

The WIHS Woman



The Connie Wofsy Women's HIV Study

East Bay Move

The WIHS East Bay office has moved! Due to up-coming construction at Highland Hospital we needed to relocate. Soon some of the old hospital wings, including C-2, where WIHS was housed, will be demolished to make way for a new hospital building. Our new office is at EBAC (East Bay AIDS Center) in Oakland at 3100 Summit Street, 2nd Floor. We now have clinic hours at EBAC on Mondays, Tuesdays, Thursdays and Fridays. On Wednesdays we will have clinic at Highland's AIC clinic, in the K building up on the 7th floor (7-C, this is where we were several years ago). Study participants are welcome to have their study visits at either place; just let the WIHS staff know which you prefer.

Along with a new address we have new phone numbers. To schedule your appointments, speak with the WIHS staff, or reach Debra directly, please call (510) 869-6972. For Karen, please call (510) 655-4000 extension 5574.

We look forward to seeing you all at your next

Women's Study visit in our new space.

Yours truly,
Julia Thomas, Debra Walter, Karen Kavanagh

WIHS Opens Enrollment January 2011

By Nancy Hessol, Project Director

I am extremely excited to tell you that we will be able to recruit new participants into the WIHS. Starting in January 2011, we will recruit HIV-positive women. Later in the year, we will also open the study to HIV-negative women. Women who meet our inclusion criteria may be eligible to join our research study.

The reason we are recruiting now is to increase our study population so we are able to continue to perform high quality research and to have the women in our study better reflect the current HIV/AIDS epidemic.

(Continued on page 2)

TABLE OF CONTENTS

East Bay Move	page 1
WIHS Opens Enrollment January 2011	page 1
Barbara G	page 2
My Angel: A Tribute to Barbara Garcia	page 3
CAB Corner	page 4
This Holiday Season	page 4
WIHS Executive Committee (EC) and Center for AIDS Research (CFAR) Meetings in Chicago 2010	page 5
Top 5 Things You Should Ask Your Doctor or Pharmacist About Your Medicines	page 6
Take Part in a Study	page 7
Fibroscan Sun Study	page 7
WIHS Goes Green	page 11

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(Continued from page 1)

We will be recruiting during 2011 and once we reach our target number of women, we will stop enrolling. Therefore any HIV-positive women who are 30 to 55 years old and interested in getting screened for enrollment should contact us right away.

Please see the flyer on the back page of this news letter for more information.

Barbara G

We mourn the loss of Barbara Garcia who passed away November 6, 2010. She was surrounded by family and friends in her final hours. Barbara Garcia was a public health hero and a fierce advocate for women living with HIV disease.

Many of you knew Barbara as the first San Francisco Bay Area community advisory board (CAB) representative, and also as our most recent one, for the women's study. She served as the WIHS CAB representative for many years and greatly contributed to the success of the study. Only two weeks before she died, she attended the National Community Advisory Board (NCAB) and Executive Committee Meeting for the Women's Study in Chicago.

Barbara also advocated for women with HIV in several other ways, and many of you may have met her through her volunteer or advocacy work not connected to the women's study.

In 1990, over 20 years ago, when being "out" was still much riskier than it is now, Barbara stepped forward as an HIV-positive woman and attended the first ever conference on Women and AIDS as a representative of Act-

Up San Francisco. Starting in 1990 and for over a decade, Barbara was a regular volunteer at the Tenderloin needle exchange site, linking drug using men and women to treatment and providing supplies to stop the spread of HIV and Hepatitis. When President Obama's National AIDS Task Force came to the Bay Area for community input into developing a national AIDS strategy, Barbara gave public testimony at Berkeley High School. Barbara was particularly committed to helping women with HIV. She served on the Board of Directors of WORLD and the Women's AIDS Network (WAN), and also on the San Francisco HIV Planning Council for many years.

Throughout the early 1990's Barbara administered the Women's Emergency Fund for the Women's AIDS Network. This money helped connect women who were not in any form of HIV care. It was Barbara who turned those appointments into life-saving moments when she would disclose her status as an HIV+ woman and a recovering addict. She earned the women's trust, and connected them to housing, medical care, HIV+ women's retreats, and other support systems. Barbara would never claim credit for this, but there are probably over 100 HIV+ women alive today in part due to some act of care, concern or connecting that Barbara undertook.

Barbara joined UCSF in the mid 1990s and worked on numerous local and national studies. This included counseling women and men about substance use, HIV, Hepatitis C, and HIV risk reduction. In 1998, Barbara was awarded the very prestigious University of California, San Francisco, Chancellor's Award for the Advancement of Women.

Throughout her decades of work as an activist for needle exchange, HIV care, and services for

(Continued on page 3)

(Continued from page 2)

HIV+ women, Barbara left a written legacy of articles and reports in the national and international newsletters for Women Organized to Respond to Life-threatening Disease (WORLD) and the Women's Interagency HIV Study (WIHS).

When Barbara was not working tirelessly to help women with HIV, she loved watching sea turtles in Hawaii, reading great mystery novels, birding around the Bay Area, and playing cards with her friends. Barbara touched the lives of everyone she met with her kindness, laughter, and love. She is survived by her mother, daughters Lori and Abbie, her son-in-law Sean, and her grandchildren Ben, Klyashay and Kolby.

A memorial service took place on November 14, 2010 with Barbara's family and close friends. Many shared memories of times with her that were special to them. We have lost a good friend and a great advocate for women and all people with HIV. We keep our memories of Barbara, of her spirit, her generosity, her independence, her openness and her kindness.



My Angel: A Tribute to Barbara Garcia

By: Nilda Rodriguez



I will never forget the first time I met Barbara at the WORLD retreat. She had a drive and a spirit that was unparalleled. When I decided to move to the Bay Area, she encouraged me to attend the San Francisco WIHS Community Advisory Board (CAB) meetings. Even though there were just a few participants at those meetings, I remember Barbara would tell us that it was her calling to be an advocate against HIV/AIDS and she taught us how we could be advocates. At that time Barbara was the National CAB representative for the San Francisco CAB and even though I was a study participant in the WIHS, there was a lot that I did not know – about HIV/AIDS, the WIHS, my rights and disclosure. More importantly, she taught me how to take care of myself and how to love myself. Because Barbara also volunteered at WORLD, she would share information to the women at WORLD about what she learned from the WIHS and vice versa.

Barbara had so much heart. Despite having her own issues she would always be there for me and the other women. I could talk to her about anything and she would help and support me. When Barbara told me the things that were going on in her life, it was good because it made me feel that I was a part of her life. I always felt good when I was around her. She was a great mother and grandmother and she stood by her family. Barbara was one of the best things in my life and I am sorry that she is gone. Our community has lost a very special person.

CAB CORNER



By Heneliaka Jones

Hello Ladies,

For those of you that were unable to attend our CAB meeting on December 2nd, you certainly missed a wonderful session! We began our meeting with an announcement from Nancy Hessol, our San Francisco WIHS Project Director. Nancy shared news that the WIHS will begin open enrollment for new study participants, beginning in January 2011.

In memory of our late NCAB representative - Barbara Garcia, we had a moment of silence and shared our thoughts and memory of Barbara. I only knew Barbara for a short period, but if I had to describe her in one word, it would be "selfless". As NCAB representative, she worked tirelessly for the women of the WIHS. I heard so many wonderful stories about how she touched the lives of so many people. As I learn more about her, I grow to admire her legacy and what she stood for. Simply put, she was an unsung heroine. So let us remember and recognize our unsung heroine - Barbara Garcia!

After the moment of silence, Nan O'Connor led a round table discussion on Depression. She began her talk by explaining the signs and symptoms of depression. She also explained how there are different types of depression, such as "seasonal" depression, also known as SADD. Nan did a wonderful job addressing our questions and personal concerns. She closed the discussion by giving us suggestions on how we can overcome depression; such as walking and exercising, eating right, talking to other people, and avoiding isolation. The bot-

tom line - if you feel that you are suffering from depression, please seek help!

If you are suffering from depression and would like to seek help, here are some resources available in San Francisco:

Positive SHE Program

Where: 400 Parnassus
When: Wednesday
Time: 8:00 - 12:00
Colleen Buggs - 353-2414

Where: SFGH on Ward 86
When: Thursday
Time: 8:00 - 12:00



This Holiday Season

By Nancy Hessol, Project Director

By now you may have realized that we did not have an end of the year WIHS participant thank you party. This was because over the past few years very few participants have attended this event and it was hard to justify the expense of the party.

Instead, this past holiday season we decided to add an extra \$5 to the gift card included in your WIHS holiday card. We hope you understand why there was no party this year and also enjoy the extra gift included in your WIHS holiday card.

We wish you a happy, healthy 2011.

WIHS Executive Committee (EC) and Center For AIDS Research (CFAR) Meetings in Chicago 2010

By Nancy Hessel, Project Director, and Niloufar Ameli, Data Manager & Statistician

Twice a year the WIHS EC gets together to review the progress of the research work and to plan for the future. The fall 2010 meeting was held on October 25th and 26th in Chicago in the medical center district.

As usual, the meeting started off with a report from the WIHS data and statistical center which summarized much of the data that has been collected from participants. This was followed by a short discussion about a new HIV viral load test that is more sensitive at finding low levels of the HIV virus (lower copy numbers). We hope to start using this assay in the WIHS in 2011.

The next part of the day was spent getting updates from the WIHS scientific working groups on their active research projects. This included updates about pathogenesis, sex steroids, cardiovascular, metabolic, neurocognition, cancer and HPV infection, hepatitis, genetics, etc.

In the afternoon, we discussed potential funding opportunities sponsored by National Institutes of Health (NIH). This was followed by a session on WIHS replenishment, that is allowing the 6 WIHS clinical sites to enroll new study participants during 2011 (see article on page 1 and flyer on back page).

The second day of the WIHS EC meeting we discussed the progress on newly funding projects, including a cardiovascular disease project, a genetic project, a hearing loss project,

and a liver scanning project.

We then concluded with additional discussions about future funding opportunities and various working group sessions.

For the first time, the WIHS EC meeting was scheduled in conjunction with the CFAR Joint Symposium on HIV Research in Women. The CFAR meeting, which started on October 27th and ended October 28th, highlighted the current HIV research in women and featured presentations from junior investigators from around the world. The first session of the CFAR meeting was about prevention of HIV transmission, the next session was about HIV medications and diseases, followed by an evening social event where we got to informally talk to each other.

The second day of the CFAR meeting and in the first session presenters discuss female-specific aspects of HIV such a reproductive issues and menopause. This was followed by the final keynote talk on the use of antiviral therapy as prevention for HIV infection.

The following were some of the research findings presented at the CFAR meeting. Although 33 million HIV-infected persons live with HIV around the world and 2.7 million new infections were diagnosed in 2008, the rate of newly diagnosed infections has been reduced by 17% over the past 8 years, in part, due to HIV prevention measures. Women are still disproportionately at higher risk of becoming infected with HIV and infection is increasing in older women. Persons dying of HIV increasingly consist of women, African Americans, and people who are older than 45 years of age. Major causes of death in treated patients with HIV are malignancy (12%), infection (8%), cardiovascular (8%), violence (8%), liver (7%), respi-

(Continued on page 6)

(Continued from page 5)

ratory (2%), and renal (1%). Life expectancy is much higher for persons infected with HIV at age 25 compared to those infected with HIV at age 55. However, patients who are 55 or older are more likely to have undetectable viral load than those you are younger. This may be in part due to better adherence to HIV medications in older patients.

The use of highly active antiretroviral therapy (HAART) has completely changed the prognosis for people with HIV. It has prolonged life and has allowed many to live relatively normal lives.

In summary, we had 3 ½ days full of interesting presentations and discussions regarding HIV infection and women. Next fall we are planning to have these two back-to-back meetings in Los Angeles.

Top 5 things you should ask your doctor or pharmacist about your medicines

By Jen Cocohoba, Pharm.D.



Taking medicines is a very important part of your health. You can remind your doctors, nurses, physician assistants, and pharmacists to check on your medicines to make sure everything is ok. Here are five important things you should ask your health care providers about your medicines:

“Are my meds working?” Every person is different. Medicines that work for some people may not work as well for other people. Your health care provider can tell if your medicines are working by examining you, checking labs, or just by asking you some questions.

“Are these the best medicines for me?”

New research studies help clinicians figure out which are the best medicines. That’s why things in medicine change all the time. You should try to tell your health care provider about any side effects you think you are having. There may be other medicines available which have fewer side effects, or that are easier to take.

“Do my medicines all go together?” Some medicines interact, meaning they don’t mix together well. If you take medicines that interact, they could stop working, or you could get a side effect. Every time you get a new medicine you should ask your doctor or pharmacist if it fits well with your other medicines.

“How can I take my medicines better?” Everyone has trouble taking their medicines perfectly. You may be afraid to tell your health care provider that you’ve missed some doses. It is really helpful for them to know that you’ve been missing your meds. They can give you tips and tricks to take your medicines better, or talk with you about choosing the best medicines for you.

“Can I get help paying for my medicines?” Medicines can be expensive. Talk to your doctor or pharmacist if you’re having any troubles paying for your medicines. They may be able to switch you to a cheaper medicine. They can enroll you in special programs (such as ADAP, or drug savings cards) that help pay for medicines.

If you have questions about your medicines, write them down. Bring this list to your next clinic visit to talk about. It is great to stay actively involved and know what’s going on in your body. Staying on top of your medicines can make them work better for you!



Take Part in a Study!

We want to know how your pharmacist talks to you about your anti-HIV medicines!

This study involves a one-time, in-person interview at UCSF which lasts about 45 minutes. At the end of the interview you will be given a \$25 gift certificate.

You may qualify if you:

- 1. Are HIV-positive**
- 2. Taking anti-HIV medicines for at least 3 months**
- 3. Pick up your anti-HIV medicines at a pharmacy**
- 4. Speak English**

If you are interested, leave a message for:

**Dr. Jennifer Cocohoba at:
(415) 574-0091.**

FIBROSCAN SUB STUDY

By Alyson Holsclaw

We are continuing to enroll women in the Fibroscan sub study. As you may know, the Fibroscan is an ultrasound scan of your liver to check for stiffness (also called "Fibrosis"). This study is being done to understand how changes in body fat and metabolism relate to HIV, Hepatitis C, or obesity and how this affects liver health. This study will also provide important information regarding the use of Fibroscan to measure liver problems in women in the United States.

If you are eligible to participate in the study, we will schedule you for a brief exam. During this exam you will be asked to lie on a table while we place a small ultrasound device on your right side, over your ribcage, to take images of your liver. The process does not hurt and usually takes between 15 to 30 minutes. You might also be asked to come in again in 6 months for a follow up exam, to see if there have been any changes.

You will be compensated \$40 for your participation each time and be reimbursed for your travel costs. The study will take place at the Clinical Research Center at Moffitt Hospital on Parnassus Avenue in San Francisco.

If you are interested in participating in the study, please call me (Alyson) at (415) 502-6291. I will ask you a few brief screening questions, and if you are eligible I will schedule you for an appointment.



*Can you help in the fight
against HIV in women?*



You can help researchers at UCSF learn about how certain hormonal contraceptives affect immune cells in the uterus and cervix.

You may be eligible if:

- & You are HIV negative and generally healthy***
- & You are 18-44 years old***
- & You have regular periods***
- & You are not using any hormonal birth control***

***If you participate, you will have three visits at Mount Zion.
You will be compensated up to \$130 plus transportation costs.***

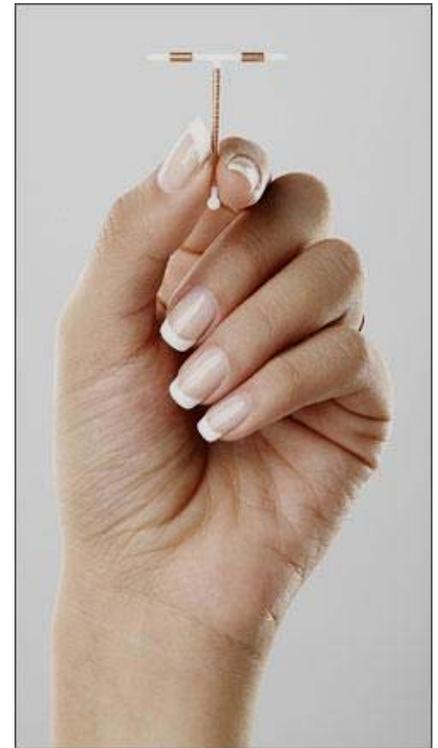
Please call Tara at 415-353-9872

Got Mirena?

You can help UCSF researchers learn how the Mirena IUD affects immune cells in the uterus & cervix.

You may be eligible if:

- & You are 18-44 years old*
- & You are HIV-negative and generally healthy*
- & You have been using Mirena for at least 6 months*



Participants will have three visits at Mount Zion Hospital in San Francisco. They will be compensated \$120 plus transportation.

Please call Tara at 415-353-9872



Female Volunteers Needed!



**You can help UCSF researchers learn
about
how menopause affects immune cells in
the cervix.**

You may be eligible if:

- ⌘ **You are generally healthy**
- ⌘ **You are HIV negative or positive. If you are positive, you are not taking HIV medicines.**
- ⌘ **You are age 18-40 and have regular periods**

OR

- ⌘ **You are at least 50 years old and have not had a period for at least a year**

Study participants will have 2 or 3 visits at Mount Zion and will be reimbursed up to \$70, plus transportation.



**Please call Tara for More Information
415-353-9872**



WIHS goes GREEN!

By Claudia Ponath



Starting April 1st, 2011 and for WIHS visit 34, we have decided to reward participants who use an environmentally friendly mode of transportation to come to their WIHS study visit. We want to support our participants in making the green choice and reduce their "carbon footprint". So if you walk, bike, roller skate, hop, skip, jump or ride public transit to your next WIHS visit, you will get an extra \$5 Safeway gift card.

Now I know that everybody these days is talking about "carbon footprint", but what does that really mean?

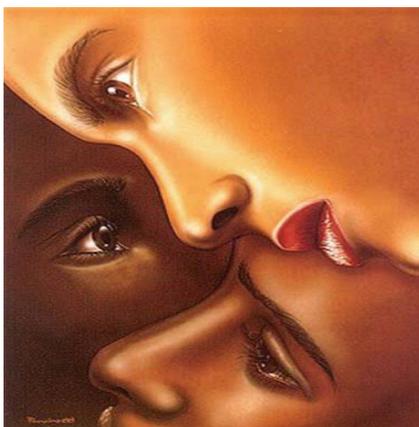
A **carbon footprint** is a measure of the impact our activities have on the environment, and in particular climate change. It relates to the amount of greenhouse gases produced in our day-to-day lives through burning fossil fuels (such as oil or coal) for electricity, heating and transportation etc.

Besides walking and taking public transit, there are other things you can do to reduce your carbon footprint. Here are some examples:

- Turn it off when not in use (lights, television, DVD player, Hi Fi, computer etc.)
- Turn down the central heating slightly (try just 1 to 2 degrees). Just 1 degree will help reduce your heating bill by about 8%. Turn down the water heating setting (just 2 degrees will make a significant saving)
- Only run your dish washer and washing machine when you have a full load - this will save you water, electricity, and detergent.

- Fill the kettle with only as much water as you need
- Car share to work or when driving your kids to school and other events
- Use public transit rather than your car
- For short journeys either walk or cycle
- Don't buy bottled water if your tap water is safe to drink
- Buy local fruit and vegetables, especially those that are in season, or even try growing your own
- Don't buy fresh fruit and vegetables that have been brought in from far away
- Reduce your consumption of meat
- Try to buy products made close to home (look out and avoid items that are made in the distant lands)
- Buy organic produce
- Don't buy over packaged products
- Recycle as much as possible





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 - 55 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 415-353-9797

Spaces are limited!!!