

One man's experience with controversial HTLV3

by Bob Andrews

In the very near future, gay men who either consider themselves at "high-risk" for AIDS or who have actual concerns regarding their health will be able to take a simple test which will determine if they have been exposed to HTLV3. This retrovirus is now being considered as the most likely cause of AIDS. Other than that (which is still speculative) little more is known about HTLV3 or what a positive test really means.

Since June of 1983, I have been a volunteer in a study at Mass. General Hospital. This research, similar to many other studies being conducted in other institutions, is a two-year longitudinal study of self-identified "high-risk" men who are asymptomatic of illness. The purpose is to establish a base-line over a period of time and to carefully monitor any changes in the individuals. Controls include individuals with AIDS and individuals not in a "high-risk" group (presumably heterosexual). Every three months I have an exam and give specimens (blood, urine and semen) that undergo a battery of tests.

Like many who volunteered for this study, I was primarily motivated by anxiety. My health was good, but I realized that my sexual history paralleled that of many of the men who had been diagnosed with AIDS. As a participant in the study I would be assured immediate medical attention should I begin to develop any symptoms. I am also hypochondriacal enough to imagine every cold or lump to be the beginning of the worst. I wanted reassurance that I was okay.

Initially my results were unremarkable. The doctors conducting the study and the nurse assisting them assured me with their sensitivity and gave adequate time to answer my questions. After the initial battery of tests I did feel relieved. I also felt positive about my contribution to this important research. In September I was informed that there had been some changes; my T cell subsets "had fallen somewhat." Again, the doctor was reassuring. Hardly alarmed, he felt this was probably a result of the flu I had just recovered from. The good news was that my lymphocyte count was not decreased. Just to be safe, we repeated the test three weeks later. Again the results were abnormal. But otherwise I remained asymptomatic — great appetite, no weight loss or night sweats. So I was once again reassured and told it is not uncommon for someone to have abnormal T-cell ratios. I was beginning to have my doubts.

I was also becoming acutely aware of my responsibility to others, especially the men I was intimate with. My doctors assured me that it was safe for me to remain sexual as long as I took certain precautions. I had developed a "safe-sex" lifestyle (no fucking, no exchange of fluids, no drugs) and followed their advice.

The third battery of tests followed the same pattern of abnormalities with a new development, my "blastogenesis and cytology" was "slightly diminished." Again the doctors were reassuring but I was beginning to feel less confident. Over the next few months I developed a persistent low-grade fever and had two incidents of night sweats. I also thought I detected a slight swelling in the lymph glands under my arms and in my groin. We waited until the fever had gone down before repeating my next tests. By this time, Dr. Gallo's research had been announced and a screening for HTLV3 was available. "Did I want to be screened?" Yes! "Why?" I'm not certain except that I was anxious and I hoped the results would be negative.

On May 31 the results arrived from Dr. Gallo's lab. I was one of the first to discover that I was positive for HTLV3 antibody. I was tested back to June of 1983 with the same results. Suddenly we were discussing my diagnosis of ARC and the treatment options available to me. I had a positive culture for CMV in both my urine and my saliva; we needed to repeat these two tests, but I could begin Interferon treatment if I chose. This was not a decision I had to make just then, and it was not even something I had to seriously consider at that time, but I should think about it. I was too numb to think about anything. There was a point where I stopped listening and felt as though I was merely observing. I didn't want to show my fear, so I refrained from asking any questions. I felt a need to reassure them at this point: "Yes, I understand"; "I'm not really surprised"; "I'll be in touch." Suddenly my life made a quantum change. Just as "coming out" twenty years ago changed my self-perception and gave me new options, being labeled ARC changed me. The issue of coming out all over again brought back much of the old anxiety. Who do I tell, how do I present it, what exactly do I say, how will my friends react?

I relate all this because we, as a community, are being encouraged to take part in research which may prove beneficial in the future, but which offers very little to those of us who volunteer as subjects. I have serious concerns about the interpretations of the test results. I am especially concerned about the government's interest in this particular area of research (screening as opposed to treatment). It has been reported that the Pentagon's germ-warfare lab at Ft. Detrick, MD will be developing diagnostic tests for persons suspected of having AIDS. It is

doubtful they have our best interests in mind. Confidentiality has been assured by our doctors and I trust their sincerity. But how many physicians are willing to face a jail sentence if records are subpoenaed? Do MGH and the Department of Public Health have the same moral integrity as the Fenway?

There are also concerns that the screening might become mandatory for certain types of employment and for insurance. We don't know what the results mean, or what the incident of HTLV3 is in the general population. However, the assumption is being made that gay men with a positive antibody are ARC. This is a bit premature. In my case, other factors may make that an appropriate diagnosis; but what of men who are asymptomatic yet test positive?

Since my diagnosis, I have developed other "symptoms." I've had short spells of headaches, low-grade fever, malaise, depression and loss of appetite. One evening I was dining with a friend, a man with AIDS, and we were discussing my test results and treatment. I passed out! I don't see myself as someone taken by hysteria, but I think that evening I scared myself and hyperventilated. I realized that I was assuming the role of a sick person, that I was suddenly developing all the symptoms I associated with the disease.

I am fortunate that my doctors have remained open to my increased demands on their time. I question whether they are prepared to deal with the anxiety of 50 more individuals like me, men who aren't really sick but need constant reassurance and monitoring. Recently, I've found myself actually pulling away from my doctors and feeling angry at them. I know they can't provide me with the reassurance I want, and I associate them with my diagnosis. Irrational, I realize, but true.

I also feel fortunate that my network of friends includes the members of the AIDS Action Committee. Through them I have found support and awareness that won't be available to many of the people who are screened for HTLV3. We, the committee, will be available for advice and support and we will coordinate our efforts with medical providers. There is concern, however, that increased numbers of anxious men suddenly aware of their exposure to HTLV3 will tax all our resources.

Throughout the AIDS crisis, the lesbian and gay community has cooperated with the medical/scientific community. We have opened up about our sexual lives and entrusted our health to them. And we have done this with an incredible amount of trust. We have to maintain that trust if we are sincere in our demand that a cure for AIDS be discovered. However, it is now time for us to assume a more assertive role in their research. At this most sensitive level of research, we need guarantees that our rights will be protected. We need assurances that confidentiality is

maintained. We need to witness an equal (if not greater) emphasis on developing a cure as there is in culling out the exposed.

My reaction to the results of my screening is that I have not been given any information that helps me personally. The direct impact is, in fact, just the opposite. Because I now know that I have been exposed (even though having antibodies may prove to be the best possible result) I have a sense of doom. I take the same precautions to protect others as I did prior to my diagnosis. I don't take the best care of myself, however, and I feel more stressed. No one else should be subjected to this increased anxiety until more substantial information is known about HTLV3. The risks are just too great. My advise to any friends who ask is that they should not participate in this study at this time. Continue to take care of yourselves, learn about safe sex, and see a physician you know and trust if you have any question regarding your health. HTLV3 has been identified. Now let them cure it!

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