The WIHS Woman



The Connie Wofsy Women's HIV Study



Spring is Here!!







National Women's History Month

By Yvonne De Souza

The theme for this year's event is:
"Celebrating Women of Courage and Vision"

"Each time a girl opens a book and reads a womanless history, she learns she is worth less." - Failing at Fairness by Myra and David Sadker

"From kitchen tables to peace tables, women propose to turn the tables on the status quo." Bella Abzug.

The <u>National Women's History Project</u> is a non-profit organization dedicated to recognizing and celebrating the diverse and historic accomplishments of women by providing information and educational material and programs.

Why is the National Women's History Project's Work Important?

By walking history's pathways, we learn to step forward with confidence. The legacy of how others shaped society sparks our own longings to contribute. Everyone needs role models -- footsteps enough like our own to inspire us. Yet in 1992, a national study found that history texts devote only two to three percent of their total content to women. History must tell the whole story. For girls, knowing women's achievements expands their sense of what is possible. For all of us, knowledge of women's strengths and contributions builds respect and nourishes self esteem which is crucial to all children and adults now, and in the

(Continued on page 2)

TABLE OF CONTENTS

National Women's History Month page 1

Oral Mucosal Lesions and HIV Viral Load in the WIHS page 3

Changes for Visit 14 page 4

Viral Resistance Study (VRS) and Resistance Testing .page 5

WIHS Staff Biographies page 6

Dynamic Study page 7

CAB Corner- Beginning, Now, and Future: Where Do We Go From Here? page 8

(Continued from page 1)

years to come. focus on women's contributions. Yet recently legislatures in three states

The need for more accurate information about women's historical contributions is further confirmed in a recent poll funded by General Motors. Conducted prior to GM's sponsorship of a Ken Burns' film on Elizabeth Cady Stanton and Susan B. Anthony, two women "who transformed a nation," the results show only one percent could identify Stanton as in some way connected with women's rights. In 1980, the National Women's History Project (NWHP) was found in Santa Rosa, California by Molly Murphy MacGregor, Mary Ruthsdotter, Maria Cuevas, Paula Hammett and Bette Morgan to broadcast women's historical achievements. The NWHP started by leading a coalition that successfully lobbied Congress to designate March as National Women's History Month, now celebrated across the land.

Today, the NWHP is known nationally as the only clearinghouse providing information and training in multicultural women's history for educators, community organizations, and parents-for anyone wanting to expand their understanding of women contributions to U. S. history. The enduring goal of the NWHP is to "make history" accurate by continuing to recognize and celebrate women's authentic contributions through its current and future projects.

"Thanks to the NWHP's successes, more teachers and students now understand women's achievements in the fields of math, science, art and literature, and know of inspiring, culturally diverse role models in a wide range of fields throughout our history. Your integration of race, national origin, and

gender issues in your training is of great importance in Nebraska where our minority students frequently feel isolated and lack role models in their school settings." - Director, Sex Equity Project, Nebraska

The National Women's History Project 7738 Bell Road, Windsor, CA 95492 Website: www.nwhp.org (707) 838-6000 Email the NWHP at nwhp@aol.com



















Oral Mucosal Lesions and HIV Viral Load in the WIHS By Dr. Deborah Greenspan

ral lesions are widely regarded by health-care providers as a means to study the progression of HIV infection. Lesions such as oral candidiasis ("thrush") and hairy leukoplakia have been connected with the presence of HIV infection along with other markers such as CD4 cell count. In fact oral lesions are among the earliest indicators of the effects of HIV on a patient's immune system. Why? One reason is that the flora (bacteria and fungi) that lives in your mouth may become harmful due to a change in your immune system.

There have been many studies published on the relationship between oral lesions and CD4 counts in men. Few studies have been reported on how oral lesions may be related to viral load or if women infected with HIV have the same oral lesions as men.

The oral lesions that the WIHS clinicians look for are:

- Oral candidiaisis or thrush is cause by a fungus called *Candida albicans*.
- Hairy leukoplakia looks like the white patches of thrush in your mouth only you cannot rub it off. It is caused by the same virus that gives you mono or the 'kissing disease'. This virus is Epstein Barr virus or EBV.
- Oral ulcers are sometimes called canker sores that may occur in your mouth and are not caused by a virus..
- Oral warts are called papillomas.
- Herpes lesions are oral lesions caused by a herpes virus.

• KS or Kaposi's sarcoma is a red tumor that is may be found in the mouth.

In the national WIHS a total of 729 women (577 HIV+ and 152 HIV-) were given oral exams at baseline. Thrush or oral candidiasis and hairy leukoplakia were the most common oral lesions found in the WIHS. Viral load and CD4 numbers were taken from the core

Lesion	% HIV+ Women	% HIV- Women
Oral candidiasis	13.7%	3.3%
Hairy leukoplakia	601%	1.3%
Herpes	.9%	1.32%
Oral ulcers	2.6%	1.9%
Oral warts	.35%	1.32%
Oral KS	.52%	0

WIHS data.

From the data examined it appears that the presence of hairy leukoplakia was associated with high viral load. Oral candidiasis (thrush) was associated with women who smoked cigarettes, and heroin/methadone use. Oral candidiasis (thrush) was also associated with women with low CD4 counts and high viral load.

This study of HIV+ and HIV- women shows that there is a relationship between oral lesions and HIV infection. It appears that cigarette smoking and heroin/methadone use put women at risk for oral candidiasis. Hairy leukoplakia may be an indicator of HIV infection.





Changes for Visit 14

By Nancy Hessol, Project Director

an you believe that we are already up to our 14th WIHS study visit? Visit 14 begins 4/1/01 and will end 9/30/01. Below is an update on the changes you can expect for visit 14.

What's new? We are very please to announce that we will be starting a pilot study of osteoporosis (bone density loss) and insulin resistance (which can lead to diabetes). These two conditions are very common problems in women, especially as they age. We are excited to have received funds to be able to study these diseases and to be able to give important test result information to you. We have also improved our consent form and our participant locator form. These changes should make your continued participation in the WIHS easier.

What's gone? As with all our even numbered study visits, we not do the tuberculosis (TB) test (call PPD). The TB test is only done once a year at <u>odd</u> numbered study visits.

What's back? For visit 14, we will do the blood tests called CBC's (complete blood counts) and flow cytometry (t-cell testing) on women who are not infected with HIV. For HIV-negative women, these special blood tests will be done once a year at every even numbered study visit. We will also add two modules (forms 23a and 26) of the interview for visit 14. The administration of form 23a is one time only but form 26 will be done once a year at every even numbered study visit.

What's continuing? We will continue to ask

you to try and fast prior to your visit 14 study appointment. The reason for this is to get a more accurate measure of key laboratory tests for things like cholesterol, lipids, and glucose. These blood test are important markers for diseases that affect women, including diabetes, heart disease, and hypertension.

The Interim Event telephone interview for HIV-infected women whose most recent (within the last 3 months) CD4 cell count was under 200 will be continuing. Also continuing will be the abbreviated interview for women who are unable to be seen for their 6-month study visit.

For women undergoing colposcopy, we will continue enrollment into a cancer tissue bank called the AIDS Malignancy Bank (AMB). Women do not need to have cancer, AIDS, or even be HIV-infected to enroll in this substudy. Women who are eligible and wish to donate tissue to the bank will have an extra biopsy and blood specimen collected for this study at the time of their colposcopy examination. We have had a great response from you to this protocol and we thank you for your help! The oral sub-study is still going strong. If you are part of this group, our field staff will set you up with an appointment with the dentists at UCSF.

In conclusion: Thank you so much for being a part of this important study. We will continue to work hard to make this study a pleasant experience for you. For those participants who have come in for a study visit after being gone for a while, we are REALLY glad to have you back. We look forward to seeing you at your next WIHS visit!



Viral Resistance Study (VRS) and Resistance Testing

By Claudia Ponath



I f you take HIV medications you may have heard the term "resistance". There are two types of tests that can measure resistance: Phenotypic resistance tests measure the amount of drug that is needed to stop a person's virus from growing in a test tube. Genotypic tests look at the mutations in a person's virus.

Genotypic Resistance tests are being done in WIHS as a part of the Viral Resistance Study (VRS) - a WIHS protocol that started enrolling participants at Visit 13. The goal of this protocol is to find out more about why antiretroviral therapies work better for some women than for others

Genotyping Test Results

HIV genotyping tests evaluate the genetic code for certain parts of the HIV virus. These parts are called the protease or PR protein and the reverse transcriptase or RT protein. These are the parts of HIV that currently available HIV medicines target. The PR and RT proteins are sometimes changed due to mutations in women who are on HIV medicines. Some of the changes or mutations can allow HIV to resist protease inhibitors and other HIV medicines. Genotyping tests look for this kind of mutation, and can give your provider an indication if the HIV in your body is resistant to certain HIV medicines.

What the test results mean?

Having resistance mutations does not always

mean that the HIV in your body will not respond to the medicines you are taking. Even with resistance, the medicines may still be useful in keeping viral load lower and maintaining CD4 counts.

The results of resistance tests should always be looked at together with your CD4 count, your viral load and your medication history. Treatment decisions should <u>never</u> be made on the basis of this test alone.

Limitations:

- If there is only a very small amount of HIV in your blood, genotyping may not be possible.
- The test does not tell us anything about resistance to medications you were not taking when the blood for the test was taken.
- Your provider can give you much more information about what this test result means in your case.

Words to know:

Resistance: HIV is "resistant" to a medication if the medicine does not stop the virus from growing in people.

Mutation: A change in HIV genes that can cause resistance. This is most likely to occur if the medicines you are taking are only partially effective, sometimes because you are not taking them regularly.

HIV Genotyping: A test that detects those mutations in HIV genes that are related to resistance to one or several kinds of HIV medicines.

HIV Genes: The genetic coding that tells the virus how to copy itself, to spread in your body, and to damage your immune system.

WIHS Staff Biographies

Hi, I'm Michelle. I recently joined the WIHS staff as an interviewer/phlebotomist and have already had the opportunity to meet a lot of great women participating in this study. My background includes extensive volunteer work in free clinics for women, including the Women's Community Clinic in San Francisco where I am a health educator. I have also taken part in organizing health educational events sponsored by UCSF, including Women's Health 2000. My experiences with the participants in the past two months have been great, and I look forward to meeting the rest of the women in the study! During my free time, I enjoy hiking, swimming, baking, and cross-stitching.

i, my name is Jian Cheng. I am a computer Engineer. I come from Shanghai, an economic center of China. During to the open policy of recent years, Shanghai has developed into an international city that keeps up with the pace of new technology. Information Technology (IT) is such an example.

Ten years ago, I earned a master's degree in computer science. After many years of work experience, I have developed great competence on information systems, especially on IT service, databases and networks. These three fields are so intertwined that I can't tell which one I prefer more.

Because these three different skills are so complementary, I found they are of great benefit in the work I perform for the WIHS.

WIHS is a research unit on Women health and

HIV at the University California San Francisco. To carry-out successful research, WIHS has applied many new technologies, including the newest information technology. Our research group has about 25 desktops of the latest models. All of these desktops are organized as a network and connected to the Internet. On the network, we maintain a database that contains all the research data.

One of my jobs is technical support. I need to help the professors and staff members to use computers efficiently, solve problems with the desktop or network, keep the backup of research data and recover the corrupt files at any time.

Another of my jobs is database development. Most of this job focuses on data entry, developing new databases for new projects, maintaining accurate research data, and designing different kinds of reports.

In order to provide better service to participants, we will develop a local web site. This will be an information center from where participants can better understand WIHS research, access the newest research results and get more assistance.

I hope I can do more for both the WIHS staff members and participants. I feel that you are all my best clients.

Thank you from the bottom of my heart.





Dynamic Study

Phyllis Tien and Sarah Ellison

You may have read about the Dynamic Study in the WIHS newsletter last year or even participated in the Dynamic Study last year, but we'd like to tell you about our study again and let you know that we are still recruiting women for the study.

The Dynamic Study is trying to understand if sex hormones, such as estrogen and progesterone, cause men and women to have different reactions to HIV. Studies have shown that women have viral loads about one third to two thirds lower than HIV-positive men but women develop AIDS at the same rate as men. These men and women were never treated with HIV medications and had similar CD4 counts. Another study found that HIV-positive women with normal periods had lower viral loads in the second half of their menstrual cycle than in the first half. Studies have already shown that sex hormones affect the immune system, which may affect how quickly HIV multiplies in the body.

Our study looks at how fast the viral load drops after starting HIV medications in HIV-positive men and in HIV-positive women in different stages of the menstrual cycle. We are also looking at what is going on in the immune system and how it affects the viral load in men and women.

We still need to recruit 30 HIV-positive women who:

- · Have regular menstrual periods
- ·Have not used HIV medications in the past year
- · Have a viral load (HIV RNA level) greater than 10,000 copies/ml

- · Are not actively using narcotic or recreational drugs now
- · Are not taking hormones such as birth control pills or hormone injections

In order to be sure that women have normal periods, 2 vaginal ultrasounds will be done 2 weeks apart. There will be one overnight stay in the General Clinical Research Center (GCRC) at UCSF's Moffitt Hospital on the same day one of the vaginal ultrasounds are done. In the hospital, we'll start the HIV medicines and check T cells, hormone levels, and viral loads then we'll need to check viral loads every day for 6 more days. All lab, ultrasound studies and medications will be free of charge. We'll also cover the transportation costs.

You can earn up to **\$235** for participating in the Dynamic Study.

If this sounds like you or someone you know and you are interested in being part of our study, please call us at 415-502-5355.













CAB CORNER

Past, Present and Future: Where Do We Go From Here?

By Donna Haggerty, National Community Advisory Board (NCAB) Representative and Paula Wichienkuer, CAB Liasion



few years from now this study will reach its 10-year mark. Hopefully, it will continue beyond 2004.

In the beginning, the forms to fill out on that first visit were long enough to make into a novel! The known and unknown were there on paper and in all our responses.

During the past seven years the forms, ideas, and challenges have changed along with the continued involvement of the women enrolled.

This coming year, with funding, we will see a new challenge for the WIHS study and the WIHS community! This fall WIHS hopes to open the study to 150 more women as a way of making sure that we include women of all ages and treatment histories in our study of HIV. We will be recruiting HIV-positive women who have never used highly active antiretroviral therapy (HAART), HIV-positive women who are using HAART, and HIVnegative women who are similar to the HIVpositive women involved in the study. Since we're all only getting older, the average woman in WIHS is now in her early 40's, and there are few women under 30 involved. Because of that, we'll be concentrating on recruiting younger women so that the ages of

women in the WIHS reflects the ages of Bay Area women infected with HIV.

To get a better idea of how we should recruit these 150 new women, we will be holding some focus groups of younger HIV positive and HIV negative women later this spring. We'll ask women in these groups things like what would get them to participate in a research study and where they think we should look for women who would be interested. As always, we also appreciate any feedback **you** can give the Women's Study about what you like about the study and what things make it hard for you to keep coming in for your study visits.

The influx of younger and newer women will bring new ideas, enthusiasm, and opportunities to rejuvenate the study--a study that will be a balance of lifestyles, needs, medical histories, etc. of both younger and older women.





