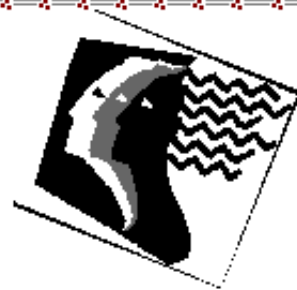
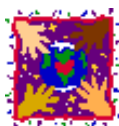


The WIHS Woman

The Connie Wofsy Women's HIV Study



Happy New Year!!



All of us at WIHS wish you a very
Happy New Year!!

Who is More Likely to Come Back for WIHS Study Visits?

By Nancy Hessel, Project Director



Even though women and people of color represent an increasing proportion of AIDS cases in this country, few research studies include these groups. We tried to find out which WIHS women are more likely to come back for their 6-month study visit.

After the first 10 study visits that occurred during a five-year period, approximately 82% of all the women enrolled in the national WIHS returned for their follow-up visits. Factors associated with not returning for follow-up visits among all women were: younger age, non-African American race, unstable housing, being HIV-negative, no past experience in studies of HIV/AIDS, and WIHS site of enrollment. Among only the HIV-positive women, white race, no past experience in studies of HIV/AIDS, WIHS site of enrollment, and no reported use of combination or HAART HIV therapy at last visit were associated with failing to return for follow-up visits. Among just the HIV-negative study participants, only WIHS site of enrollment was associated with returning for follow-up visits.

These results show that women with and at-risk for HIV infection, especially African American women, can be successfully recruited and retained in long-term research

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studies. We are also actively working on better ways of reaching women who don't have stable housing so we can let them know about their follow-up study visits.

If it has been more than six months since you last had a study visit, please call us and let us know you want an appointment. In San Francisco call (415) 476-9356 and in the East Bay call (510) 437-8551.



WHY IS COLPOSCOPY IMPORTANT?

By Debra Walters, Nurse Practitioner

WIHS women know that at each six-month study visit, a pap smear is collected along with other vaginal samples. If your Pap test result is abnormal, or if the WIHS clinician sees something abnormal, then the clinician wants to do COLPOSCOPY or the "vinegar test", as some of you have renamed it.

- Why is colposcopy so important, and why do the WIHS clinicians always recommend it?

Colposcopy is a painless exam where the clinicians look at the surface of the cervix, the walls of the vagina, the vulva and the anus to look for abnormal changes. Usually the changes are picked up by the Pap smear test but sometimes we can see changes

or lesions with our eyes. These changes or lesions are usually the result of genital warts, caused by HPV or Human Papilloma Virus infection.

A medical practitioner with special training performs the colposcopy using a magnifying microscope, which shows the clinician where the areas of abnormality are located. In addition, the vinegar and/or iodine helps to locate any abnormal areas. When an abnormal area is found, with your permission, samples are taken and sent to a pathologist who determines exactly what type of cells are present. These samples are called biopsies and are small pieces of skin or tissue the size of the end of a grain of rice. The biopsies feel like a small pinch or a cramp when it is taken. There is usually a small amount of bleeding, so a medication is applied to stop this and you are advised that nothing be placed in your vagina for a number of days. This is important to prevent infection and also for healing.

The colposcopy is an important test because along with the Pap smear, it shows us:

- if there is an abnormality and
- the type of the abnormality
- whether the abnormality is something that should be treated or just observed

When you receive your Pap smear results from WIHS, there can be different results listed under the diagnosis:

- WITHIN NORMAL LIMITS - this is a normal reading
- ASCUS (atypical squamous cells of uncertain significance) - is a Pap smear result that is in-between normal and abnormal. It is usually the result of an injury to the cervix from an infection or other cause and in most cases it goes away without any treatment. In the WIHS study, we recommend colposcopy for this reading to make sure that the changes are not hiding anything serious.
- AGUS (atypical glandular cells of uncertain significance) - This is not a common reading, and

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needs to be investigated with colposcopy. Often we recommend an additional test called an endometrial biopsy (which evaluates the cells of the uterine lining) to make sure that abnormal changes are not occurring in the uterine lining. This test can also cause a brief crampy pain.

- **LGSIL** (low-grade squamous intraepithelial lesion) - This describes a condition also known as dysplasia, where the cells of the cervix have changed in either shape or size. This reading can be caused or associated with genital warts or HPV. This reading should be evaluated with colposcopy to determine that the changes are LGSIL and not hiding anything more serious. If LGSIL changes are found on your colposcopy, your provider may recommend close follow-up with pap and a repeat colposcopy every 4-6 months or they may recommend that you have treatment. The follow up for LGSIL is very individualized and should be discussed with your provider. LGSIL rarely progresses to cervical cancer in women with healthy immune systems, but there is a greater risk of progression in HIV positive women.
- **HGSIL** (high-grade squamous intraepithelial lesion): The cells on the cervix show an abnormality that involves more than just the top layer of cells. These lesions are often more serious than LGSIL and are more likely to progress to cervical cancer in HIV-negative and HIV- positive women if left untreated. It must be stressed that HGSIL is not cancer and almost never will become cancer IF adequately and completely treated. The type of treatment that is most often recommended is LEEP in which a wire loop is used to remove the abnormal tissue, or by cryo-therapy, which is the freezing of the outside of the cervix. For a HGSIL lesion that goes up into the cervical canal, a cone biopsy is necessary. A cone biopsy is surgical removal of the abnormal area and is done under anesthesia, and may involve a short

stay in the hospital.

- **Malignant** (cancerous or precancerous cells) this reading on a Pap smear does not absolutely mean that there is cervical cancer, but rather there are precancerous or cancerous cells present. This reading must be evaluated by colposcopy and treated immediately.

What puts me at risk for abnormal pap smears?

Risk factors for cervical disease are as follows:

- **SMOKING**
- previous abnormal pap smears
- early first intercourse
- a large number of sexual partners

Many of you are already dealing with multiple health problems and the news that you have an abnormal Pap smear is just one more worry. But, it is important to remember that colposcopy is the next step in finding out why a woman has an abnormal Pap smear. By having pap smears regularly and by having colposcopies when they are indicated, your risk of developing cancer of the cervix, vagina, vulva is greatly reduced. Lesions that may with time be cancerous can be treated when they are first discovered at a much earlier stage. If you are afraid of colposcopy, talk with your WIHS clinician about your fears. You will find that there is a great deal that can be done to make the colposcopy a less frightening experience.



CAB CORNER

by Paula Wichienkuer,
Community Liaison



Thanks to everyone who came out for this year's WIHS Thanksgiving Luncheon at the SF AIDS Foundation on Thursday, November 16! It was a great event, and we all had a lot of fun eating, listening to gospel performers, getting our pictures taken, and winning fabulous raffle prizes. Of course, we celebrated in the traditional manner with roasted turkey, stuffing, cranberry sauce, sweet potatoes, collard greens, and mashed potatoes topped off with pumpkin and sweet potato pies. The UCSF Gospel Choir set a festive mood and provided us with soulful tunes while we dined, and WIHS staff member Patricia Winston served as an expert photographer producing beautiful instant portraits of WIHS women, guests, and children. Thanks to the generosity of many people, we raffled off FIVE wonderful prizes: a turkey-themed basket and a beauty pampering basket both made by Baskets Etc., a three-month family membership to the Downtown Oakland YMCA, a bath products package donated by WIHS staff member Elizabeth Glazier, and a full-hour massage treatment at the Kabuki Springs and Spa in San Francisco. But no one left empty handed...kids (and the young at heart) left with coloring and drawing sets while adults took home leftover-ready tupperware containers.

Let's just say that this was a full afternoon made possible by the efforts of many people, including all the volunteers staffing the lunch, the San Francisco AIDS Foundation, the UCSF Gospel Choir, the Downtown Oakland YMCA, and the Kabuki Springs and Spa. If you weren't able to join us this time, we hope you'll be able to make it our future WIHS events.

Not long after the WIHS Thanksgiving, we held a Community Advisory Board (CAB) meeting at the WORLD office in Oakland on Thursday, December 7. One of the purposes of the CAB is to make sure that the WIHS women can have their voices heard regarding how the Women's Study is run, so please come join us at our next meeting to have YOUR voice heard! This December we talked about the different needs of older versus younger women in the Women's Study (e.g., the need for childcare) and about better ways of keeping in touch with WIHS women, for instance, when they move or when their phones are disconnected. We also discussed the mission of the CAB itself, with CAB members emphasizing the role of the CAB in educating WIHS participants on issues relevant to their lives. The CAB does make a difference in what the Women's Study does, so thank you to all of you who came to the December CAB meeting for your time and input. We hope to see others of you at the next CAB meeting. Women attending for the first time strongly encouraged to come! We always have good food! We switch locations between San Francisco and Oakland.

Questions or suggestions about the CAB or other WIHS events? Call Paula at (415) 502-6284!



Viral Resistance Study (VRS) Updates

By Claudia Ponath



The VRS is a new WIHS protocol that started with visit 13. Since October, WIHS clinicians have been inviting eligible WIHS women to participate in this new protocol. This will continue throughout visit 13. In the new year, we will start to call eligible WIHS women who chose to participate in the VRS to make appointments for their first 3-month VRS visits. For these visits, participants will be asked to take their HIV medications in clinic and to have their blood drawn four times over the course of two hours. There will also be an interview in between blood draws. The four blood draws are done to look at levels of HIV medication in a person's blood. We will also do viral loads, T-cell counts and genotyping (a test that looks at the kind of virus a person has in her blood). The purpose of the whole study is to find out why HIV medicines work better for some women than for others.

We have been very pleased with the good response we've gotten from participants so far, and we look forward to seeing you at your next visit. Thank you for participating in this important new protocol.



WIHS NCAB Meeting

By Donna Haggerty



The WIHS NCAB meeting was not held at the same time as the WIHS executive meeting. The NCAB meeting took place in Atlanta, Georgia, a day after the U.S. AIDS Minority Conference. The NCAB members attended both meetings.

[U.S. Minority AIDS Conference, Oct 1-4, 2000.](#)

This was a large conference and really the first one of its kind since the meeting that was held in LA several years ago. The topics varied as much as the clothing did the on the people that attended the meeting.

The opening and closing ceremonies were impressive and gospel music filled the air. There were important speakers such as Sandra Thurman (Office of AIDS in Washington DC), a charming young man that stole everyone's hearts from South Africa, Nikosi Johnson (I met him and was quite impressed), Bill Campbell, the Mayor, and many more people. The mayor invited Nikosi Johnson to a reception at City Hall.

The most touching moment at the meeting was when the South African quilt panels were brought into the hall and brought up to the stage to be added to the AIDS Memorial quilt that was started in San Francisco by Cleve Jones. As the music was playing each quilt panel was opened and displayed. The hall was filled with deep emotion and silence. I was deeply moved.

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The topics of the workshops were quite varied.

Examples of the various topics were:

- Community Impacts of Ryan White Care Act Reauthorization
- HIV Prevention for Prisoners
- Engaging the Role of Church in HIV/Education Programs
- Housing
- Human Rights and HIV
- The Needs of the Growing HIV/AIDS Population in the Rural Community

The face of AIDS/HIV has changed so much that the talk given during the Tuesday luncheon was given in Spanish and headsets were available for English translation.

In closing I would like to include some of the comments that were given to the news staff at the conference that really showed a variety of feelings from many different people.

"There is still hope and the youth should be helped to carry on the work."

"I was deeply moved by the boy from South Africa and the presentation of the South African AIDS Quilt. I leave with renewed hope and a call for justice and resources for people who remain needing them so desperately."

"This conference has shown us we can work together. It was a conference not just for one color, not just gay, not just straight but for all of working for a cause and a cure."

WIHS NCAB Meeting- October 5, 2000.

We met at the Hilton Hotel and got a late start. Instead of beginning at 9AM we met at 9:45 AM because many of us had not seen each other for a long time and we started to talk and ask about one another - you know how it is.

Only 10 people showed up for the meeting and Chicago did not have any NCAB representation. This concerned all of us, and Lisa and Jeannette said they would check into this.

Dr. Kathy Anastos, from New York, gave us an informative account of our study. She was so nice and reliable.

Dr. Anastos said that the last 6 months have been very busy in regards to funding for the WIHS. For example, expansion of the cohort has taken many written drafts and a lot of effort from all the researchers. In the mean time everyone is still collecting specimens and data from visit 13 while they are writing up the expansion study.

Expansion of the cohort is important because we have to change with the times. In 1994 when the study started, many of the medicines we take today were not invented. We also need more women to study disease progression, such as cervical cancer. Many women will die from cancer than from AIDS. Another reason for expansion is to study younger women and compare them with older women. Someone in the audience suggested recruiting young girls starting at age 13. Others brought up the issue of parental consent and thought it is best to recruit young adult women.

Other areas of interest for possible future studies are:

- Osteoporosis (thinning of the bones) - do woman suffer from this due to HIV or their therapies or both? They have found that men do not suffer from this.
- Metabolic changes

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· Wedge Program. The Wedge Program sends HIV+ people (I have done this) out to talk to young students in school. I enjoyed speaking to students and received many letters from these students sharing their thoughts about HIV and AIDS with me.

· At local CAB meetings, have a raffle drawing for \$50 worth of certificates (Safeway, Wendy's, etc.). This may encourage women to see if it is worth a try.

· At local health fairs in major cities, we should have booths to introduce women to WIHS and give them enrollment and study information.

· Reach out to women who do not speak English with brochures written in Chinese, Vietnamese, Spanish, etc.

· Bring in female children of current study participants.

Another important topic we talked about was making the autopsy card for the current WIHS study. Copies of living wills should be made and given to women during their next visit and the interviewers should talk to us about this issue. A draft of the autopsy card was given to me and I will pass it onto Paula to put in future issues of the newsletter.

UNITY Project

By Yvonne De Souza

Would like to learn how to improve your health while living with HIV? If so, you may be interested in participating in the UNITY Project.

You can earn over \$400 and learn to:

- Cope with stress
- Solve problems
- Feel happier
- Deal with health care professionals
- Stay healthy
- Get close to others
- Improve health and well being
- Educate us about what it is like to live with HIV
- (and more.....)

This project is a study of the [University of California at San Francisco -Center for AIDS Prevention \(CAPS\)](#). The study location is half a block off the Montgomery MUNI/BART stations in downtown San Francisco.

Participation in this study involves 7 interviews and 15 one on one meetings over a 30 month period.

For more information or to schedule an interview call 415-597-4669.

