

[Knowing is Beautiful – The Hidden Face of HIV – Part 1](#)

[GNN](#), *Accuracy in Media* and “[Tutto in Vendita](#)“

April 28th, 2006

by Liam Scheff

As a journalist who writes about AIDS, I am endlessly amazed by the difference between the public and the private face of HIV; between what the public is told and what’s explained in the medical literature. The public face of HIV is well-known: HIV is a sexually transmitted virus that particularly preys on gay men, African Americans, drug users, and just about all of Africa, although we’re all at risk. We’re encouraged to be tested, because, as the MTV ads say, “knowing is beautiful.” We also know that AIDS drugs are all that’s stopping the entire African continent from falling into the sea.

The medical literature spells it out differently – quite differently. The journals that review HIV tests, drugs and patients, as well as the instructional material from medical schools, the Centers for Disease Control (CDC) and HIV test manufacturers will agree with the public perception in the large print. But when you get past the titles, they’ll tell you, unabashedly, that HIV tests are not standardized; that they’re arbitrarily interpreted; that HIV is not required for AIDS; and finally, that the term HIV does not describe a single entity, but instead describes a collection of non-specific, cross-reactive cellular material.

That’s quite a difference.

The popular view of AIDS is held up by concerned people desperate to help the millions of Africans stricken with AIDS, the same disease that first afflicted young gay American men in the 1980s. The medical literature differs on this point. It says that that AIDS in Africa has always been diagnosed differently than AIDS in the U.S.

In 1985, the World Health Organization called a meeting in Bangui, the capital of the Central African Republic, to define African AIDS. The meeting was presided over by CDC official Joseph McCormick. He wrote about in his book “Level 4 Virus hunters of the CDC,” saying, “If I could get everyone at the WHO meeting in Bangui to agree on a single, simple definition of what an AIDS case was in Africa, then, imperfect as the definition might be, we could actually start counting the cases...” The results – African AIDS would be defined by physical symptoms: fever, diarrhea, weight loss and coughing or itching. (“AIDS in Africa: an epidemiological paradigm.” *Science*, 1986)

In Sub-Saharan Africa about 60 percent of the population lives and dies without safe drinking water, adequate food or basic sanitation. A September, 2003 report in the Ugandan Daily “New Vision” outlined the situation in Kampala, a city of approximately 1.3 million inhabitants, which, like most tropical countries, experiences seasonal flooding. The report describes “heaps of unclaimed garbage” among the crowded houses in the flood zones and “countless pools of water [that] provide a breeding ground for mosquitoes and create a dirty environment that favors cholera.”

“**[L]atrines are built above water streams.** During rains the area residents usually open a hole to release feces from the latrines. The rain then washes away the feces to streams, from where the [area residents] fetch water. However, not many people have access to toilet facilities. Some defecate in

polythene bags, which they throw into the stream.” They call these, “flying toilets.”

The state-run Ugandan National Water and Sewerage Corporation states that currently 55% of Kampala is provided with treated water, and only 8% with sewage reclamation.

Most rural villages are without any sanitary water source. People wash clothes, bathe and dump untreated waste up and downstream from where water is drawn. Watering holes are shared with animal populations, which drink, bathe, urinate and defecate at the water source. Unmanaged human waste pollutes water with infectious and often deadly bacteria. Stagnant water breeds mosquitoes, which bring malaria. Infectious diarrhea, dysentery, cholera, TB, malaria and famine are the top killers in Africa. But in 1985, they became AIDS.

The public service announcements that run on VH1 and MTV, informing us of the millions of infected, always fail to mention this. I don't know what we're supposed to do with the information that 40 million people are dying and nothing can be done. I wonder why we wouldn't be interested in building wells and providing clean water and sewage systems for Africans. Given our great concern, it would seem foolish not to immediately begin the “clean water for Africa” campaign. But I've never heard such a thing mentioned.

The UN recommendations for Africa actually demand the opposite –“billions of dollars” taken out of “social funds, education and health projects, infrastructure [and] rural development” and “redirected” into sex education (UNAIDS, 1999). No clean water, but plenty of condoms.

I have, however, felt the push to get AIDS drugs to Africans. Drugs like AZT and Nevirapine, which are supposed to stop the spread of HIV, especially in pregnant women. AZT and Nevirapine also terminate life. The medical literature and warning labels list the side effects: blood cell destruction, birth defects, bone-marrow death, spontaneous abortion, organ failure, and fatal skin rot. The package inserts also state that the drugs don't “stop HIV or prevent AIDS illnesses.”

The companies that make these drugs take advantage of the public perception that HIV is measured in individual African AIDS patients, and that African AIDS – water-borne illness and poverty – can be cured by AZT and Nevirapine. That's good capitalism, but it's bad medicine.

Currently MTV, Black Entertainment Television and VH1 are running advertisements of handsome young couples, black and white, touching, caressing, sensually, warming up to love-making. The camera moves over their bodies, hands, necks, mouth, back, legs and arms – and we see a small butterfly bandage over their inner elbow, where they've given blood for an HIV test. The announcer says, “Knowing is beautiful.” Get tested.

A September, 2004 *San Francisco Chronicle* article considered the “beauty” of testing. It told the story of 59 year-old veteran Jim Malone, who'd been told in 1996 that he was HIV positive. His health was diagnosed as “very poor.” He was classified as, “permanently disabled and unable to work or participate in any stressful situation whatsoever.” Malone said, “When I wasn't able to eat, when I was sick, my in-home health care nurse would say, ‘Well, Jim, it goes with your condition.’ That's the way I thought,” he said.

In 2004, his doctor sent him a note to tell him he was actually negative. He had tested positive at one hospital, and negative at another. Nobody asked why the second test was more accurate than the first (that was the protocol at the Veteran's Hospital). Having been falsely diagnosed and spending nearly a decade waiting, expecting to die, Malone said, “I would tell people to get not just one HIV test, but multiple tests. I would say test, test and retest.”

In the article, AIDS experts assured the public that the story was “extraordinarily rare.” But the medical literature differs significantly.

In 1985, at the beginning of HIV testing, it was known that “68% to 89% of all repeatedly reactive ELISA (HIV antibody) tests [were] likely to represent false positive results.” (NEJM – New England Journal of Medicine. 312; 1985).

In 1992, the *Lancet* reported that for 66 true positives, there were 30,000 false positives. And in pregnant women, “there were 8,000 false positives for 6 confirmations.” (_Lancet_ 339; 1992)

In September 2000, the Archives of Family Medicine stated that the more women we test, the greater “the proportion of false-positive and ambiguous (indeterminate) test results.” (Archives of Family Medicine. Sept/Oct. 2000).

The tests described above are standard HIV tests, the kind promoted in the ads. Their technical name is ELISA or EIA (Enzyme-linked Immunosorbant Assay). They are antibody tests. The tests contain proteins that react with antibodies in your blood.

In the U.S., you’re tested with an ELISA first. If your blood reacts, you’ll be tested again, with another ELISA. Why is the second more accurate than the first? That’s just the protocol. If you have a reaction on the second ELISA, you’ll be confirmed with a third antibody test, called the Western Blot. But that’s here in America. In some countries, one ELISA is all you get.

It is precisely because HIV tests are antibody tests, that they produce so many false-positive results. All antibodies tend to cross-react. We produce antibodies all the time, in response to stress, malnutrition, illness, drug use, vaccination, foods we eat, a cut, a cold, even pregnancy. These antibodies are known to make HIV tests come up as positive.

The medical literature lists dozens of reasons for positive HIV test results: “transfusions, transplantation, or pregnancy, autoimmune disorders, malignancies, alcoholic liver disease, or for reasons that are unclear...”(_Archives of Family Medicine_, Sept/Oct. 2000).

- “[H]uman or technical errors, other viruses and vaccines” (_Infectious Disease Clinician of North America_ 7; 1993)
- “[L]iver diseases, parenteral substance abuse, hemodialysis, or vaccinations for hepatitis B, rabies, or influenza...” (_Archives of Internal Medicine_ August, 2000).
- “[U]npasteurized cows’ milk...Bovine exposure, or cross-reactivity with other human retroviruses” (_Transfusion_,1988)

Even geography can do it:

- “Inhabitants of certain regions may have cross-reactive antibodies to local prevalent non-HIV retroviruses” (_Medicine International_ 56; 1988).

The same is true for the confirmatory test – the Western Blot.

Causes of indeterminate Western Blots include:

- “lymphoma, multiple sclerosis, injection drug use, liver disease, or autoimmune disorders. Also, there appear to be healthy individuals with antibodies that cross-react...” (_Archives of Internal Medicine_, August 2000).
- “The Western Blot is not used as a screening tool because...it yields an unacceptably high percentage of indeterminate results.” (_Archives of Family Medicine_, Sept/Oct 2000)

Pregnancy is consistently listed as a cause of positive test results, even by the test manufacturers.

“[False positives can be caused by] prior pregnancy, blood transfusions... and other potential nonspecific reactions.” (_Vironostika HIV Test_, 2003).

This is significant in Africa, because HIV estimates for African nations are drawn almost exclusively from testing done on groups of pregnant women.

In Zimbabwe this year, the rate of HIV infection among young women decreased remarkably, from 32.5 to 6 percent. A drop of 81% – overnight. UNICEF’s Swaziland representative, Dr. Alan Brody, told the press “The problems is that all the sero-surveillance data came from pregnant women, and estimates for other demographics was based on that.” (_PLUS News_, August, 2004)

When these pregnant young women are tested, they’re often tested for other illnesses, like syphilis, at the same time. There’s no concern for cross-reactivity or false-positives in this group, and no repeat testing. One ELISA on one girl, and 32.5% of the population is suddenly HIV positive.

The June 20, 2004 Boston Globe reported that “the current estimate of 40 million people living with the AIDS virus worldwide is inflated by 25 percent to 50 percent.”

They pointed out that HIV estimates for entire countries have, for over a decade, been taken from “blood samples from pregnant women at prenatal clinics.”

But it’s not just HIV estimates that are created from testing pregnant women, it’s “AIDS deaths, AIDS orphans, numbers of people needing antiretroviral treatment, and the average life expectancy,” all from that one test.

I’ve certainly never seen this in VH1 ad.

At present there are about six dozen reasons given in the literature why the tests come up positive. In fact, the medical literature states that there is simply no way of knowing if any HIV test is truly positive or negative:

“[F]alse-positive reactions have been observed with every single HIV-1 protein, recombinant or authentic.” (Clinical Chemistry. 37; 1991). “Thus, it may be impossible to relate an antibody response specifically to HIV-1 infection.” (_Medicine International_, 1988)

And even if you believe the reaction is not a false positive, “the test does not indicate whether the person currently harbors the virus.” (_Science_, November, 1999).

The test manufacturers state that after the antibody reaction occurs, the tests have to be “interpreted.” There is no strict or clear definition of HIV positive or negative. There’s just the antibody reaction. The reaction is colored by an enzyme, and read by a machine called a spectrophotometer.

The machine grades the reactions according to their strength (but not specificity), above and below a cut-off. If you test above the cut-off, you’re positive; if you test below it, you’re negative.

So what determines the all-important cut-off? From The CDC’s instructional material: “Establishing the cutoff value to define a positive test result from a negative one is somewhat arbitrary.” (CDC-EIS, “Screening For HIV,” 2003)

The University of Vermont Medical School agrees: “Where a cutoff is drawn to determine a diagnostic test result may be somewhat arbitrary...Where would the director of the Blood Bank who is screening donated blood for HIV antibody want to put the cut-off?...Where would an investigator enrolling high-risk patients in a clinical trial for an experimental, potentially toxic

antiretroviral draw the cutoff?” (University of Vermont School of Medicine teaching module: Diagnostic Testing for HIV Infection)

A 1995 study comparing four major brands of HIV tests found that they all had different cut-off points, and as a result, gave different test results for the same sample: “[C]ut-off ratios do not correlate for any of the investigated ELISA pairs,” and one test’s cut-off point had “no predictive value” for any other. (INCQS-DSH, Brazil 1995).

I’ve never heard of a person being asked where they would “want to put the cut-off” for determining their HIV test result, or if they felt that testing positive was a “somewhat arbitrary” experience.

In the UK, if you get through two ELISA tests, you’re positive. In America, you get a third and final test to confirm the first two. The test is called the Western Blot. It uses the same proteins, laid out differently. Same proteins, same nonspecific reactions. But this time it’s read as lines on a page, not a color change. Which lines are HIV positive? That depends on where you are, what lab you’re in and what kit they’re using.

The Mayo Clinic reported that “the Western blot method lacks standardization, is cumbersome, and is subjective in interpretation of banding patterns.” (Mayo Clinic Procedural, 1988)

A 1988 study in the Journal of the American Medical Association reported that 19 different labs, testing one blood sample, got 19 different Western Blot results. (JAMA, 260, 1988)

A 1993 review in Bio/Technology reported that the FDA, the CDC/Department of Defense and the Red Cross all interpret WB’s differently, and further noted, “All the other major USA laboratories for HIV testing have their own criteria.” (_Bio/Technology_, June 1993)

In the early 1990s, perhaps in response to growing discontent in the medical community with the lack of precision of the tests, Roche Laboratories introduced a new genetic test, called Viral Load, based on a technology called PCR. How good is the new genetic marvel?

An early review of the technology in the 1991 Journal of AIDS reported that “a true positive PCR test cannot be distinguished from a false positive.” (J.AIDS, 1991)

A 1992 study “identified a disturbingly high rate of nonspecific positivity,” saying 18% antibody-negative (under the cut-off) patients tested Viral Load positive. (J. AIDS, 1992)

A 2001 study showed that the tests gave wildly different results from a single blood sample, as well as different results with different test brands. (CDC MMWR, November 16, 2001)

A 2002 African study showed that Viral Load was high in patients who had intestinal worms, but went down when they were treated for the problem. The title of the article really said it all.

“Treatment of Intestinal Worms Is Associated With Decreased HIV Plasma Viral Load.” (J.AIDS, September, 2002)

Roche laboratories, the company that manufactures the PCR tests, puts this warning on the label:

“The AMPLICOR HIV-1 MONITOR Test...is not intended to be used as a screening test for HIV or as a diagnostic test to confirm the presence of HIV infection.”

But that’s exactly how it is used – to convince pregnant mothers to take AZT and Nevirapine and to urge patients to start the drugs.

The medical literature adds something truly astounding to all of this. It says that reason HIV

tests are so non-specific and need to be interpreted is because there is “no virologic gold standard” for HIV tests.

The meaning of this statement, from both the medical and social perspective, is profound. The “virologic gold standard” is the isolated virus that the doctors claim to be identifying, indirectly, with the test.

Antibody tests always have some cross-reaction, because antibodies aren't specific. The way to validate a test is to go find the virus in the patient's blood.

You take the blood, spin it in a centrifuge, and you end up with millions of little virus particles, which you can easily photograph under a microscope. You can disassemble the virus, measure the weight of its proteins, and map its genetic structure. That's the virologic gold standard. And for some reason, HIV tests have none.

In 1986, JAMA reported that: “no established standard exists for identifying HTLV-III [HIV] infection in asymptomatic people.” (JAMA. July 18, 1986)

In 1987, the *New England Journal of Medicine* stated that “The meaning of positive tests will depend on the joint [ELISA/WB] false positive rate. Because we lack a gold standard, we do not know what that rate is now. We cannot know what it will be in a large-scale screening program.” (Screening for HIV: can we afford the false positive rate?. NEJM. 1987)

Skip ahead to 1996; JAMA again reported: “the diagnosis of HIV infection in infants is particularly difficult because there is no reference or ‘gold standard’ test that determines unequivocally the true infection status of the patient. (JAMA. May, 1996)

In 1997, Abbott laboratories, the world leader in HIV test production stated: “At present there is no recognized standard for establishing the presence or absence of HIV antibody in human blood.” (Abbot Laboratories HIV Elisa Test 1997)

In 2000 the Journal AIDS reported that “2.9% to 12.3%” of women in a study tested positive, “depending on the test used,” but “since there is no established gold standard test, it is unclear which of these two proportions is the best estimate of the real prevalence rate...” (AIDS, 14; 2000).

If we had a virologic gold standard, HIV testing would be easy and accurate. You could spin the patient's blood in a centrifuge and find the particle. They don't do this, and they're saying privately, in the medical journals, that they can't.

That's why tests are determined through algorithms – above or below sliding cut-offs; estimated from pregnant girls, then projected and redacted overnight.

By repeating, again and again in the medical literature that there's no virologic gold standard, the world's top AIDS researchers are saying that what we're calling HIV isn't a single entity, but a collection of cross-reactive proteins and unidentified genetic material.

And we're suddenly a very long way from the public face of HIV.

But the fact is, you don't need to test HIV positive to be an AIDS patient. You don't even have to be sick.

In 1993, the CDC added “Idiopathic CD4 Lymphocytopenia” to the AIDS category. What does it mean? Non-HIV AIDS.

In 1993, the CDC also made “no-illness AIDS” a category. If you tested positive, but weren’t sick, you could be given an AIDS diagnosis. By 1997, the healthy AIDS group accounted for 2/3rds of all U.S. AIDS patients. (That’s also the last year they reported those numbers, CDC Year End Addition, 1997).

In Africa, HIV status is irrelevant. Even if you test negative, you can be called an AIDS patient:

From a study in Ghana: “Our attention is now focused on the considerably large number (59%) of the seronegative (HIV-negative) group who were clinically diagnosed as having AIDS. All the patients had three major signs: weight loss, prolonged diarrhea, and chronic fever.” (Lancet, October, 1992)

And from across Africa: “2215 out of 4383 (50.0%) African AIDS patients from Abidjan, Ivory Coast, Lusaka, Zambia, and Kinshasa, Zaire, were HIV-antibody negative.” (British Medical Journal, 1991)

Non-HIV AIDS, HIV-negative AIDS, No Virologic Gold standard – terms never seen in an HIV ad.

But even if you do test “repeatedly” positive, the manufacturers say that “the risk of an asymptomatic [not sick] person developing AIDS or an AIDS-related condition is not known.” (Abbott Laboratories HIV Test, 1997)

If commerce laws were applied equally, the “knowing is beautiful” ads for HIV testing would have to bear a disclaimer, just like cigarettes:

“Warning: This test will not tell you if you’re infected with a virus. It may confirm that you are pregnant or have used drugs or alcohol, or that you’ve been vaccinated; that you have a cold, liver disease, arthritis, or are stressed, poor, hungry or tired. Or that you’re African. It will not tell you if you’re going to live or die; in fact, we really don’t know what testing positive, or negative, means at all.”

**Read The Hidden Face of HIV Part 2 – [Sex Crimes](#)*