Health WIHS

Spring 1999

Why the Same Old, Same Old?

by Kathleen Weber, Project Director & Alice Kim, Consortium Administrator

The WIHS is in its fifth year and still going strong. Most of you have had nine WIHS visits and are preparing for Visit 10. We know that your WIHS visits can sometimes be grueling — long, tedious, redundant and even boring — especially after all these years. As one participant said, “You ask the same questions all the time!”

The interview is certainly repetitive at times. But your answers are very important to this research study! (I’m sure you’ve heard that before!) All of your answers are entered into a computer so that researchers can investigate any trends and patterns that may be useful in helping women with HIV. We can only do this comparison between questions at each visit if we ask exactly the same questions using exactly the same words.

At your last visit, you probably noticed that new questions have been added to the interview about changes in body shape and adherence to HIV medications. These questions will provide data for researchers to investigate the effects of new therapies for HIV such as the protease inhibitors. As the study continues, you will probably notice more changes to your WIHS visit. The changes are intended to reflect new treatments and findings that have become available.

For example, during your physical clinicians will now measure participants’ body fat. Women on the National Community Advisory Board voiced concerns about changes in women’s bodies as a result of anti-retroviral therapy. WIHS investigators added body fat measurements and BIA (Biolelectric Impedence Analysis) to the visit as one way of looking into these changes.

You should know that all of the poking and prodding, the tubes of blood, and your answers to the interview questions ARE making a difference. We very much appreciate that you’re still hanging in there with us!

Hi WIHS Women,

My name is Chinniese Peterson and I’m a participant on the National and Local WIHS Community Advisory Boards — I’m proud to say!

Ladies, please get involved. I once asked the same question — why bother? I figured it wouldn’t interest me. It seemed too technical, too professional.

Well, some of it is technical. But when I saw that I could be on the front line addressing my concerns, I got involved. I want to be able to ask scientists and doctors questions about my health, about a cure! I want to be seen and heard.

Get Wise. Get Involved!

Mark Your Calendars:

“Everything You Want to Know About Your Meds”
Friday, May 21 at 11:30AM
(see p. 8 for more details!)

INSIDE:

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.

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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
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Kathleen Weber, BSN
Rose Gottlieb, FNP, MPH
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CHANGES . . .

to Your WIHS Visit!

Here are changes you can expect & why. . . .

PHONE CALLS: If your CD4<200, you will be receiving a phone call every three months so that we can check up on how you are doing.

BODY FAT MEASUREMENTS: During your physical, you will now have the opportunity to have your body fat measured. Clinicians will take measurements with measuring tape, skin calipers and a special measurement machine. This extra step was added in response to concerns about changes in body fat that many women were experiencing as a result of their medications.

QUESTIONS IF YOU ARE PREGNANT: If you're pregnant, interviewers will ask you several additional questions. That way we can investigate issues related to pregnancy and HIV.

NEW SUBSTUDIES: Chicago participants now have the opportunity to participate in a number of new substudies. These substudies will help us look into even more aspects of HIV disease and how it impacts women. Take a look at the chart on page 3 for details.

COMMUNITY ADVISORY BOARD (CAB): In addition to the workshops, we're now holding quarterly CAB meetings where participants will have the opportunity to voice concerns about the study and any new ideas for research.

WIHS 1999 Substudies

by Rose Gottlieb, Cook County WIHS Program Administrator

Name of substudy	What's the purpose?	Who's eligible?	What's involved?	Any incentive?
Intercurrent Illness	To investigate the effects of common illnesses on HIV progression	▪ CD4<300 ▪ Doctor at WIHS site ▪ 12 weeks of antiretroviral therapy	▪ Consent ▪ Phone calls ▪ Blood work	$ 10 food voucher

WIHS Women Speak. . .

in the mood!
by Wilma Lee

There is something about your touch I would like to get to know better. Days have gone by and I still want you to touch me. Went to bed last night thinking about you. Couldn't sleep, thinking about you. Tossing and turning, me
thinking about you and your hands on me. Body hot from breast to thigh, inside and out. Ooooh yeeeaah, thinking about you and wanting to be touched.

If you had been there we would have been all over each other, forehead to forehead, eye lashes to eye lashes, nose to nose, mouth to mouth, tongue to tongue. Shoulder to shoulder, breast to breast, scars to scars, stomachs to stomachs, thighs to thighs, knees to knees. Toe to toe, blending as one. Hips gently swaying to the rhythm of our heat.

Hot bodies all night about
touching one another.

Morning was no better. Awoke, hot. Washed, hot. Dressed, hot. Ate, hot. All day long, hot, hot, hot, wishing you were under my desk making

hotter. Wishing we could meet in a dark conference room or empty stairwell to make the hotter still hotter. Hot dogs for lunch. Banana split and hot fudge for desert. Tasty, hot is so very, very tasty.

I am in the mood and want to do it with you right now. We must find a way to be together tonight, and don't worry, I'll bring the condoms.

You Can Call Me Amy, and I Would Like to Tell You My

In 1992, I went for my annual check-up and was told that I had been exposed to HIV. At that time, my T-cell count at 248 was already below what was considered "normal."

I began taking AZT in liquid formula because I had difficulty swallowing pills. Unfortunately, the AZT didn't work too well and my immune system took a major beating several times over.

I began to experience tremendous pain in my ankles. After weeks of being unable to walk upright gracefully, wear shoes or pantyhose, I went to the doctor only to be told that he had never witnessed anything like this before. My ankles were bigger than my head! Okay, so that's a bit exaggerated, but that's how I felt.

It turns out that I had a special kind of arthritis and inflammation of the skin. I was treated with steroids and a very thick pair of therapeutic support hose (the kind that grandmother's wear.)

Then, I began to experience a sinus drip in the back of my throat, which ultimately caused me to have a dry cough and to sneeze up to seven times in a row all day long. It also caused my soprano voice to turn baritone.

My heart was broken. I tried cough drops and syrup, tea, lemons, and mom's chicken soup.

Unfortunately, it was not that simple. I lost 40 pounds in six months and developed "sinus disease" which ultimately led to surgery.

Then I came down with bronchitis and was hospitalized for over a week. My hair started falling out, my scalp was dry and lumpy, my skin was always itchy.

At this point in time, I was still fighting swollen ankles, sinuses and simple fatigue. I was tired from all of the emotional stress I was facing. I decided to quit my job, even though this decision also broke my heart.

One week later, my doctor called me with the results from my blood work. I was told that my T-cells had increased from 5 to 196 and that my viral load which had been at 14,000 copies was now undetectable!

I had started taking anti-viral medications and now they were paying off. Of course this was great news, but I had already quit my job. So, for the next year, I sat on my big butt being bored, depressed, tearful and an emotional wreck. Oh, did I mention all of the humiliating and embarrassing visits down at the Public Aid and Social Security Administration's office? How do you spell STRESS?

Then I learned that I had cancer — my last vaginal biopsy detected stage three dysplasia. Thank God that the laser surgery was able to remove the affected area.

Through all of the physical pain, mental, emotional and financial stress — and losing friendships along the way — my faith in God has been a constant. In addition, I have met some beautiful people from my doctors to new friends through support groups.

After all that I've experienced, I am now living comfortably. I'm taking classes. I'm staying strong and keeping the faith. My last t-cell count was 663, and my viral load is still undetectable.

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Letters to and from

Want Advice? Need to vent?
Any words of wisdom? Can you relate?
WRITE A LETTER TO

"WAITING FOR A REACTION: THE MOST DIFFICULT THING"

I have been asked several times in the past, what is the most difficult thing to deal with in facing my illness. . . . **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 is a difficult thing for me to face. . . .

— by Norma

DEAR NORMA,

As I read your letter, I felt that I knew exactly what you are going through. I'm sure most of our readers feel the same way. We are not alone. One thing I used to do when I was thinking about telling someone of my status was to casually bring up the subject of AIDS with that someone and see how he or she responds. If it's negative I won't tell. If it's positive I will. You can try that and see if you like it. At least this way you'll know where you stand beforehand.

I believe that everyone has a fear of rejections at one point or another in their lives. Our fears are based on the responses that we get from those who are uninformed (putting it mildly) about AIDS. One way to deal with this ignorance is to accept that you will always come in contact with people who are ignorant about matters that don't affect them personally. This is especially the case when it is something that is not accepted by society.

The bottom line is that people can't make you feel anything unless you allow them to. If someone responds negatively, so be it. The way I look at it, it's their loss. We're already dealing with a tremendous load. We should all be commended, just like anyone else who is living with cancer or any other life-threatening illness.

Only surround yourself with positive people. And remember, YOU ARE IN CONTROL.

Sincerely,
Flowers

Feedback on your Feedback!

by Maryanne Zarrella,
WIHS Research Assistant

From January to March of this year, 115 participants completed the feedback forms. Here's what you had to say:

Top 2 Reasons for Participation

- General concern about my health and body
- Free health care

In Your Own Words. . .

- "Too many of the same questions, repeated in another form!"
- "The visits are like a complete inventory of my body."
- "If there's anything wrong, it will be found."

Questions for other women

- Who do you tell about your status and how do you do it?
- How do you live life to the fullest even though you have this disease?
- How do you cope with multiple diagnoses?

Ladies, share your experiences!

Write a letter to Health WIHS:
WIHS (Attn: Alice Kim)

WIHS STATISTICS

Based on data collected from WIHS visits

by Sally Urwin, WIHS Data Manager

Congratulations! Most of you recently completed your ninth visit. Beginning in April, we moved on to Visit 10. (Visit 10 appointments for all WIHS participants will occur between April 1, 1999 and September 31, 1999.)

Here are some interesting statistics and trends:

- 208 Chicago WIHS participants (80% of enrolled participants) were seen for Visit 9 between October 1, 1998 and March 31, 1999.
- Good news! General trends indicate that Chicago WIHS participants are experiencing better health, as evidenced by higher CD4 (or T-cell) counts, lower viral load counts, and fewer deaths.
- At visit 9, the majority of HIV+ Chicago participants reported taking some type of protease inhibitor medication.
- At visit 9, approximately 38% of Chicago participants were employed.
- At visit 9, approximately 29% of Chicago participants reported use of some type of alternative therapy.
- At visit 9, 31% of Chicago participants were married or living with their partner; 28% of women were divorced or separated; 12% of women were widowed; and 28% of women were never married and single.

If you have any questions about the data that the WIHS has collected or statistics that you would like to know, make sure you write to us and we'll address them in our next newsletter!

WIHS Workshop. . .

"Everything You Want to Know about Your Meds"

At this workshop, Blake Max, Clinical Pharmacist for The Core Center, will tell you what you need to know about your medications. From the latest meds to side effects, Blake will answer all your questions!

Date: Friday, May 21
Time: at 11:30 AM
Place: Leona's Restaurant
1936 W. Augusta
(1/2 block east of Damen)

Buffet lunch. . . Childcare available. . .
Tokens provided. . .

To reserve your space, call Alice
at (312) 633-5720 by Wed, May 19th.