

The WIHS Woman



The Connie Wofsy Women's HIV Study

Changes for Visit 37

By Claudia Ponath

Another six months have flown by, and visit 37 is just around the corner. Over the past 20 months, and with your help, we have enrolled 88 new participants into the WIHS. Enrollment is now complete for this round. Below is a description of what you can look forward to at your next WIHS visit:

What's new?

There is a series of new questions about pain and pain medications in the interview for this visit. We know that pain is a big concern and the source of considerable distress and disability for many women in WIHS. The WIHS National Community Advisory Board (NCAB) has advocated for adding the study of pain to the WIHS science agenda. The goal of this study is to learn how pain impacts the health and well-being of women with HIV. We hope that the findings will be helpful for both patients and providers and useful in developing treatment guidelines.

What's continuing?

Please remember to bring your medications in their original bottles, your medi-set, or a list of the medications you have taken since your last visit to your study visit. For those of you on HIV meds, we'll also need the dose information. Bringing this information to your interview is incredibly helpful, and it will make your interview go more smoothly. And if you have been bringing this information, please continue to bring it. Both you and your interviewer will be glad you did.

Please fast (don't eat or drink anything, except water, for at least 8 hours) before your WIHS core visit. Although many beverages, such as black coffee, plain tea, and diet sodas, don't contain any calories, they do contain other ingredients that can affect some of the measurements. It is also good to know that even sugar-free gum has a couple of calories. So, please drink only water for at least 8 hours before your core visit. This is crucial for getting an accurate test result for your cholesterol, lipids, and glucose. These blood tests are important markers

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for diseases that affect women, including diabetes, heart disease, and high blood pressure. If you have concerns about fasting, for example, if you have certain medications that need to be taken with food and at certain times, or if you are diabetic, please discuss this with your medical provider

If you are HIV-positive, we will ask your permission to cut a small amount of your **hair** (about 20 strands). These hair samples are being tested for levels of HIV medications. So far, we have looked at levels of Lopinavir and Raltegravir and found that levels of those drugs in hair are a very strong predictor of your response to HIV treatment.

The **Neuro-cognitive component** of the WIHS will continue during visit 37. If you did the neuro-cognitive assessment 2 years ago, we will ask you to do it again this visit. The neuro-cognitive tasks are administered verbally, using paper and pencil, and using a pegboard. You will be asked to read words, recognize shapes, solve problems, memorize things and engage in other mental tasks. Some of the tasks will be familiar from previous WIHS visits and some will be new. The purpose of this component is to look at cognition – that is, mental processes such as memory and learning. It takes about an hour, and we reimburse you an additional \$20 for your time and effort to complete it.

The **Musculoskeletal (MSK) Study** will continue during visit 37. This study looks at the effects of transition to menopause on bone mass and structure, muscle mass and strength, and how other factors, such as changes in fat distribution and immune function, might affect these associations. If you are eligible for this study, we will approach you about it before you come for your WIHS visit. If you agree to participate, you will have some additional tubes of blood

drawn at your WIHS visit. Then you will be scheduled to come back for an additional visit, which consists of a DEXA scan to measure bone density, tests of your muscle strength and function, measures of the curvature of your spine, a questionnaire, and a quantitative computed tomography (QCT) of your spine and hip. The visit takes about 4 hours and the reimbursement is \$85.

The **CIDI study** will continue during visit 37. Your interviewer will let you know if you are eligible to participate. The purpose of this study is to learn about women's emotional health and well-being, both now and when they were children. It consists of an interview only, which will be done by either Karen in the East Bay or Alyson in San Francisco. The reimbursement is \$40.

The **Pulmonary Study** will continue during visit 37 and consists of a blood draw, interview, a lung function test and a chest CT scan. All procedures take place at the UCSF Mount Zion campus. The study visit takes about 3 hours and you will be reimbursed \$60. We have reached our target number and are now doing only follow-up visits on the enrolled women. Most, but not all, women who had an initial visit will be asked to come back for a follow-up visit. Alyson is coordinating this study and will contact you when it is time for your follow-up visit.

Abbreviated visits will continue for women who are unable to have an in-person core visit. If you do have an abbreviated visit, we will now ask you a few short questions about pregnancies.

For women undergoing colposcopy, we will continue to ask if you want to donate tissue to the **AIDS and Cancer Specimen Resource**

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(ACSR). Women do not need to have cancer or HIV to enroll in this sub-study. Women who are eligible and wish to donate tissue to the bank will have an extra biopsy, oral rinse, and one tube of blood collected for this study at the time of their colposcopy examination.

What's gone?

The **Fibroscan Study** has been completed. Thank you very much if you participated. We are currently analyzing the data from this study, so stay tuned.

The **Pharmaco-Kinetic (PK) study** has also been completed. We will be testing the last batch of specimens and then analyze the data. Thank you so much to those of you who took the time to participate in this very important study. We are very appreciative of your contribution!

We are also done with the **questions about sexual risk behaviors** asked last visit. Thank you all very much for giving information on this topic.

In conclusion

I would like to welcome all our newly enrolled participants into the study. We hope to have you with us for many years to come. I would also like to thank all our continuing participants for their dedication and contributions to the study. This is a very important study, and we value and appreciate your time and effort in coming to all of your study visits. We look forward to seeing you at your next WIHS visit, and we will endeavor to make it as pleasant for you as possible.

AIDS 2012 - XIX International Conference

By Adrienne

It was such a lovely and timely experience for us to have representation at this year's International AIDS Conference. This year was the first time in 22 years that the conference was held on US soil. The last one was in 1990.

The theme for this year's event was "Turning the Tide Together". The motif reflects a unique moment in time, emphasizing that the HIV epidemic has reached a defining moment. By acting decisively on recent scientific advances in HIV treatment and prevention, the momentum for a cure, and the continuing evidence of the interventions in the most-needed settings, we now have the potential to control the HIV epidemic". You can check out the conference website here: (<http://www.aids2012.org>)

When the AIDS epidemic first started, its face was male. But increasingly women are outpacing men in terms of new infection rates. This is tragic and people who care are now focusing more on how to stem that tide.

The Women's Networking Zone is a community based forum that serves as a vehicle to educate women that has run parallel to the AIDS conference for over 10 years. The Networking Zone is designed for sharing ideas, discussions on stigma and discrimination, gender based violence, social and reproductive issues, criminalization, and sex workers rights.

We attended an education session on Sexual health which focused on prevention. One of the workshops discussed increasing the use of Female Condoms. Although the new female con-

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doms are still in clinical trials in the US, participants were given samples to take with us so that we will be able to try them on our own.

We also enjoyed the Condomize event which portrayed young people dancing to rap music that was filled with the importance of condom use.

The conference was so packed full of activities and events and still it seemed like everyone was taken care of. Kaiser Permanente sponsored the "Positive Lounge", which was a place for positive delegates to get away from the conference for a while and relax. It included chair massages, computer access, MAC makeovers, healthy snacks, and many more amazing things for our comfort.

The "Positive Lounge" also offered basic HIV education, counseling, support group meetings, positive living courses, yoga and meditation classes, spiritual discourse, career counseling, and guidance apart from the fun filled activities, music and movies, and many more "pick me up" activities.

We also attended several workshops in the Global Village. The Village included a mobile HIV testing Van, women's advocacy groups, sessions on clinical trials and current research findings. PrEP (Pre-Exposure Prophylactics) was one the most interesting topics discussed. PrEP was approved by the FDA in July 2012. This is a prevention tool that can be used before someone is exposed to HIV. People who do not have HIV can take a pill daily to reduce their risk of becoming infected. This is especially important for women who are trying to conceive without the fear of becoming HIV infected.

The beautiful AIDS quilts were on exhibit, and all countries were represented. The "Faces of

AIDS" were paintings created by children from all over the world. This made a powerful statement at one of the exhibits in the Global Village.

There were so many people and so many stories. One of those that stayed with us is that of Annah Sango. Annah is a 24-year year old young lady from Zimbabwe. She is HIV positive and a peer educator. Even though she is HIV positive she went through pregnancy and had a safe delivery.

One of the big takeaways from this year's event was the focus on encouraging young positive women not to walk away from dreams of child-bearing, simply because they found themselves to be infected with HIV.

In conclusion, the conference was a great learning experience which empowered women from all over. We were treated with dignity and respect with every encounter. It felt so good to be a part of such a great event. Thanks to WIHS for the opportunity.

Here are some websites with information related to this article you may want to check out:

Salamander Trust (Women Networking Zone) Videos

<http://vimeo.com/43237958>

Positive Lounger (Kaiser Permanente)

<http://www.kaiserpermanentehistory.org/latest/the-hivaids-lounge-at-the-2012-international-aids-conference/>

Women Living with HIV (Annah Sango)

<http://www.youtube.com/watch?v=0dEjPuj4lvs>

Prepping for HIV-PrEP

By Jennifer Cocohoba, Pharm.D.

Many people have been hearing the buzzword “PrEP” in the news and on the radio. In this article we discuss some basic facts about PrEP for HIV.

What is PrEP? PrEP stands for Pre-Exposure Prophylaxis. It is a method of preventing HIV transmission from one person to another. With PrEP, a person who is HIV-negative takes medication every day to reduce their risk of getting the virus. The U.S. Federal Drug Administration approved the HIV drug Truvada® (tenofovir/emtricitabine) to be used for PrEP on July 16, 2012.

How do we know PrEP works? Several randomized, double-blind, placebo-controlled studies looked at whether PrEP was effective. The iPREX study looked at 2,499 men who have sex with men. Men who were taking PrEP were less likely to get HIV. Results from this trial helped the FDA decide to approve Truvada® (tenofovir/emtricitabine) for prevention of HIV transmission in men who have sex with men. Researchers also studied PrEP in heterosexual men and women. VOICE is one of these trials. It is still collecting data and its results will not be available until 2013. The Fem-PrEP study also tried to evaluate PrEP. It was stopped early. The medication was not working because the patients in the study were not taking enough of it. Another study conducted in Uganda and Kenya was called the Partners PrEP study. Partners-PrEP included 4758 couples where one partner was HIV-positive and the other partner was HIV-negative. In Partners-PrEP, new HIV infections were reduced 75%. The

TDF2 study also looked at heterosexual men and women. New HIV infections in this study were reduced 62% for the patients taking PrEP. Partners-PrEP and TDF2 helped the FDA decide to approve Truvada (tenofovir/emtricitabine) for prevention of HIV transmission in heterosexual men and women.

What medications are used for PrEP? Right now Truvada® (tenofovir/emtricitabine) is the only drug approved by the FDA for PrEP. This medicine must be taken every day so that the person can stay protected from HIV. The most common side effects of Truvada® are nausea and vomiting. Less common side effects include kidney damage, rash, and problems with bones. People who decide to take PrEP should visit their doctor regularly to get blood tests and HIV tests. The blood tests will tell whether PrEP is safe for the liver and kidney, and whether a person is pregnant. In the clinical trials PrEP was not 100% perfect. This means that anyone at high risk should get tested for HIV regularly, even if they are taking PrEP. It also does not protect against other sexually transmitted diseases (STDs) or pregnancy. People using PrEP should still use condoms to prevent STDs and/or pregnancy.

A pill a day to prevent HIV? Why doesn't everyone take this? There are still a lot of questions about PrEP. This is why it is not widely recommended for everyone. One question that we don't know the answer to is, “How much medicine is enough?” Right now, patients must take PrEP every day. If they do not take it every day, they can become HIV-infected. If they are not tested regularly they will not know that they have become HIV-infected. This could be bad be-

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cause their HIV virus could develop resistance to the medicine. They could pass on that resistant virus to another person. Because of this, persons taking PrEP have to be very committed to taking the medicine faithfully. Long-term side effects of PrEP are still unknown. It is also very expensive. Insurance companies have to decide whether or not they want to pay for it. Remember, PrEP isn't 100% perfect at preventing HIV transmission. But, it gives people a tool to help fight against getting HIV. Because there are still a lot of questions, the U.S. Centers for Disease Control and Prevention only recommend PrEP if you are HIV-negative and you are at high risk of getting HIV.

What is the next step for PrEP? Although there are still many important questions, PrEP marks an exciting era for HIV prevention. Future data from clinical trials will help scientists understand how much PrEP you really need to take to prevent HIV infection. New studies will help researchers understand whether or not people change their risky behaviors because they feel "safe" from HIV taking PrEP. Studies will also help us understand how to best help patients stick to their PrEP every day. Lastly, drug companies will test new (and old) medications for PrEP. The PrEP story is not complete. As these new pieces of information are revealed, you may hear more that prepares you to understand PrEP.

CAB CORNER



By Joyne Taylor & Adrienne

Hello Ladies, if you missed our August CAB meeting, you missed an interesting discussion. The meeting was held at EBAC at our Eastbay WIHS Site. We enjoyed a nice lunch, games and raffle prizes.

Our guest speaker was our very own Dr. Wendy Katzman, a physical therapist, and professor at UCSF. We discussed kyphosis (curvature of the spine). Many of us had no idea what kyphosis was, but by the end of the meeting we were all well informed.

Kyphosis is a curving of the spine that causes bowing or rounding of the back, which leads to hunchback or slouching posture. In adults, Kyphosis can be caused, by osteoporosis, or by compression fractures. It can occur at any age, although it is rare at birth. Symptoms may include fatigue, mild back pain, round back appearance, and difficulty breathing. Complications can include decreased lung capacity, disabling back pain, and neurological symptoms including leg weakness or paralysis. Dr. Katzman presented slides to show the actual curvature in the spine at different levels. We were able to see the normal vs. abnormal curvatures that can occur in the spine. She also gave us exercises that we can do to help reduce kyphosis.



These exercises can be viewed on You Tube at Wendy Katzman Stand Tall Trailer. Some things you can do to help reduce kyphosis are

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to reinforce good posture while strengthening core and back muscles.

We also heard from our NCAB representative Adrienne, who gave a report back from the International AIDS conference in Washington DC. Both NCAB representatives from our WIHS sited traveled to the conference. This was their first conference and they both enjoyed the experience very much. Adrienne provided pamphlets from the Women's Network Zone, which held roundtable discussions on women's health throughout the conference. NCAB representatives from all the WIHS sites were able to participate in a panel discussion to share their experiences in the women's study. Adrienne also shared a new Female Condom with the group, which has not been approved in the US. The visual aid led to an interesting discussion on sexual health.



Finding Reliable Health Information on the Web

By Julia Thomas, NP

How often have you heard “don’t believe everything you read on the web”? The internet can be a great source of health information. But do you know how to tell the difference between information you can trust and information that is wrong or could even be dangerous?

Here are some guidelines you can use when evaluating web sites or any health information you find on the internet.

1. Find out who created the website. Look at the address. If it ends in *.gov*, *.edu*, or *.org*, the website is run by the government, an

academic institution like UCSF or a non-profit agency. Sites like these are usually well researched and provide nonbiased information. When sites end in *.com* do a little investigating. A site that is run by a hospital will say so and usually has information you can trust; for example *Mayo-Clinic.com*. Some sites are run by a particular company or person who wants you to buy their product. These sites may provide biased information. Advertisements should be labeled as an “Advertisement” or “From our Sponsor”. You should double check information you find on these sites. Sometimes *.com* sites are run by an individual. You might be able to find great advice about coping with certain illnesses. However, it is important to double check any health information you find on these sites. Some sites may contain rumors that aren’t based on facts.

2. Find out whether the health information you’re reading about is up to date. Information about HIV medications should be current while information about coping with the loss of a loved one doesn’t have to be. Most websites will post the date the document was last reviewed. This date is usually found on the bottom of the page. If the page you’re reading hasn’t been reviewed in the past year, look for more recently updated information.
3. Always protect your privacy. Health information should be confidential. If the site says “We share information with companies that can provide you with useful products”, then any information you share isn’t private.

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Want more information on this subject? Log on to the WIHS Web Site at:

<http://clinicalpharmacy.ucsf.edu/wihs/>

Remember: Information that you find on a website does not replace your doctor's advice. If you read something on the web that is different from what your doctor has told you, ask her or him about it.

Don't have a computer? You can reserve a computer for up to one hour at San Francisco, Oakland, and Berkeley Libraries. You must have a library card.

Check out some of the following websites.

www.womenshealth.gov or

www.4woman.gov, the websites of the Office on Women's Health, part of the Department of Health and Human Services. This website includes A-Z health topics, a monthly newsletter as well as news on women's health.

www.ashastd.org The website of The American Social Health Association. A source of reliable information not only on STD's/STI's, but women's overall sexual health.

www.cdc.gov/women/ The Centers for Disease Control and Prevention's site that has information on diseases and conditions as well as healthy living information.

www.healthcare.gov Up to date information about The Affordable Health Care Act.

www.choosemyplate.gov includes healthy eating and weight management tips and healthy eating on a budget.

www.fda.gov Information on staying safe and healthy. Includes information on food safety, medications, cosmetics and

pet safety.

www.cancer.org Dedicated to helping persons who face Cancer.

www.smokefree.gov Help for you or someone you care about quit smoking.

www.womenhiv.org/ Women Organized to Respond to Life Threatening Disease (WORLD) An information and support network by, for and about Women with HIV/AIDS

<http://hivinsite.ucsf.edu/> Comprehensive, up to date information on HIV/AIDS treatment, prevention and policy from the University of California, San Francisco.

www.pwn-usa.org The website for The Positive Women's Network (PWN) a project of WORLD. The PWN's mission is to prepare and involve HIV positive women including transgender women in all levels of policy and decision making to improve women's lives. Includes updates on local and national news, action alerts and events.

www.hivwisdom.org Dedicated to the prevention of HIV in older women and to life enrichment for those who are infected."

www.projectinform.org Provides information on the diagnosis and treatment of HIV and Hepatitis C. Also advocates for funding policies that benefit the HIV community.

www.thewellproject.org A not for profit corporation developed by HIV positive women and those who are affected by HIV. The website includes basic information on HIV, treatment, drug trials, and Diseases and Conditions.

www.TheBody.com The Body's mission is to "demystify HIV/AIDS treatment, improve the quality of life for all people liv-

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ing with HIV/AIDS, and foster community through human connection.” Has an “Ask the Experts” section.

www.poz.com Online version of the magazine. Offers daily news, treatment updates, personal profiles, investigative features, videos, and blogs.

AIDS.gov/ Information from the federal government about prevention, testing, treatment and research.

www.blackaids.org/ Website of The Black AIDS Institute whose mission is to stop the AIDS pandemic in Black communities by engaging and mobilizing Black institutions and individuals in efforts to confront HIV.

www.apiwellness.gov/ Website of The Asian and Pacific Islander’s Wellness Center, the oldest and largest nonprofit in North America focusing on sexual health and HIV in the Asian and Pacific Islander communities.



Are you a POSITIVE WIHS Woman?

You can help researchers learn about how the anti-HIV drug Tenofovir gets distributed in the blood and reproductive tract.

You *may* be eligible if:

- ◆ You are taking Tenofovir, Viread, Truvada, Complera or Atripla
- ◆ You are 18-45 years old
- ◆ You have regular menstrual cycles

Participants will have 2 visits at Mt. Zion Hospital, and will be reimbursed up to **\$200** plus transportation.

Please call Jane at **415-502-8801**