Spring 1998 Volume 2, Issue 2

The WHS Woman

SPRING IS HERE

Spring is finally here. I am sure all of you are tired of the rainy days and cold nights. All the daffodils and tulips are in bloom, fruit trees full of promise to deliver their juicy sweet fruit, and the air filled with fragrance and bird song.

I would like to share a poem with all of you (I have both English and Spanish versions). The poem was written by the famous Chilean poet, Pablo Neruda. Pablo Neruda was awarded the Lenin peace prize in 1953 and the Nobel Prize for literature in 1971.

Spring

The bird has come
to give the light:
from each trill of his
water is born.

And between water and light that unroll the
air now the spring is inaugurated,
now the seed knows that it has grown,
the root is portrayed in the corolla,
at last the eyelids of the pollen unclose.

All this was done by a simple bird
from a green branch.

La primavera

El pájaro ha venido
a dar la luz;
de cada trino suro
nace el agua.

Y entre agua y luz que el aire desarrollan
ya está la primavera inaugurada,
ya sabe la semilla que ha crecido,
la raíz se retrata en la corola,
se abren por fin los párados del polen.

Todo lo hizo un pájaro sencillo
desde una rama verde.

From: Mitchell, Stephen. Full Woman, Fleshy Apple, Hot Moon. Selected poems of Pablo Neruda. 1997. HarperCollins, publisher, New York, NY.

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ASK DOCTOR WIHS

Question: Is there treatment for AIDS dementia?

Answer by Richard Price, MD
San Francisco General Hospital

The short answer is - yes, but it might be better to phrase the question "what are the best available methods for preventing and treating AIDS dementia?" Since the beginning of antiretroviral drug use, people saw that these drugs also could prevent and treat an important complication of HIV infection known as **AIDS dementia complex** or ***ADC***. ADC patients often have difficulty with concentration and memory, and with muscle coordination, particularly with walking. Although ADC results from advanced HIV infection and occurs under the same conditions as opportunistic infections, this disorder is thought to be caused by direct infection of the brain by HIV rather than some other virus or bacterium. It is not known why some people with AIDS develop ADC while others do not, but it may have to do with different varieties of the AIDS virus that infect or undergo change in people infected with HIV. While many researchers feel that ADC is less common now than earlier in the AIDS epidemic, it still occurs and can both alter quality of life and contribute to early death.

The first large study of AZT (zidovudine) found that those taking the drug had both and increased survival and better neurological performance. Subsequent studies of AZT confirmed that this drug could stop the progression of ADC, and actually improve the neurological function in adults with ADC. Similar beneficial effects were also noted in children with AIDS who suffered the pediatric counterpart of ADC.

As new drugs and drug combinations for treatment of HIV have been introduced, their effects on ADC have not been examined, so we don't know how well they work in preventing and treating ADC. However, most clinicians caring for ADC patients have found that some respond very well to combination antiretroviral treatments. Since we know these types of drugs *can* work in ADC, we can presume that drug combination that are good for general body HIV infection (by reducing the viral load in the blood and increasing the CD4 counts) are also likely to help with ADC.

However, if ADC is caused by direct HIV infection of the brain it may be important that anti-HIV drugs penetrate into the brain to suppress multiplication of the virus there. Unfortunately, certain drugs do not penetrate well into the brain because of what is called the *blood-brain barrier*, which stops these drugs from traveling from the blood vessels into the brain. Antiretroviral drugs vary in this respect, and as a result it may be that some drugs are better for treating ADC than others, though this has not been directly proven.

I now follow these treatment recommendations:

1. For patients with more advanced ADC (Stages 2-4), **aggressive combination antiretroviral therapy** should be given. This usually means combinations of 3 or 4 drugs.

2. The first criterion for selecting drugs should relate to the individual patient's history of previous antiretroviral drug use and

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their known or presumed resistance. This follows exactly the guidelines that caregivers use for treating HIV infection in general.

3. Within these limitations, **at least two** of these drugs should be chosen from those with known central nervous system penetration if possible. However, absence of good penetration should not prohibit inclusion as the 3rd or 4th drug (and if none of the available drugs is thought to penetrate, they should be given anyway). Among the drugs presently known to have 'good' penetration are the nucleosides zidovudine (AZT), stavudine (d4T), abacavir (1592U89) and probably to a lesser extent, lamivudine (3TC). Among the non-nucleosides, nevirapine and efavirenz (DMP266) penetrate fairly well. More uncertain are the protease inhibitors among which indinavir may be the only one with fair penetration. This list is based upon surprisingly limited and sketchy information and likely will need to be revised to both delete some of these and add others as penetration of each is defined better.

It goes without saying that for these treatments to work properly it is critical that the patient's neurological difficulty is not result from some other cause (for example, related to another infection of the brain, a toxicity of some medicine or an illness not even related to AIDS). Accurate diagnosis is therefore critical, and is up to the caregiver managing the patient. Also, while these direct treatments are the primary approach to ADC, there are other general measures that should be taken to protect patient safety and to maximize both patient comfort and ability to enjoy life, despite neurological disability. This may involve other medications, the creation of

a supportive environ

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Sequential HIV infection, if it could be documented, is uncommon. It is likely that the first HIV infection prevents re-infection by a second HIV. The first virus to enter the body is likely to gain a significant foothold in critical body cells and tissues ('niches') that the virus grows in. In effect, this first virus is well adapted to grow in the infected individual, and is a tough competitor for any new HIV intruder. In addition, the immune response mounted against the first HIV infection, although unable to clear the infection, may serve to discourage and or prevent infection by new intruders.

"*My CD4 cell count was 400 last week and 150 this week: should I be worried?*"

Answer by: Ruth Greenblatt, MD
UCSF, WIHS Principle Investigator

CD4 cell counts are very useful tests for determining how your immune system is doing after infection with HIV. Like many medical tests, CD4 cell counts can vary and sometimes can be wrong. Your CD4 cell count varies naturally:

- It changes with time of day
- It may increase or decrease (a lot) if you have an illness, even a cold
- It may increase or decrease after a vaccine

So, if a result is very different than the one before it the test should be repeated. Be sure your medical provider knows if you have a cold or another illness on the day you are having your blood drawn.

In addition, problems can occur that can make your CD4 cell count inaccurate:

- If your veins are not very good, a tiny

CAB CORNER

by Moher Downing, Community Liaison

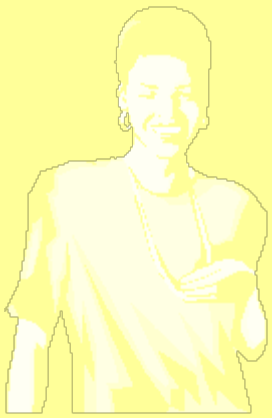
Community Advocacy Training

On Thursday, April 9, 40 HIV+ women gathered at the San Francisco AIDS Foundation to teach each other how to become "community advocates." The second annual Community Advocacy Training was sponsored by WIHS, WORLD, the California Partners Study, Ward 86, the Women's AIDS Network, and the San Francisco AIDS Foundation.

Food, food, and then more food. Three wonderful meals were served, breakfast, lunch, and a graduation feast. Childcare was full. The agenda was full, and so were our stomachs. Topics ranged from "How not to Burn Out" to "Understanding Research" to "How to Give Good Meeting."

Our sisters told their stories. Some shared with us how they evolved from "being in the closet about their HIV status" to becoming inspired by the work of other women and then taking their first step towards working in their community. Hugs, cheers, inspiration, tears, laughter, and tiredness—we felt it all that day. For those of you who missed the training last year and this year, we hope to see you next year. Thanks to all the volunteers who worked so hard to make this event so successful.

WHERE ARE YOU?



Your CAB has been meeting without you. We miss you. We miss your participation. We miss your WIHS words. How much longer will we have to meet without you? Will you be at our next meeting? We are moving our East Bay meeting to the WIHS site at Highland Hospital just so you'll know exactly where to go. Meetings are held the third Thursday of every month from **2:30 to 4:30 PM.** We alternate between San Francisco and the East Bay. The **May 21st** meeting is at Highland. The **June 18th** meeting is in San Francisco at the Community Consortium, 3180 18th Street at Folsom, second floor. You will call me, **Moher Downing, at 415-597-4654 if you need a ride. You don't want to miss the great food, do you?**

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WIHS Clinically Relevant Lab Tests by Dr. Herminia Palacio, MD

***Renal Panel**: Measures how well your kidney is working by checking the chemicals they produce*

Laboratory Test	Measurement	Abnormal	Meaning of Abnormal Results
Sodium (Na)*	the amount of salt in your blood (salt is actually too chemicals together, sodium and chloride)	too high or too low	your kidneys are not keeping the right balance of salt and water in your blood: this can happen from things like dehydration, medication side effects, etc.
Potassium (K)	the amount of potassium in your blood	too low or too high	your kidneys may not be working well; or you are loosing more potassium than you eat (for example you have a lot of diarrhea)
Chloride (Cl)	this is the other half of the chemical "salt"	too high or too low	another indication of the amount of salt balance in your blood
Glucose (Glu)	sugar	too high (high blood sugar)	this means you might have to get checked for Diabetes
Creatinine	this is a chemical that your kidneys process	too high	this might mean your kidneys may not working as well as they could
BUN	this is a chemical that your kidneys process	too high	this might mean your kidneys may not working as well as they could

SUNSCREEN, MEDICINES, AND YOU by Herminia Palacio, MD

CAB Question: Why did the WIHS include sunscreen as one of the gifts offered to participants?

The sun + some medicines = bad rash

The sun gives off rays we can see (called visible light), and rays we can't see (called ultraviolet radiation, or UVR for short). Both UVR and visible light from the sun can cause severe skin rashes in people who are taking certain medicines. The rash can look many different ways. It can look like a severe sunburn with blisters which then gets much darker than your usual skin color. It can also look more like a dry, scaly allergic rash. Your health provider may call these rashes "drug-induced photosensitivity rashes" or "drug-induced photodermatitis". People of all skin colors, from very light to very dark, can get this type of reaction if they are exposed to the sun while they are taking certain medicines.

Some of the medicines that can give this type of rash are very commonly used, for example sulfa drugs (like Septra), coal tar, and many others. Septra is an antibiotic pill often used to treat bladder infections and to prevent or treat a type of HIV-related pneumonia called PCP. Coal tar come as a shampoo and lotion and is used to treat skin problems like dandruff or psoriasis. If you are taking medicines that can give you a "photosensitivity rash" (ask your provider), one way to protect yourself is to use sunscreen. Sunburn and Skin Cancer UVR can cause sunburn and more skin damage that can lead to skin cancers. Sunscreen helps protect the skin against sunburn and other types of skin damage. In general, people with lighter skin burn more easily and get skin cancers related to sun damage more easily than do people with darker skin. The faster you burn in the sun, the more important it is to use sun-

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screen.

How to Choose and Use Sunscreen

The number you see on sunscreen bottles is called the Sunscreen Protection Factor, or SPF for short. Basically, the higher the SPF number, the longer it will take for you to get a sunburn. For example, if the SPF = 5 it will take you 5 times as long to get sunburned than it would if you did not use any sunscreen. To get the most out of your sunscreen: 1) put it on about half an hour before you go out, 2) put on all of the skin that will not be covered by clothes (and remember all those places we tend to forget, like the

WIHS FACTS by Nancy Hessol

At one of our recent Community Advisory Board (CAB) meetings, members suggested that some basic information be given out on the women we have enrolled in our study. Here are some data describing our WIHS site.

Between October 1994 and 1995, we enrolled 427 women into our study: 49 women at the East Bay AIDS Center (EBAC) in Berkeley, 133 women at Highland hospital in Oakland, 68 women at San Francisco General Hospital (SFGH), and 177 women at the University of California San Francisco (UCSF). Fifty-six percent (56%) of our study participants are African American, less than 1% are American Indian, 1% are Asian/Pacific Islander, 12% are Latina, 26% are White, and 4% are of other racial or ethnic origins. Of the 427 women enrolled in our site, most women are between 30 and 50 years old and 79% are HIV positive.

Every month we give out updated information on our WIHS women. If you are interested in receiving the monthly reports, please call 476-1956 and ask to be put on our toring report mailing list. You can also ask our staff for a copy of the report when you come in for your WIHS visit. If there is specific information you would like to see reported, call us or go to one of our CAB meet-

MOVING ON

Congratulations Rochelle!!!

Rochelle Hayes has been with the WIHS project since the very beginning of the study. She started out as a Project Assistant and was promoted to Senior Project Assistant a few years later. On May 15th, Rochelle will be leaving us to embark on a new adventure. She has been accepted to the UCSF School of Nursing's nurse practitioner program. The entire UCSF WIHS team would like to congratulate Rochelle Hayes for getting into nursing school, but we all want to tell her that she will be sorely missed!!! Good luck and thanks for all your hard work and effort on the WIHS project.

Words from Rochelle's colleagues and friends:

For Rochelle...I've always thought you were swell.
Getting into nursing school seems right on.
But what will we do after you're gone?
Study hard, empty those bedpans,
but don't forget we are your fans.
Rhyme requires Moher Time

Best of luck, really. You'll do terrifically, I'm sure. Keep up with running and swimming, sure you'll have lots of stress to manage. Now that you are leaving, who's going to be around to tease me, I guess Debbie will do that. Sincerely, **Sharon Alpert**

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Rochelle, remember when we first met at those WIHS organizational meetings? Trying to determine which vendors we should order from, etc.? How about those never-ending courier issues? I enjoyed working with you and I was always impress by your dedication to this project. The world of nursing is gaining a great asset in you and we at WIHS will miss you. Take care, enjoy school, have fun, and I will see you at the library, bookstore, courtyard, in the East Bay, etc. Congratulations! All my best, **Yvonne**

Rochelle, the next few years will pass quickly and then you'll need a preceptor, and then we can work together again and then….I'm excited for you and this new chapter in your life. Take care of yourself and I'll see you around the neighborhood. **Debra Walter**

Rochelle, farewell. This isn't goodbye cause at least you'll be nearby. We wish you well cause you're so swell. With you as nurse people won't leave in a hearse. **Specimen Bank Gang**

Congratulations HERMINIA!!!

Dr. Herminia Palacio, the co-Principle Investigator of the WIHS study at UCSF is taking a new job. She will be the new Assistant Advisor for health policy to the Director of SF Department of Public Health, Dr. Mitch Katz. Dr. Palacio will continue to be active in the WIHS as well as continue to see patients at SFGH. We wish her the best of everything and congratulations from all of us at WIHS.

A Vaccine to Stop HIV?

by Susan Buchbinder, MD and Joe Wright

Eighteen years ago, officials at the World Health Organization made an amizing announcement: smallpox, a killer virus that spread across the world in unstoppable epidemics, had been eliminated. A lengthy world-wide vaccination campaign eventually protected all of the world's people against smallpox infection, and the virus ran out of places to go. The smallpox vaccine made smallpox extinct in the natural world. Could an effective HIV vaccine limit or eliminate new infections with HIV? More and more people think it is possible. President Clinton pledged to find a preventive HIV vaccine by 2007, and a growing number of researchers and community activists are working towards that goal.

VACCINES WARN THE IMMUNE SYSTEM

The idea of a preventive vaccine is to help the immune system recognize and destroy HIV before it gets a chance to hide out in people's cells and stay in their bodies. If a vaccine worked against HIV, it would be like showing a picture of HIV to the immune system. Then, as soon as HIV showed up, the immune system would be able to recognize HIV and destroy the virus before the virus could go find hiding places.

Although some other vaccines (like the polio vaccine) work by simply weakening a virus and causing a very minor version of an infection, many people are worried about the potential dangers of using such an approach with a virus like HIV. That's why researchers are focusing on other ways to show the im-

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Some day, an HIV vaccine could prevent HIV infections and stop the HIV epidemic among people around the world. Meanwhile, there are many unanswered questions remaining. By serving on community advisory boards, working as activists, or volunteering for vaccine clinical trials, everyone can make a difference in this important effort. If you're interested in vaccine development, give Joe Wright a call at 415/554-9065, and he can tell you more ways to get involved, or sign you up on