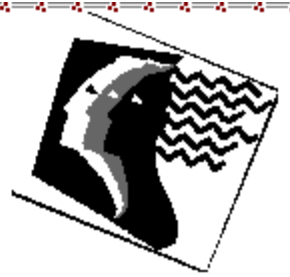


The WIHS Woman

The Connie Wofsy Women's HIV Study



SPRING HAS RETURNED

by Charles Haseloff

Spring has returned. The earth is
like a child who knows poems.
Many, manyShe gets the prize
for the hardship of extensive learning.

Her teacher was strict.
We liked the white in the old man's beard.
Now, as to what the blue is, the green.
we can ask her: She knows, she knows.

Earth, off from work, lucky one, play now
with us children. We want to catch you,
jubilant earth. The most joyous succeeds.

Ah, what the old man taught her - the manifold
and what is written in roots and in long,
difficult stems: She sings, she sings.

*Taken from: World Poetry,
Washburn, K and Majors, JS, eds.,
1998, W.W. Norton & Company,
New York, NY.*



What's New For Visit 10?

by Nancy Hessel, Project Director

Our core WIHS study visits are now on 6-month cycles, which means that new forms and study protocols occur every 6 months while old protocol get retired. Visit 9 began 10/1/98 and ended 3/31/99 and so visit 10 began 4/1/99 and will end 9/30/99.

What's ending? For visit 10, we stopped doing the tuberculosis (TB) test (call PPD) and the skin anergy tests. These skin tests were placed on your forearms and you needed to return 48-72 hours later to have us read the skin results. The TB test will be done again at visit 11 (every odd numbered study visit).

We also stopped the "butt" study interview and specimen collection (oral rinse and anal swabs). In the future, if more funding is received for this study then we may start it back up.

What's starting? For visit 10, we are adding a pregnancy protocol for women who are or have been pregnant within 6 months of their visit 10-

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study visit. Women who are eligible for this substudy will have additional questions asked of them and, with permission, their prenatal and delivery medical records reviewed by our study staff. For women who are currently pregnant, we may ask you to return for one additional visit. The purpose of this substudy is to learn more about how pregnancy influence the course of HIV-infection in women. Both HIV positive and HIV negative women are eligible for this substudy.

Also for visit 10, we are adding more anthropometric (body shape and size) measurements during your physical examination. This will include weight, tape measuring upper arms, breast, waist, hips, and thighs, skin fold measurements using a caliper, and an electronic device called a Bio-electrical Impedance Assay (BIA) to measure body fat. The idea behind this substudy is to monitor the effect that new HIV medications have on body fat and weight distribution. This will be done on all participants as part of your regular WIHS visit.

Another new substudy for visit 10 is looking at one of the herpes viruses, HHV-8, that has been associated with causing Kaposi's sarcoma (KS). 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.

One last study beginning in visit 10 is a study of the

immune system in HIV-infected women. Specifically, we are looking at one of your t-cells (the CD8) and how the immune system reacts to changes in your health. This study is called the CD8 substudy and only a select number of women will be eligible. No additional blood or other specimens will be collected but a few additional questions will be asked by our study clinicians.

We look forward to seeing you at your next WIHS visit!



Directions to UCSF/Mount Zion Medical Center 1600 Divisadero Street San Francisco



Traveling by Car From Marin County

From the Golden Gate Bridge, take the Downtown exit to Lombard Street. Turn right on Divisadero Street and continue to the hospital at 1600 Divisadero.

From the East Bay (Hwy 80)

From I-80, take the Fell Street exit and follow Fell to Divisadero. Turn right on Divisadero Street. Continue to the hospital at 1600 Divisadero.

From the Peninsula (Hwy 101, Hwy 280)

Follow signs for 101 North/Golden Gate Bridge. Take the Fell Street exit and follow Fell to Divisadero. Turn right on Divisadero Street. Continue to the hospital at 1600 Divisadero.

Parking

Public parking is available across the street from UCSF/Mount Zion. Enter the garage on Post Street between Divisadero and Broderick Streets. In addition, there are other parking lots within

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walking distance of the hospital.

Traveling by Muni

UCSF/Mount Zion is easily accessible via Muni bus routes No. 2 (wheelchair accessible on week-ends), 38 (wheelchair accessible daily), 4 and 24. The No. 1 California stop at California and Divisadero is three blocks north of the hospital.



USE THE MAIN HOSPITAL ENTRANCE AT 1600 DIVISADERO, and after passing through the lobby take the elevators in the short corridor to your right. Go to the 6th floor, and to the 6 West Wing, on your left when exiting the elevators. This is the new site of the UCSF GCRC. If you don't see one of our project staff, just ask someone in 6W where to find them.

IF YOU NEED TO CONTACT US on the day of your appointment, please call us at our new Mt. Zion location: **(415) 353-7438**

IF YOU WANT TO LEAVE A MESSAGE, please call:

Debbie/Julia/Debra: 476-6018

Jill/Marquita/Donna/Maribel: 476-5109



Update on Fat Redistribution

by Kathy Mulligan

Some people call it "fat redistribution;" others call it "lipodystrophy;" still others call it "body shape changes." We call it just plain puzzling. Whatever term you choose, the unexpected changes seen in men and women with HIV infection have gotten a lot of attention. However, despite all that has been said and written about fat redistribution in the last year and a half, there is still very little that is known. It is clear that body shapes are changing in both men and women. The types of changes that have been seen include fat gains in the belly, breasts, back of the neck (also called a "buffalo hump"), and other assorted places; as well as fat loss in the arms, legs, buttocks, and face. We know that these changes can seriously affect the way people feel about their bodies. That is about all that we know for sure. We don't know why some people get these changes and some don't, or why some people change in one area but not others. Most importantly, we don't know what is causing these changes. At first, most people assumed that the changes are a result of being on protease inhibitors. However, not everyone who gets fat redistribution is on a protease inhibitor, and not everyone on a protease inhibitor gets fat redistribution. For example in a study published recently on fat redistribution in women seen in a clinic in Italy, 12 of 32 women who had fat redistribution had never been on a protease inhibitor!

In addition to fat redistribution, many people with HIV infection are having increases in the levels of fats and cholesterol in their blood and alterations in the way they process sugars. A few people are developing diabetes. Diabetes is rare, however. Some people are connecting the "metabolic" changes with the fat distribution changes and with

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protease inhibitors, but we don't yet know if the changes are linked. We also don't know what the long-term medical risks of these changes might be. In HIV-negative people, increased fat around the belly and abnormalities in sugar and fat metabolism can increase their risk of having heart disease. It's too early to know these changes in people with HIV infection also increase the risk of heart disease, but this possibility is being studied.

Another question that we can't answer yet is whether the changes in women and men are different and whether women get these changes more or less often than men. Because different hormones in women and men control fat distribution and muscle mass, it would not be surprising if there turned out to be gender differences in patterns of abnormal fat distribution. Most of the published studies so far are in either men or women but not both and not all the studies agree on how often fat redistribution happens. For example, the rate of occurrence of these changes in groups that were mostly men has ranged from 2% to more than 80%. Each of these studies seems to use a different way to define fat redistribution or lipodystrophy, or whatever they call it, so it is not surprising that they would come up with a different result. The range of reports of fat redistribution in women is from 10% to more than 50%. We should be very cautious in attributing differences to gender alone, however. There are a number of other factors that can affect fat redistribution, including race, age, how fat or lean you are at the beginning, whether you are gaining or losing weight, as well as diet and exercise patterns.

One change that has been particularly troubling to women is an increase in breast size. In many cases this is noticed easily because of increases in bra size or changes in the way bras fit. In some women, this increase in breast size seems to come with an increase in waist size and a decrease in fat

in the buttocks and legs. Keeping track of numbers such as bra, waist, and hip size are helpful in determining the extent of these changes and when they began to happen.

Because we do not yet know the role, if any, of antiretroviral therapy, viral suppression, or other factors in fat redistribution, it is hard to make recommendations on how to prevent or reverse it. Apart from extreme abnormalities in sugar and fat metabolism, we also do not know whether there is some medical risk associated with these changes. As mentioned earlier, we do know that these changes are very troubling and can have a negative effect on the way people feel about their bodies. Some studies have been started to see if switching from a protease inhibitor to some other antiretroviral regimen can reverse fat redistribution, but it is too early to tell if switching will make a difference. In addition, some patients in these studies who switched off their protease inhibitors have had increases in their viral load.

What can you do? If you think you are experiencing any of these changes, discuss them with your regular medical provider. Abnormalities in sugar and fat metabolism can be best assessed in blood samples collected under fasting conditions - that means having nothing to eat or drink other than normal amounts of water for at least 8 hours before the blood is taken. As mentioned above, you can help by keeping track of your bra and belt sizes. If you have a measuring tape, you could even measure the distance around your waist and hip. For these measurements to be useful, you need to do them carefully. The tape measure should be parallel to the floor, and you should hold it so that you hold it so that it just touches your skin, rather than squeezing. The easiest way to measure your waist is to find the smallest distance around and measure that. For the hip, you should find the largest distance around. Using a

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mirror might be helpful. If you are interested in taking a little time to follow these changes, there is a nutrition study at San Francisco General Hospital that you could join. For this study, you would come in every 6 months for measurements of how much fat you have in your body and where it is distributed, fasting blood samples, and other measurements as

well. A visit typically lasts about 3 hours. If you are interested in enrolling, please call Viva Tai, MPH, RD, at (415) 206-4090.



CAB CORNER

by Moher Downing, Community Liaison



This edition of the newsletter comes at a time of great change in the world of women and AIDS. What's happening ?? Well, now more than ever your participation is needed in a variety of planning and advisory boards and committees. Part of the mission of this column has been to inspire you, a WIHS participant, to join the large, active, loving, and vital community of women with HIV or AIDS who are working to bring much-needed resources to women affected and infected with HIV.

Many of you have completed HIV U, the WIHS Community Advocacy Training, the Women's AIDS Network Lobby Day Training, or one of the many AIDS training activities over the past ten years. It has been great to see so many new faces working together and making new friendships, especially at the new WORLD offices in Oakland.

How did they get involved? Were these women always activists? When confronted with a life-threatening issue, did they always respond actively? How did they know where to meet people? How did they know what to say? How did they know what to wear? Those of you still at home wondering how "those woman with HIV" made the transition from their living room chair to the Board of Directors need not worry about where to begin. Many of "those women" that I

have talked to told me that the first event they attended was a WORLD mailing. The atmosphere is very warm and friendly. While getting the newsletter ready to mail, they eat pizza, gossip, and joke and share treatment information. They also talk about their projects and the political scene in their county. Check the calendar in the WORLD newsletter for the date of the next mailing. That calendar of events was mentioned as the number one way a great many of the women that I talked to found out what was happening. If you see an event that you would like to attend, give me a call and I will either go with you or find someone to go with you. Don't let shyness keep you from getting involved.

Please see the enclosed flyer for information about upcoming WIHS-sponsored Events. And don't forget to call me at (415) 597-4654 if you're sitting at home watching TV and wondering how to get involved in HIV community work. I look forward to seeing you around.



Sixth Conference on Retroviruses and Opportunistic Infections

by Yvonne De Souza

The 6th Annual Conference on Retroviruses and Opportunistic Infections was held Jan. 31 - Feb. 4, 1999, in Chicago. This research meeting provided a forum for basic and clinical science investigators to present, discuss, and critique developments in the field of human retrovirology and related opportunistic complications. This meeting is where HIV researchers from around the globe come to discuss and learn the current state of the art in HIV research as well as other retroviruses. Many WIHS investigators from various sites attended and presented data at this meeting. Topics included:

- Diagnostics
- Epidemiology
- Host-Virus Interactions
- Immunology
- Pathogenesis
- Pathology
- Pharmacology
- Prevention
- Therapy
- Vaccines.
- Virology

New studies concerning the diagnosis, treatment, and prevention of associated opportunistic infections were also included. The meeting featured lectures, roundtable discussions on controversial scientific issues, original slide and poster presentations of new data, poster discussion groups, and late breakers consisting of important preliminary research findings. Many of the interesting presentations this year involved research that crossed various disciplines. The following is an outline of some of the highlights that were presented at the meeting:

DAY 1 - SUNDAY, JANUARY 31

The Origins and Entry of HIV - James I. Mullins

DAY 2 - MONDAY, FEBRUARY 1

New Antiretrovirals: What is in the Pipeline? -
Antiretroviral Therapy: State of the HAART -
Can We Restore and Preserve Immune Reserve?

DAY 3 - TUESDAY, FEBRUARY 2

Pharmacology and Drug Interactions: Improving
Care or Complicating It?
The Most Potent Antiretroviral Weapon -
Cellular Immunity
HIV and the Central Nervous System -

DAY 4 - WEDNESDAY, FEBRUARY 3

Studies in Naïve Patients: The Best-Case
Scenario, But for How Long?
Metabolic Complications of Antiretroviral
Therapy
Understanding Pathogenesis: Reservoirs,
Receptors and Latently Infected Cells

DAY 5 - THURSDAY, FEBRUARY 4

Immune Reconstitution -
Highlights from the Late-Breakers
More Highlights from the Late-Breakers

If you have access to the Internet you may log
onto the following address to read about some of
the presentations that were made:
<http://www.retroconference.org>.



YOUR WIHS WORDS



Again we are proud to include your comments and feedback about your participation in the WIHS Study. Some of you have been in the study for 6 years and we hope you continue to provide us with feedback about your experiences in the Study.

"I like this place better because they treat me like a human being."

"The TB study is totally inconvenient. I rarely participate because I can't return for a reading most of the time. Everything else is great though."

"Behind this study are many, many women, who like myself, keep a detailed eye-out on their body and what it's doing. And from time to time we focus on all the negative aspects of this virus/disease. Whatever part affects you-- HIV+ or AIDS related complications-- I want to say that its good when good news is given. All the "needle sticks" that were difficult...All the questions that seemed to go on forever...All the "pussy-poking" (smile...pap smearing...It feels real good to be told that your HTLV results have no infection. This definitely reinforces my "spirit" that I must be doing the right thing and that I've made friends with my HIV and it's doing fine by me."

"I have been very happy with the treatment, both emotional and physical I have received with the women I've come into contact with through the program. They have always been kind, courteous, and gentle. I'm glad to hear that the study has been extended."

"Sure, I wouldn't mind a little television while waiting or a psych on call for stress management problems that are presently troubling me. We could talk in between questions and physicals."

"I actually enjoy my WIHS visits. Maribel, Donna, and Debra have become my friends and I feel comfortable talking to them about anything (medical or not) and I never feel as if I'm being looked down upon for my addiction or that possibly I don't know what I'm talking about even when it relates to my very own body."

"I feel that the visit could be shorter. I don't understand why it should take so long to answer the same questions over and over again. You should be asked if anything has changed in six months or not. Not go through the whole stack of paper work again and again. Other than that, it's a very interesting study."

"I am very much interested in the women's study. I love for Donna and Maribel to take all my information but please send Donna back to Highland. We miss her so much, PLEASE!!! Thank You."

"Donna was really nice. I haven't been to the study for 2 years but because of Donna and her caring ways, I will be back. I wish she were in SF all the time. I hate getting the anal swab but I know it's important."

"I enjoy this study because it keeps me informed about what's going on with me. The people here are great and I feel close to them. Thank You."

"Thanks for bringing Donna back. I really missed her and now I was able to get my blood drawn. She is the only one who can get me. Thank God for Donna."

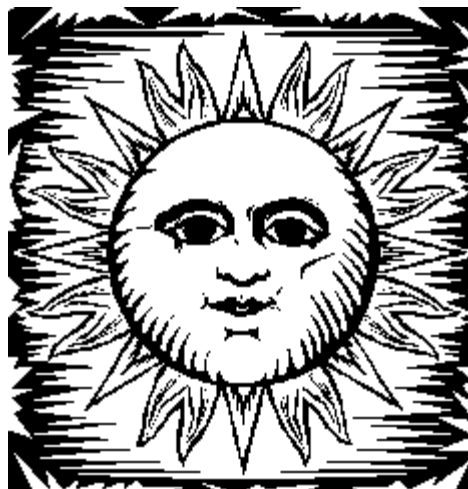
"To whom it may concern: Maribel has been a great help and support to me, more as a friend instead of a case manager, etc. She takes her time as if she was the client and never rushes me. She is very patient with her work. Too bad there aren't more women like her. I feel very comfortable with Ms. Rodriguez (Maribel). I think she is a wonderful and very cheerful young woman. I'm glad someone like her is working here and supporting us mentally at the same time."

"Yes...yes...Donna's back. Thank you. Thank you. It wasn't the same without her. She is the best."

"Well, I think everything is all right. Thank You."

"To whom it may concern: The new forms added to the study on medication needs to be revised. The questions are put in such a way that I felt like they were trick questions. Also, since having added these additional forms, it has lengthened the interview time and I feel I should get more money as well as the interviewer. PS. Can we please start getting Safeway vouchers?"

Note: "We now have Safeway vouchers."- Nancy Hessol.



WEB Sites of Interest



The following is a list of WEB sites that some of you may find of interest. If you do not have access to a computer and the Internet please see The WIHS Woman, Fall 1998 (volume 2, issue 4) newsletter. You will find a fairly complete listing of public libraries that have public access to the Internet. If you are looking for a particular Web site for fun, recreation, health issues, or whatever, please do not hesitate to contact Jessica at (415) 502-6290.

WIHS WEB Site -

<http://www.statepi.jhsph.edu/wihs>

UCSF/SFGH HIV WEB Site

<http://www.hivinsite.ucsf.edu>

Project Inform

<http://www.ProjectInform.org>

Project Inform is a national, non-profit, community-based organization working to end the AIDS epidemic. Its mission is: to provide vital information on the diagnosis and treatment of HIV disease to HIV-infected individuals, their caregivers,



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and their healthcare and service providers. Project Inform also advocates for enlightened regulatory, research, and funding policies, affecting the development of, access to, and delivery of effective treatments as well as to fund innovative research opportunities. They also hope to inspire people by enabling them to make informed choices amid uncertainty, and to choose hope over despair.

WISE Words is the three-times yearly publication of Project WISE, Project Inform's interdepartmental program focused on HIV/AIDS treatment information and advocacy for women.

Project Open Hand

<http://www.openhand.org>

Project Open Hand provides comprehensive nutrition services to thousands of men, women and children living with symptomatic HIV and AIDS in San Francisco and Alameda counties in California.

Womens Health Sites

1.

<http://www.plainsense.com/Health/Womens/>

This WEB site has medical information on children, men, and women. The address above is focused on women's health questions. They have articles on breast cancer, fibroids, cervical cancer, etc. This particular site helps people with medical terminology and some basic medical questions.

2. <http://www.womens-health.com/>

This is another WEB site devoted to women's health issues and they have an interactive site that helps to facilitate the exchange of information among its participants.

3. <http://www.womens-health.com/GynHealthCenter/>

This WEB site is part of the WEB address (#2) above but it focuses on gynecological (GYN) issues. There is a Gyn Center Guide who will give you guided tour of their site. It will help you find the information you are looking for, and give you some insights about WHI's interactive design.

4.

<http://www.coffeewomenscenter.com/cwchealth.html>

This WEB site posts articles on various womens health topics that you can print out to read.

5. <http://www.healthy.net/womenshealth/>

This WEB site covers many areas of womens health and provides some alternatives to Western medicine.

