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The WIHS Woman

Impression of the 12th International Conference on AIDS

by Nancy Hessol, WIHS Project Director

We are devoting much of this issue of *The Wlt18 Woman* to report back from the recent International Conference on AIDS held in Geneva, Switzerland. I would therefore like to share some of my impressions of this conference to go along with the other scientific aspects of the meeting.

The locale: **Geneva** is a picturesque moderately sized city that favors tourism so most places are very kind to foreigners. Unfortunately, since the AIDS conference is so large, there were not enough hotels to accommodate all the participants in town so many people who attended the conference were a long train ride away. Fortunately, Geneva and its surroundings have a very good public transportation system.

The conference facilities: The meetings were held in the Palexo, which is made up of several large Quonset hutlike structures connected by narrow corridors. The oral sessions, posters, and exhibits were distributed throughout the conference facility and it wasn't easy to get from one end of the place to another. The community exhibits, such as WORLD's booth, had a good central location and were staffed by really friendly folks (such as our own Nilda Rodriguez). The big hall for the main oral presentations was very nice but the makeshift rooms for other oral sessions were lacking (poor sound and video quality). As usual, there were long lines for the women's bathroom facilities.

The selections of oral and poster presentations: The conference organizers tried to balance the presentations so that countries from all parts of the world were represented. Some people at the conference felt that too much emphasis was placed on geographical diversity rather than scientific excellence. As in years past, I felt there were some great presentations that were only accepted for poster presentation and there were some terrible presentations that were featured as oral presentations.

Currently most researchers try to publish their newest findings in journals rather than save them to present at this meeting. However, the conference is a good place to learn more about things that have been published. The conference is also an excellent place for networking with others who are doing work similar to your own. The International AIDS conferences are now held every other year with the next one scheduled for Durban, South Africa, in July 2000.

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CAB CORNER

by Moher Downing, Community Liaison

WIHS CAB PLANS INTERNATIONAL AIDS CONFERENCE UPDATE

COMMUNITY ADVOCATES COME TOGETHER AGAIN

This year the International AIDS Conference was held in July in Geneva, Switzerland. Not many of us could attend because of the high costs, but a lucky few got scholarships or have jobs that paid for them to go. (See our own Nilda Rodriguez's story below about Geneva.) Your CAB would like to bring a little bit of Geneva to the WIHS participants.

We can't bring the Alps to you but we can bring information and chocolate! Plus you can be one of the first to see WORLD's new office in Oakland. Here's the deal...

THURSDAY, SEPTEMBER 17, 1998

FEAST & RECEPTION 2 PM to 3 PM UPDATE 3 PM to 5 PM

LOCATION: WORLD'S NEW OFFICE 414 13TH ST., 2nd FLOOR OAKLAND, CALIFORNIA

½ Block from 12th St. BART
½ Block from Broadway

Free Childcare & Help with Transportation Call Moher at 415-597-4654.

There will be a planning meeting on Thursday, August 13th, at WORLD, at 1 PM.

Refreshments will be served. Please call Moher if you would like to get involved in the planning. On Saturday, July 25th, many of the participants from the Second Annual Community Advocacy Training came together again with their Mentors at a picnic on Lake Merritt in Oakland. It was a lovely day--not too hot, and not too cold! Mentors and Mentorees enjoyed great food supplied by the WIHS Study and the San Francisco AIDS Foundation. Many of the women brought their children and their grandchildren who had a great time playing at the nearby, fabulous Lake Merritt Playground.

We hope this picnic is a first step towards helping the mentors and mentorees forge strong relationships that will continue over time. If you would like to be hooked up with a mentor (that's someone who helps you go to meetings) and gives you information about what's going on with a particular group or issue), please call Moher Downing at **415-597-4654.** It's never too late to find a mentor. You don't have to have attended either of the Community Advocacy Training's to be given the phone number of another woman who is interested in the same issues as you. We can also arrange to have a mentor call you just to talk. If you are sitting at home and lonely or waiting to join some group, please call Moher **RIGHT NOW** so you can have your very own mentor!



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INTERVIEW WITH THE FABULOUS NILDA RODRIGUEZ

By Moher Downing

I interviewed Nilda at her home in the Bernal Heights district of San Francisco, where she lives with a friend and an assortment of dogs and birds. Both women are HIV+ and truly fit the definition of what it means to be an "activist." I brought my dog with me who had a great time playing with the 5 other dogs. Nilda's roommate was busy taking care of the birds and photographing the dogs in different costumes. I noticed she wore a mask when she tended to the birds, which is a smart thing to do if you are HIV+. She volunteers once a week at PAWS (Pets Are Wonderful Support). Nilda was nursing an ear and bronchial infection, but was excited to share her adventures over the last few months with the readers of the WIHS Woman newsletter. I am writing this story about Nilda with the hopes that it will inspire some of you WIHS women who are sitting at home and feeling isolated from the world.

Nilda moved to the Bay Area from Los Angeles less than two years ago. Since that time she has become one of the guiding lights in the positive women's community here. She sought out WORLD and was soon involved in the WIHS CAB and a variety of other projects too numerous to mention. Of course, like most activists, she quickly became over-extended and had to start saying "No" to important requests for her expertise and perspective.

Recently WIHS asked Nilda to represent our CAB at the bi-annual NCAB (National Community Advisory Board) meeting in imagine yourself flying to New York City, staying in a midtown hotel, and meeting HIV+ women from all over the country? Nilda told me there was a time when she couldn't have even imagined doing that. Nilda was impressed with the women she talked to from the other WIHS sites (Los Angeles, Chicago, Washington D.C., Brooklyn, and the Bronx. She was inspired by some of the doctors she met and their commitment to women with HIV. Unfortunately, Nilda had a bad cold and couldn't attend all of the discussions, but she learned a lot from the ones she did attend.

Then in July Nilda received a scholarship to the International AIDS Conference in Geneva. This was Nilda's first trip overseas. Her dear friend and our long-time NCAB representative, Carol Siporen, was unable to go with her because she has been struggling with some severe HIV-related illnesses. Nilda said she really missed Carol on the trip. She went with Rebecca Denison, and they were housed an hour and a half away from the conference by public transportation. After 4 days and nights of the long trek back and forth to the conference, their complaints were finally answered, and they were housed closer to the conference.

Nilda said the convention center was so huge that people with neuropathy really suffered from walking such long distances to attend the different sessions. Nilda did not attend any sessions, but concentrated on networking with HIV+ women from all over the world. By tabling for WORLD, she got to talk with women from Zimbabwe, Morocco, Nairobi, and other parts of Africa, from Thailand, and from Russia. Nilda said that 60% of the scholarships went to people from Africa. New York City. Nilda was going to New York anyway to visit her brother, but now she would have her trip paid for by the NCAB. Can you

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She learned that it is only in places like the United States, Canada, Australia, and Europe that people with HIV can afford to take AIDS drugs. One woman from South Africa told her that it takes three years salary for one month of AIDS drugs.

Nilda told me a lot more about the conference, she wants to tell you about it herself at the WIHS International AIDS Conference Update on September 17^{th at} the WORLD office in Oakland. I hope you will come and be inspired by Nilda's story. If you can't imagine any of these things ever happening to you, you should call me at 415-597-4654 so that I can help you get to the Update. "





WIHS Staff Comings and Goings

by Nancy Hessol, WIHS Project Director

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HERE'S WHAT YOU HAD TO SAY Comments from the Clients

Once again we are pleased to bring you the feedback that we have gotten from all of you about the study over the last few months. This is what you had to say about the study. None of your words have been changed. Can you find your quote?

I don't have anything negative to say. Donna and Maribel are so pleasant to talk to. Sometimes I'm here 30 minutes or longer, because we get off the track with my personal life. I'm so impressed that they allow me to bend their ears. And they give me their honest thoughts and not what they may feel I want to hear. "L"

Maribel is a nice person and Donna is excellent and respectful. The fanny pack I got was nice for being on time.

I have not had problems with the way the WIHS program is going now and before. I appreciate everything that the WIHS program has to offer. I would like to see the program take on more women for the study.

I really love the study. Donna is really good at what she does. She goes over and beyond the call of duty.

As a working participant I think the best thing you can do to improve the study for me is to have some evening appointments. I like the study because it allows me to monitor my health without compromising my medical privacy. Keep up the good work but try to add a few evenings.

I feel that it's a very nice study. Donna and all the other ladies are very nice and understanding and they take out a lot of their time to help the women of the study. RC I like you a lot. You are a very nice person. I love to hear you talk. You have a sweet voice and I also think you are so cute.

The study has been positive for me. It enables my life to feel better about myself. I know that this study does more than my clinic. Therefore, I can relax and enjoy life better. I know that if anything is wrong, they will find it. Yours truly...

Yes, my name is DH. I have been in this women's study for the last 3 years. I really think the staff is wonderful people. They are very respectable women and caring especially Donna and Maribel. I just love them so much. They even care about me in my recovery. They try to keep me on my toes. I wouldn't want to give myself to any other research. WIHS/BARCWA are very special people in my life today. Keep inspiring the women and keep up the good work. I love you all. Sincerely... R

Donna, yes, she's the most wonderful lady to be a client of. It really can't get any better. And may I say "they just don't come any better nowadays, in any and every way a job can be performed. Thank you...DW

I love Donna, Debra, and Maribel and the entire WIHS staff at Highland. I enjoy the study and have learned quite a lot. I just wish there weren't as many questions.

One time I went to the WIHS and they needed to draw blood, but my veins are so shot, I need a doctor to draw it. They tried to find one but couldn't until 2:00 PM. The nurse tried and it was funny because every vein she found would collapse or burst.

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I have no complaints about my visits, everything and everyone (meaning staff) are very friendly, and my visits are mostly always pleasant.

My name is "B". I've been in the study since it began. I was the second woman to enroll at Highland Hospital. All the staff is "A O.K.", leaving time to explain everything to you if asked. Donna and Maribel are the best. They treat you as a person more like a friend, not a client and that's what so great. Also Debra.



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

Laboratory Test	Measurement	Abnormal	Meaning of Abnormal Results
Hepatitis B surface Antibody**	measures if you have pro- duced any antibodies against Hepatitis B virus	positive	you have either been infected with or vaccinated against Hepatitis B virus sometime in the past
Hepatitis B surface Antigen	measures if there is evi- dence of Hepatitis B vi- rus in your blood	positive	you have an active infection with Hepatitis B virus
Hepatitis C Anti- body**	measures if you have pro- duced any antibodies against Hepatitis C virus	positive/ reactive	you have been infected with Hepa- titis C virus sometime in the past (and probably have chronic infec- tion with this virus)
RPR and MHAT-P*	tests if you have evidence of syphilis infection	positive for both tests	you have been infected with syphi- lis and may have an active infec- tion
Gonorrhea LCR test^	tests for infection of your cervix with gonorrhea	positive	you have gonorrhea
Chlamydia LCR test^	tests for infection of your cervix with Chlamydia	positive	you have Chlamydia
Herpes simplex virus culture (of ulcers)^	tests an ulcer for Herpes virus I and II	positive	you have Herpes

Diagnostic Tests: Identification of various infectious agents.

Key:

* = test done only once a year

** = test done only at baseline visit

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12th Annual World AIDS Conference - Geneva, Switzerland 28 June - 3 July 1998

Abstracts

Serum Albumin as a Predictor of Survival in the WIHS

Feldman J, Anastos K, Bacchetti P, et al.

Objectives: To learn whether at the time that a women entered WIHS her blood level of albumin, a simple protein widely distributed throughout the body, could predict her subsequent survival.

Methods: Data were analyzed from WIHS, a prospective study of 2058 HIV+ and 567 HIV- women recruited in 5 U.S. cities from 10/94-10/95; clinical, virologic and immunologic information was obtained every 6 months. Notification of death was obtained from friends and relatives, etc. Associations between entry albumin levels and survival were estimated accounting for potential differences in age, height and weight, and measures of disease stage such as CD4 count and viral load. This was done to increase the chance that associations between albumin and death were valid and not merely a reflection of the association of albumin with age or weight or HIV stage.

Results: There was complete data available for 183 deaths in 1493 HIV+ women. Half the women were in the study for at least two 2 years. We could not find 11% of HIV+ women. Mortality after two years was 13.7% overall but varied significantly by

than 3.5 (N=78), 3.5-4.0 (N=449), 4.0-4.2 (N=279), 4.2-4.5 (N=418), 4.5-4.7 (N=159), and greater than 4.7gm/dl (N=110). This trend was so strong that we can be pretty certain that it was not due to chance fluctuation. The association of albumin level with mortality persisted even after accounting for differences in CD4 count, viral load, height, weight and age among the women. These are factors that also affect mortality and possibly could be responsible for an association of albumin with mortality if they are not considered. This could happen, for example, if women with low albumin also had low CD4 count and high viral loads. A woman with an albumin level less than 3.5 was .1 times more likely to die than a woman whose albumin level was greater than 4.7, irrespective of CD4 count or viral load. If a women had an initial albumin value between 3.5-4 she was 2.5 times more likely to die than if her albumin value was greater than 4.7. If initial albumin was 4-4.2 the risk of death was 2.6 times greater; if initial albumin was 4-2-4.5 the risk of death was 1.5 times and finally if albumin was from 4.5-4.7 the women was also 1.5 times more likely to die than if her albumin level was over 4.7. For purposes of comparison, a women with a CD4 count less than 200 at enrollment was 6.4 times more likely to die than a women whose CD4 count was over 500, and similarly a women with a viral load over 500,000, was 5.9 times more likely to die than a women with a very low viral load.

Conclusion: The increase in mortality for women with albumin less than 3.5gm/dl was similar to that for patients with low CD4 counts or high viral loads. Serum albumin appears to be an important predictor of survival in HIV+ women. We need to verify this and to study the reasons why blood level entry albumin value; it was 41%, 17%, 14%, 10%, 9%, and 4% for women with albumin levels less

of albumin is a strong predictor of survival and how albumin may be influenced by HIV disease progression. For example, albumin level may re

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