

The WIHS Woman



The Connie Wofsy Women’s HIV Study

25 Years of AIDS

Twenty five years ago on June 5, 1981 the Centers for Disease Control (CDC) wrote an official document on an unknown disease, later to be known as AIDS. A month later, Dr. Paul Volberding saw his first case of AIDS at SFGH. His patient was a 22 year-old young man with a rare skin disease, Kaposi’s sarcoma (KS). At the end of 1981, nine people died from this mysterious disease.

Over the next few years, the number of cases of this mysterious disease increased dramatically. In January 1983, Dr. Volberding established the first HIV outpatient clinic in the US, Ward 86 at SFGH. Dr. Diane Havlir now directs this clinic and the clinic is now called the Positive Health Program.

From the beginning, UCSF was on the front lines, fighting this unknown disease. AIDS began to spread exponentially, not only as a sexually transmitted disease, but through intravenous drug use and blood transfusions (blood was not screened yet since no one

knew what caused the disease). In September 1983, Dr. Jay Levy from UCSF was one of the first scientists to isolate and characterize the retrovirus, HIV. Today, Dr. Levy is studying the immune systems of people who have carried HIV at least 10 years and have never gotten sick. These people are called long-term nonprogressors and they make up about 3-5% of HIV+ people. Dr. Levy is examining these nonprogressors in order to determine how to stop the virus.

Once the virus was identified, drug treatments were the next steps for many researchers. AZT began to be used in 1987 but it was quite expensive and had to be taken every 4 hours. Many of those stricken with AIDS could not afford to take AZT thus the birth of AIDS activism began and still goes on strong today.

In 1995, Dr. Charles Craik, a professor in the School of Pharmacy at UCSF, developed a drug called a protease inhibitor. A year later, scientists developed a triple cocktail, which

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was a combination of 3 HIV-suppressing drugs, each with less toxic quantities.

In 1983, Dr. John Greenspan, Professor from the School of Dentistry, along with Drs. Paul Volberding and Marcus Conant started the UCSF AIDS Specimen Bank (ASB). The ASB is one of the largest biorepositories of HIV specimens that processes and stores specimens from large HIV cohorts, clinical trials, and HIV clinics. The ASB sends specimens worldwide to HIV researchers and the bank currently houses many of the WIHS specimens. Today the bank is under the direction of Dr. John Greenspan and Ms. Yvonne De Souza.

In the mid to late 1980's there were several large epidemiological cohorts looking at the natural history of HIV in gay men. Gay men were considered to be at the highest risk for AIDS. In the 1990s there was a dramatic increase in new AIDS cases among women. In 1994, UCSF faculty member, Dr. Ruth Greenblatt, along with 5 other physicians from across the United States, were awarded a large grant funded by the NIH to study the natural history of HIV in women. The name of the study is the Women's Interagency HIV Study. The WIHS is still going strong with over 3,772 women enrolled. The WIHS is considered the largest study in the US focused on HIV infection in women.

In 1997 Dr. Haile Debas, former Dean of the School of Medicine at UCSF, created the AIDS Research Institute (ARI). The ARI brings together scientists to a central location for collaboration and the development of multidisciplinary programs of AIDS. Today, ARI has more than 50 programs that are studying the biology, epidemiology, and social economic factors of the epidemic.

From drug resistance, vaccine development, prevention and education, and global studies, UCSF still remains a leader in HIV research.

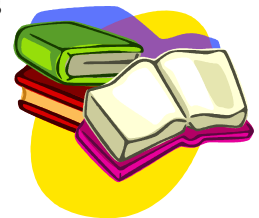


WIHS Participant Shares Her Life Story In Her New Book

By Michelle Barry

I had a chance to speak with Loretta Wilson, a WIHS participant, about her new book, which includes details of her journey from living on the streets to her current role as a community educator. In her book, Loretta is very open about her experiences because she wants others to learn from her mistakes. By the age of twenty, Loretta was living on the streets and heavily into drugs. After spending some time in jail, Loretta realized that this was not how she wanted to spend the rest of her life. She reached a turning point when she saw friends suffering and dying in prison. "I wanted to live my life," says Loretta.

In her book, Loretta explains how she was infected with HIV and the consequences of not taking care of herself. She found out about her HIV status indirectly when her ex-boyfriend died of



AIDS. Because of complications from an AIDS-related herpes infection in her eyes, Loretta is now blind. She shares the details of the painful tests and treatments that she had to endure with her eye infection. At this point, she went into denial, started doing drugs again, and stopped taking her HIV

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medicines. In fact, she got very sick and almost died. Hoping to help Loretta kick her drug habit and take better care of her health, her mother came to San Francisco to take her back under her care. Under her mother's guidance, Loretta returned to the church and took on a more positive outlook on life. She has now been clean and sober for about 20 years, visits her doctor regularly, and follows her doctor's advice closely. Loretta was very proud to tell me that she is now in good health. Her T cells have jumped from 7 to 600, and her viral load is now undetectable! She says that her mother played a very important role in turning her life around and that she is very thankful for this.

Loretta's life journey inspired her to share her story with others to prevent them from making the wrong choices. She speaks at high schools, churches, and youth centers to send a message out to young people about the importance of finishing school, staying off drugs, being in healthy relationships, and practicing safer sex. Interestingly, she has found that many young women believe they are safe from HIV infection and that only men can get infected. Her focus is on opening people's eyes to the reality that anyone can get HIV; it does not matter what age, gender, or ethnicity you are. She feels that when people meet her, this becomes a reality, especially for those who have never met someone with HIV. Loretta also tells others that it is never too late to change. If she was able to change her life around, then others can too. Today, Loretta tells me that she takes life one day at a time and encourages others to take on the same outlook.

She was inspired to write a book so that she could share her experiences with many more people. With help from her mother who transcribed her story from taped recordings,

Loretta now has her story in print. When I talked to her in May, she had already finished writing her book and was waiting for it to get copyrighted. The name of the book is *Where Do I Go From Here?* She is planning on sending a copy to celebrity talk show hosts, including Oprah Winfrey, Montel Williams, and Maury Povich. If you are interested in getting a copy, please call Heneliaka Jones at 415-502-6284 or ask about it at your next WIHS visit.



Seeking Women in the Metabolic Study

Phyllis Tien, MD

Dear WIHS women in the Metabolic (Bone) Study:

Do you remember that oral glucose tolerance test (GTT) you did a couple years back, where you fasted and then got to drink that bubbly orange drink and had a DXA (pronounced DEXA) scan (where you laid down on a narrow table and had your body scanned)?

We are now doing the follow up for the Metabolic Study. Your participation in the follow up visit is *extremely* important, because it will allow us to understand what has happened to your body fat, blood sugar, and bone density over the two years and how much of it is related to HIV, the HIV drugs, or just plain getting older. Your participation in the follow up study will help us understand the best way to prevent fat changes, diabetes, and bone problems in women with or without HIV.



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Some of you have already come in for the follow up study. Thank you for taking the time to come back! We are still seeking women who participated in the Metabolic Study a couple years ago to return for follow up.

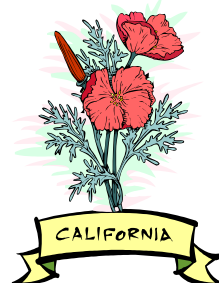
At the follow up visit, we will do the GTT and the DXA scan again. In case you forgot, for the GTT, you need to fast for at least 8 hours. When you come in for your study visit, your blood is drawn first, then you drink a bubbly orange drink and blood is drawn again 30 minutes, 60 minutes, and 120 minutes after you started the orange drink. The GTT allows us to see if you may be at risk for diabetes or have diabetes. The DXA scan is done between the 60 minute and 120 minute time point for the GTT. The DXA scan allows us to measure the amount of fat you have in your legs, arms, and chest and belly and bone loss. You will be reimbursed \$50 for completing both the GTT and the DXA scan, in addition to transportation costs.

A new addition to the follow up visit is an MRI of the abdomen. The MRI will specifically measure the amount of fat you have around your gut and in your liver. Some researchers think that the more fat you have around your gut, the more at risk you are for problems with blood sugar and cholesterol. Some researchers also think that fat in the liver may put you at risk for liver disease. If you agree to undergo an MRI scan of the abdomen, you may be asked to come in on a separate day for the MRI. You will be reimbursed \$50 for the MRI scan, in addition to transportation costs.

We hope to see all of you (who participated in the Metabolic Study a couple years ago) this summer and fall. Thanks!

Welcome Heneliaka! Our New Sub study and Community Advisory Board (CAB) Coordinator.

Hello everyone! My name is **Heneliaka L. Jones** and I am the new WIHS site coordinator for San Francisco. Although I graduated from Tennessee State University with a BS in Biology, I am a native of San Francisco. I previously worked with the Center for AIDS Prevention Studies (CAPS) at the University of California San Francisco. For as long as I can remember, I have had a passion for working in the health care field. My long-term career goals are to implement health care programs in the field of HIV/AIDS for underserved communities both nationally and internationally. Having only started this position a month ago, I have already met some dynamic women. One of my goals as site coordinator is to increase participation at our local CAB gatherings and make each event as informative and fun as possible. I am looking forward to meeting more WIHS participants in the near future. In my spare time I enjoy traveling, reading, participating in church activities, and hanging out with friends. Please feel free to contact me at (415) 502-6284 or heneliaka.jones@ucsf.edu with any suggestions or ideas that you may have. Hope to see you soon!



Genetics Testing in the WIHS

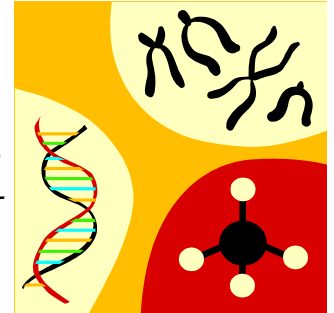
By Monica Gandhi, MD

Each person's response to an HIV medication is different. You may have no side effects from an antiretroviral, but your friend has weird dreams or nausea from the exact same medication. With new research findings, we are beginning to understand that the reason each person's response or side effects on a medication is different probably has a lot to do with our genes! Just like genes determine if someone has blue or brown eyes, curly or straight hair, genes also help determine how we respond to various infections and the medications used to treat those infections. HIV is no exception.

For instance, some people take a long time to progress from HIV to AIDS, even without any HIV medications, whereas other people get sick from the virus more quickly. Although some of these differences has to do with differences in the actual HIV viral strains that people get, the genetics of the person definitely seems to affect the course of disease. Another example is the development of body fat changes with HIV infection. Although there is still a lot of debate out there whether the virus itself leads to these body fat changes (often showing up as thinner legs and arms, but larger bellies and breasts) versus the HIV medications, it seems that genetics plays a role in how the body may change with HIV infection.

Finally, your genetics help determine how you process the HIV medications. For example, antiretroviral medications first get absorbed by the stomach and then go to the liver. Different enzymes or proteins help break down or metabolize the drugs in the liver and send them out to the general circulation to help act on the virus. These metaboliz-

ing enzymes are encoded by our genes and may vary by race and ethnicity, and even from person to person. Therefore, even though everyone essentially gets the same dose of a medication from their doctor, different people metabolize these drugs differently. This means that some people may have higher drug levels in their body even with the same dose of drug, which may lead to a higher incidence of side effects from the medications.



Because genetics may influence the course of HIV disease and the response to highly active antiretroviral therapy ("HAART"), the WIHS is looking at different genes as part of their mission to understand HIV in women. As you know, the WIHS consent form asks if you would be willing to have some genetics testing done as part of the WIHS study. This means that we are looking at some of the genes that are known to lead to differences in the course of HIV disease and influence the metabolism of antiretroviral agents. We know that some of these genes were identified in studies of men. We want to figure out if these genes have an influence in HIV disease in women and, if so, how much.

Why is this important and how could this eventually help women living with HIV infection? One benefit is in the dosing of antiretroviral medications. If a person has the genetic type of liver metabolism that leads to very high levels of HIV drugs in her system and has a lot of side effects from the medications as a result, we may be able to give her a lower dose of a particular HIV drug. This would allow us to "individualize" or tailor doses of

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antiretroviral drugs to each person depending on their genetic makeup. Another benefit of genetics testing is determining what HIV medications to use. For instance, if a person has a lot of problems with high cholesterol levels, we may want to offer her HAART therapy at the start that doesn't lead to changes in cholesterol levels.

The WIHS is expanding scientific investigation into the world of genes because each of you is a unique, amazing, and special individual, and each of us has unique and special genes! Those genes have a role in determining how you manage HIV infection and how you deal with the HAART medications. By looking at your genes, we hope to explain some of the reasons why people have such different responses to HIV and HAART.

Please feel free to call on us anytime if you have questions at (415) 502-6290

Thanks, as always, for your participation in this important study!

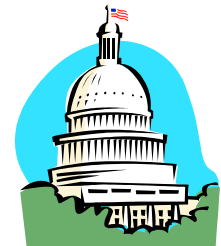


CAB CORNER



Shelia Bryant Reports on the 2006 Semi-Annual WIHS Executive Committee Meeting

The San Francisco National Community Advisory Board (NCAB) representative and co-chairperson, Shelia Bryant, attended the Semi-annual Meeting of the Women's Interagency HIV Study (WIHS) in Bethesda, Maryland, during the month of May. Shelia had the opportunity to attend a variety of workshops at the conference and therefore received information on a wide range of topics. At the NCAB meeting one of the topics that were of particular interest was about the epidemiology of HIV and non-HIV associated cancers among women in the WIHS, presented by Nancy Hessol. These findings compared cancer rates in women with HIV to non-infected women. In addition to learning about the rates of cancer in WIHS women, she learned about what types of foods, vitamins, and exercise help to prevent certain types of cancers. For the afternoon session, Dr. Audrey French gave a presentation about the cause of death among women in the WIHS. During this time, the NCAB representatives were also able to discuss changes and improvements that they would like to see happen in the WIHS. Some of the ideas included more research on CMV in the eyes and ways in which all the sites can interact more with each other.

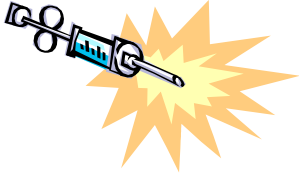


One of the highlights for the NCAB representatives was having lunch with Dr. Stewart

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Massad. He spoke with the women about gynecological issues. Shelia posed a question to Dr. Massad concerning the new Human Papillomavirus (HPV) vaccine that will be administered to non-sexually active children between the ages of 5 thru 18. The women found this discussion to be very interesting. After their meeting with Dr. Massad, the NCAB representative expressed an interest in wanting Dr. Massad to be a part of their working lunch group in the future.



Each representative had the option of choosing a workshop of choice. Shelia chose to attend the Behavioral/Substance Use breakout session. She learned about an intervention study on the Alcohol/Tobacco Cessation Program and Stress Reduction in which the client will use a computer to take a 30-minute study survey.

Overall Shelia had a wonderful time at the 2006 Semiannual meeting and is looking forward to attending the 2006 United States Conference on AIDS in Hollywood, Florida scheduled for September 21 - 25. As always, she will be eager to share with other WIHS participants about what she learned.



The Balance Project is a study testing a counseling intervention to help people living with HIV achieve an active role in their health care, with particular attention to the challenges of taking HIV medications. The study is a UCSF research project located at the Center for AIDS Prevention Studies. Compensation is provided. 415-597-9184.



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. 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. 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. 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