one who drove us to the glaucoma clinic.

There was a time, not so long ago, when I kept hoping that one fine day, Dr. E would greet me by saying: “Gustavo, it turns out you don’t have glaucoma after all.” It’s taken me years to relinquish the fantasy, but I’ve finally made peace with my imperfect eyes. I can’t say I’m eager to see Dr. E every few months, yet during my appointments, I’m no longer in panic mode. Even the visual field exam has become routine, almost. And I’m not worried about jinxing myself by telling the story of my eyes.

## MEET THE AUTHOR

### GUSTAVO PÉREZ FIRMAT

Mary Anne Pérez Firmat



I never thought I'd be able to write this essay, not because I know too little about the subject, but because I know a little too much. My family's history of blindness—*ceguera* in Spanish—has made eyesight seem to me the most precarious of our senses. Some years ago, when I began to have vision problems, my long-standing dread escalated to manic heights. How I've been able to ease my way down is the story in "The Story of My Eyes."

Gustavo Pérez Firmat's imaginative writing has been published in the *Paris Review*, *Ploughshares*, the *Southern Review*, the *Carolina Quarterly*, *Michigan Quarterly Review*, the *Baltimore Review*, and other journals. His books include *Next Year in Cuba*, a memoir; *Life on the Hyphen*, a study of Cuban-American culture; and *A Cuban in Mayberry*, a reluctant immigrant's take on an iconic portrayal of small-town America, *The Andy Griffith Show*. He has also published several poetry collections in Spanish and English, including *Equivocaciones*, *Bilingual Blues*, and *Scar Tissue*. His last book is *My Favorite Monster* (2024), a translation of poems by the Spanish poet Luis Alberto de Cuenca. A fellow of the American Academy of Arts and Sciences, he is the David Feinson Professor Emeritus of Humanities at Columbia University, where he taught Latin American literature. His website: [gustavoperezfirmat.com](http://gustavoperezfirmat.com).