

The WIHS Woman

The Connie Wofsy Women's HIV Study



World AIDS Day

By Yvonne De Souza

Since 1988, December 1st has been a day bringing messages of compassion, hope, solidarity and understanding about AIDS to every country in the world. The Joint United Nations Programme on HIV/AIDS (UNAIDS) and its co-sponsors and partners have chosen to focus the 1998 World AIDS Campaign on young people. The main reason for this focus is that over 50% of new infections with HIV are now occurring in young people in the 10-24 age group. Global HIV infections increased 10% in 1998 and half of all new infections are in 15-24 year olds. Young people are particularly vulnerable to HIV infection and are being very seriously affected by the epidemic. The main goal of the Campaign is to mobilize young people to reduce the spread of HIV infection and to strengthen support for young people infected and affected by HIV/AIDS. To promote and protect their human rights.

Young people have the power to change the course of the epidemic. Young people are not only being infected and affected by HIV/AIDS, but they are also a key resource in mobilizing an expanded and effective response. The campaign will be a chance

to sustain the momentum created during last year's campaign on the theme of "Children living in a world with AIDS" and to build on some of the initiatives that were begun over the past months. Similarly, it is hoped that the activities initiated during the course of this year will be carried over beyond the year-end, and that the campaign will be seen as an occasion to develop new approaches and to achieve consensus about what needs to be done in both the immediate future and the longer-term.

It was the intention of the Steering Committee of UNAIDS (which is composed of UNICEF, UNDP, UNFPA, UNESCO, WHO, World Bank, Association François-Xavier Bagnoud, Education International, the International Federation of Red Cross and Red Crescent Societies, MTV International, Rotary International, and the World Assembly of Youth.) that the campaign be used as a real opportunity to set up and strengthen processes for involving young people in reducing the spread of HIV, as well as mobilizing support for young people who are already suffering from the impact of the epidemic on their own lives, their families and their communities. The campaign also provides a platform for emphasizing the links between HIV/AIDS and other factors that are critical to young people's health and development including, in this anniversary year of the Uni

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versal Declaration of Human Rights, the promotion and protection of their rights.

UCSF-WORLD AIDS DAY

At UCSF the AIDS Research Institute (ARI) conducted the Second Annual World AIDS Day Symposium, entitled: On the Road to an HIV Vaccine. The program highlights were:

Observance at the Grove in Golden Gate Park from 11 AM -1 PM. Special guests were actress/activist Judith Light and writer Armistead Maupin. Dr. Thomas J. Coates, Director of the UCSF AIDS Research Institute, participated at the observance program.

Symposium – UCSF, Cole Hall

*Lawrence K. Altman, MD
Medical Correspondent,
The New York Times*

Perspectives on the Challenges of the AIDS Vaccine.

Dr. Lawrence Altman is one of the few medical doctors working as a full-time daily newspaper reporter. Dr. Altman delivered a very meaningful presentation on the issue of human experimentation and the development of vaccines. Dr. Altman mentioned examples of researchers in the past that has tested drugs on themselves prior to working with human volunteers. He also discussed the importance of review boards and the issue of testing vaccines on HIV negative individuals.

PANEL PRESENTATION- THE CURRENT STATE OF THE VACCINE

*Moderated by Jay A. Levy, MD
Professor, Department of Medicine
Research Associate, Cancer Research Institute*

The panel included distinguished scientists in the

fields of clinical medicine, epidemiology and ethics, including Susan P. Buchbinder, MD; James O. Kahn, MD, and Bernard Lo, MD.

The moderator, Dr. Jay Levy is an internationally recognized researcher, immunologist and virologist. He has been involved in research from the beginning of the epidemic, and is acknowledged as a co-discoverer of HIV in 1983. Under the vehicle of the ARI, he has organized a campus-wide effort on vaccine research.

KEYNOTE SPEAKER

*Neal Nathanson, MD
Director, National Institutes of Health
Office of AIDS Research*

Why is an AIDS Vaccine So Hard to Develop?

Dr. Neal Nathanson was named Director for the National Institutes of Health (NIH) Office of AIDS Research in May 1998. The Office of AIDS Research has made HIV vaccine development a high priority and is providing significantly increased resources towards this effort.

Dr. Nathanson's presentation was encouraging for those involved in HIV vaccine development. Dr. Nathanson is still quite active in research and his discussion highlighted the many important points in the design of a vaccine. He could not predict when a vaccine would be fully developed but he encouraged researchers to continue to pursue vaccine design with care and with scientific fervor/passion.

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LOOKING BACK, LOOKING FORWARD The UCSF AIDS Research Institute: 1998 Accomplishments and Vision for 1999

Thomas J. Coates, PhD, Director UCSF AIDS Research Institute

Dr. Coates announced three major new programs for the ARI in 1999, which will be aimed at preventing HIV infection. "Despite all of our efforts, we can expect thousands of Americans and millions around the globe to become infected with HIV next year and each year thereafter. The goal of these new initiatives is to make sure prevention is working as well as it can while we are simultaneously working on an HIV vaccine and better therapies."

"We need to do all we can to prevent new HIV infections, and we feel these projects represent a new era in which prevention efforts bridge two worlds that have long been separated: the HIV-infected and the uninfected populations."

The new program initiatives are: Primary prevention among gay men -- designed for HIV negative persons who continue to engage in high-risk behavior, a new individualized counseling approach named EXPLORE will be tested at half a dozen sites across the country. This is expected to involve more than 7,000 men, it will be the largest study to date on primary prevention.

Unlike conventional counseling that provides two brief sessions with standard advice, EXPLORE is directed at the individual and ways he can change particular patterns of risk-taking. Each person will have the same counselor for 10 visits, and the focus will be on new behavior options, such as ways to meet people and establish relationships without risk, personal strategies to reduce the risk of infection when using alcohol or drugs, and plans to communicate with partners about risk, safety, and a future that will remain free of infection.

This multi-site study will be the first to test directly whether counseling can reduce the rate of new HIV infections, according to Margaret Chesney, PhD, UCSF Professor of Medicine with the UCSF ARI. Drs. Chesney and Coates designed the new counseling approach. If the strategy proves effective, they hope it will become a model for HIV prevention worldwide.

Reduction in spread of HIV infection -- This initiative targets HIV-infected men and women through risk-reduction counseling. Based on the same principles as EXPLORE, this project will not use group counseling but will focus on working with each individual to design personal strategies to reduce risk behavior and enhance quality of life. The project will be coordinated initially through the UCSF ARI and three other major HIV research centers: UCLA, Columbia-Presbyterian Hospital in New York, and the Medical College of Wisconsin in Milwaukee.

This approach is a response to evidence that HIV-infected people periodically engage in behaviors that risk the spread of the virus. Counseling will cover coping with the stress and stigma of HIV as well as advice on adhering to the current complex but life-saving medication regimens for HIV infection. Dr. Chesney is the project principal investigator. The project is funded by the National Institutes of Mental Health.

Prevention planning -- The UCSF ARI Policy Center, directed by Steve Morin, PhD, received core funding from the Until There's A Cure Foundation to continue its efforts to develop into a major center on policy issues.

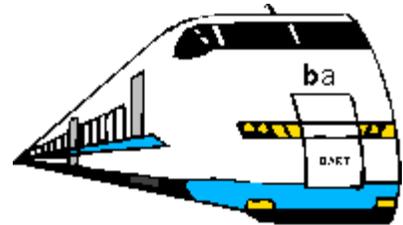
The Center is now organizing the first demonstration project" in the country targeted at disease prevention in young people. Funded by a grant from the San Francisco Foundation, the project will cover five Northern California counties and will work to develop programs on preventing HIV and

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sexually transmitted disease and on planning for good reproductive health. If the project proves successful, it is expected that it will be extended statewide with federal support, according to Morin.

Later this year the UCSF ARI will announce major plans in the area of vaccine development. Research efforts will be focused on understanding the mechanisms underlying the body's ability to avoid HIV infection or to delay progression of infection.



EBAC moves in Berkeley and new clinic site to open in San Francisco

by Nancy Hessol, Project Director

This past November, the East Bay AIDS Center (EBAC) moved to a new medical building located at 2850 Telegraph Ave, Suite 110, in Berkeley. The new building is just down the street from the old one and is much larger and should be more enjoyable for your study visits.

In San Francisco, we are gearing up to move to a new clinic site in San Francisco at Mount Zion Hospital. The clinic will most likely be open for use in March of 1999 and will be located on Ward 6-West in the main Hospital building on Divisadero near Sutter Street. Once the renovations to 6-West are completed, we will shift our clinics from 350 Parnassus to Mount Zion. The new Mount Zion clinic will be much bigger than the one at 350 Parnassus and should be better for our study visits.

Our other clinics at San Francisco General Hospital and Highland Hospital will remain the same. I hope you enjoy the new clinic sites. You can give us your feedback on these new locations at your next study visit; just complete the feedback forms.

CAB CORNER

by Moher Downing, Community Liaison



What is an activist? According to the dictionary it is someone who "practices vigorous action in support of or in opposition to one side of a controversial issue." What does this have to do with AIDS? Indeed, what does this have to do with you? We at the WIHS Study are not only committed to understanding how HIV lives in your body, but also how we can help you cope with HIV on a broader, social and educational level. What that means is that we offer training and educational events for our study women. This gives us a chance to see each other outside of the clinic setting and to meet other women who are working for improved HIV treatment, care, services and prevention for women. These women support your right to have the best care and treatment we have in this country. These women oppose treating women with HIV as second-class citizens or social outcasts. They are activists. They are AIDS activists. We hope more of you will come to our events in 1999 and meet these activists. For those of you who have over committed themselves and wishing for a break, we will be planning more "mentoring events." These events will be an opportunity for you to work with another HIV+ woman who is interested in learning more about whatever it is that you do.

I would like to take this opportunity to wish you the very best in 1999, and to offer you my sincere hope that when we send you a flyer advertising one of our events, you will consider attending. You can always call me at 415-597-4654.

I had the honor of meeting the National Community Advisory Board (NCAB) representatives the first week in December. They were in San Francisco to attend the national WIHS meetings here. The NCAB reps came two days early to attend a training that was organized for them at WORLD. The purpose of the training was to give them the skills needed to review clinical study proposals and to understand study results. Rebecca Denison and Nilda Rodriguez conducted the training. A worthwhile day was held by all.

Your Human Herpesvirus 8 Results from the WIHS

by Ruth Greenblatt

What they mean to you !

Words to know:

Herpesvirus: a group of viruses that are common in people; herpesviruses cause many routine illnesses, such as genital herpes, chicken pox, CMV and cold sores. These viruses tend to remain latent (present but inactive) in people who are infected. These inactive viruses can sometimes become active again and this can cause new illness such as recurrent cold sores, genital herpes outbreaks or shingles. Often the viruses become active without causing any symptoms

(asymptomatic shedding or reactivation).

Kaposi's sarcoma: KS is a type of cancer that is associated with HIV infection. Kaposi's sarcoma is much more common in men, especially gay men, than in women. KS can produce purple colored skin lesions and can involve internal organs. It is treated with chemotherapy and appears to be less common in people who have been on HAART (highly active antiretroviral treatment), such as protease inhibitors.

Human herpesvirus 8 (HHV-8) is a virus that was dis

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covered only a few years ago. The virus was found in tissue from Kaposi's sarcoma (KS) lesions. More recently antibodies to HHV-8 have been found in KS patients and in HIV-negative or HIV-infected gay men. HHV-8 has also been found in patients with a very rare type of lymphoma, another type of cancer. We know that most people with KS have antibodies to HHV-8. However, having antibodies to HHV-8 does not mean that KS, or other kinds of cancer, will definitely occur.

Little information is currently available about HHV-8 infection in women. The test results you are receiving today have come from screening tests done through the WIHS. These tests looked for the presence of two kinds of antibody to HHV-8 in blood samples: "lytic" and "latent". Both lytic (meaning active virus) and latent (meaning inactive or sleeping virus) antibodies indicate that HHV-8 infection has occurred; other differences between people who have each type of antibody are not yet known. In all of WIHS, 6% of women had latent antibody and 13% had lytic antibody. KS does occur in women, but very infrequently. Among the 2600 women in WIHS, only about 25 women have had KS. We think that women who have antibody to HHV-8 are at risk for KS, but that risk is probably very low. Many other aspects of HHV-8 are unknown, such as how the virus is spread, and what parts of the body are actually infected with the virus.

In order to find out more about HHV-8 in women, WIHS is conducting a new study of HHV-8 in saliva. This study may help us understand how HHV-8 is spread to others. You may be asked to participate in this study.

Summary:

- HHV-8 is a new herpesvirus that is found in people with Kaposi's sarcoma but also in people who do not have KS;
- KS is uncommon in women;

- HHV-8 infection occurs in women, but there are many questions remaining about this infection;
- Presence of antibody to HHV-8 means that you have been infected with this virus, but does not necessarily mean that you will get KS or lymphoma;
- Your medical provider or WIHS clinician can answer your questions or concerns about your test result;
- We will give you more information about HHV-8 as we learn about it- check future newsletters.

What Do My HTLV-I and HTLV-II Results Mean?

Herminia Palacio, MD

How does HTLV-I and HTLV-II compare with other WIHS Lab Tests?

The WIHS runs many different kinds of laboratory (lab) tests on the blood and other specimens we collect from you during your study visit. These tests can be divided into 3 different groups. Group 1 has routine lab tests (for example, a "CBC" or complete blood count). We usually get results from group 1 tests within 2 - 4 weeks from your visit. Group 3 has lab tests used only for research and uses techniques that are very new. These techniques are so new that even hospitals and clinics can't perform them yet (for example, viral loads on vaginal fluids). We sometimes do not get group 3 test results for months or even years. Group 2 falls somewhere in between group 1 and group 3. Group 2 has tests that health providers can order in very special cases, but usually do not order on most people. The HTLV-I and HTLV-II tests belong in group 2. Because the WIHS is a research study, we order these tests on all of our participants. It takes longer to get group 2 test results than group 1 tests, but this is

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o.k. because it is very unlikely that your health providers would want or need these results to continue taking good care of you.

What exactly are HTLV-I and HTLV-II anyway?

HTLV stands for Human T-Lymphotropic Virus, and there are 2 kinds, type I and type II. Breaking down the name, HTLV-I and HTLV-II are both viruses which infect humans, and which like to live in T lymphocytes (T-cells). Even though HTLV-I & II infect T-cells, these viruses do NOT cause AIDS. HTLV-I and II look a lot like each other, and the tests available in the U.S. for HIV-I and II are not perfect yet. This means that sometimes all we can tell is that a person has either type I or type II, but we can't tell which one of the two it is.

How do you get HTLV-I or HTLV-II?

HTLV-I can be transmitted from a mother to her child, or through sex, or through needle-sharing. (In the U.S. donated blood which tests positive for HTLV-I/II are thrown out to prevent transmission from a transfusion). HTLV-II is probably transmitted in all the same ways HTLV-I. HTLV-II is more common in people who inject drugs, or who have sex with someone who injects drugs.

What do we know about HTLV-I /II in WIHS women?

A look at the data we had available (on about 533 women across all 6 WIHS sites) shows that only about 10% (52 women) were infected either HTLV-I/II. Most of these women (43 of them) had HTLV-II. For the other 9 women, we could not tell for sure whether it was HTLV-I or HTLV-II.



Does HTLV-II cause any diseases?

HTLV-II, which is the most common one in WIHS women, has NOT been clearly associated with any diseases.

Does HTLV-I cause any diseases?

HTLV-I, which is very rare in WIHS women, has been associated with 2 illness; a specific disease of the blood (called adult T-cell leukemia/lymphoma), and a specific disease of the nervous system (called HTLV-I associated myelopathy/tropical spastic paresis). While these names may sound scary, it is really important to remember that: HTLV-I infection is extremely rare (on average probably only about 1 person out of every ten-thousand people is infected with HTLV-I in the United States) and even among people who do have HTLV-I infection, development of either of these 2 diseases is very rare.

What should I do if my test is positive for HTLV-I/II?

There is no treatment currently available for HTLV-I/II infection and current health recommendations focus on preventing the spread of the disease to others. Because of the ways in which HTLV-I and II are transmitted from one person to another, and because both are lifelong infections, it is recommended that infected persons not share needles, donate blood, or breast-feed babies. It is also recommended that they consider using latex condoms during sex if the partner is negative for HTLV-I/II.

Happy New

