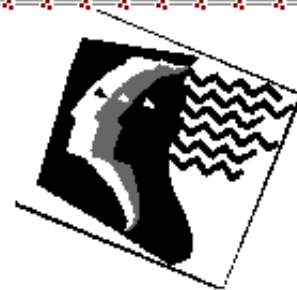


The WIHS Woman

The Connie Wofsy Women's HIV Study



Cats' Dream



by Pablo Neruda*

How nicely a cat sleeps,
sleeps with its paws and its gravity,
sleeps with its cruel claws,
and with its sanguinary bloods,
sleeps with all the rings
which, like burnt circles,
compose the geology
of a tail the color of sand.

I would like to sleep like a cat
with all the hairs of time,
with the tongue of flint,
with the dry sex of fire,
and after speaking myself over the whole world,
over the roof-tiles and the ground,
intensely determined
to go hunting the rats of dream.

I have seen how the cat as it slept
would undulate: the night
flowed in it like dark water,
and at times it was going to fall,
maybe it was going to plunge
into the naked snowdrifts,
or it grew so much as it slept
like a tiger's great-grandfather

that it overleapt in the darkness
Roofs, clouds, and volcanoes.

Sleep, sleep nocturnal cat,
with your ceremonies of a bishop
and your mustache of stone:
supervise all our dreams,
manage the darkness
of our slumbered powers
with your sanguinary heart
and the long collar of your tail.

*This poem is taken from: Full Woman, Fleshly Apple, Hot Moon. Selected poems of Pablo Neruda, Harper Collins, publisher, 1997.



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Changes for Visit 11

By Nancy Hessol, Project Director



Our core WIHS study visits are on a 6-month cycle, which means that new forms and study protocols begin every 6 months while old protocols end. Visit 11 starts 10/1/99 and will end 3/31/00.

What's ending? For visit 11, we stop doing 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.

Also stopping, for visit 11, is one of the modules (form 26) of the interview. This means your interview will be approximately 10 minutes shorter! For all study participants, the administration of form 26 will be done once a year at every even numbered study visit.

What's starting? For visit 11, we are bringing back the tuberculosis (TB) test (call PPD) and the skin anergy tests. These skin tests are placed on your forearms and you return 48-72 hours later to have us read the skin results. The TB test will be done once a year at every odd numbered study visit.

Mid-way through visit 10, we began the Interim Event protocol. This is a telephone interview that lasts about 5-10 minutes and is meant for HIV-infected women whose most recent (within the last 3 months) CD4 cell count was under 200.

We will also continue to enroll women into a new substudy that looks at one of the herpes viruses, HHV-8. Women who are eligible for this substudy are those who have tested positive for HHV-8 and who are HIV-positive. This new protocol will involve 3 additional study visits and collection of blood, saliva, and anal swabs and be done by both the core WIHS clinicians and the dental study clinicians.

For women undergoing cervical colposcopy, we will be adding 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 cervical biopsy and blood specimen collected for this study at the time of their colposcopy examination. We had hoped this substudy was going to start with visit 10 but, due to unforeseen delays, this will start with visit 11.

Thanks for being a part of this study and we look forward to seeing you at your next WIHS visit!

CAB CORNER



by Moher Downing,
Community Liaison

WIHS WOMEN LEARN TO SURF THE WEB-UPDATE

In our last issue of the WIHS newsletter you read about eight of your WIHS sisters attended a computer class here at the University of California, San Francisco, to learn how to "Surf the WEB." They were given free e-mail addresses at "Chickmail.com." Yes, these lucky women are now on the Internet and can receive e-mail from anyone and from any part of the world! Here is what one of your WIHS sister had to say about having access to the WEB:

"As you know, I have really gotten the chance to see if I need e-mail...."

I found out that the computer is like a man--you can't live with them and can't live without them.

As rep. for WIHS, it was necessary for me to have and use e-mail, but the confusion began instantly for me because I was not familiar at all with a computer!

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I don't know about the others who took the class, but, I have spent a lot of time talking out loud to the computer and sometimes it has not been a friendly conversation!!

Situations like losing my words before they go anywhere. But, classes opened a door for me."

Donna

Notes from the editor: If you have comments that you can send via e-mail. Please send them to ydes@itsa.ucsf.edu. We love to hear from you.

If you are interested in a future class, please call **Moher Downing at (415) 597-4654** and let her know.

F U N E V E N T

What do eyeliner, lipstick, nail polish, and body lotion have to do with your CAB? Well, on August 16, the WIHS CAB sponsored an educational forum on exercise and nutrition at the San Francisco AIDS Foundation. The positive women who attended this gala and fun event received free make-up as an incentive for their participation. They also received free movie passes, got to eat great food, participate in a fabulous raffle and play with their very own set of "resistance bands." What are resistance bands and what do they have to do with HIV? Resistance bands are multi-colored latex strips that are used to strengthen different parts of your body. By simply slipping one under your foot, for instance, and then pulling the ends up towards your torso, you stretch the muscles in your legs, thereby strengthening them. Strong body mass is important in the management of HIV disease especially if you are suffering from HIV wasting disease.

The women also got to talk with a nutritionist who answered lots of questions about junk food, vitamins, and Project Open Hand. Over 40 women attended this event, many of whom brought their

children. For their children, we had free gifts and special foods in the day care room. This event was supported by BTG Pharmaceuticals. We thank them for their enthusiasm and their funds.

THANKSGIVING WIHS STYLE

In November, WIHS will be hosting a special Thanksgiving feast for study participants and their children. The free turkey lunch will be at the **San Francisco AIDS Foundation, second floor conference room, on Tuesday, November 23rd, from noon to 1:30.** See attached flyer. At this event, there will no educational speakers, no raffles, no computer learning just turkey and all the trimmings. Want to come? Want to bring your children? Just call Sharon at (415) 476-9356 and tell her how many of you and your kids will be attending. We will not have childcare because we thought it would be nice for everyone to be able to eat together, but we will have volunteers ready to help with the kids. Hope to see you there.

WOMEN AND VIRAL LOAD

WIHS is in the process of planning a joint conference in January 2000, with Project Inform, and the Center for AIDS Prevention Studies on women and viral load. There have been several studies looking at the differences in viral load between men and women, but none of these studies have been conclusive. Some of them have even gotten contradictory results. This conference will bring researchers and providers together along with consumers like yourselves to talk about their different experiences with this important topic. Stay tuned for more information and details.



Women and HIV

A Brief Review:

By Dr. Malcolm John



The impact of the HIV epidemic on women continues to be a significant and worrisome issue. Women represent one of the fastest rising groups of new cases of HIV/AIDS and now make up 40% of all AIDS cases worldwide and about 22% of newly diagnosed AIDS cases in the United States in 1997. While overall deaths from AIDS declined in 1996 for the first time in the United States, deaths in women from AIDS rose 3% during that period. Possible reasons for this finding include the fact that the HIV epidemic began later in women than in homosexual or bisexual men; that women may not have the same access to health care as men; and that health care providers may not be aware of the signs of early HIV disease in women, potentially delaying the start of necessary medications.

How HIV is Spread to Women

The most common way HIV is spread to women today is from sex with men who are either users of intravenous drugs or who are bisexual. In addition, many women get infected by the use of injectable drugs when they share needles with someone who is already infected with HIV. Risk factors for the sexual transmission of HIV to women include the presence of any sexually transmitted disease (STD) such as herpes or gonorrhea in the HIV-negative partner; an uncircumcised male partner; sex during a woman's period (menses); bleeding during sex; receptive anal sex; and advanced HIV disease in one's partner. There is no clear evidence that hormonal contraceptives such as the contraceptive pill affect the chance of getting HIV. There is little information about the spread of HIV among women who have sex with women although such instances have been clearly identified. To decrease the risk of spreading HIV, it is important to use a condom during sex; to not use a used needle without cleaning it correctly in bleach and water; and

for HIV-infected partners to be treated as needed. Women who have sex with women should use a condom on sexual toys such as dildos and wash all sexual toys with a 1:10 dilution of bleach and water and consider the use of "dental dams" when in contact with vaginal secretions.

The Women Who Get Infected

The majority of women in the United States with AIDS are unemployed, live in households with less than \$10,000 per year, and are single parents in significantly larger numbers than men. Thus, in addition to their HIV disease, women often have many social issues that impact their ability to receive good care. Several studies have shown that women with AIDS are less likely to receive medications for HIV, hospital admissions and necessary follow-up care compared to men. This contributes to the reason women with HIV appear to do worse compared to men with HIV.

HIV Levels in Women

There have been conflicting reports on the amount of HIV in the blood of women compared to men with the same CD4 counts. There appears to be slightly lower levels in women than in men; the importance of this is not known. However, the risk of disease progression appears to be the same in men and women if equal access to health care occurs.

Different Signs of HIV Infection in Women

One example of the different signs of HIV infection between men and women is that the most common reason HIV-infected women seek medical help is repeated episodes of vaginal yeast infection. The other early signs of HIV infection are similar to that in men and include swollen glands, pneumonia, fever, night sweats, and/or weight loss. Another difference between women and men is that HIV-infected women are very unlikely to get Kaposi's sarcoma (KS) while it has been a significant disease in HIV-infected men. On the other hand, HIV-infected women are at risk of developing cervical cancer. For this reason, it is very important that HIV-infected women get routine PAP smears

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and that any abnormal PAPS get followed-up closely and treated as needed. Yeast infection of the throat may also be more common in women. Otherwise, the possible signs of HIV infection in women are similar to that in men.

Gynecological (GYN) Problems

As suggested above, gynecological (GYN) problems are very common in HIV-infected women. Vaginal yeast infections may not only be the presenting sign of HIV infection, but may also worsen HIV disease if chronic yeast infections are not treated. Other common GYN problems include genital infections with herpes, syphilis, and trichomonas. In addition, pelvic inflammatory disease and cervical infections from gonorrhea, chlamydia, and other bacteria are relatively common. Fortunately, the treatments for these infections are the same as in HIV negative women but early recognition and treatment of these infections are important. Some have suggested that HIV infected women may have irregular menstrual periods or other related menstrual problems. This has not been supported however, there is evidence that levels of HIV in a woman's blood vary with her monthly cycle suggesting that monthly hormonal changes may affect the way HIV spreads and progresses in women. Finally, women with HIV have a higher rate of abnormal PAP smears; a higher rate of these abnormalities progressing to cervical cancer; and a higher rate of recurrence of these abnormalities after they are treated. Although the chance of repeat abnormal PAP smears is increased in HIV-infected women, the treatment of abnormal PAP smears and cervical cancer is currently the same as in women not infected with HIV. Fortunately, the rate of cervical cancer in HIV-infected women in the United States has not risen significantly probably due to routine PAP screening.

HIV and Menopause

There is little information on the effect of HIV infection on women during or after menopause. There are some reports that sex after menopause may have a higher risk of spreading HIV because of

thinning of the vaginal walls in such women. Although getting HIV infected at an older age leads to more rapid progression of HIV disease in men and women, it is not clear if the going through menopause affects the HIV-related health of women infected earlier. It is important that women after menopause continue to have regular PAP smears as cervical cancer increases with older age. In addition, regular exams for breast cancer and other health issues related to women after menopause whether or not they have HIV is important.

HIV Medications and Women

Little is known about the different effects of HIV medications between men and women possibly because the number of women in early HIV drug trials has been rather low. Recent studies suggest that HIV medications may be as effective in women but with different side effects. The drug ritonavir (Norvir) causes similar side effects in men and women but women may have more nausea, vomiting, fatigue, and numbness/tingling around the mouth. Men tend to have more diarrhea. The drug nelfinavir (Viracept) may result in more belly pain, itching, and skin rash in women. Interestingly, one study reported that nelfinavir may cause a somewhat larger increase in CD4 count among women compared to men. Protease inhibitors, a type of HIV medication that includes nelfinavir and ritonavir, have recently been found to cause abnormal fatty collections and high cholesterol levels in some patients. This appears to occur equally in men and women; however, women may be more likely to have increases in breast size and fat in the belly. Men may be more likely to have high cholesterol, thinning of the arms and legs, loss of fat in the buttocks, and increased fat on the back of the neck.

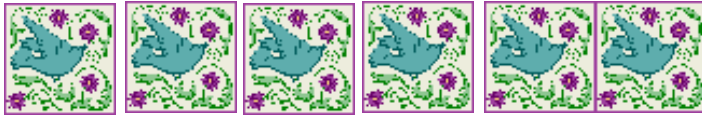
Summary

In summary, the HIV/AIDS epidemic continues to be a major health problem for women worldwide. Women continue to be a group increasingly at risk for getting HIV, progressing to AIDS, and doing more poorly from their in

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fection. Reasons for this include lack of understanding of the differences in the signs of HIV infection between women and men; lack of understanding of differences in the way HIV can progress between women and men; and differences in access to health care between women and men. Studies such as the WIHS help improve our understanding of these issues and emphasize the importance of regular health care follow-up for women with HIV/AIDS.



WIHS NCAB Meeting Chicago, June 5-9, 1999.

By Donna Haggerty



My trip to Chicago was my first out of town trip for the WIHS. It was also my first plane trip in 12 years! My instant discovery was how many people are now at airports and that I had the wrong luggage!

Everybody, everywhere, including kids had portable luggage on wheels! I kept thinking - they all know when looking at me that I have not been anywhere in years.

After settling into my hotel room, I discovered just how far outside of Chicago we were. We were in the high tech suburbs with Merrill Lynch directly across the street! I felt I was in the Silicon Valley surrounded by concrete high rises.

The next morning, representatives from the other WIHS sites met for our own meeting before the others arrived that evening. We were in one continuous meeting all day.

The most serious concern brought up by the women was the current way the interviews were being done. It appears that it is very difficult for many women to completely open up and be honest when answering some very direct and sensitive questions. The overall feeling was that some of the participants felt that the interviewers are sitting in judgement of them as they speak their true feelings. This issue was brought up many times during our meeting. Everyone felt a change needs to be made. One suggestion was that at the beginning of each visit a screen would be set up to separate the interviewer from the study participant. This may not be a good idea because we often see the same staff member over a period of time and there is already a connection between the two parties, thus the feeling of confidentiality is no longer present.

Another issue CAB members felt was important was that new ideas are needed to bring in new women into the CAB. Keeping a constant interest is not always possible. Even trying to bring women into the conference calls does not guarantee a woman will continue with the CAB. We all know that there are many obligations in each of our lives. We often feel pulled in many directions at once.

At the end of the meeting all NCAB representatives concluded that there needs to be a review of our previously discussed issues that are still on the table on a local level.

The conference left us with no time to see the Chicago area, but it certainly kept us busy! The next WIHS NCAB meeting will be held in Washington, D.C. during the first week of December.

In conclusion, I feel since being able to attend the national meetings in San Francisco last December and being able to attend this last session, I have been introduced to the vastness of this study. I see that a large amount of work still needs to be done if we are to bring an end to this virus and I am glad to see the many

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people whose knowledge and caring will help this to happen sooner than later.

I was grateful that I was able to attend these conferences and hope that I may attend future ones.



INTERESTING WEB SITE



The California Partners Study II (CPS II) which is from the Department of Obstetrics & Gynecology and Center for AIDS Prevention Studies (CAPS) at UCSF has updated their web site. Their web address is <http://www.caps.ucsf.edu/projects/Capartners.html>.

Their web site contains a description of the CPS II study and some of their research findings. There is a copy of an abstract posted on their web site, which is entitled, The Management of HIV, Sex, and Risk among HIV Serodiscordant Heterosexual Couples.

The CPS II group has also published a booklet "10 Ways to Help Someone Prevent HIV" which outlines 10 easy steps to implement and maintain safer sex. You can download this file from web as long as your computer has a reading software program called Adobe Acrobat Reader. This software allows you to files created for the web that are called PDF files (portable document format). You may download this reader for free from the Adobe software web site (<http://www.adobe.com>).

For those of you who do not have access to the Internet, we have briefly summarized this booklet for your information.

10 Ways to Help Someone Prevent HIV by the California Partners Study II. This booklet contains a short list of strategies for helping patients, clients, students, customers or friends in their efforts to prevent HIV.

1. *People don't change when they feel bad about themselves.* Effective, consistent HIV prevention requires that a person care enough about herself or himself to want to save her or his own life. In

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your ongoing interactions you can make a difference by demonstrating that you have faith in that person and hopes for their future even if they don't. **Never miss a chance to pay a compliment or show interest in a goal or plan!**

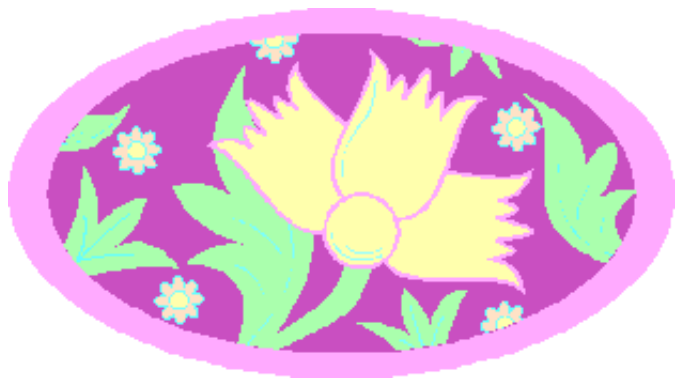
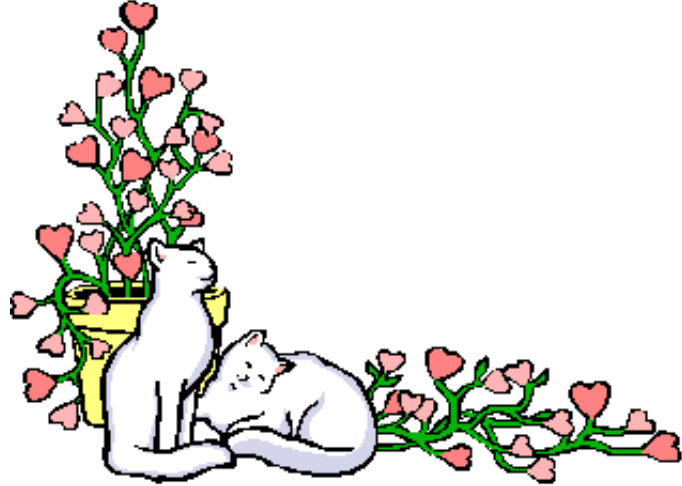
2. *Communication is a skill.* When it comes to having safer sex, no one, not even someone in a long-term relationship, can always guess what a partner is thinking. Talking about sex and sharing decision making can help make sex safer---and better! Plan to talk when you will both have time and privacy. Try to find a time when you are feeling close, but not sexual. Make sure you talk **with** your partner, not just **to** your partner.

3. *What are the reasons behind unsafe behavior?* There is a reason why someone may have a hard time practicing safe sex. **Don't try to convince someone that their reasons are not important; you cannot help them by making their feeling seem meaningless.** Instead, give a person space to express anger, resentment, sadness, or frustration at having to limit themselves to protected sex.

4. *Routes of transmission.* HIV needs 3 things to be transmitted from one person to another.

- One of the people must already be infected with the virus.
- The virus must exit that person's body in a fluid that had a high enough concentration of HIV. Fluids with a high enough HIV concentration to transmit the virus from one body to another: blood, semen, vaginal fluids, menstrual blood, breast milk.
- The virus must have a way to enter person's blood stream before it dies.

5. *The HIV virus doesn't care.* The virus has no feelings. It does not discriminate between married or single people, it doesn't care if you are gay or straight, and it does not care if you are mean or nice. In other words, do not give HIV a chance to get into your blood stream.



FAMILY HOLIDAY PARTY



The annual San Francisco AIDS Foundation Family Holiday Party is Wednesday, December 15, 1999, from 4 to 7 PM. Please call the AIDS Foundation to sign up and for more details. Everyone must sign up so that they can have presents for all the children and the women.

