



Home HIV Testing Is Near

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“This HIV home kit scares me to death. It’s not like pregnancy which is good news. These people are fearful. They need good quality pre- and post-test counseling or they’ll be at risk for suicide, massive depression, isolation, loss of perspective,” says Dennis Ouellet, director of HIV services at the L.A. Free Clinic. “I found out my results over the phone. It was devastating, and there was no place for me to put my feelings. You go into emotional shock no matter how prepared you are. HIV is still a terminal disease no matter how we try to deny it. HIV is too serious, too profound to have someone do it on their own. A 1-800 line can’t hug you when you’re crying.”

That kind of talk just sets self-described AIDS diva Connie Norman off -- so she notes she’s speaking for herself and not the San Gabriel Valley, California AIDS Service Center where she is the public policy director nor ACT UP/LA where she is a prominent member. “I am sick of sitting around these funding tables and hearing the latest statistics that show that two-thirds of people are presenting themselves for treatment at level three -- already sick. We need to do whatever we can to get folks into treatment faster. We need every single member of the American population to voluntarily get anonymous testing. I’m worried that we don’t know what the picture of AIDS is,” she says.

For some it’s a question of numbers. Do more people commit suicide when they first find out they’re positive or do more people come down with *pneumocystis carinii* pneumonia (PCP) because they didn’t know they were HIV positive and therefore were not getting appropriate PCP prophylactic treatment. Never one to mince words, Norman blasts “bleeding heart liberals” who are worried that a positive result will cause suicide. “Honey, I got news for you. They’re already doing it. It comes down to individual choice. Our case management and counseling palaces are going to have a visceral reaction to home test kits because the liberal ideology seems to be that people can’t take care of themselves and make their own decisions without the ever-present counselor. And yet there are people like myself, who never attend support groups. The only counseling I ever had was my post-test counseling from Kaiser [Permanente, an HMO] where I spent more time reassuring her than she spent taking care of me. I’m sick of paying in lives. Home test kits will work.”

The HIV home testing kits don’t actually work exactly as their name implies. They are not like home pregnancy tests which give you an instant result. Rather the Direct Access Diagnostic kit produced by Johnson & Johnson, the one most talked about by AIDS activists which is currently being considered for approval by the Food and Drug Administration (FDA), is an HIV home *collection* kit.

Here's how it works: You buy the kit over the counter, go home, read the illustrated instruction insert written by former Surgeon General C. Everett Koop, use the lancet provided to prick your finger, draw a bead of blood, dab the blood on a provided blotter, mail the dried blood sample off to an FDA-licensed lab (with confirmatory testing for accuracy) in a provided envelope; then, referring to your enclosed number, call the 1-800 number a week later for your test results.

The 1-800 number can be accessed anytime after purchasing the kit for pre-counseling, counseling while you're waiting for your results, post-counseling and referrals. JJ/DAD's hot-line counseling has been developed by the American Social Health Association, former AIDS Project Los Angeles hot-line director Thom Mosely and others using a specially-created computer database that employs and expands upon the culturally-sensitive referrals provided by the Centers for Disease Control (CDC). According to Johnson & Johnson, they will be able to switch or conference call the anonymous caller with a resource nearby if the caller wants.

If you believe CDC statistics, there is a huge demand for private HIV testing and several companies are about to plunge in. According to a survey conducted by the CDC's National Center for Health Statistics, existing testing options have been available for the last six years and less than 15 percent of the adult population has been tested for HIV infection; when asked if they intended to avail themselves of existing testing options, only 8 percent of those not yet tested indicate that they would get tested in the upcoming year; when asked what they would do if a home access HIV test were available, the number tripled to 24 percent indicating that they would be tested in the upcoming year.

"This has been an issue that has been controversial over a number of years," says Dan Bross, executive director of AIDS Action Council which has drafted a statement of principles to serve as a guide. It notes that AIDS Action Council has historically opposed home testing for HIV because it does not promote prevention or access to early treatment. They also worry about issues of abuse and discrimination. "There are a number of people who don't have access to testing -- and that's a very legitimate reason to be for the kit," says Bross. "But that needs to be balanced with the potential problems. Reasonable people can disagree on this issue."

A profound understatement.

Darrell Cummings, director of Health Services for the Los Angeles Gay and Lesbian Community Services Center is torn on the issue. "Home testing is far less desirable than free and anonymous testing with pre- and post-test counseling," he says. However, "Because of lack of access, we also value the consumer's ability to make a choice to seek testing in ways they feel are appropriate to them."

But easy access can lead to inappropriate uses. The kits could be abused by family members or employers. There are a lot of problems with existing testing, but does this or any kind of home-based testing kit solve them or create others? HIV Home Testing Kit creator Elliott Millenson believes the kits solve some existing problems. "We feel we're making a strong contribution in trying to get this service on the market."

He continues, “We will also be making a financial contribution for each test kit purchased -- creating a fund to be used to fund medical research, education and services organizations. We haven’t established the structure of it yet, but we’ll let an outside group help decide how to distribute the fund.”

In a letter to FDA Commissioner David Kessler, Health Policy and Research Foundation, and AIDS advocacy group working with Johnson & Johnson, uses compelling CDC data to support their position: “While [some] clinics may be offering quality counseling, most people report receiving inadequate counseling; 55 percent report receiving no pre-test counseling and 69 percent receive no post-test counseling; furthermore, 17 percent report receiving results by phone and 15 percent by mail. As long as we require a face to face confrontation as a condition of getting tested, a significant number of Americans will avoid being tested. The CDC data would suggest that, in the first year it [the JJ/DAD test kit] was made available, we could test more Americans for HIV than have been cumulatively tested in the last six years.”

Many AIDS activists support the concept of HIV home testing kits while expressing serious reservations.

John Gurrola, spokesperson for National AIDS Policy Coordinator Kris Gebbie, says their office is constrained from making product endorsements but is meeting with two product developers. They are concerned about the counseling component but will adopt a “wait and see” stance until the FDA makes a decision.

Mark Senak has had a “real evolution of thought” on home testing. While he was director of legal services at Gay Men’s Health Crisis, he thought “no one should take the test.” But now, as director of planning at AIDS Project Los Angeles (which hasn’t yet determined a policy), he looks at the data which suggests that most people don’t go to test sites but rather to doctors for their results. “And, not to slam doctors, but sometimes the best counseling they get is ‘bend over and kiss your ass goodbye.’ There is no standard of counseling.”

Privacy is another cause for concern. ‘Confidentiality is the key issue,’ says Marisa Cardinale, executive director of the Community Research Initiative on AIDS. “Right now we have confidentiality everywhere. But that is being increasingly threatened. This is absolutely an example of how AIDS hasn’t been treated just like any other disease because of its association with homophobia.” While expressing concerns about misuse, especially by employers, she says the control should be in people’s hands.

Another supporter, Project Inform’s Martin Delaney says, “The bottom line may yet prove to be money. Some clinics may be exercising a certain degree of self-interest in terms of how it will impact their funding. People should look at the whole package.”

But for all the promise and drama over HIV home testing kits, don’t expect to pick one up on your drug store soon. FDA spokesperson Arthur Whitmore says that even though Johnson & Johnson has asked that approval be expedited, it will still take a long time. A decision may not come before

sometime in 1995. Nevertheless, Broadway Cares executive director and former executive director of GMHC Rodger McFarlane, sums it up accurately: "I think HIV home testing is inevitable."

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