Out Of Sight

There’s a lot more to survival than meets the eye. Just ask Joe Westmoreland.

July 1, 2003 By Joe Westmoreland

Last summer I was on a mini road trip from New York City to a beach in Asbury Park, New Jersey, that was being hyped as the Next Fire Island when I realized I was going blind. Again.

As my friend Lori drove down the Jersey Turnpike, I navigated—or tried to: I couldn’t read the tiny print on the map and the yellow letters on the turnpike signs kept blurring into their green background. I wanted to scream, “Oh my God! I can’t see!” But I bit my tongue. I didn’t want Lori to freak out on a crowded freeway. Luckily she found the Asbury Park exit on her own.

This wasn’t my first health crisis, by far. I’ve had HIV since 1982 and got really sick for the first time in 1995. It hit me like a sledgehammer: CMV, pneumonia, MAI, KS, wasting…you name it. HIV grabbed every opportunity it had to wreak havoc in my body. I almost didn’t make it out alive. When the CMV hopped from my lungs to my eyes—creating tiny blind spots and sapping my peripheral vision—saving my sight became one of my biggest battles. I lived with a Hickman catheter—a long brown rubber tube sticking out of my chest—for more than three years so intravenous foscarnet and ganciclovir could protect my retina from even more damage. By 1999, the CMV was under control. I even got into a drug trial for valganciclovir, which meant I could take one pill a day instead of my daily six hours of IV infusions. With the Hickman unplugged, I was back to a somewhat normal life, starting my days with a spot of tea, not a drip of IV. Did I live happily ever after?

Not quite. About a year and a half ago, my ophthalmologist told me that cataracts were forming. I bet you thought only old folks got cataracts! Mine, of course, were not the result of aging. (I may feel like I’ve outlived my own death, but I’m only 46.) They were a side effect of my steroid treatment, which has helped me regain my weight and energy.

Left untreated, the milky substance that hardens on the lens causes blurred vision and, eventually, blindness. My eye doctor assured me that the surgery would be a “piece of cake”—but it was hardly elective. She advised me to get it done as soon as possible. I filed that bit of info away as one of those “What next?” type of things that comes with long-term AIDS survival.

You might think that having survived CMV I had conquered my fear of going blind, but the fear was just as strong and sharp now with cataracts. I love watching life—whether it’s staring out the window of my local Greenwich Village diner and seeing all the gay guys and aging beatniks pass by or just looking at my two old black cats napping next to me. The prospect of losing all this and becoming dependent on others again filled me with dread.

You might also think that having survived HIV and all, I'd know enough to take care of this problem ASAP. Even though friends had told me the procedure worked for their grandparents, I tried to block out any thoughts of my own surgery. But my mind would slip into an operating-room fantasy, in which I imagined giant needles coming at me and my head swathed in strips of white gauze. Then, as in an old Twilight Zone episode, the doctor would slowly unwrap the gauze, and we'd wait, scared yet brave, for the first ray of light to shine through.

Besides the fear factor, I was just plain tired of being poked and prodded. I couldn't bear to go through it again. Months went by…until I was walking down the street one day, not long after my turnpike adventure, and the Don't Walk sign was a big orange blur. When a car nearly steamrolled me, I knew I couldn't postpone any longer.

My doctor set a date for the following week. We'd do the left eye, give it six months to fully heal, then the right. To calm me down, she explained the operation, holding a big plastic model of an eyeball. She'd make a tiny incision, vacuum out the old lens and slip in a new, artificial one. It would take only 30 minutes; I'd wear a patch on my eye for 24 hours. No gauze. No terror. And, amazingly, I could keep taking steroids because cataracts can't grow on a fake lens.

The surgery was no piece of cake. It lasted twice as long as normal (thanks to my squishy cataracts that didn't want to separate from my eyeball). But within days I was out and about.

However rapidly my left eye had improved, the right one had deteriorated just as quickly. The first operation was tolerable because it was a new experience; I could hardly wait for the sequel to end. This time I knew what to expect, all the way from the sponge booties to the eyelid clamps. Still, the hardest part was dealing with my fear.

Today my eyes are healed. True, I have blind spots and floaters and only partial peripheral vision. I have to be extra careful not to trip over poodles on expanding leashes. I need to wear strong reading glasses. But who's complaining? My fear of walking city streets is gone. Sunlight is much brighter. And, best of all, I can sit by the diner window and watch, in technicolor focus, all the amazing people passing by. This summer, I'm looking forward to another trip with Lori. And that beach had better be worth it.