

The WIHS Woman



The Connie Wofsy Women's HIV Study



The WIHS Opens Enrollment

By Nancy Hessel, Project Director

We are pleased to announce that the WIHS is accepting new women for enrollment into our study. Beginning October 2001, the staff members at the WIHS will be able to recruit at least 150 new women study participants. HIV-positive women who do not have AIDS may be able to join the study, depending on their HIV medication history. HIV-negative women who are at risk for getting HIV may also be able to join WIHS. The new recruits can be either English or Spanish speaking and we are particularly interested in recruiting women who are under 40 years old.

If you know of women who you think might qualify for enrollment, please ask them to call our *toll-free* telephone numbers at **(877)-262-WIHS** in the East Bay or **(866) 476-5109** in San Francisco and the South Bay.

Hispanic Heritage Month

Hispanic Heritage Month takes place on September 15 – October 15. Check your local newspapers for celebrations taking place during this month.

Hispanic women have contributed tremendously to our country's rich heritage and accomplishments. The following is a list of just a few of the women who have been recognized and honored:

- ♦ "Albita" Rodriguez -- World-renowned Cuban singer -- Music, Drama and Theater
- ♦ Tania Leon -- Composer and conductor of the New York Philharmonic Orchestra -- Fine Arts & Dance
- ♦ Adriana Ocampo-Uria -- Planetary Geolo-

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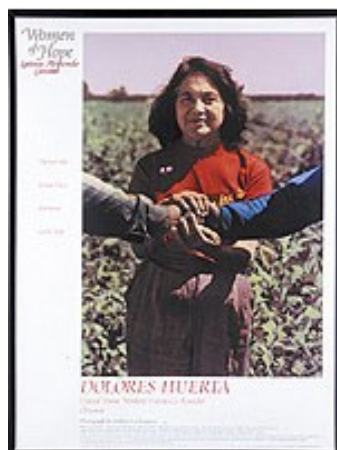
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- gist currently working on the MARS project -- Science and Technology
- ♦ Elvira Reyna -- Texas State Representative -- Education
- ♦ Hon. Margarita Esquiroz -- Florida Circuit Court judge
- ♦ Liz Alicea-Velez -- Vice President for Central America and the Caribbean for Western Union Financial Services
- ♦ Lourdes Aguila -- Organizer of "La Liga Contra el Cancer" -- Community Service
- ♦ Berta Diaz -- Cuban Track and Field Record Holder and Olympic Gold Medalist
- ♦ Marjorie Agosin -- Professor at Wellesley College and Proliferate Writer
- ♦ Aslin Castrodad -- Accomplished Executive with Sears Roebuck & Co.

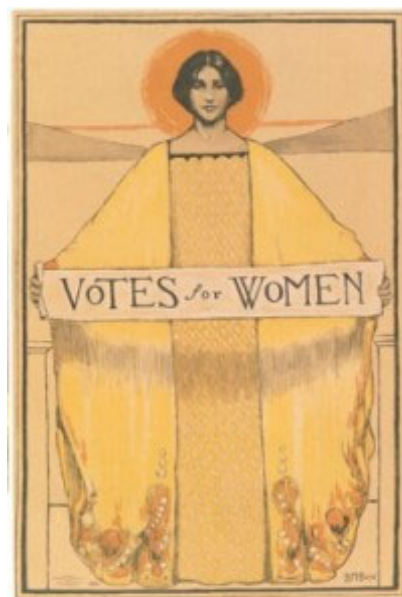
The National Womens History Project is selling beautiful posters that depicts photographs of contemporary Latinas who are pioneers in a wide array of fields. Included are Sandra Cisneros, Dolores Huerta, Tania León, among others.



Womens Right To Vote



On October 10, 1911, nine years before the federal amendment was passed, women in California won the right to vote. The dramatic and hard-fought victory came with only a 3,500 vote margin, which was the equivalent of one vote per precinct. It is a story of incredible tenacity, courage, and vigilance, and a story every Californian needs to celebrate.



California Celebrates The 90th Anniversary of California Women Winning the Right to Vote.



Changes for Visit 15

By Nancy Hessol, Project Director



This fall we launch the WIHS visit 15. Below is an update on the changes you can expect for these visits.

What's new? We are now reimbursing study participant **\$50** for their semi-annual core study visits! We are also adding a family medical history questionnaire to be asked only one time. We are interested in learning more about your family's health history, as it relates to yours.

What's gone? For visit 15 and all odd numbered visit, we don't ask the mood questions on form 26. We also don't do the blood tests called CBC's (complete blood counts) and flow cytometry (t-cell testing) on women who are not infected with HIV.

What's back? As with all our odd numbered study visits, we will do the tuberculosis (TB) test (call PPD). The TB test is only done once a year at odd numbered study visits. Also, at all odd numbered visits will ask the health utilization supplemental questionnaire.

What's continuing? We will continue to ask you to try and fast prior to your visit 14 study appointment. The reason for this is to get a more accurate measure of key laboratory tests for things like cholesterol, lipids, and glucose. These blood tests are important markers for diseases that affect women, including diabetes, heart disease, and hypertension.

We are winding-down our pilot study of osteoporosis (bone density loss) and insulin re-

sistance (which can lead to diabetes). Most of you have already been contacted regarding this Bone study but for the few still waiting to be scheduled, we will be in touch.

The Interim Event telephone interview for HIV-infected women whose most recent (within the last 3 months) CD4 cell count was under 200 will be continuing. Also continuing will be the abbreviated interview for women who are unable to be seen for their 6-month study visit.

For women undergoing colposcopy, we will continue enrollment into a cancer tissue bank called the AIDS Cancer and Specimen Bank (ACSB). Women do not need to have cancer, AIDS, or even be HIV-infected to enroll in this substudy. Women who are eligible and wish to donate tissue to the bank will have an extra biopsy and blood specimen collected for this study at the time of their colposcopy examination. We have had a great response from you to this protocol and we thank you for your help!

The oral substudy is still going strong. If you are part of this group, our field staff will set you up with an appointment with the dentists at UCSF. Also, we are looking to enroll additional HIV positive women.

In conclusion: You are the reason why our research is so successful!! Thank you so much for being a part of this important study. We will continue to work hard to make this study a pleasant experience for you. For those participants who have come back for a study after being gone for a while, we are REALLY glad to have you back. We look forward to seeing you at your next WIHS visit!



WIHS/NCAB Meeting Atlanta, Georgia

By Donna Haggerty, National
Community Advisory Board (NCAB)
Representative



The WIHS/NCAB meeting took place on August 16, 2001 in Atlanta, Georgia

We held our NCAB meeting the day after the Prevention Conference. We knew that the major portion of our meeting would be on the expansion of the study. It was cooler inside than outside (90 degrees and humidity to boot) but I felt a damp warm towel was over me!!

It was mentioned that visit #15 would have an additional interview sheet that would concentrate on family history of diseases that could be passed on such as heart attack, strokes cancer, and female fractures.

We were told that the study expansion would start enrollment October 1, 2001. Information that would be needed from the new women would be similar to our first visit such as consent and medical records, part history to HIV/AIDS. There will be women with no diagnosis, women not on HAART, women on HAART. This time there will a large percent of negative women.

The discussion on having a flyer on WIHS expansion was important to everyone due to the fact that the more information we get out there the better. Of course, the final design must be approved by the Independent Research Board.

The flyer would be titled "Welcome to the WIHS" and would contain easy to read, informative information that would hopefully encourage interest in calling and joining. Saying thank you for your wise participation. WIHS is the beginning of helping you find your way through life. If you have further questions please call (local site phone #) The NCAB is here for you. The size of a flyer would be similar to a bookmark.

There was a great deal of time spent discussing how the new women would be welcomed to the study. Due to the confidential nature of the study I suggested holding a meeting every few months where women, who have been a part of the study for a while, and the new women would meet for a question and answer period. This would not have to be a CAB meeting, but rather an informal gathering with some food – and maybe with a sit-down in a circle or in small group setting.

Shown in the afternoon session were 2 videos on colposcopy. The video was actually an interview with the doctor telling and answering a patient's questions and the procedure. We all commented that one woman was too rehearsed in her appearance (her makeup and hairdo made us think she was a model) and the other woman was more sincere and real showing a voice of being a little afraid).

The meeting ended with knowing that there was a lot of work to be done in the coming months. A WIHS flyer and a WIHS brochure need to be designed. Having new women join the WIHS study, making them feel welcome and keeping them involved through informal get togethers, the WIHS newsletter and local CAB meetings will present a challenge to everyone involved!



HIV Prevention Conference –
Atlanta, Georgia
August 12-15, 2001

By Donna Haggerty, National
Community Advisory Board (NCAB)
Representative



This conference was attended by approximately 2500 people. There were many sessions on a variety of topics relating to prevention issues – the written program consisted of 623 pages. In order to go to any session it became necessary to tear pages out of the “phone directory”!!

In my notes there were many words and to make them easy to read I will put them down in simple sentence form. As at any conference there are good speakers and then there are not so great speakers. The few that stood out received standing ovations, making us wish that the others spoke with such great enthusiasm and in layman’s terms. I, for one, have always felt that if a person speaks in down to earth language, they will always have an audience who will hear, listen, and remember what they talked about.

Here are some of the comments I heard and wrote during the conference:

Care in primary clinics for the poor, which has the latest equipment is sometimes better than the care at other clinics

People on HAART are living longer and healthier lives. Because of this, they can still transfer the virus to others through risky be-

havior. HIV will continue to spread.

HAART will help HIV+ people decrease illnesses.

Mixed reaction/crossroads/where to go in the future? Communities are living longer, healthier lives, but different areas of the country have different levels of care.

Today if you live in poor areas where the HIV virus is not well-known or talked about, there is no care.

Older adults—HIV is still a silent illness among older people. Rest homes are the one place you never thought about. There is a lot of sexual activity happening in those rest homes. These homes require a well trained doctor that will help to keep patients in good health.

I must mention the name of Dr. Cornelius Baker, who spoke at the opening ceremony. He is an excellent speaker and got a standing ovation...he said:

“That without food, rent, the necessities of life, the “healthiness” will not be there. All agencies should communicate – NIH, CDC, and government in order to integrate care, especially communication among scientists. Previous thinking was treat early, save later. We wonder if there was risk in introduction to early therapy.”

Scott Evertz, Director, White House Officer of National AIDS Policy, said to we need to reach out to new faces of HIV/AIDS- men to men sex, transgender, sex workers, drug users.....

40,000 new diagnoses this year but it is level-

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ing off . Communication and cooperation on education, care, treatment, and drug access may help to stop the spread of HIV in prisons. Information needs to be provided to high risk persons. There are 300,000 infected in United States and do not know they are infected. Our youth must know more about HIV. HIV infected womens' needs are different on every level from men. Older people do not use condoms thus we need to educate the elder in rest homes. If we do not educate the elderly they will continue to sneak off to each others' room. Spirituality - there are those who look to God, who believe that God will protect them

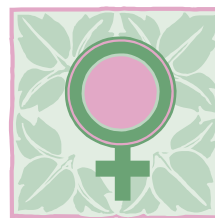
Nancy Emory said that HIV prevention programs among people with special needs such as the deaf and recent immigrants, are needed. For example, Haitian communities exhibit fear and denial of HIV and they have distrust of providers, which are their advocates in the community. However, the providers are fighting for them and these people see that they are helping them and by using Haitian media and faith based community forums. They have been able to share date with community and have ongoing coalition meetings.

A surprise involvement was the program of HIV knowledge and prevention done at the Home Depot through assistance with the American Red Cross. A program they call "Build Better Health"...managers are given time off for training (usually done in 2 hrs. since the stores will allow only that amount of time). They are given HIV training which helps store managers with learning about care and concern for those working for them that are HIV+ and they have more understanding of HIV/AIDS transmission. To date, 97-99 managers are trained. To be continued.....

Another great speaker was a gentleman from the AFL-CIO labor union who is also a business

representative to the AIDS Program at CDC since 1999. We all know how large this union is and the number of employees they have contact with on a daily basis. The union in all their situations believe in working from the bottom up-not from the top-down. He told stories about the places which the HIV virus can present itself - in sewers and in school yards. He said that when speaking with a group, do not jump right into talking about HIV or AIDS - first, speak about general health issues then work up to AIDS. The conversation will flow easier and lot of times that is all that is needed.

Last but not least was Dr. Zorrilla speaking on Prevention and Care for women. AIDS in women began the same year as men but care has always been different for women then in men. Access to treatment outside of a clinic has been less for women, hospital care would only happen if there were complications. "Real power comes from knowledge". Those who show concern about the cost of HAART should realize that the cost for care and intervention is the same in other diseases (mammograms, etc.). Women under the care of a HIV doctor (who would have up to the minute knowledge) have better care. Other illnesses such as leukemia need to be looked into. Providers need to do more than pap smears and T-cell tests. They must improve therapies and simpler regiments that will bring better adherence. Adherence is important (a complicated life sometimes affects adherence).



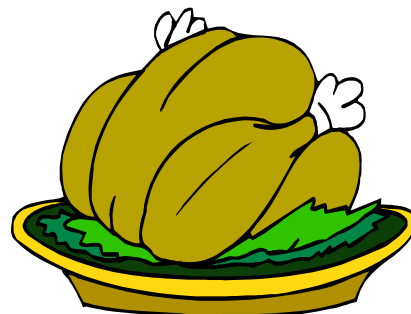
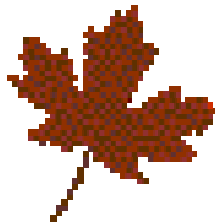
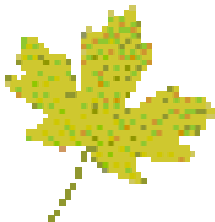
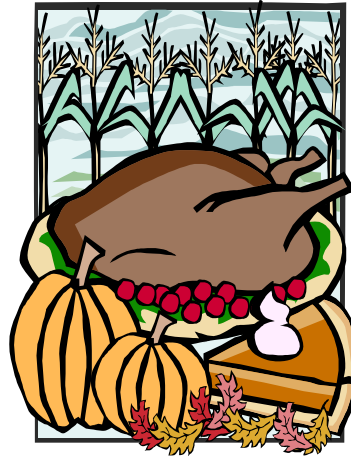
CAB CORNER

By Paula Wichinkuer
CAB Liaison



I hope everyone had a great summer! There are a couple of events to look forward to from the CAB corner this fall. We'll be holding our Third Annual WIHS Thanksgiving Luncheon in November. So, get your stomachs ready for another delicious feast laced with entertainment, gifts, and other surprises. This is another opportunity for the Study to show appreciation for all your contributions to this important research. It's also a good time for us all to meet other women and staff involved in this study.

This fall we also plan to hold our next Community Advisory Board (CAB) meeting. This is a forum for you to give your input into the Study. What do you think about how we're running the Study? Do you have ideas about what we should be doing, especially with the enrollment of more women into the study? Stay tuned for an upcoming time, place, and topics for the meeting! As always, we'll have food and help with transportation. The CAB is a way for you to provide input and comments for the Women's Study. Even if you cannot attend a CAB meeting, please know that you send your questions and comments through our staff, or contact Paula at (415) 502-6284 or paulaw@itsa.ucsf.edu. See you soon!



Results of the WIHS Focus Groups

By Niloufar Ameli



In August and September 2001, we hired Wilson & Associates to conduct several focus groups and one-on-one interviews in San Francisco and the East Bay to help us understand the opinions and desires relative to participating in WIHS. We developed recruitment flyers in English and Spanish. The flyers were distributed throughout San Francisco and the East Bay (Oakland, Berkley) to health and social service agencies. HIV-infected women and HIV-uninfected women who were at risk for HIV were eligible for participation in the focus groups. Participants were paid \$50 in cash as an incentive. We conducted two focus groups. The first was a group of HIV-negative at-risk, English-speaking women in San Francisco. The second consisted of HIV-positive, English-speaking women from both San Francisco and the East Bay. There were not enough Spanish-speaking women in either category for a focus group. We decided that it would be best to conduct one-on-one interviews with these individuals to obtain their opinions, preferences, etc.

Each group was asked to agree to confidentiality among the participants and to commit to keeping private information within the group. Participants were then asked to introduce themselves and to identify what it was that motivated them to attend the focus group. The facilitator then asked questions relative to recruitment techniques, study information needs, transportation, childcare needs, other motivators and incentives for joining research studies and for staying in the study over a long period of time. The questions also covered the con-

venient use of and comfort with the four available clinics used in the study and the times available for study appointments.

The HIV negative, at-risk, English speaking group was very well attended with 14 participants. They were enthusiastic, vocal, and eager to express their opinions. They were mostly single and only 2 had dependent children. A few of the women knew each other and had either seen the posters together or had passed them to each other. The group was motivated to participate by the cash incentive, free transportation, and concern with HIV. Participants made suggestions about recruitment site, appointment schedule, incentives, best ways to keep in touch with them, ways to receive details about the study, and what will make them feel comfortable about participating in the study. Some suggestions for the recruitment sites include: SF weekly and Bay Guardian, radio, community colleges, Women's service agencies, drug recovery programs, and SAGE. The majority of women in the negative, at-risk group were able to make appointments within the currently available time slots. The group appeared to be pleased with the sample gift bags that currently are offered to the WIHS participants. The group mentioned other items like a dental kit, safe sex items such as flavored condoms, tampons and sanitary napkins, razors, deodorant, and mouthwash. For this group of women, phone was the key to keeping in touch with them. The second option was e-mail. The women preferred that a live person answers the telephone and that a personable, trustworthy and reassuring person (like the one handling the focus group recruitment) be available to provide the details of the study along with assurance of confidentiality and study legitimacy. Rapport

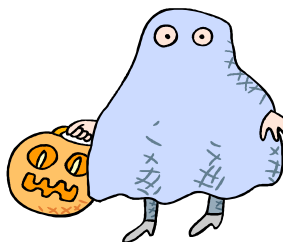
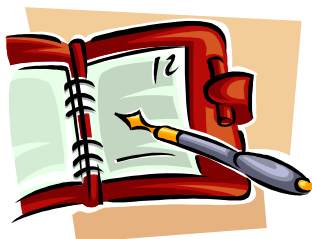
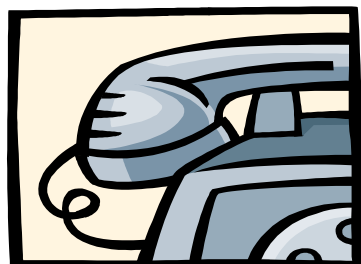
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with the study team, being respected by the team members, compassion, the “human touch” were all cited as key to feeling comfortable and wanting to stay in the study.

The HIV positive, English speaking focus group was conducted with six women in attendance. This group was significantly different from the negative, at-risk group. First, it was more difficult to find these women and they were far less likely to respond to a flyer. Second, five of the six women had children and families to care for. These women were very interested in wanting to know more about HIV in women and wanting to educate themselves and others about the disease. They were also eager to meet other women with HIV and having the opportunity to discuss their individual experiences. Best ways to stay in touch with this group was cell phones and voice mail. Some women in this group said in order to accommodate childcare needs; they would appreciate flexible clinic hours, which include evening appointments after five. The cash incentive and free transportation was an important part of motivation for this group to participate.

HAPPY HALLOWEEN



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