AIDS and cancer: one patient's story

By L. Joel Martinez

I have always had a distaste for writing autobiographically when I write for this publication. It stems from a personal belief in and conviction for the so-called "scientific method"—an early indoctrination that disease could and would be conquered. AIDS has been the great curve ball. Still, in my heart I have always had this deep-seated sentiment that what HIV/AIDS research and medicine lack most is the scientific authority that comes from sufficient process and analytical thinking.

Having been diagnosed with HIV around 1986 and involved in some form of advocacy and information dissemination since that time (sometimes loosely, other times in a more structured setting), much of the information I have written about has been "light" on the science and "strong" on the proverbial "this worked for me; maybe it will work for you."

The anecdote, or as we jokingly refer to it here at The Center for AIDS (CFA): "the N=1," has been an integral part of the AIDS battle. Anecdotal information has often been best simply because sometimes it has been the only information available. This has not been helped by the epidemic's history of hurried, sloppy, and huge mood swings regarding treatment guidelines.

So I begin this strange story of my HIV disease with an admission of guilt: to write anecdotally goes wholly against my grain. Striking my computer keys to record these words keeps me on the verge of upchucking at times. Still, in some strange way I hope this story is useful to someone, maybe only because it reflects the unusual nature of HIV disease and the true lack of knowledge of the body's immune system, and because it may sadly illustrate how clinical defeat is possible despite "HIV surrogate number" success.

As with most persons diagnosed in the mid-1980s, I too clung to the mystic of bloodwork—the numbers, the markers we later learned to identify more accurately as surrogates for other, more important clinical events such as opportunistic infections (OIs) or death. As with many early patients, I lived for the numbers, anxiously and impatiently knowing that they "must" be imbued with the magic of continuous health or decline. These were numbers whose minute fluctuations could as easily drive me to ecstasy as to fantastic depression.

I remember my first T cell count as a nice round 350 cells; at that time the number had no realistic point of reference, except that it looked better than my friends' lower numbers and worse than those with higher, more robust numbers. I could start to see in my friends with lower numbers the more frequents bouts of fatigue, the increase in hospitalizations, and the plain deterioration that had been predicted by my doctor.

From the beginning, except for some minor white markings on my tongue that my doctor identified as "oral hairy leukoplakia," I seemed to be lacking any of the classic signs of HIV disease. I could work a full day, I could party, I could carry on my life as usual. Still, the underlying strain of knowing I had this "terminal" disease had its own debilitating effects. And I was not one to live comfortably in denial. If I could nip this disease in the bud, I was going to do it and I was willing to take the chances of doing myself more harm than good.

I remember sitting in my doctor's office while he held up a chart of the stages of AIDS as he knew them then. In his usual, somber way he explained the correlation between T cell decline and health

problems. Psychologically, it was a harrowing experience (although I tried my best to be stoical about it). Having someone explain the likely course of the rest of my possibly short life, its probable medical deterioration, and its possible end, in a small half-poster was unexpected to say the least. The last line of the chart's simple algorithm showed a path that diverged to either "death" (strangely marked in red) or what seemed like an errant "?" (equally strangely marked in blue). I knew in the balance of things, that death carried more weight even in my doctor's desperate reach for optimism. And I was not immune from the onslaught of the media's overblown take on the great pandemic.

My symptoms of HIV never seemed to follow the predicted course for the epidemic. Still, I took AZT monotherapy shortly after its approval and after a short stint of crossing into Mexico to carry over boxes and boxes of Ribiviran. Despite the steady decline in my T cells, I never developed PCP, fevers, or long bouts of fatigue. Then in December of 1989, I had approximately 5 seizures that quickly depleted my platelets to dangerously life-threatening levels and hospitalized me for a week. This was my first real encounter with the word "idiopathic." Idiopathic: of unknown origin or cause. Idiopathic: also signaling the end of some form of clinical invincibility.

Soon after my seizures, I began to develop some small tumors I suspected to be Kaposi's sarcoma (KS). Of course, the physical manifestations were not typical either, since the tumors, while raised, never turned purple. I could see them tracing the veins in my left leg and along my upper arms. My doctors ordered biopsies and the diagnosis of KS was confirmed. Luckily for me, one of my doctors was a lead researcher for Doxil and I was able to enroll in the protocol almost immediately. My response was quick and definite, and the twice-monthly infusions seemed to keep the KS from progressing.

As time passed, I began to develop more classic signs of AIDS: fatigue, fever, and exhaustion, which accompanied the decline in my T cells to single digits. By the mid-1990s, I had a T cell count of 1, but continued to live a fairly active life, volunteering in treatment information and then being instrumental in starting The CFA. Protease inhibitors were around the corner and the advent of viral load tests promised to be a boon for those with immune systems that were still "salvageable."

I remember my doctor saying wisely, "even if I could kill every HIV particle in your body, I would still need a way to restore your immune system." In retrospect this seems like an unusually prescient prediction. Still, when the early results of Crixivan and Norvir studies began to be made public, it seemed that the body could perhaps mount its own robust recovery that, while not complete, could ward off many of the OIs that had terrified most of us as patients. Having participated in a series of monotherapies and dual therapies by the time highly active antiretroviral therapy (HAART) came around, my underlying viral resistance was sufficient that HAART had only temporary and minor successes in my immune reconstitution.

In 1997, my treatments with Doxil suddenly stopped working, and what I had gotten accustomed to in terms of "melting tumors" changed to more numerous tumors that started affecting other parts of my body. A change to Daunaxome as a treatment for KS had no effect. Then after a few weeks of struggling and further biopsies, I was told that I had large B-cell, non-Hodgkin's AIDS-associated lymphoma. At the time, I still had a T cell count of 1 and my treatment with HAART seemed ineffective.

After 7 grueling rounds of chemotherapy, I achieved partial remission of my NHL, but it soon started recurring, mostly around my lower limbs. During this time, I had several intestinal CMV lesions, which responded to therapy. However, the recurring NHL had to take priority and I received radiation therapy to large sections of my legs.

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After many rounds of radiation, my tumors kept returning and I was given the choice of more radiation (with the risk of developing continuously weeping and open sores) or to retry chemotherapy. I spent several weeks in Colorado reviewing my options and returned to Houston to further stage my tumors before making a decision on how to proceed. During a thorough and confusing sonogram, the technician informed my doctor that I had no tumors to be found. Nothing in my immune status had changed dramatically; I still had remarkably low T cell numbers and no other signs of obvious immune reconstitution, but something in my body had changed to eliminate the NHL.

This change in my body's response to NHL continues to be a mystery to all involved, even baffling my family, with its strong belief in "gift-granting" miracles. The recovery from NHL finally gave me sufficient time for 3 new antiretrovirals to come to market. This was the first time in my disease history that I was able to start multiple antivirals without having some underlying resistance. The results were remarkable and soon I was flaunting T cell counts of 600 and viral loads that came extremely close to being undetectable.

This unexpected flourishing of health lasted about a year before I noticed that my T cell numbers were rising too rapidly and too robustly. When my T cell numbers started to climb into the 900s, I began to suspect something was wrong. After more tests, it was determined that the sudden increase in T cell numbers was accompanied by a huge increase in my white cell count without any signs of infection. Then came the determination that I had developed chronic myelogenous leukemia (CML). As in some prophetic pronouncement, the FDA announced the approval of a drug to treat CML just a few months before my diagnosis. The drug, known as Gleevec, was highly selective and effective at treating CML. Before starting this promising therapy, I encountered a slight medical detour in that I suffered a heart attack that required me to have open heart surgery with a triple bypass. As with other things, this too passed and soon I was on an effective dose of Gleevec that has kept my CML at bay.

With my HIV and CML under some form of control, what else could go wrong? In January 2002, I developed squamous cell carcinoma of the tonsil without really having any of the major risk factors for this type of cancer. The carcinoma has spread to both sides of my neck and I have endured and survived both radiation and chemotherapy, but I still have a persistent mass.

As with the 3 other major cancer events in my life, the development of this cancer has been accompanied by the recent approval of a new drug called Iressa that, while not specifically indicated for head and neck cancers, appears to have some activity against them. The Iressa seems to have the short-term effect of forestalling the progression of the squamous cell carcinoma. Still, its long-term effects are much in question.

So once again, I find myself in a strange stage of limbo, knowing finally all the names (trademark and generic) of my biggest friends: HIV drugs, and now having to learn a completely new language having to do with cancer. In the end, I cannot help but wonder that this is all connected with prolonged immunodeficiency (naturally occurring because of a virus and perhaps also induced by therapy). The question remains whether increased immunosurveillance of my HIV with the help of HAART will help or whether further treatment of the squamous cell carcinoma will have any effect at all. For now, I have decided that there must be something else for me to accomplish on this earth. Why else am I here? I am constantly thinking it over and searching for a way to clear this latest hurdle.