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The WIHS Woman

The Connie Wofsy Women's HIV Study

Fall WIHS Executive Committee (EC) Meeting in Los Angeles, CA

By Nancy Hessol, Project Director

The semi-annual WIHS EC meeting was held in Los Angeles, CA, November 29th through December 1st, 2006. This meeting was different from past EC meetings. There were fewer invitees and the main focus was on the future WIHS Scientific Agenda. The reason for this focus is that the current 5-year funding period is ending (WIHS III) and a new one about to begin (WIHS IV). With this new funding period comes an opportunity to alter both the routine and special activities of the WIHS. This includes deciding what gets done at the core WIHS study visit, what WIHS sub studies will be done, and what tests and analyses will be performed.

The meeting began with presentations from the WIHS Project Leaders who discussed the following four areas of investigation: 1) HIV pathogenesis, 2) Neurocognition and aging, 3) Metabolic and cardiovascular, and 4) Cancer and HPV infection. After these there were presentations on the 7 WIHS cores; 1) Administrative, 2) Collaborative, 3) Laboratory, 4) Genomics, 5) Epidemiology, 6) Behavioral, and 7) Liver and hepatitis.

We then got to hear from four external scientific experts who reviewed different sections of the draft scientific proposal. These reviewers were extremely helpful with their feedback of the strengths and weaknesses of the proposal. In general, the reviews were very good.

The second day began with the Chair of the National Community Advisory Board (NCAB), Lisa Sanchez, who gave an update on the activities of the NCAB. This included a brief report from all the WIHS site NCAB representatives (who were not in attendance at this meeting). The next presenter discussed potential future collaborations with the National NeuroAIDS Tissue Consortium (NNTC), for those WIHS sites in LA and New York City. This was followed by presentations and a discussion of laboratory specimens and

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testing. The last item on the agenda for the day was an open discussion of the scientific agenda, as presented and reviewed on the previous day. Day two was capped-off by a lovely reception, hosted by the LA site, at a Cuban restaurant. The food (tappas or small plates) and beverages were delicious.

On the third and last day of the EC meeting, we discussed some budget issues and plans for finalizing the scientific agenda. Since the WIHS IV grant proposals are due March 13, 2007, the plan is to get a semi-final draft of the scientific agenda completed by mid January.

The next WIHS semi-annual meeting will be held in Bethesda, Maryland, in May 2007.

What happens to body fat measures after stopping the HIV drug stavudine?

By Phyllis C. Tien, MD

Several studies have found that the HIV drug, stavudine, also known as d4T or zerit, is associated with fat loss, especially in the hips and legs, which is a concern to many patients with HIV. Stavudine has also been associated with other side effects including tingling or numbness in hands and feet (also known as peripheral neuropathy) and changes in fat in the blood. So, it is not surprising that use of this drug in the WIHS has declined in the past few years.

One remaining question is once stavudine is stopped, does the fat that was lost come back? If so, how long does it take before the fat comes back?

We recently studied what happens to fat in different parts of your body after you stop taking stavudine. We looked at the changes in your waist, chest, arm, hip and thigh size in women who continued using stavudine, those who discontinued stavudine, and women who did not have HIV. The results of our study were published in the Journal of Acquired Immunodeficiency Syndrome. We found that HIV-infected women continued to lose fat in the different parts of the body that were measured, regardless of whether they continued or discontinued stavudine, while HIV-uninfected women continued to gain fat in the different parts of the body. But, the loss of fat per year was less in those women who stopped stavudine. In particular, the fat loss in the hip seemed to significantly slow down after being off the drug for more than two years when compared to those who continued to use stavudine. When compared to those who had stopped stavudine for less than 2 years, fat loss in the hip and also thigh significantly slowed down. So, it seems that being off stavudine for more than 2 years may be the time when fat loss in the hips and thigh really slow down. Finally, the fact that we found that fat loss continues in HIV-infected women (although more slowly when off stavudine) suggests that other factors such as HIV infection itself may cause fat loss.

CAB CORNER

2006 United States Conference on AIDS (USCA) Hollywood, Florida

by: Heneliaka L. Jones, CAB Liaison

" We are at the point in the HIV epidemic where drug therapies are our best hope for both life saving responses and slowing disease progression; and there are exciting new approaches to HIV treatment on the horizon."

These eloquent words, spoken by Phill Wilson, Founder and Executive Director of the Black AIDS Institute, set the tone at the 2006 United States Conference on AIDS. People from all over the world met in Hollywood, Florida to be a part of this wonderful event. Among the attendees were our National Community Advisory Board (NCAB) representatives, Sheila Bryant and Linda Scott. Their agenda was filled with so much to do. They started the conference by joining Magic Johnson at the kick-off reception, where he talked about living with HIV and his involvement in the community. The next day they met with other National CAB representatives to discuss various issues as they pertain to the Women's Study. Each day they had an opportunity to speak with pharmaceutical companies at the exhibit and network with other attendees.

In addition to the activities mentioned above they each attended different workshops ranging from *Men on the Down-Low* to *Social Aspects of Women*. Sheila was excited to share what she learned at a workshop called, *The Balm of Gilead in the Black Church,* presented by Jeremiah Brewer and Reginald Diggs. In this workshop the presenters discussed the major challenges that are faced when it comes to discussing the AIDS epidemic among faith-based organizations. ***The Balm in Gilead*** is an international model designed to help African American faith-based organizations develop programs that will teach African American communities HIV prevention education.

During the workshop, they watched a documentary / film, entitled, "Who will speak for me?" This film is a mobilization model that has been effective in engaging African American faith organizations to talk about the spread of HIV/AIDS in the black community. The film teaches healthy dialogue by practicing judgmental rules of engagement. This technique helps to humanize the HIV epidemic among people of African descent. The film is laced with personal stories and educational tools; and it provides steps for moving individuals towards actions that address issues and provide support for individual families who are directly impacted with HIV/AIDS. Sheila found the entire workshop to be not only useful for herself, but for many churches in the Bay Area.

Another interesting workshop that Sheila attended was on the co-infection of HIV and Hepatitis C in which she learned that approximately 30% of the people living with HIV in the United States are co-infected with the Hepatitis C virus (HCV). HCV liver disease has been one of the leading causes of death among people living with HIV. New research shows that people with HIV can be successfully treated for Hepatitis C, but a number of challenges in question remain; such as, who should be treated and how to manage side effect. This workshop gathered the most recent data on HIV/HCV co-infection, including epidemiology, natural history, and major clinical trials of Hepatitis C treatment: AACTGA5071, Ribavic, and Apricot. Hepatitis C can be suc-

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cessfully managed and treated in people living with HIV, but our systems of care and support have not adapted to the challenges of co-infection. After the presentation, the group discussed problems and solutions for moving forward with HIV/HCV.

At the closing of the conference, both Sheila and Linda were refreshed, renewed, and ready to work. It was an electrifying end to a hopeful beginning. The message taken away from the conference was very simple: take what you have learned and share it with others.

Linda Scott on USCA September 2006

At the USCA I attended a class titled the Social Aspect of Women. There were many speakers in this full-day session and I found it to be the most inspiring. Among the speakers was Dr. Robert Fuller and, from SFSU, Dr. Cynthia Gomez, Director and Professor of Health Equity Initiatives.

Dr. Fuller discussed community organizing. This is something that seems to be lacking in every state. Many community outreach programs tend to focus mainly on the topic of HIV/AIDS. This is not working well. We need to adapt and adjust; create situations that facilitate discussions. Dr. Fuller's research has found that "to be successful in reaching the general public, do not mention HIV/AIDS." Give them what they want/need instead. Start with discussions on their immediate issues, i.e. incarceration. Once the discussion is rolling , you can lead around to the topic of HIV in the prison system.

To Successfully organize a community we must move from being a group of individual clients to being neighbors and a community as a unit working together on common causes. This helps in making issues turn to being empowering parts of our support system to fight your disease and improve overall health. We do not need to change everything at once, "change 10% and you will see an expansion to the other 90%. Family becomes its own resources."

Dr. Cynthia Gomez's discussion was on Challenges to Effective Prevention & Care for Women in the United States. She explained that the U.S. is moving towards similar patterns of risk for women as those of women around the world. We are moving from being portrayed as vectors to victims. Now we are being seen as victims of society.

There is a complexity of determinants. First is the perceived vulnerability. Some statistics given include:

- 30% of positive women do not know how they became infected.
- Nine out of ten women in China do not believe they can become infected.

Eastern Europeans believe this is only an IV drug users and gay person's disease.

There is a pervasive lack of information and skills, including low literacy and language barriers. Therefore, we cannot only give information; we need to help others learn to use the information they receive.

Many of these issues surround sexual science. Parents and couples need to work on open communication. Society needs to realize that

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giving young people information does not remove the values we work to instill in them, but instead, it prepares children for when they make important decisions.

For women, we have some major social issues to overcome. We need to work on gaining more control over sex (i.e. insistence on condom use), coercion, and violence, especially in domestic settings. Women have competing priorities; basic needs, child rearing, family stress, etc. Then we have cultural issues: culture on youth in this country, seclusion in society (stemming mainly from our competing priorities), ethnic/racial issues, and gender roles (views toward sexuality).

The list of needed changes includes:

- Removing the stigma surrounding disease.
- Improved education and sexual education
- Specific economic option for women.
- Stronger enforcement against violence.
- More alternatives; i.e. Microbicides.
- More programs that target heterosexual men.

The overlying theme throughout this session was working together as a unit to achieve goals for the majority. By pooling resources, we can achieve far more than when we work as individuals looking out for ourselves and competing for few precious resources.

Another Interesting Luncheon

by Heneliaka L. Jones, CAB Liaison

Did you know that Osteoporosis can be prevented with diet, exercise, good posture and medicine? Or did you know that testing for hearing should begin as early as age 18? Well these are just a few of the topics that were discussed at our quarterly CAB luncheon at Highland Hospital in October. Nurse Practitioner, Deborah Royal, did a presentation on Health Maintenance discussing everything from hearing loss to osteoporosis. She talked about general health and how to stay healthy as women are living longer with controlled HIV disease. More specifically she discussed the types of screenings and vaccinations women should get and at what age they should be getting them. As a visual, the women were handed a General Health Module, designed by Dr. Claire Borkert and Deborah Royal, to serve as a guideline for health management. The module outlines what health screening a woman should have in each decade of her life, beginning in her 20s. The module also spelled out the ABCs of diabetes: **A** is for the **A1C Test**, to test glucose levels in your blood; **B** is for **blood pressure**; and **C** is for **cholesterol**. At the end of the presentation, participants asked questions about preventative health and voiced concerns about their personal health.

After the presentation, Community Advisory Board (CAB) representatives, Sheila Bryant and Linda Scott, introduced themselves to the women, and briefly shared what they learned at the 2006 United States Conference on AIDS in Hollywood, Florida, this past September. Of the many workshops they attended, each chose to talk about one workshop that inspired them the most. Linda talked about the full-day ses-

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sion she attended on "Social Aspects of Women", and Sheila talked about a workshop she attended called "Men on the Down-Low". Both topics generated an interesting and emotional discussion on HIV/AIDS and how it has affected our families, our community, and society as a whole.

We ended our luncheon discussing ways in which the Women's Study can be more efficient. Everyone present felt that having the vaccination cards was a great addition to the study. Additionally, the women suggested that having a refrigerator magnet that list the names and phone numbers of the San Francisco WIHS Staff would also be helpful. Lastly, the participants felt that at least each quarter, an outstanding WIHS participant should be recognized as "Woman of the Year". Although the details were not fully discussed on what exemplifies a "Woman of the Year", the CAB representatives will definitely be brainstorming some ideas, so stay tuned…

Overall the luncheon was very productive. As the new CAB liaison, I would like to take this time to thank all of the women who took time out of their busy schedules to attend the quarterly luncheon. I enjoyed meeting you all! Remember the CAB is designed for women in this study to give their input and suggestions on how to better the WIHS and to report back to the community with important findings from the WIHS. So I would like to encourage past members to return and new members to attend. Not only will you be able to enjoy food, fellowship, great prizes and gain new knowledge, but you will also be given a chance to let your voice be heard!

Lay Language Summary

Herpes simplex virus infections in women with HIV infection, and those who are at high risk for it:

Epidemiology and effects of antiretroviral therapy on clinical manifestations.

By Niloufar Ameli, Project Statistician

Genital herpes is an infection caused by the herpes simplex virus or HSV. There are two types of HSV, and both can cause genital herpes. HSV type 1 (HSV-1) most commonly infects the lips, causing sores known as fever blisters or cold sores, but it also can infect the genital area and produce sores. HSV type 2 (HSV-2) is the usual cause of genital herpes, but it also can infect the mouth. A person who has genital herpes infection can easily pass or transmit the virus to an uninfected person during sex.

Both HSV 1 and 2 can produce sores (also called lesions) in and around the vaginal area, around the anal opening, and on the buttocks or thighs. Occasionally, sores also appear on other parts of the body where the virus has entered through broken skin. Genital herpes, like other genital diseases that produce lesions, increases a person's risk of getting HIV.

HSV remains in certain nerve cells of the body for life, and can produce symptoms or outbreaks from time to time in infected people. We analyzed the WIHS data to find out what percentage of the HIV-positive and HIV-negative women are infected with HSV. We also looked at how often genital sore occurs in

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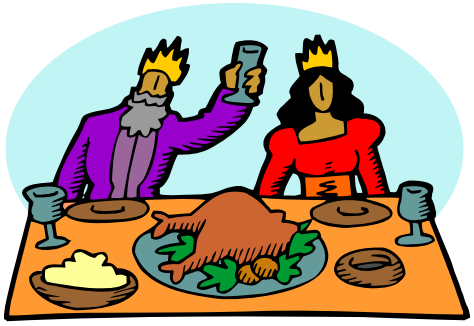
HIV-positive women treated with HAART and compared this rate to HIV-negative women. We found that 18% of the HIV-positive and 28% of the HIV-negative women were infected with HSV-1. Infection with HSV-2 was found among 20% of the HIV-positive and 18% of the HIV-negative women. Approximately half of all women were infected with both HSV types. Most women were unaware of their infection with HSV since only 22% reported during interview that they have ever had genital herpes. Women who were infected with HSV-2 were more likely to be African American or Latina, be older, have more lifetime male sexual partners, have less than a high school education, and have an annual household income of less than $18,000. Infection with HSV-1 was associated with the African American race, and Latina - ethnicity, and an annual household income of less than $18,000.

When we compared the self-reporting of genital sores between HIV-positive and HIV-negative women we found that HIV-positive women, who were treated with HAART for a year or more, and had T-cell counts higher than 350, were 5 times more likely to report genital sores than HIV-negative women.

We concluded that, unlike many opportunistic infections, genital herpes outbreaks remain a common complication of HIV disease even in women who are treated with HAART.



WIHS Holiday Party 2006

Once again, the San Francisco WIHS had another successful holiday party! This year our annual holiday party was held on Wednesday, December 13, 2006 at The University of California, San Francisco Faculty/Alumni House. Despite the gloomy weather, we had a wonderful turnout.

Music and laughter filled the air, while delicious food filled our bellies.

Participants mingled with one another and met WIHS staff members. As with our past holiday parties, participants also brought family and friends to join in with the celebration.

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Without a doubt the highlight of the party was the raffle prize gift give-away. The donated items included gift boxes from M.A.C. Cosmetics, Golden State Warrior basketball tickets, the San Francisco Zoo, Regal Cinema movie tickets, and free YMCA membership passes to the Oakland Downtown branch or the San Francisco Embarcadero branch. WIHS participants and staff members also donated gifts to the raffle drawing.

Because of the joint generosity from all of those who donated gifts, all of our attending participants, including the children, were fortunate to go home with something to remember this event..

On behalf of the WIHS staff, we would like to thank all of the women and their family members who participated in making our holiday party a joyous occasion. Until next year, the WIHS wishes you and your family members a Merry Christmas and Happy New Years!

Women's Immunity Study

HIV Positive

We're studying how the menstrual cycle affects the immune cells of the uterus and cervix in HIV+ women.

If you are 18-40, HIV+, have regular menstrual periods and are not using birth control or hormones, you may be eligible to participate.

The study involves 3 visits at UCSF, Mt. Zion Hospital. Participants will be reimbursed $140.00 for participation.

Please contact Becky Packard at 415-317-5360

Veterans Affairs Medical Center
University of California
San Francisco
UCSF

Men Living with HIV and Hepatitis C Needed

For a study on new ways to look at liver damage and how changes in the liver may affect blood sugar

Criteria

- **Men between the ages of 30 and 70**
- **Active HCV infection (detectable HCV viral load)**
- **Have never been on HCV therapy**
- **Have never been told that you have cirrhosis**

You will be **reimbursed** up to **$175** for your time & effort. Your travel expenses will also be covered.

For More Information

Contact Jane (415) 353-9767
OR
Toll Free (866) 476-5109

Women's Immunity Study

HIV Negative

You can help us determine how your monthly cycle and how contraceptive gels affect immune cells in your uterus and cervix.

We are recruiting for participation in a clinical study women who:

- **Are 18 years of age or older**
- **Have regular menstrual periods**
- **Are HIV negative**
- **Are not using birth control or hormones**

Study participants will:

- **Come to 4 visits at Mt. Zion Hospital (part of UCSF)**
- **Be reimbursed with up to $150 for their time and effort**

If you are interested or you have questions about this study, please contact **Portia Daniels** at **415-885-7675**

WIHS Women with HIV and HCV Co-Infection

Are you interested in learning about the health of your liver?

We are recruiting WIHS women with **HIV and Hepatitis C (HCV) infection** for a sub-study to learn about new ways to study fat in the liver. HCV, HIV, certain kinds of antiretroviral drugs, obesity, and drinking alcohol can all cause fat to deposit in the liver. To be eligible for this study, you must be both HIV and Hepatitis-C positive.

If you are eligible, we will ask you to come in for two visits. During the first visit, you will have blood drawn and a MRI scan of your liver. Having a MRI scan is similar to having a CT scan, where you lie in a tunnel, but there is no radiation involved in a MRI scan. The MRI scan will measure the amount of fat in your liver and the amount of fat in your belly.

At the second visit, you will have a liver biopsy done by an expert in liver disease - only if (1) you have not had a liver biopsy done in the last few years (2) the MRI scan does not show severe liver disease already, and (3) you do not have a bleeding disorder - the blood that we draw at the first visit will check for this.

A liver biopsy is the best way to find out about the health of your liver and is recommended in people with HCV, especially if you are thinking about getting treatment for your HCV. We want to see how good the MRI is compared to the liver biopsy in measuring liver fat. If the MRI is just as good or better, than maybe in the future, we can use a MRI scan instead of a liver biopsy to follow the amount of fat in the liver. You will be reimbursed **$50** for the MRI scan and **$100** for the liver biopsy.

If you are interested in being in this study and have HIV and HCV, please call Jane at 415-353-9767 or toll-free at 866-476-5109