

Update from Professor Gey

March 2009

Recent visits and calls from my chief minders, Kristie and Megan, have prompted gentle requests for another update regarding my condition. In light of the fact that you guys are once again going to attempt suicide-by-triathlon, it seems the least I could do. So here goes.

Given what has happened in the last twelve months, it is impossible to strip out of this update all of the melodrama, so apologies in advance for sending along something that looks like it could come from a cheap novel or a Hallmark holiday made-for-TV movie.

It is probably best to just give you the facts, more or less unadorned. After sending around the last update, my condition deteriorated fairly rapidly. The first thing that happened was that my intestines shut down. This led to a cascade of effects, the most distressing of which was that I lost the ability to eat solid food. For over a month, I lived on nothing more than bottles of Ensure, a/k/a Breakfast of Champions. Needless to say, this almost killed me. Alas, literally. For this entire period of time (March through early April), I was continuing to teach my two classes, although soon after the semester began it became impossible for me to attend the classes in person. The students were kind enough to permit me to teach over the phone from my bed at home, and do make-ups electronically. Believe it or not, this actually worked fairly well for a while.

Unfortunately, my health was worsening, and by the last week of classes I had become too weak even to teach over the phone. All of this came to a head roughly a week after last year's triathlon, so what follows might in part explain why some of you were so horrified when you saw me at that time.

I am relating the details of the next few days secondhand, because I don't remember any of it. Apparently, on the Monday of the last week of classes, I tried to teach but failed. By this point my weight had dropped to 85 pounds, and even sitting up in a chair was impossible. Bowing to the inevitable, I announced to my students that someone else would have to teach the last few classes. For the remainder of the day, my wife Irene, and my colleagues Rob Atkinson and Curtis Bridgeman were engaged in conversations with doctors and insurance companies, trying to obtain authorization to transport me to see my doctors at the Emory ALS clinic in Atlanta. For various reasons, we never made it that far. To make a long story short, I found myself in an ambulance the next day on my way to Tallahassee Memorial Hospital. Several Fellini movies later, it was determined that I was too weak to go to Emory, and so, after roughly 14 hours in the emergency room, they finally admitted me to the ICU in Tallahassee.

One of the problems that drove me into the hospital was malnutrition stemming from my inability to eat solid food. A partial solution to this problem was the insertion of a feeding tube. Unfortunately, I had lost so much weight and become so weak that the insertion of a feeding tube became potentially a life-threatening endeavor. On Wednesday, we found a gastro doctor willing to insert a feeding tube, but then my

pulmonologist expressed the view that because of my respiratory weakness I might not come out of the operation alive. Probably the low point of this period was sitting around late Wednesday night with my wife, my research assistant Karen, and Curtis, drawing up hand-written lists of assets, life insurance policies, and bank accounts just in case the next morning's operation went badly. Considering that I'm writing this, things went better than expected, and the feeding tube was inserted without a hitch. I was released from the hospital approximately one week later with my bright shiny new feeding tube, but with no solution to the problems that put me in the hospital in the first place.

Since leaving the hospital, some things have improved, and other things have gotten worse. The good news is that I can once again eat small amounts of solid food and have managed to gain almost twenty pounds since leaving the hospital. I am now a whopping 112 pounds, soaking wet. It is important to look on the bright side, so when people say that I look like Kate Moss's brother, I just assume that they mean I look like a supermodel. How does that song go? "I'm too sexy for my hospital gown." The bad news is that my lungs have now deteriorated to the point where I have to be on a respirator 24 hours a day, with brief respites for food and showers. If my nurse keeps me in the shower for even five minutes too long, my hands and feet turn blue from lack of oxygen. Colorful, but ever so slightly scary. One of the big problems this creates is that I can no longer leave the house even for doctors' appointments, because my respirator is not portable. The other bad news is that I have now lost all use of my hands and arms. This creates certain obstacles for, say, typing, but I have gotten around these obstacles through a combination of voice-activated software, the Windows on-screen keyboard, and a large trackball that I can manipulate with my feet, which still sort of work. Of course, these alternative methods of communication create problems of their own. The ever-frustrating voice-activated software, for example, continues to entertain more than enlighten. Lately it has taken to gently suggesting that maybe my time is almost up. Whenever I tell it to type "2009," it now types "2000 died." Subtle, yes?

And then, as if all of this weren't enough, they were a few other distractions during the second half of last year. August was especially sweet. During Hurricane Fay, for example, the back half of my house flooded. This means that for the last six months all of the bedrooms in my house, two of the bathrooms, and the library have been uninhabitable. This may seem like a disaster, but I have decided that I kind of like living in the still-habitable living room, because I can talk to the UPS guy without getting out of bed. And the travesties don't stop there. About a week after the flood, I heard from Bank of America that someone had stolen my identity, created several new bank accounts in my name (which I guess by this point was also their name), and started to transfer some funds. This was unnerving, but at first Bank of America seemed to have things well in hand. That is, until a few months later, when I got a letter from a collection agency. It seems that Bank of America had turned my name over to the collection agency because of an overdraft created when Bank of America withdrew funds from an account that the identity thieves had opened. The bank wanted to charge me interest, too. The story goes on, but you get the idea. Every night I send someone out to cast their gaze toward the west. I know that there are swarms of locusts coming; it's just a matter of figuring out when.

Now if much of this sounds depressing, well, that's because it is. But you have to look on the bright side. Think of the good things that have come my way. For example, my nurse this morning informed me that I was having someone shower me just like the Pharaohs in ancient Egypt. I'm royalty! I also have someone feed me, turn me in bed every 30 minutes, trim my fingernails, and take me to the bathroom. Let the Pharaohs match that. I also get to spend all day, every day in my pajamas. I'm sort of Hugh Hefner without the baby rabbits. And although I continue to write law review articles, at least I don't have to attend faculty meetings anymore, which leaves me lots of time to renew my abiding love for French movies. Indeed, my present circumstances have given me a whole new perspective on the nouvelle vague. I now find Jean-Luc Godard's *Weekend* oddly comforting. So you see? This whole fatal disease thing isn't all that bad after all.

All kidding aside, there is an aspect to serious illness that seems to bring out the best in people. I mentioned that Professors Bridgeman and Atkinson helped out in the hospital. I have not yet mentioned the extent to which they helped out. They stayed in the hospital overnight throughout the period I was in the hospital. They dealt with doctors, cleaned me, fed me, and generally made sure that the medical establishment didn't make a mistake with my name on it. Since I was admitted to the hospital on April 15, Professor Atkinson even had to file my taxes for me. (He also offered to fly the medevac helicopter to Emory, although for some reason this seemed to make the official pilots nervous.) Meanwhile, Professor Stern taught my last few classes and then, in the ultimate sacrifice, wrote and graded the exams in both of my classes. In the days since I left the hospital, students, former students, and colleagues have brought us dinner every night. People have gone shopping for us, made videos for us, run interference with insurance companies, tracked down generators, and generally come by to entertain us. Professor Wexler is here almost every day, and among many other things, managed to keep me breathing on an early trip home from the doctor's office when the car broke down. On the night of the flood, one group of students and colleagues (including Professor Wexler) cleared out the rooms that were about to be flooded before the furniture got ruined (hence the bed in the living room). Then, the next day, when it became clear that the professional services that deal with flooded buildings could not come for over a week, I looked up to see ten sturdy young law students standing before me. It turns out, my research assistant Kelly had made a few phone calls. "We heard you needed some help," they said before launching into one of the dirtiest jobs I can imagine -- cleaning up flood water and removing wet carpet. And to top it off, they wouldn't even accept beer money.

So what is one to make of all this? The first thing is that fatal diseases are a bummer, but the second (and more important) thing is that people's responses to fatal diseases make the human race look downright respectable. The truth is, my existence has become very precarious, and but for the unsolicited generosity of all these people, I would already be dead. It saddens me that I will never be able to repay any of you for what you've done. But please understand that if you could cash out gratitude, you would all be rich beyond belief.

ALS is a wasting disease. Anyone with ALS soon becomes like the Black Knight in Monty Python's Holy Grail, with no arms and no legs, and no ability to move or to act on the world. The only thing we can hope for is to retain the Black Knight's ability to curse our condition and everything it represents. As the limbless Black Knight said to King Arthur, "Come back here and take what's coming to you! I'll bite your legs off!" It is clear that I have not gone through the worst of the disease, because barring some unexpected medical advance, the disease will soon kill me. In fact, statistically speaking, most ALS patients die within three years of the onset of symptoms. That means my expiration date is this coming July. Kristie and I have a deal that if you guys keep abusing yourselves in these triathlons, then I will keep living. So far we've both kept our ends of the bargain. I have my doubts that I will be able to say the same thing next year, but for now let's all celebrate the fact that I'm still alive and you're all still crazy. And come by the house after the race so I can bite your legs off.