

# The WIHS Woman



## The Connie Wofsy Women’s HIV Study

### We’ve Moved!



The WIHS San Francisco field team office has moved and our phone numbers have changed. Don’t worry; we will still see you for study visits at Mount Zion and at San Francisco General Hospital, although we now have space to conduct some study visits at our new location at 1515 Scott Street #1 – right across the street from Mount Zion.

Along with a new address we have new phone numbers. They are listed below:

### Main WIHS study line (for appointment etc) (415) 502-8800

Yael Danovitch	415-502-8804
Bernice Ferrer	415-502-8812
Alyson Holsclaw	415-502-8805
Tara Ilsley	415-502-8802
Jane Pannell	415-502-8801
Janice Rothstein	415-502-8804
Joyne Taylor	415-502-8803
Julia Thomas	415-502-8807
Carol Thuman	415-502-8806

We look forward to seeing you all at your next Women’s Study visit.

### Fall 2011 EC Meeting in Los Angeles

*By: Adrienne*

Our National Community Advisory Board (NCAB) was held on Sunday, September 25, 2011 in Los Angeles, CA. We began our meeting with general business and talked about what we can do as NCAB representatives to make the local Community Advisory Board (CAB) meetings a better experience for the women. One suggestion was to have a support group for our CAB members at least 30 minutes before our CAB meetings.

Throughout the course of the day, there were several presentations from WIHS researchers. The first presentation was given by Dr. Jean Richardson. She talked about a new study that examines the relationship of pain frequency and the intensity as it relates to disease characteristics of licit and illicit substance use. It was noted that 30-88% of persons living with HIV/AIDS experience pain. Some studies find that women experience more pain. Therefore, re-

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searchers want to know if pain is experienced differently by those of different ages, ethnicities, or education levels; or do those of different ages, ethnicities or education levels report it differently.

Next, Julie Cederbaum talked about a research study that takes place at a camp for women with HIV and their daughters. The program is currently going on in Los Angeles and Minnesota. Julie said the WIHS is interested in gaining more information about children born to mothers with HIV and how information is communicated about abstinence and safe sex.

The next presentation was given by Dr. Marek Norwicki about blood draws for research studies. He explained how the maximum amount of blood sampling is calculated by body weight and other individual lab markers. He also discussed how several types of cancers are higher in women with HIV than in women without HIV.

Joel Milam talked about the use of hair cortisol as a biomarker for chronic stress among women living with HIV. Cortisol is a biomarker of the stress response.

On Monday at the WIHS EC meeting NCAB representative - Jeanette Carter, reported that the NCAB is in favor of expanding the study on mothers with HIV and their children. She also reported that the NCAB is working on submitting an abstract to the International AIDS Conference in Washington D.C. Dr. Levine agreed to help with the abstract. The topic is "What gives us strength to keep coming back to the Women's Study." The NCAB also wanted to know if study participants can get their results from genetics studies. Lastly, a concern was raised about the length of the CIDI sub study visit and the amount of com-

pensation for that study.

In closing, I would like to add that research is amazing! I have learned so much about myself as a woman. It is great to know that the WIHS is really putting forth an effort to find answers, cures, and solutions for HIV/AIDS.

## CAB CORNER



### Fall CAB Meeting

*By: Heneliaka L. Jones*

We had a full agenda at our last Community Advisory Board (CAB) meeting in September. "Ask Dr. WIHS," was the theme. Dr. Amy Garlin did a wonderful job addressing questions and concerns from those in attendance. Surprisingly, the most interesting topic was on "gas". We learned that gas from the stomach passes through the mouth, while gas in the large intestine passes through the rectum. She talked about how some HIV medications may increase gas producing bacteria in the large intestines. Certain foods and age may also be factors.

During the meeting WIHS evaluation forms were passed around the table to get everyone's input. WIHS feedback forms will be available at your perspective WIHS clinics in the near future. These forms are anonymous and will let us know how we can improve your WIHS visits and/or what we should continue doing at your WIHS visits. It is just another tool that will allow you to voice your opinions. Also, our NCAB representative Lynnell, shared what she learned at the fall Executive Committee (EC) meeting in Los Angeles, CA. Lastly, we announced that the WIHS is enrolling HIV negative women and to share the news with

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your friends and family.

We closed our meeting with the well-anticipated raffle prize drawing and two lucky women went home with gift cards. After our meeting there was plenty of bar-b-que chicken, greens, potato salad, corn bread and beans to make to-go plates. We had a wonderful afternoon. I hope to see more new faces at our next CAB luncheon in March! In the meantime, if you have any topic suggestions for our CAB, please call or email me: Heneliaka jones - 415-502-6284 or [Heneliaka.jones@ucsf.edu](mailto:Heneliaka.jones@ucsf.edu). I look forward to hearing from you.



## HIV Lipodystrophy: What's New in Treatment?

By: Phyllis C. Tien, MD, MS

Since the introduction of highly active antiretroviral therapy (HAART) in the mid-1990's, lipodystrophy has been of concern to men and women with HIV. Lipodystrophy is a general term that has been used to describe any signs of lipohypertrophy (or any fat gain in the belly, breast, and upper back) and/or any signs of lipoatrophy (or fat loss in the arms, legs, and cheek area of the face). Severe fat loss in the cheek area of the face and leg can be very disturbing to patients and can affect how they feel about themselves. In addition, fat gain in the belly or upper back can also be a major source of concern. Research in the WIHS and other studies suggests that fat loss is a direct effect of HIV and fat gain could be due to normal aging or becoming healthy again after starting HAART. Among the HIV drugs, stavudine and less so, zidovudine or AZT, are risk factors for fat loss. Fortunately few HIV- positive pa-

tients in the U.S. use these drugs today, because of the development of newer drugs that don't have this side effect.

How to treat lipohypertrophy and lipoatrophy in HIV has been a major question.

In terms of *fat loss*, certain drugs that are prescribed for diabetes and lowering cholesterol, as well natural supplements have been studied, but how well these drugs work to increase fat in areas of significant loss is questionable.

A treatment for severe fat loss in the face in HIV-positive patients has led to improvements in how patients feel about themselves. Poly-L-lactic acid (also known as Sculptra®) is a facial injection treatment that works as a filler and is approved for use in HIV positive patients with severe fat loss in the face. This drug must be injected into the face multiple times and be performed every few weeks for a total of 4 to 6 visits depending on how severe the facial fat loss is. Some patients will report feeling small firm bumps under the skin after the injection, but usually these are not noticeable and can be reduced by massaging the face multiple times over several days after the injection. The downside with this drug is that it only lasts for about 2 years. Some patients will get reinjected to maintain the fullness in their face. This procedure can be expensive. Some health insurance plans will cover this, if the fat loss is severe.

In terms of *fat gain*, metformin, a drug used to treat diabetes has been studied to reduce belly fat, but how well it reduces belly fat is questionable. Furthermore, it may also cause fat loss in the arms and legs. Early on, the fat gain seen in HIV was blamed on the use of protease inhibitors, but studies have shown that switching from a protease inhibitor regimen to a non-

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protease inhibitor regimen was not significantly associated with reductions in belly fat. Others have also studied the effect of exercise on fat gain, and have shown some benefit, but maintaining a regular exercise schedule can be difficult.

In 2010, the first drug to treat lipohypertrophy was approved for use in HIV. This drug, tesamorelin works to stimulate production of growth hormone in the body. The increased levels of growth hormone are thought to lead to decreases in belly fat. The downside with this drug is that it is an injection and once you complete a course of treatment, the belly fat returns. Little is also known about what happens to patients long term if they give themselves this drug. Tesamorelin can lead to increases in the hemoglobin A1C level, which is a test used to monitor diabetes. Tesamorelin can also increase insulin-like growth factor (IGF) levels. There is some concern that the increased IGF may be associated with cancer. So while this drug is approved, patients and providers should use caution when considering whether to start this drug in an HIV-positive patient with increased fat in the belly.

Investigation of new drugs to treat lipoatrophy and lipohypertrophy are needed.



## WIHS Open Enrollment

*By Nancy Hessol, Project Director*

We are still recruiting new participants into the WIHS! HIV-positive and HIV-negative women who meet our eligibility criteria may be able to join our research study.

Here are some statistics on our current recruitment efforts, both nationally and locally, as of 12/14/11. There are six WIHS sites around the country that are enrolling new study participants and so far the Bronx site has enrolled 20 HIV-positive women, Brooklyn has enrolled 21 HIV-positive women and 3 HIV-negative women, Chicago has enrolled 64 HIV-positive women and 13 HIV-negative women, Washington DC has enrolled 14 HIV-positive women, LA has enrolled 28 HIV-positive women, and our San Francisco Bay Area site has enrolled 53 HIV-positive women and 13 HIV-negative women. This makes a grand total of **200 new HIV-positive women and 29 HIV-negative women** to date. All sites are still enrolling and we will keep you updated as to our progress in future newsletters. Also, please see the recruitment flyers on the back page of this news letter for more information.

To our newest recruits, a warm welcome and I hope you enjoy the experience and stay with us for many years to come. And to all our study participants, best wishes for 2012 and beyond. Happy Holidays!



## T'is the Season

By: *Heneliaka L jones*

On Thursday, December 8, 2011, we held our End of the Year Participant Appreciation Party at the UCSF Faculty Alumni House and it was great! We had a wonderful turnout with delicious food, terrific gifts, and the highlight this year were chair massages, sponsored by the San Francisco School of Massage. Thank you to those participants and family members that came out to celebrate with us- your presence made this year's party a success. It was a delight to see long-time WIHS participants and meet new participants. We would also like to recognize the following organizations for donating gifts: Winslow & Associates, Breast Cancer Emergency Fund, Booker T. Washington Community Center, YMCA - Downtown Oakland branch, and the San Francisco WIHS staff! Because of their generosity, all participants - including children, were able to go home with a gift. The WIHS family wishes you and your family a Happy Holiday Season!



## Summary of Recent Research Findings in the WIHS

By *Alyson Holsclaw*

**“Influence of adherent and effective antiretroviral therapy use on human papillomavirus infection and squamous intraepithelial lesions in human immunodeficiency virus-positive women” by Minkoff et al., 2010**

HPV (human papillomavirus) is a common sexually-transmitted virus that can cause cervical cancer or genital warts in people with or without HIV. HPV can sometimes cause cells on the cervix-- which connects your uterus to your vagina-- to change in abnormal ways, resulting in squamous intraepithelial lesions (SILs), or pre-cancerous cells. Many women living with HIV also have or are at risk for HPV.

In this study, WIHS researchers examined the effects that taking HAART can have on HPV. They compared the presence of HPV infection and SILs in WIHS women before and after they began taking HAART. Women who took their HAART treatment regularly (took it as prescribed at least 95% of the time), and for whom HAART was most effective over several years, were less likely to have HPV infection. Those who took HAART regularly and still had HPV infection were also less likely to have SILs, the pre-cancer cell growths associated with HPV.

These findings show that taking HIV medications regularly can help protect against HPV developing into cervical cancer. This may explain why in the “HAART era,” rates of cervical cancer have not increased even though women with HIV are living longer. And it's one more good reason to stick with your HIV treatment regimen!

## Here's to Your Health

### *How Much Physical Activity do Adults Need?*



Physical activity is anything that gets your body moving. According to the *2008 Physical Activity Guidelines for Americans*, you need to do two types of physical activity each week to improve your health, this entails aerobic (i.e., brisk walking) and muscle-strengthening.

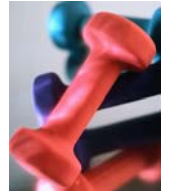
Adults need at least 2 ½ hours of moderate intensity aerobic activity each week, along with a muscle strengthening activity on 2 or more days in the same week that should involve all major muscle groups such as legs, arms, hips, back, chest, abdomen and shoulders. Wow! That's a lot of work. No it's not! Ten minutes at a time is fine. Spread your activity out during the week, break it up into smaller chunks of time during the day. As long as you're doing your activity at a moderate or vigorous effort for at least **10 minutes at a time**. Your daily routines such as shopping, cooking, doing the laundry is not sufficient enough to get your heart rate high enough to make a difference.

What is Moderate Intensity Aerobic Activity? Here are a few examples:

- Walking fast ( I mean fast) on flat ground,
- Walking up a street that's inclined. Start off slow and feel your body react. If you feel any pain anywhere (i.e., chest, abdomen, back, joints) stop immediately, be prudent.
- Walk up stairs at a slow rate, one or two flights at first, and increase this activity over time, keeping in mind to listen to your body. Remember stairs are everywhere.

Next is Muscle Strengthening Activity. What counts as muscle strengthening? Activities that work all the major muscle groups of your body (arms, chest, shoulders, abdomen, hips, back, and legs). Muscle strengthening entails repetition and strain. Remember the push up and the sit up? Start with these two simple activities, and go from there. Repeat in sets of five or ten as you progress through the weeks and months. You will be pleasantly surprised how many you will accomplish in just a few weeks.

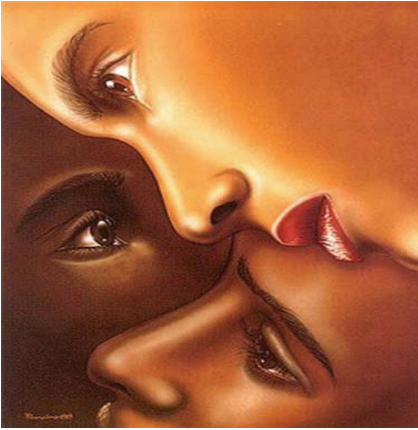
Doing exercises that use your body weight is essential in the beginning of your new found strength and health. If you are confident and healthy enough to go past push ups and sit ups then try lifting small hand held weights and add resistance to your overall exercise regimen.



Another resistance device that is popular today are resistance bands. Start with the lowest resistance, and do a lot of repetitions. Remember to follow the instruction booklet that comes with these resistance bands. As you develop strength in all you major muscle groups, move to higher and higher resistance. Take it slow and be disciplined about this, you will get results.

**Aerobic exercise** (breathing faster than when at rest) and **muscle strengthening resistance activity**, coupled with a healthy diet, and you will gain a confidence in yourself that you though you never had.





# Join the WIHS

## **What is the WIHS?**

**It is the largest study of HIV among women in the US. The study is being conducted by researchers at the University of California at San Francisco (UCSF) and includes women who are living with HIV and women who do not have HIV.**

## **What will happen if I join?**

**You will have a study visit twice a year including an interview, physical exam and laboratory tests. Study visits will take place in our San Francisco and East Bay Clinics. You will receive \$50 for each study visit, your travel will be compensated, and food and thank-you gifts will be available. All information collected is confidential.**

## **Who can join?**

**If you are an HIV-positive woman and are 30 - 39 years old. Participants will include women of all backgrounds to represent the diversity that the Bay Area is known for.**

## **How do I join WIHS?**

**Call to speak with a member of the WIHS staff. They can determine if you are eligible for the study and answer your questions.**

**PLEASE CALL 415-502-8800 or 510-869-6972**

**Spaces are limited!!!**

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## What is the WIHS?

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## What will happen if I join?

You will have a study visit twice a year including an interview, physical exam and laboratory tests. Study visits will take place in our San Francisco and East Bay Clinics. You will receive \$50 for each study visit, your travel will be compensated, and food and thank-you gifts will be available. All information collected is confidential.

## Who can join?

If you are an HIV negative woman and are 35 - 60 years old. Participants will include women of all backgrounds to represent the diversity that the Bay Area is known for.

## How do I join WIHS?

Call to speak with a member of the WIHS staff. They can determine if you are eligible for the study and answer your questions.

**PLEASE CALL 415-502-8800 or 510-869-6972**

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