Winter 1999 Volume 3, Issue 5

The WIHS Woman

The Connie Wofsy Women's HIV Study

21st Century

History is a nightmare from which I am trying to awake, Stephen Dedalus said, famously in James Joyce's book, *Ulysses*.

The 20th century left us with many images - good and bad. We draw strength and gained knowledge from the past 100 years. Where will the next 100 years take us? We are currently in the information age. What will our next step be?

The 20th century left us with a diverse cast of characters that have helped shaped the 20th and beginnings of the 21st century. People such as Martin Luther King Jr., Winston Churchill, Thomas Edison, Bill Gates, Jonas Salk, Albert Einstein, Leonor Michaelis & Maud Menten (2 women noted for their work in enymology), Eleanor Roosevelt, Bela Abzug, Betty Friedan, Margaret Sanger ("mother" of birth control in the US), Barbara McClintock (Nobel prize winner for her discovery in the 1920s that chromosomal exchange of genetic material occurs), and the women and men of NASA, to name a few, have affected the way we live today. Technologies such as molecular cloning, the silicon chip, cellular phones, World Wide Web, etc. are taking us into the 21st century and where will technology go from here?

No matter what happens the future is what you make of it. We at WIHS wish you all the best in this new century and in the next millennium.

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Staff Comings and Goings

By Nancy Hessol, Project Director

The new year is ushering in some changes in our field staffing. Leaving the project are our two interviewers Marquita Reyes and Maribel Rodriguez. Rejoining our group is Rochelle Hayes, who is now a clinical nurse. Also joining our field staff is Sarah Ellison, a Nurse Practitioner. I will keep you posted of any other changes in our field staff. We wish Marquita and Maribel good luck and welcome aboard Rochelle and Sarah.

CAB CORNER

by Moher Downing, Community Liaison

YUM YUM, GOBBLE, GOBBLE

Yum, yum, gobble, gobble. That was the consensus from the WIHS women and their children who attended our Thanksgiving luncheon at the San Francisco AIDS Foundation on Tuesday, November 23. We had roast turkey, corn bread stuffing, greens, mashed potatoes and gravy, cranberry sauce, pumpkin and apple pie, salad, rolls, fruit, and I don't even remember what else. It was lovingly served by a group of happy volunteers and enjoyed by one and all. I don't want to make you feel bad that you missed it, but the next time you see one of our events listed here in the newsletter or advertised at WIHS, please remember that we always have great food and a great time. We raffled off $25 gift certificates from Pasta Pomodoro's restaurant. All the women and all the children received free t-shirts for attending. (The t-shirts will also be available at your next clinic visit).

We hope you make our next event which will be some time soon in the new millennium in the East Bay. We are planning something very special. Look for details in the WORLD Calendar.

Here are some of your comments about your study visits. **We love hearing from you:**

My visit to the study is just fine with me. Everyone is very nice to me. Just keep the study going because there are women that don't like to talk to everyone about their sex life here at the study. People talking about you. You can trust the women at the WIHS Study. And here I don't have to worry about a man doctor. I am not relaxed with a man doctor. People here always have smiles on their faces and that makes a difference.

I really find the study interesting and the staff quite pleasant and good spirited. I look forward to my visits. Good news always comes from then. Smile.

I enjoyed my visit with Donna. She was pleasant.

I've been with the study for five years, every

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one connected with it is still wonderful. I think it's a great way to monitor my health. I really liked the phone card in addition to the cash. Hope the funding keeps on because the results are important.

I really like the new research assistance. She is very professional. She and Donna made me feel very comfortable. She didn't even hurt me when she took my blood and it usually really hurts.

Can we have deodorant for under our arms and we should talk about our body. We should be closer to each other and have more to read about being positive and negative. My man is negative and it is hard on him when I get sick.

Hey! I have been with the study for about 2 and ½ years. I have no complaints. Everybody is wonderful and very professional. The staff will go out of their way to help you. I also learned from this study about my body.

Hepatitis C Virus (HCV) and HIV--A Brief Overview

By Dr. Malcolm John

Hepatitis C Virus (HCV) and Human Immunodeficiency Virus Type I (HIV-1) infections continue to be major global public health problems with 60-180 million HCV-infected persons worldwide (about 1-3% of the world's population). Meanwhile, there are an estimated 33.4 million HIV-infected individuals throughout the world. These viruses share common routes of transmission: intravenous, sexual, and from mother to infant. Thus the possibility of infection with both HCV and HIV-1 exists and is being seen more often.

Hepatitis C Virus Infection

Hepatitis C Virus was first identified in 1989. It has since been shown to be the cause of 80-90% of the cases of what used to be called transfusion-related "non-A, non-B" Hepatitis. When first infected with Hepatitis C (acute HCV infection), most persons usually do not have symptoms (60-70% of infected persons) or very mild with jaundice/yellow skin color (20-30% of infected persons) or nonspecific symptoms (10-20% of infected persons) being the most common findings. After the initial infection, 75-85% of infected persons will go on to have chronic HCV infection, defined as abnormal liver function tests or the intermittent presence of Hepatitis C virus in the blood (measured in much the same way as HIV viral loads). Abnormal liver function tests develop in 60-70% of chronically infected persons and this indicates active liver disease. The course of chronic HCV infection is often not apparent but progressive with 10-20% and of those with chronic infection developing cirrhosis (severe scarring of the liver) and 1-5% developing liver cancer (also called hepatocellular carcinoma, HCC) over an average period of 20-30 years. About 10% of those chronically infected remain healthy long-term nonprogressors while others have nonspecific complaints such as loss of appetite, fatigue and malaise.

Impact of Hepatitis C Virus Infection

Today, Hepatitis C Virus is the most common chronic blood borne infection in the United States. Approximately 36,000 new infections were reported in 1996 after peaking at an average of 230,000 new infections annually in the late 1980's. Currently, an estimated 3.9 million (1.8%) Americans have been infected with

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HCV and approximately 2.7 million of these individuals are chronically infected. Most persons infected with Hepatitis C in the United States are between the ages of 30 and 50 years of age and got infected because of intravenous drug use or unprotected sex.

It is important to note that most chronically infected persons are unaware of their infection. Nonetheless, all infected persons are a source of transmission to others and are at risk for chronic HCV-related disease, most notably chronic liver disease. Chronic liver disease is the tenth leading cause of death among adults in the United States, accounting for approximately 25,000 deaths (1%) each year. Population-based studies indicate that 40% of chronic liver disease resulting in 8,000-10,000 deaths annually is HCV-related. In addition, HCV-associated end-stage liver disease is the most common cause for liver transplantation among adults. Medical and work-loss costs of HCV-related acute and chronic liver disease (excluding transplantation) exceed $600 million each year.

Infection with Both HCV and HIV

In the United States, there were over 650,000-900,000 persons infected with HIV in 1996 with approximately 40,000 new infections occurring each year. That year there were 242,000 persons living with AIDS in the United States and 60,634 additional cases were diagnosed in 1997. Fortunately, many significant advances in treatment and management of HIV-infected persons have occurred over the past several years. These include the use of highly active antiretroviral therapy (HAART) such as those that include protease inhibitors in HIV-infected persons. In addition, HIV RNA levels (viral loads) have been added to CD4 counts to better assess treatment response and HIV disease progression. Such changes have resulted in an impressive decline in HIV-related illnesses and deaths. Indeed, in 1996 there was a decline in AIDS-associated deaths in the United States for the first time, from 50,000 in 1995 to 37,5000 in 1996 in the United States and this trend continues. With the decrease in HIV-related illnesses and deaths has come the increased recognition of other causes of illness in HIV-infected individuals including liver disease. Patients previously dying from complications of HIV now live long enough to have complications of Hepatitis C infection.

In studies looking at general populations, 8-30% of individuals with HIV also are infected with Hepatitis C. In those exposed to blood or blood products, particularly intravenous drug users (IVDUs), transfusion recipients prior to July 1992, and recipients of clotting factors made before 1987 (e.g. hemophiliacs), 52-90% of those infected with HIV are also infected with Hepatitis C. This is important as most new Hepatitis C infections are due to IVDUs (50-60%) or sexual behaviors of individuals (20%) rather than transfusion-related Hepatitis C infections as seen over ten years ago. It is noteworthy that while risky sexual behavior continues to be the major factor associated with HIV infection in the United States, IVDUs represent a growing proportion of new HIV infections. Thus it is not surprising that infections with both Hepatitis C and HIV is not uncommon and may increase significantly in the future as AIDS-associated illnesses continues to decline.

Effect of Infection with Both HCV and HIV

There has been much concern over the impact of infection with both Hepatitis C vi-

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rus and the HIV virus on an individual. A review of the studies that looked at this question suggests that HIV infection accelerates the progression of Hepatitis C related liver disease. One study estimated that HIV might cause Hepatitis C-related liver scarring to occur twice as fast compared to those only infected with Hepatitis C. However, Hepatitis C infection does not appear to have a direct effect on the course of HIV infection. Nonetheless, liver disease from Hepatitis C may limit the use of certain medications used in the management of HIV and its associated complications. This may become more of an issue in the years ahead as HIV-infected persons live longer and more active lives.

Treatment of Hepatitis C Infection in HIV-infected Individuals

Fortunately, response to treatment of Hepatitis C in persons also infected with HIV appears to be similar to that of persons not also infected with HIV. The goal of therapy is to clear the chronic Hepatitis C infection and thus prevent further liver damage. This is important as the liver has several major functions. These include: clearing toxins or poisons from the blood, providing nutrition between meals, and producing factors needed to help our blood clot. The decision to treat any Hepatitis C infection requires consultation with your primary care doctor and a liver specialist. The current standard treatment consists of treatment with a combination of recombinant interferon-alpha (rIFN-a) with ribavirin. This has resulted in sustained response rates of about 40%. The main side effects of interferon include flu-like symptoms. In addition, interferon can worsen conditions in those with a history of thyroid problems or depression. The main side effect of ribavirin include a decrease in ones blood count (anemia). Studies of other therapies are ongoing with evidence that treatment with another drug, lamivudine (3TC) that is also used to treat HIV, may be of benefit against Hepatitis C.

In addition to medical treatment, it is important that persons with Hepatitis C and HIV avoid drugs and infections that affect the liver. This includes alcohol, several medications, and other viruses that infect the liver such as Hepatitis B virus and Hepatitis A virus. For this reason, such persons should receive vaccinations against Hepatitis A and B if they have not already been infected; avoid alcohol; and consult your physician about medications including a common one, Tylenol.

Summary

Hepatitis C infection is a disease that frequently persists in a chronic form with a risk for significant liver disease. However, current treatment will clear Hepatitis C infection in less than 40% of these persons. With continued improvement in the care of HIV-infected persons, the number of HIV-infected individuals at risk for significant liver disease from Hepatitis C infection will continue to increase. Therefore it is important that HIV-infected persons protect themselves from getting Hepatitis C by practicing safe sex, and using clean needles if injecting drugs. Those who are already infected with Hepatitis C should also follow these steps to prevent the spread of Hepatitis C to others and to avoid getting strains of Hepatitis C that are not responsive to therapy. In addition, such persons should take steps to avoid further damage to their liver

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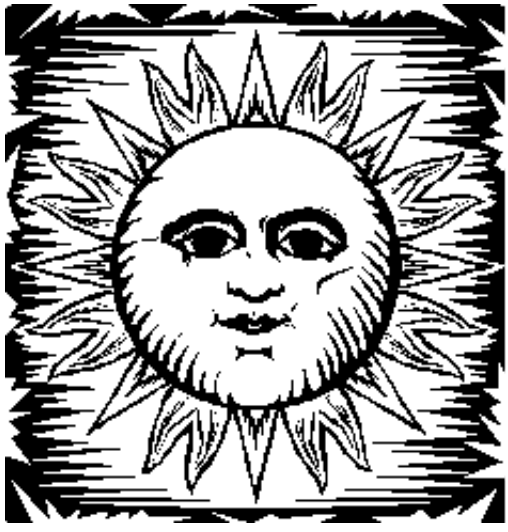
as outlined above and need to be followed closely by their physician.



A Note from the NCAB

During your interview, several questions are asked of you that may be embarrassing. Please remember that we want to know what you are about. We want you to answer the questions so that your responses reflect what you are all about, not what you think we want to hear. We at WIHS are not here to judge you!

The WIHS is collecting information that will help you, your friends, and your family in the near future.

WIHS NCAB Meeting

By Donna Haggerty

The national meeting of the Community Advisory Board took place on Wednesday, December 1, 1999 in Bethesda, Maryland at the Bethesda Holiday Inn. The temperature inside was a lot warmer than the outside-- 37 degrees when going out the door! I must admit I love the cold air since I come from Pennsylvania.

Over the next few hours, the reps from the other WIHS study sites met and brought old and new issues to the table. As anyone knows who is part of a study, discussion goes back and forth many times before study changes finally occur.

Something that has always been of major concern is how to continue the interest and participation of the women in the study. The length of the study, which we have been told had been funded through November 2003, is perhaps a major factor in keeping interest going.

Each rep, including myself, mentioned the low turnout at the CAB meetings. As many know, even our local CAB, has not had a meeting in quite some time. This is because of the low turnout and the in the majority of cases the local WIHS staff may be the only people attending the meetings.

Mary Young, of the executive committee, mentioned at the joint sessions that it is important to obtain the input of the WIHS women. One thing she said was that the lo

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cal CABs' help to keep the staff in touch with the needs of HIV+ women, who are part of the study.

Each site talked about their plans for the upcoming holidays, which always bring WIHS women together. Getting together at any time brings a positive atmosphere. It is good to see and know that we are still here.

One issue that was instantly decided was to present an abstract of the WIHS Study at the next International Conference on AIDS, which will be in South Africa. Each NCAB representative from each study site will write on a specific topic to be put into the abstract.

The topic that was of the most concern and interest and took a great deal of time in discussion was the issue of autopsy. If this is to come about, it is going to take the cooperation of many people, from the HIV+ woman, her family, immediate or chosen, the WIHS staff, and the hospital involved.

It has been suggested one of the ways to reach women on this important issue is to include information in the next newsletter, so this process can start. The newsletter would provide the information of what a study participant needs to do in order to be a part of this. Things such as adding to their living will, inform family of their wishes, tell their primary care giver or doctor, carry a card, etc., with them, as people do for other serious illnesses.

The above is just in the planning stages. WIHS (each site would purchase the card for their participants) would design the card, having 5 lines with the person's name, WIHS information, site, contact person, and phone number.

Each site would request information from each client, first asking if she would like to have autopsy performed. When speaking to a client, you must inform her what an autopsy is and the benefit it would give to women in the future, such as telling her that a second set of slides would be made at the hospital and given to the WIHS study to help doctors further their understanding of HIV. Since the family has the final decision, it is important that they know of your request. WIHS staff would be willing to help families have autopsies performed by putting it into a letter for them.

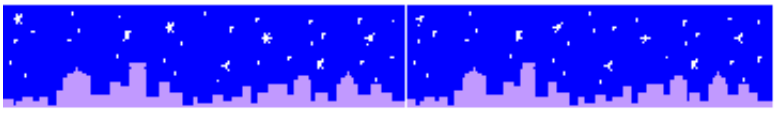
Educate clients to inform their next of kin of their wishes and put it into writing. It is important to do all of these things when you are healthy and to have a piece of mind that what you want will happen.

On a more positive note, information gathered through this study indicates that 80% of women on HAART adhere to their medication and therapy. Many of us are living longer and doing things we never thought we would continue to do - returning to work, raising families, and participating in life. Yes, we are still HIV+, that will not go away...yet. With hope and continuation of the WIHS study, changes will come and they will help us to continue with our lives.

Women's HIV Conference

By Donna Haggerty -SF WIHS NC AB Rep

The conference brought together more than



900 HIV+ women from all 50 states along with women from Canada, Puerto Rico, Mexico, Hawaii, and Argentina. This brought the grand total of 1200 people attending the meeting. I asked a woman, who was working at the conference why they chose Los Angeles over Pasadena, which is much nicer place than LA. She informed me that the conference had grown so much in the past 2 years that LA had to be selected.

As with any large meeting, this conference has its problems. Although I did not hear the majority of complaints, but I did hear that the lack of bed space (there were situations of 4 women in a room and some of them had to sleep on the floor) and the absence of food. Some women came to the conference with scholarships and believed that they would be taken care of but some of these women were quite disappointed.

Sadly, one of the women from Arizona became very ill while attending the conference and passed away on the morning of the closing ceremony. There was a tribute to her during the ceremony. From what was said, although she was very ill she wanted to be there to offer her support. These moments are difficult to deal with, but make us realize that being there was a precious gift.

The size of the convention center and the number of workshops being offered made it difficult to choose a session and run to it. There were several times I wanted to attend several sessions but they were held at the same time or if they occurred at different times it took forever to get to a session due to the size of convention center. Many women stated that next time something can be dome to improve the system.

One thing I felt, and this was mentioned by others at the plenary session, was a need to create a policy and advocacy agenda for HIV+ women. This is because of this conference, like many other conferences, we felt left out. We were sitting in sessions being talked to by others that did not really know how we think and feel. In fact, this meeting was the one I felt was for us, especially with the interaction between the women. The women who stood up to say what they felt, actually made the meetings come alive. We were not in a room with someone who did know where we were coming from and when finished with their prepared speeches, took a few questions and then left the room.

These women felt that there needs to be a better format for these meetings. Yes, between meetings, women connected and there was this great feeling. But, why were we there? If it is just to hear more chart information, then this concept or style is not working.

The plenary session was only for 1 and a half-hours and could have been longer and possibly the most important session of the conference. I am not saying that other sessions were not important, they were. There were meetings for various needs, older women, women in prison, women with children, etc. I think what made this session have substance was that…women, who are positive, had a place to vent our frustrations, needs, questions, and ask where do we go from here?

The closing ceremony was special. A

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woman from each state and other locations carried the flag of their state/country into the hall. It was quite a feeling. The women who had done all the work to make this conference happen were brought on stage and spoke. One of the gentleman who was in charge did admit that mistakes had been made and that they would learn from them.

I met several nice women (including other WIHS reps) whom I plan to keep in touch with. I was also able to take pictures and can hardly wait to see if they turn out well.

I came home with stuff from the exhibits along with memories, both good and sad.