

Health WIHS

Winter 1999

WIHS UPDATE: Rosemarie's WrapUp

by Rosemarie Gottlieb, WIHS Program Administrator

This issue of HealthWIHS is just packed with information for you. Flip through the pages and you'll find tips and tricks to help you feel better. You'll also find some interesting opinions and ideas.

We've included a new section in this issue, "News from Your Site" which includes any new information related to your research site that may be useful to you.

Other information you may find useful are the WIHS phone numbers. One of those is my pager (312) 647-1540. I'm Rosemarie Gottlieb, the new Program Administrator for the Cook County WIHS. You can page me if you have any questions or problems and I'll do my best to satisfy your needs.

Speaking of satisfaction, one of the articles in this paper is about those feedback forms you have been filling out at each visit. Maryanne Zarrella wrote up an interesting analysis. I'd like to address some of your suggestions for change.

One suggestion was for more money. This would be great, but due

to grant restrictions there is no more money available for your regular visit! Participation in substudies (like the interim event and intercurrent illness substudies) do bring additional money for participants.

People also suggested shorter visits and a shorter feedback form. We know that the new Drug forms do take a long time to answer. The information from these forms is important and will be used to help improve medication adherence and realistic drug regimens. We appreciate the time and patience you give for the interviews.

By taking the time to fill out the feedback forms completely, you help us do our best to keep you satisfied. Also, we are currently revising the Feedback Form to be shorter with Visit 10.

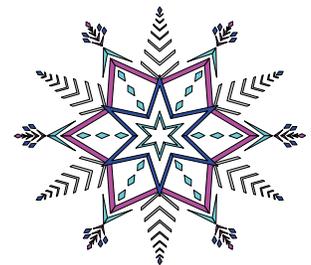
Finally, there was a suggestion to have more flexibility in scheduling visits. The WIHS requires that all sites do the interviews first with the physicals immediately afterward, but we will try our best to work within your schedule. We ask that you come to your appointment on

time so you can help make sure that everything runs smoothly.

I'd like to close by congratulating all WIHS participants for staying with the study. There are not many large studies that look at women in particular. Each of you are vitally important to the future of HIV/AIDS knowledge, treatment and prevention. We, the WIHS staff, all thank you very much for your selflessness and courage.

TIPS TO STAY WARM & HEALTHY!

- * cover head and hands
- * drink lots of water
- * drink less alcohol
(alcoholic beverages can numb the feeling in your toes so you may not



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Health WIHS

Health WIHS is a publication of the Women's Interagency HIV Study (WIHS) in Chicago.

Health WIHS is a newsletter for, by and about women living with and affected by HIV. A person's HIV status should not be assumed based on any written material in this newsletter or their participation in WIHS.

If you have a personal story, poem or any other creative work that you would like to share with readers of Health WIHS please submit to:

**WIHS - Cook County Hospital
Administration Building
1900 W. Polk St., Rm. 1240
Chicago, IL 60612**

You can use your real name or an assumed name for publication, but please include your name and phone number with your submission so that we can call you to discuss your work.

Non-commercial distribution of articles in this newsletter is encouraged.

Any questions or comments, call Alice Kim,
Newsletter Editor, at (312) 633-5720.



WHAT IS WIHS?

The purpose of WIHS is to learn about the effects of HIV infection on the physical, emotional and social health of women. The results of this study will be used to help improve the health of women with HIV. In Chicago, four hospitals take part in WIHS:

Cook County Hospital / The Core Center
Mardge Cohen, MD
Audrey French, MD
Kathleen Weber, BSN
Rose Gottlieb, FNP, MPH
(312) 572-3715

Northwestern Memorial Hospital
Patricia Garcia, MD
Gabiella Meredith, RN
(312) 908-2643

Rush Presbyterian - St. Luke's Hospital
Beverly Sha, MD
Ruth Gilmore, RN
(312) 942-5865

University of Illinois at Chicago Hospital
Ronald Hershov, MD
Doris Carroll, BSN
(312) 413-1366

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FEEDBACK ON YOUR FEEDBACK

by *Maryanne Zarrella, WIHS Research Assistant*

What happens to the feedback forms after you complete them at the end of your visit?

Your input provides WIHS staff with invaluable information on how we're doing at meeting your needs and making your visit as pleasant and efficient as possible. Here's a brief summary of some things you have been telling us through the feedback forms over the past year.

WHAT DO YOU HAVE TO SAY?

- ⇒ "The visits keep me informed about my health and what I need to do to stay healthy."
- ⇒ "I need to be actively seeking ways of getting better or at least maintaining good health."

HOW SATISFIED ARE YOU WITH WIHS?

- ⇒ 94% of participants said that they were extremely or mostly satisfied with the research care and referrals they receive through WIHS.
- ⇒ 98.5% of participants said that staff were extremely or mostly courteous and considerate.
- ⇒ 94% of participants said that the visit ran smoothly.

WHAT'S THE BEST PART OF YOUR VISIT?

- ⇒ The kindness and concern of staff
- ⇒ Information about your health
- ⇒ Complete examinations
- ⇒ Getting paid

WHAT'S THE WORST PART?

- ⇒ Blood draws
- ⇒ Pap smears
- ⇒ Waiting
- ⇒ The long walk to the dentist

SUGGESTIONS FOR CHANGE!

- ⇒ More money
- ⇒ Shorter interviews
- ⇒ Better (and free) parking
- ⇒ Flexibility in scheduling visits
- ⇒ A shorter feedback form

Thanks for taking the time to fill out the feedback forms at the end of your visits. The information you provide is invaluable for our attempts at improving WIHS!

By the way, at Visit 10, the feedback form will be shorter and simpler!

Prostitutes Organize to Fight AIDS in India: An Inspiration to All of Us

by Alice Kim, Newsletter Editor

“I’m very frightened about AIDS,” said Milan Sarakar, a 21 year old prostitute in Calcutta, India.

“My son and my whole family depend on my income. My father is old and won’t be able to continue working. I have to live here for them. And it is a terrible pressure.”

Like many other women who sell their bodies for money, Milan was forced into prostitution because she was desperately poor. To feed her family, Milan risks the threat of HIV infection everyday.

USING CONDOMS — A RIGHT?

Milan now uses condoms with her customers. But this wasn’t always the case. In 1992, the government sponsored a safer sex initiative in Sanagachi, the red-light district of Calcutta, to promote condom use among prostitutes.

But it took more than

“Milan and other women in her profession had to fight for their right to demand that

information and condoms to promote condom use. Milan and other women in her profession had to fight for their right to demand that customers use condoms!

How could the women enforce condom use with their customers? Could they get their madams to require condom use from customers? What about protection from hoodlums who tried to steal from them or refused to wear condoms? These are the questions that the prostitutes faced as they began to understand that condom use could literally save their lives.

THE COURAGE TO FIGHT

Their courage to save not only their own lives, but the livelihoods of their families is incredibly inspiring. The first women who attempted to spread the word about condoms and HIV in Sanagachi faced enormous hostility from other members in their community. They were spat on, threatened, even kicked and beaten. But the women stood strong, convinced others to join their cause, and over time, became a force to be reckoned with.

In a remarkable show of strength and solidarity, in one instance, where a madam refused to require customers visiting her brothel to wear a condom, the nine prostitutes who worked inside disappeared for several days until the madam gave in to their demand.

Organized prostitutes have also forced the police to protect them against hoodlums. On a number of occasions, hundreds of prostitutes have picketed police stations to demand action against criminals. Once, when men who had brutally tortured two prostitutes with blades and cigarette butts had gone unpunished by the police, a group of prostitutes held a protest which pressured the police to arrest the men and beat them up!

As the women began to feel their strength, many took on a renewed interest in their personal education. On their own, prostitutes who knew how to read began holding classes to teach others who did not yet know how to read. They even intervened to rescue child prostitutes who had been sold or duped into the trade.

THE WOMEN’S COLLABORATIVE COMMITTEE

Then, in 1995, the women formally organized the Women’s Collaborative Committee to fight for their rights. The Committee, which functions much like a labor union, now has about 30,000 members in West Bengal, each paying dues of about 50 cents a year.

Because of the women’s own initiative and organization the Sanagachi project -- which pays prostitutes \$1 a day to spread the

- **Condom use has soared, from 3% in 1992 to 90% in 1998.**
- **HIV infection rates among prostitutes have stayed at**

word about HIV and condoms -- has been a success.

Condom use has soared, from 3 percent in 1992 when the project began, to 90 percent in 1998. Researchers have also found that HIV infection rates among prostitutes here have stayed at about 5 percent — a fraction of the more than 50 percent of prostitutes infected in Bombay.

For me, the women who formed the Women’s Collaborative Committee and their actions are examples of activism and struggle that point the way forward in our fight against the AIDS epidemic.

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This article was based on a story in the January 4, 1999 issue of the **New York Times**, “Going Brothel to Brothel, Prostitutes Preach About Using Condoms.”

What is Viral Load?

by Kathy Schilder, FNP, WIHS Research Nurse

A **viral load test** measures the amount of HIV particles in a blood specimen. This test shows how active the virus is in the blood. The higher the number the more active the virus.

Why is viral load testing helpful?

Viral load results provide important information that is used with the CD4 count to show how advanced the disease has gotten and to predict its future course. Your health care provider uses viral load testing to make recommendations for medication therapy.

There is good evidence that keeping the viral load as low as possible for as long as possible will decrease the likelihood of developing complications of HIV infections and prolong life.



What does “undetectable” mean?

This means that there is so little virus in the blood specimen the test cannot measure the amount of virus present. This does not mean that the virus is gone or cured. There may still be active virus in the lymph nodes.

Patients have to take their medications every day in order to suppress the virus. When a patient is started on medication, we hope to see the viral load fall to “undetectable” levels. As a general rule, any patient who has a viral load of 10,000 or greater should start medication.

COOK COUNTY HOSPITAL WIHS:

HAPPY NEW YEAR TO ALL OF YOU! Exciting news! The WIHS clinic has moved to The Core Center, a new building dedicated to the treatment, prevention and research of Infectious Diseases.

The Core Center is located at 2020 W. Harrison St. , near Damen Ave. Your interview and your exam are now in the same building! On the day of your appointment, go straight to the Core Center and register at the Front Desk.

Here are some Important Phone #'s:

WIHS Main Office (312) 572-3715

WIHS Main Fax (312) 633-4912

To reschedule your appointment, call. . .

Adriana Valenzuela (312) 572-3714 (office)

(312) 400-3508 (pager)

For information about CAB activities, call. . .

Alice Kim (312) 633-5720 (office)

With questions about the study, call. . .

Mardge Cohen (312) 633-4551 (office)

(312) 572-4559 (fax)

Rosemarie Gottlieb (312) 633-3125 (office)

(312) 647-1540 (pager)

Northwestern Memorial Hospital WIHS:

We are very excited to announce that Laura McGregor, MA, was hired as the HIV Women's Program Social Worker to replace Beth Bollenbach, who left us in November last year. Laura worked with the Chicago Health Outreach in an administrative position that manages HIV prevention and primary care services. Please help us make Laura feel welcome.

Rush Presbyterian St. Luke's WIHS:

A few of you already know that we have a new WIHS interviewer.....Danielle Merten. Danielle is a Clinical Research Nurse for the Section of Infectious Diseases at Rush and has a desire to be more involved with HIV positive women. We are pleased to welcome her to the Rush WIHS group!

We very much appreciate your continued involvement and interest in this important study. We are so proud of the committed women that we have at Rush. Keep it up, ladies! As always, if you have any questions or concerns about your study participation, please call Ruth anytime at 312/942-6017.

University of Illinois at Chicago (UIC) WIHS:

Greetings to all in the new year from your WIHS team at UIC! While supplies last, UIC is now offering **FREE PARKING** for WIHS study visits. If you drive and park in one of the UIC parking garages, please remember to bring your parking stub to the clinic for validation (see Doris). Best wishes, always. See you at your next visit!

Letters to and from WIHS Women . . .

"Waiting for a Reaction: The Most Difficult Thing"

I been asked several times in the past, what is the most difficult thing to deal with in facing my illness.

Is it taking medication regularly? Is it getting the medication that you need? Is it the realization that your time is limited and could be cut short?

Is it possibly leaving your children behind and not seeing them develop into adults? Is it constant visits to clinics and doctor's offices? Is it constant blood tests and pokes?

I guess all these things are difficult. **But I think that the most difficult is telling others of your status and then waiting for their reaction.**

Will it be positive? Will it be negative? Will they still love you? How will this information change the way they treat you or feel about you?

Do you have to tell them? Do they need to know? Is it living with the fear that people may find out before you even have a chance to tell them and look at you differently?

Is it the fear that you

may be labeled a bad person because you have such an evil disease? Wouldn't the sharing of all these difficulties be a major contribution to eliminating the spread of this disease?

So why is it so difficult to talk about this? Why is it so difficult to share this information?

I have to admit that in the 13 years that I have been dealing with this dilemma **I have had many more negative reactions than positive ones.** Even the ones that were rather indifferent at first eventually had negative outcomes. So I guess it's understandable that this would be a difficult thing for me to face.

I heard that a new and trendy thing to do is to **tattoo your status somewhere on your body with really awesome designs of self-expression.** Gee, how simple. Could that possibly be the answer? Then you don't have to talk about it, you don't have to share, you don't have to tell. It's told without a word. But I'm not into tattoos.

Will that one day be a requirement or a

Hi, my WIHS sisters,

I have just a few words that I want to share with you. One of the WIHS providers mentioned to me that some women think of their WIHS visit as their regular clinic visit.

I'd just like to say that I think that it's necessary to visit your regular doctor in between WIHS visits, especially if you have any particular concerns about your health. For example, if you're my age, you may need to see a doctor about possible menopausal effects.

The WIHS providers give us excellent care, but it's only every six months, and it's a research project not a healthcare clinic.

Sisters, I just want to encourage every woman to advocate for themselves and get the healthcare that you deserve and need.

Your WIHS sister,
Patricia Ellis
NCAB Representative

WANT ADVICE?
NEED TO VENT?
ANY WORDS OF
WISDOM?
CAN YOU RELATE?



You can write for *HealthWIHS!*

"I love HealthWIHS. It's fun and I get to read about other participant's experiences."

"I enjoy the updates, most of all, women looking forward to life with support."

HealthWIHS is a quarterly newsletter for, by and about WIHS women. *HealthWIHS* is your newsletter — share your experiences, your knowledge, your opinions with other WIHS women. Be creative!

Send your stories, letters and poems to:
WIHS / Attn: Alice
Administration Building
1900 W. Polk St., Rm. 1240
Chicago, IL 60612

- Please include your name and phone number, so that we can contact you for any clarifications.
- Your writing can be published anonymously, with an assumed name or your real name.

ANY QUESTIONS,
CALL (312) 633-5720.

WIHS Chicago Community Advisory Board

JOIN US . . .

- ◆ For updates on the WIHS research agenda including new substudies & any changes in your WIHS visit.
- ◆ For the latest findings based on the data we have compiled from your research visits.
- ◆ To provide feedback about the study and voice any concerns.
- ◆ To meet other women in the WIHS.

Date: Thursday, February 25

Time: 12 noon to 2:00 pm

Place: The Core Center
2020 W. Harrison
Conference Room B

A light lunch will be provided.

Childcare is available if advance notice is given.

Please call (312) 633-5720 if you plan to attend.

CAB CORNER

by Marta Santiago,
Chicago National Community
Advisory Board Representative

Hello Ladies and a happy and healthy New Year to you.

With the start of the new year, those of us who have been active in the Chicago Community Advisory Board (CAB) for the WIHS would like to encourage you to get involved.

I have been involved with the CAB since the WIHS began in 1994. And I can tell you from my personal experience, that the CAB has been a rewarding experience for me. Of course, I've had my own ups and down, but what I do know is that by getting involved in the CAB, you're doing yourself a favor. You're advocating for yourself and for other women.

When you're involved with the CAB you get to tell the doctors and scientists who are in charge of the WIHS what you want out of the study.

The CAB gets to give input on everything about the study — from what substudies are being done to how many tubes of blood are being drawn from our bodies!

The CAB is here for you to bring up your personal concerns and to ask questions that you have about the study and about women's health.

I invite you to be part of the WIHS Chicago CAB, to bring up your own issues, to listen to others' issues, and to be a part of helping figure out solutions to problems.

The CAB is a way to keep our heads above the water in our ongoing fight against HIV disease in women.

See you on Thursday, February 25th at 12 noon at our next CAB meeting. Don't miss it!

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