

Brought to you by the Chicago WIHS Consortium. . .

Health WIHS

Winter



INSIDE this issue...

| | |
|--------------------------------------------------|-----|
| HIV/AIDS Cross- word Puzzle | 2-3 |
| Viral Resistance Substudy: Initial Results | 2 |
| How to Deal with Stress | 4 |
| Cervical Cancer and HIV | 5 |
| "The Journey" WIHS Women Speak | 6 |
| Announcements Crossword Key | 7 |
| Feedback! | 8 |



CAB CORNER

by Marta Santiago, Chicago NCAB Rep.

Dear Ladies,

It's been a whole year. I can't get over that. As I write this, 2003 is right around the corner. I've been the NCAB chair this past year, and it's already time for me to step down and let someone else take over. Time has gone by so fast. So, now I'm going to take a little bit of time to reflect. What did we do this year? Quite a lot. Here are some of the highlights of the year as I see it.

We had our first ever joint meeting between the WIHS and the MACS (the male equivalent of the WIHS that has been in existence probably twice as long as the WIHS) to discuss ways that we can work together. This meeting was truly historic because it showed how far we have come in our efforts in research. From the start, the WIHS has always had a very active NCAB – and our voices have helped to make the WIHS what it is today.

The NCAB had two poster presentations at the 14th World AIDS Conference in Barcelona, Spain this past July entitled "Who's Afraid of Colposcopy: Peers Confront Women's Fears" and "Peer Initiatives in the Enrollment of a New Cohort in the Women's Interagency HIV Study." These presentations reflected the ways in which the WIHS NCAB addressed real issues facing women in the study. I had the honor of representing the NCAB at the World AIDS Conference.

The NCAB also attended the United States Conference on AIDS in Anaheim last September. We had another poster presentation at this conference entitled "The National Community Advisory Board Welcomes a New Cohort." And the NCAB held its second annual meeting at this time. We identified several important issues for local CABS to address in the coming year: 1.) hepatitis C and HIV; 2.) re-infection and safer sex; 3.) micro-bicides.

And, of course, we successfully completed the enrollment of a new cohort! We still have much work ahead of us, but I feel that things are looking promising for us. So Ladies, I'd like to share my wish list with you. Actually, it's just one wish but it's a BIG ONE! I wish for that one magic pill to be developed – and I'm not talking about a protease inhibitor - I'm talking about the pill that will bring about peace, health and happiness all over the world.

Happy Holidays. May all YOUR wishes come true.

An Important Reminder!!!

from your NCAB representative, GiGi Nicks

You are valuable to the WIHS Research and we appreciate each and every one of you for your participation. We encourage your continuation in the WIHS.

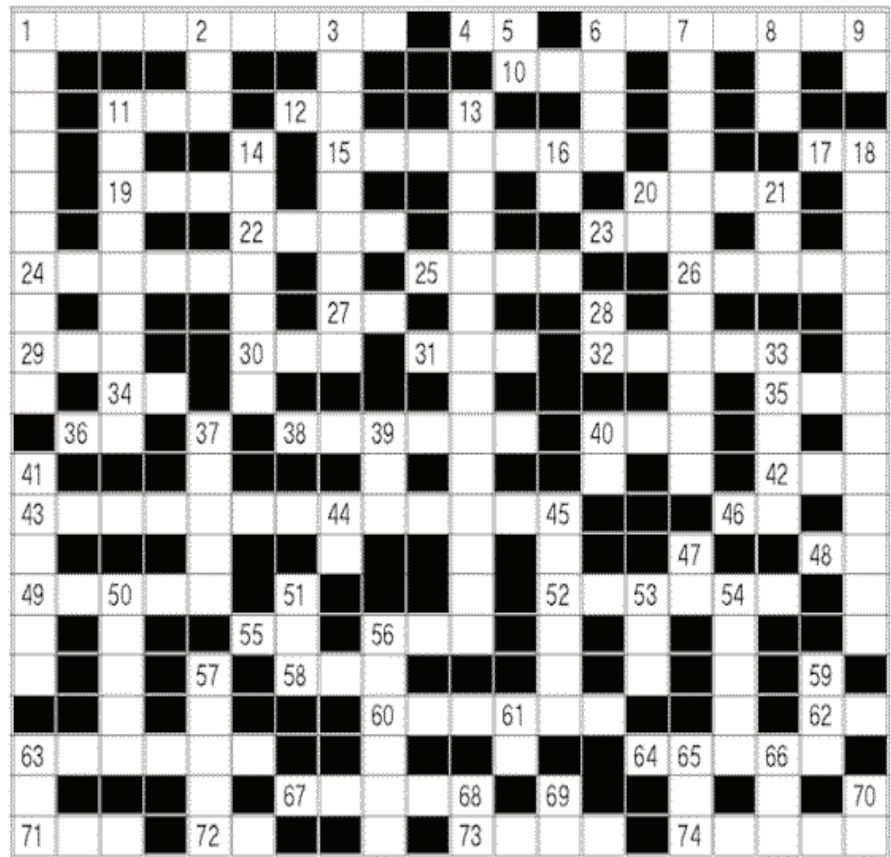
HELP US HELP YOU!! Remember to FAST (no food or beverage except for water after midnight) before coming in for your WIHS appointments. The purpose of your FASTING is for the gathering of important information through the blood samples that you give. Testing blood drawn after a period of FASTING enables us to have a better understanding of the risks for conditions such as diabetes and heart disease.



HIV/AIDS Crossword Puzzle

A few WIHS participants requested a crossword puzzle, so here it is! Use the hints on the right to fill it out and then check your answers with the key on page 7. Good luck!!

*Thanks to Barbara VanCortlandt for creating this crossword puzzle and allowing us to include it in Health WIHS! Barbara VanCortlandt is an HIV/STD Training Coordinator with the Bureau of Epidemiology and Disease Prevention at the Kansas Department of Health and Environment.



Viral Resistance Study – Initial Results By Monica Gandhi and Claudia Ponath

It is widely known that highly active antiretroviral therapy (HAART) prolongs the lives of many people living with HIV. Nevertheless, large studies have shown that about half of the patients who take HAART are not able to totally suppress their HIV viral loads. This is considered treatment failure. Researchers think that treatments might fail because a person doesn't get enough drug in her system. That may happen because she doesn't take her medication as prescribed all the time, because the medication is not absorbed properly in her body, or because it is cleared out of her body too

fast. These can all be affected by interfering substances such as other medications, herbs, or drugs. "Adherence" is the medical term for taking one's medications as prescribed. So, a person with total adherence will take all of her prescribed doses all of the time, a person with 80% adherence takes about 8 out of 10 doses and so forth. This analysis looks at the relationship between adherence as reported by participants in the Viral Resistance Study and the concentration of HAART drugs in their blood plasma.

We were able to include data from 87 participants at 5 WIHS sites

in this study. All of them came to clinic before taking their medications the day. They had their blood drawn to determine the "trough" plasma concentration for their respective HAART medications. (The "trough" is the lowest concentration a drug will fall to before the next dose is taken). Participants also reported when they took their medications in the last 24 hours, and how good their adherence had been in the last 3 days and in the last 6 months.

Here is what we found: The trough concentrations varied a lot between participants and were

(Continued on page 5)

Crossword Clues

Down

1. The most commonly available blood test to determine if a person has HIV looks for these substances which are produced in response to disease agents.
2. Sharp noise produced by a dog.
3. Type of precautions used to protect patients and health care workers from exposure to HIV.
5. Abbreviation for morning.
6. Oral, _____, and vaginal sex can lead to HIV infection.
7. This type of testing means a person's name is recorded.
8. Acronym for the virus that causes AIDS.
9. Abbreviation for Los Angeles.
11. An HIV-infected woman can infect her baby during this.
13. The ADA Act of 1990 protects persons with disabilities, including HIV, from this happening in the workplace or public accommodations.
14. Bites from these pests do not spread HIV.
16. Short for advertisement.
18. HIV-infected women can infect their babies through this.
20. Hugging is not __ HIV risk behavior.
21. Abbreviation for Supplemental Security Income.
28. Disease caused by bacteria which usually affects the lungs.
33. Blood, _____, and vaginal secretions are the most common fluids that can cause HIV infection.
37. Human Immunodeficiency _____.
39. Acronym for magnetic resonance imaging.
40. Short for identification.
41. Made of latex, the use of this during sex has been proven to be effective protection against HIV when used consistently and correctly.
44. Just say __!
45. _____ contact with an HIV-infected person does not put you at risk for HIV infection.
47. Spanish for "yes."
50. Fluid from the kidneys that does not transmit HIV.
51. Acronym for any of many diseases transmitted by sex.
53. It is against the ___ to intentionally infect someone with HIV.
54. Substance brought up from the stomach that does not transmit HIV.
56. The time between infection and development of enough antibody to show on the HIV test is the _____ period.
57. Product from the bowels that does not transmit HIV.
59. Oral, anal, and vaginal ___ can lead to HIV infection.
61. Just __ it!
63. Purchase.
65. First drug licensed in the U.S. that attacks HIV.

Across

1. Type of testing when a person's name is not recorded.
4. Do, re, mi, ___...
6. Using this or other drugs can lead to risk behavior.
10. Both women and ___ can be at risk for HIV infection.
11. Acronym for Pneumocystis carinii pneumonia.
12. Do, re, mi, fa, so, la, ___...
15. Oral, anal, and _____ sex can lead to HIV infection.
17. Acronym for Western Blot, a type of HIV-antibody test.
19. _____ you could become HIV-infected through risky behavior.
20. A result of HIV infection.
22. Using precautions against HIV is recommended, unless you know for _____ your partner does not have HIV.
23. Oral, anal, ___ vaginal sex can lead to HIV infection.
24. You cannot get HIV-infected if you do this with your blood.
25. _____, anal, and vaginal sex can lead to HIV infection.
26. Acronym for enzyme-linked immunosorbent assay, a screening test for HIV antibody.
27. Abbreviation for antibody.
29. A long period of time.
30. '___ death do us part.
31. Acronym for American Medical Association.
32. Insect _____ do not spread HIV.
34. Abbreviation for California.
35. A small, mythical being with pointed ears, shoes, and cap.
36. It is __ responsibility to protect myself from HIV.
38. The _____ system acts as the body's defense against foreign substances.
40. Acronym for immunofluorescence assay, a type of HIV- antibody test.
42. Adam and _____.
43. People who have HIV may get these types of infections because HIV weakens the immune system.
46. A condom should be put __ after the penis becomes erect.
48. Abbreviation for opportunistic infection.
49. Use of alcohol and other _____ can lead to risk behavior.
52. Fluid from the mouth that does not transmit HIV.
55. Just do __!
56. Let's ___ the battle against HIV!
58. Acronym for didanosine, a drug used to slow HIV.
60. HIV may be spread if this is contaminated with blood when piercing ears, other body parts, or injecting steroids or other drugs.
62. Abbreviation for emergency room.
63. Proper cleaning of drug injection equipment involves cleaning with water and _____ several times.
64. Condoms made of this have been proven to be effective protection against HIV when used consistently and correctly.
67. _____, semen, and vaginal fluid are the most common fluids that cause HIV transmission.
71. ___ can protect yourself from HIV infection.

HOW TO DEAL WITH STRESS!

Tips from the WIHS workshop (Wed, November 6, 2002)

With Dr. David Goldberg and Dr. Arthur Hoffman of Cook County Hospital

IDENTIFYING STRESS:

It's not always easy to know when you're stressed out. Some of the women at the workshop said that "getting sick" was their body's way of telling them that they needed to take a break. A lot of times, we just get so used to living with stress. But try paying more attention to your physical feelings. For example, ask yourself—are your eyebrows furrowed or relaxed? If they're furrowed, this may be a sign of stress! Or maybe your shoulders are tense. Or maybe your jaw is tight. Try to relax these parts of your body as you identify your stress.

MINDFULNESS:

Consciously pay attention to your present experience without judging. This way of thinking can help you be less stressed.

A workshop exercise: try this at home!

Take a moment (one to three minutes) to sit quietly and pay attention to your feelings. Afterwards, jot down your experiences or discuss with a friend.

At the workshop, participants described a wide range of experiences. We learned that several women felt entirely relaxed while other women had many things on their mind. Some participants experienced a feeling of "racing." This racing feeling is often a sign of stress.

How to deal with the "racing" feeling?

The distance between your mind racing and letting go of this racing or between pleasant and unpleasant is instant. It's not like you have to climb a mountain to get there. It's the instance of now that has the potential to make the difference between racing and quiet in your mind.

BUT REMEMBER: If you're in a situation that's dangerous, you need to find a way out of that situation. Stress reduction is not a replacement for one's basic needs.



* * * * * Stressors and what we can do... * * * * *

* **Stressor:** Wishing we were in two places at a time or wishing that we were in a place that we aren't. We spend so much of our time not in the here and now. * * * * *

* **What to do about this?** Honor this feeling without getting annoyed. Acknowledge it. Pay attention to it. Allow it to be what it is. But let go and be here now. * * * * *

* **Stressor:** Agonizing about a future event. For example, assuming that the train ride home is going to be a pain in the butt. * * * * *

* **What to do?** If you know what the train ride is going to be like—accept what you can't change about it. Or make a change in your own actions that can alleviate the stress. Bring a paperback book that you can read standing up. But don't constantly re-hash the ride home. * * * * *

* **Stressor:** When you're in a tough situation, wanting people who surround you to be different. * * * * *

* **What to do?** Ask yourself what you can change. Sometimes, it's just telling yourself you won't let that somebody get to you today. * * * * *



Cervical Cancer and HIV By Dr. Stewart Massad

The Pap smear helps to prevent cervical cancer. We've known that for decades. But does it work for women with HIV? That's been one goal of the WIHS, and the study is finally far enough along to begin to answer the question.

Authors from all the WIHS sites are finishing work on a study of the risk of cervical cancer among women in the study. We looked at new cancers identified after the first visit. HIV-negative women haven't had any new cancers identified. That's not really a surprise. The great news is that there have been only two cervical cancers found in the HIV-positive women since 1995. That risk is about the same as the risk of death from heart disease, for example, and much less than the risk of death from AIDS, as Dr. Cohen has shown in a paper she published last summer.

At the start of WIHS, cervical cancer was a big concern. Cervical cancer begins with infection with human papillomavirus (HPV).

HPV is a sexually transmitted virus that causes genital warts, but women can be infected even though they've never had a wart. In some cases, DNA in the virus gets mixed with DNA in cervical cells, causing cells to grow out of control. Pap smears work by detecting these abnormal cells before they begin to invade the body--when they're precancerous rather than cancerous. When abnormal cells are removed at a precancerous stage, before patients get pain, bleeding, or other cancer symptoms, the path to cancer can be blocked.

HPV is a particular problem for women with compromised immunity. Antibiotics can't control these viruses, but in most women immune cells kill them. Without active HPV, cervical cancer can't develop. When the immune system doesn't function well, the viruses are more likely to persist in the cervix. The longer they're around, the higher the chance that cancer will arise. Unfortunately, as WIHS investiga-

tors and others have shown, women with HIV have more HPV, more abnormal Paps, more precancerous changes in the cervix, and a lower success rate with treatment of precancerous changes than women who don't have HIV. That's why many clinicians were concerned when the WIHS began that cervical cancer would become an epidemic problem.

What the new study reveals, however, is that in spite of this trouble, we can still block the path to cancer for most women. The process is a rocky one, involving repeated Pap smears, colposcopies, biopsies, LEEPs, conizations--sometimes even hysterectomy. The new study doesn't mean that beating cervical cancer isn't a lot of hard work or that it won't involve discomfort, even pain, from embarrassing and sometimes frightening procedures. But it seems to be worth it now that we know we're preventing cancer successfully.

(Continued from page 2 - Viral Resistance Study)
often quite different from what might be expected after seeing concentrations that have been published in the medical literature. Most published numbers were from studies done in groups of mainly men or volunteers who are HIV negative, so that may be part of the reason why our numbers were different

The plasma levels we measured did not correspond very closely with the self-reports of adherence. There was some correlation between the plasma drug levels and the self-reports of adherence over the last 24 hours, but hardly any relationship was seen between plasma levels and the self-reports of adherence over the past 3 days or 6 months. This might be due to the fact that it is harder to

remember doses of medication taken far back in the past, and that there are lots of other things that figure into a drug getting into the system besides adherence. Some of those other things may include differences in how people metabolize drugs, how they absorb medications, or how they clear the medications.

Having the correct drug levels in your body is obviously important for two reasons. First, if there is too little drug in a person's system, the HIV virus will not be stopped from replicating. If the virus keeps replicating, it's likely to develop resistance to the medication, and then the medication is not as useful anymore. Secondly, if there is too much drug in a person's system, it is more likely that she will have unpleasant or

even toxic side effects.

We are now looking into other ways to measure women's exposure to medications because we don't know so many of the other reasons (besides adherence) why people have such different drug levels, and because a single drug level may not tell us very much in what a person's drug levels are long-term. One of the new ways we're looking to develop is to measure medication levels in the hair. This may tell us how much drug gets into the body over a longer period of time. Stay tuned for more results from this study, and the next time you come in for a study visit and we ask to cut some of your hair (just 10 strands), you'll know why!



The Journey

Hello, my name is Mary. So far, my HIV/AIDS journey has lasted for at least 13 years. I say “at least” because I can look back and see, way in the distance, the January day in 1989 when I learned I’d tested HIV+. And I say “so far” because I can look ahead and imagine, way in the distance, many more days to come—a string of uncountable numbers, as long as life itself.

I wish I could say I’m glad you’re here, with me on this journey. The truth is, I’d rather not see so many of us on the path. It always saddens me to notice new faces because that probably means there are more women who have tested HIV+, and I wish that weren’t the case. However, I can and do say welcome to the journey. The rest of us “old-timers” who have been on this path for a while will do what we can to make room for you. We’ll try to make your journey seem easier. We won’t judge you or question how you got here. We remember how it felt when we got here and when you’re ready to talk, we’ll listen.

That’s what makes WIHS so important. Yes, the Women’s Interagency Health Study involves a lot of stuff related to medicine such as drawing blood, measuring weight and body mass, and taking part in a questionnaire. Gathering data helps everyone involved in WIHS keep track of our health. But besides all that medical stuff, what WIHS really means to those of us with HIV/AIDS is that we’re part of a group. None of us is out here alone, living with this experience. So whenever you feel like no one cares or understands what it’s like to deal with HIV/AIDS, remember us, crowded around you on the path. If you’ve got questions, WIHS is here to help you answer them. If you’ve got suggestions, the WIHS-CAB wants to hear them. If you just want a place where you can go and feel less lonely, afraid, confused, or hungry (for food or information), we’re here for you—for us—with this newsletter, our regular meetings, our own doctors, and our own way of dealing with HIV/AIDS

In September of 2002, I celebrate my 48th birthday. Yes, I celebrate; I’m glad to be alive and even happier to have WIHS in my life. As my generation used to say, this journey has been quite “a trip.” I’ve just finished writing a book about a lot of my own journey (help me out, ladies, and say a prayer on behalf of the book; I’m looking for a publisher). Now I’m on to a new book because thanks in large part to WIHS, I keep on keepin’ on down the road.

Mary C. Lewis

HETEROCHAT SUMMIT IS COMING TO CHICAGO!!!!

Heterochat, established six years ago, based in Arizona will be moving to Chicago. Heterochat is dedicated to bringing the HIV positive heterosexual community together, in love, life, health and relationships. Presently, the conference is scheduled for the **July 4-6 weekend**, and will be held at the Best Western Inn of Chicago (162 E. Ohio St., Chicago, IL 60611) conveniently and centrally located at a hotel downtown near Michigan Avenue. Call Leatrice Simpson at (773) 373-8454, email her at aay46@hotmail.com or visit the heterochat website at www.heterochat.org for hotel and conference information about this exciting opportunity!

Peace, Blessings and Love, Leatrice

Announcements from your site. . .

A list of all WIHS publications is now available. Please call (312) 572-3715 to request a copy.

www.wihschicago.org—Don't forget to check out the WIHS Chicago website!

GOODBYE to Landra Tilman and Michele Cummings. *We'll miss you!*

Reminder to Northwestern participants: *Every Thursday the Women's Group takes place at 12:30 in 13-205 Galter. Lunch is provided

*"SHE" (Support Health & Empowerment), Thursdays, 7:30-9:00pm. At TPAN (Test Positive Aware Network), 5537 N. Broadway, Chicago, 773.989.9400. Support group for women, emphasis on art expression; guest speakers on nutrition, healing, and alternative therapies

*Heterosexual Group "Straight Talk", At TPAN, Monday's 7:30-9pm

A Word from the WIHS: About that dreaded rectal exam!

Many of you have let us know exactly how you feel about the rectal exam. We know many of you are hoping that the exam could be eliminated from the WIHS exam. First of all, WE HEAR YOU and we do listen to your ideas and try to make adjustments whenever possible. We know that the exam may be uncomfortable, however the rectal exam is actually an essential part of the complete pelvic exam.

Rectal exams allow us to check an area behind the cervix and vagina that is not accessible when doing the vaginal exam alone. We may be able to find tumors or masses we might otherwise miss. This is what WIHS is all about—doing the most thorough exam possible to uncover problems. Remember that WIHS was started and continues today in order to address the health problems of women with HIV—problems that may have been previously overlooked because most

Crossword Puzzle Key

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Health WIHS

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.

Readers are encouraged to submit personal stories, poems and other creative work. To submit a story or if you have any comments or questions, please contact Alice Kim, Newsletter Editor.

WIHS
Administration Building

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:

**The Core Center/
Luke's Hospital
Cook County Hospital**
Mardge Cohen, MD
Audrey French, MD
Kathleen Weber, BSN
(312) 572-3715

Rush Presbyterian—St.

Beverly Sha, MD
Ruth Davis, RN
(312) 942-5865

Northwestern Memorial Hospital University of Illinois at

**Check out the WIHS Chicago website!
www.wihschicago.org**

FEEDBACK on YOUR FEEDBACK by: Sage Hales, WIHS Research Assistant

Thanks so much for completing the feedback forms. Your input is very helpful to us. Here are a few issues that came up during visit 16 and 17:

- ◆ A number of participants suggested that we have a workshop on "How to read lab results." In the past we've had workshops on this topic and we will be sure to plan another soon!
- ◆ Many participants also requested information on how HIV/AIDS is spread and how to prevent it. This is a very important topic and we will have a workshop that addresses this issue. Until then, you can always ask your WIHS clinicians any questions or call the National AIDS hotline:

English Hotline: 800-342-AIDS
Spanish Hotline: 800-344-SIDA

- ◆ Lots of WIHS women reported that they are interested in writing for Health WIHS. In response, we sent out a mailing requesting submissions. Thanks to those of you who replied with your insightful writing! And please keep it coming! We encourage everyone to write for Health WIHS.
- ◆ Many WIHS Women also indicated that they would like to participate in the NCAB. We will contact those of you who reported this in the near future. So keep an eye and ear out for information on upcoming NCAB meetings!

