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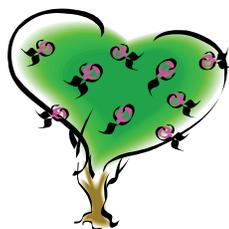
Health WIHS

Spring 2002



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CAB CORNER

by Marta Santiago, Chicago NCAB Rep.

Yay! Spring is in the air and I have reached a milestone in my life. I turned 50 in March! I think the idea is still sinking in. I don't really feel any different than I did when I was 49 or 48 years old.

The one thing that is amazing to me is that I now believe that I will be around to see retirement. And to be honest, I can't wait!

For a while I thought my meds were making me look older, but with a little make up and hair color I feel just fine about my appearance. And overall, I feel great. I have taken meds for many years now. I think I started back in 1990. I can't remember all the meds I've taken, but I've come a long way. From AZT to nucleosides and non-nucleosides and now the

protease inhibitors. And that's not including all of the vitamins, supplements, and all the yogurt I've consumed.

Because of all the advances in HIV treatment, the WIHS is expanding and we have been enrolling new women in the study all over the country and here in Chicago. The expansion will allow the WIHS to better examine important questions about HIV disease in women.

As for myself, I've been taking care of myself and I feel good about that. Acupuncture and massage work for me. They help me to de-stress and relieve my back pain. I have tried to sustain an exercise program – I'm still working on that one. Now that my son joined Bally's Health Club, it might be more of an in-

centive for me.

My son also turned 21 years old this year. And as I celebrated his birthday with him, I felt as if I was getting a life appreciation gift from him.

I want to thank everyone who gave me a thought on my 50th birthday (okay, here we are at the Oscars!): my daughter, my son and his friends, my co-workers, and of course all of the WIHS staff.

To celebrate my birthday, I ate so many yummy and different foods with all of my favorite people. What better way to enjoy a birthday – good people, good food, and good health.

So now I want to take the time to wish all you ladies all the happiness and good health that you so well deserve!

WELCOME!

To all the new women in the WIHS!

So far, 112 new women have enrolled in the WIHS. We're getting close to our goal of 139 new participants.

THANKS for being a part of the WIHS. Your participation is making a difference for all women living with HIV!

MEET the National Community

What is the NCAB?

The Community Advisory Board (CAB) provides opportunities for you to get more involved in the WIHS. Locally, the CAB hosts educational workshops; contributes to the Chicago WIHS newsletter, HealthWIHS; and gives feedback to the WIHS staff about our study visits and the WIHS research agenda. Several participants from the Chicago WIHS also serve as representatives on the National CAB, a group of WIHS participants from each of the six WIHS sites, nationally, who provide ongoing input to WIHS researchers.

“I’ve been a WIHS participant since the beginning of the study in 1994. We, the NCAB, give our personal feedback (and what we hear from other women) to WIHS researchers. The study has had a positive influence in my life. Because of my participation in it, I’m much more aware of the issues affecting my health. Why has my body gone through so many changes? What are the side effects of the medications that I’m taking? Why do I sometimes feel so tired? The NCAB makes me feel as though we, women, have a say in a study that is for and about women.”

— **Marta Santiago, NCAB Chair**

“I’m new to the WIHS and to the NCAB, but I’m looking forward to my new role. I’m excited about learning more about women’s health and helping other women!

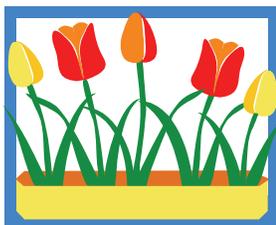
— **Alice Williams**

“I am a long term survivor of AIDS. I was infected by transfusion on January 11, 1981. I’ve been a part of the CAB since 1994. I began to attend meetings as the CAB was still in the planning stages. We had brainstorming sessions and put to paper all the client/consumer input. Although I’ve been a part of the CAB since its inception I haven’t been able to be as active as would have liked due to recurring physical incapacitation. But other CAB members and staff have always kept in touch with me and told me about major events and activities. So I’ve never had to feel that I was out of the loop of the CAB goings-on. I appreciate their confidence in the healing power of determined human spirit. Thank you ladies!”

— **Waver Frankie Franklin**

“I am new to the CAB, but I have been a participant since the beginning of the study. Before I joined the CAB my voice was always heard through the WIHS staff before joining the CAB. I liked the local CAB meeting I attended, because it allowed me to get an update as to what the CAB is involved in. New to me are the WIHS working group conference calls. They have been educational for me. They are a little over my head (scientifically speaking), but I am learning.”

— **Gigi Nicks**



The Anal PAP Study by Dr. Joel Palefsky

Most of you know that women, whether HIV+ or HIV-, are at risk of cervical cancer. You also know that the reason we do a Pap smear of the cervix is to detect tissue abnormalities known as squamous intraepithelial lesions (SIL), which can sometimes progress to invasive cancer if they remain untreated.

We also know that women are at risk of anal cancer, which is similar in many ways to cervical cancer, but is less common. When the HIV epidemic began, we did some studies of HIV+ gay men for SIL in the anus, and found that it was very common in that group. We also found that almost all (93%) of HIV+ gay men had human papillomavirus (HPV) infection of the anus, the same virus that causes SIL and cancer of the cervix in women.

Since SIL and HPV infection were so common in the anus in HIV+ gay men, we decided that it was important to do the same study in women, especially since we know that HIV+ women are at high risk of having HPV infection and SIL in the cervix.

Based on those results, we did a pilot study a little while ago at

the San Francisco WIHS site. In addition to their regular cervical Pap smears and HPV tests the women had anal Pap smear and anal HPV testing. To many, it was known as the “butt study”.

Women who had abnormal anal Pap smears (also known as a “tushpap”) were then asked to see our study clinician to have an anoscopy and to sample the anal tissue to provide the most accurate diagnosis possible.

So what did we learn in that study? Well, like the men, a high proportion (more than half) of the HIV+ women had HPV infection of the anus. 76% of HIV-positive and 42% of HIV-negative women had anal HPV infection and in both groups, anal HPV was more common than cervical HPV infection!

What about the anal Pap smears? Well, we found an abnormal anal Pap smear in 26% of the HIV-positive women and 8% of the HIV-negative women. The HIV-positive women who were most likely to have an abnormal anal Pap smear were women who also had an abnormal cervical Pap smear, anal HPV infection, a lower T cell count and a higher

HIV viral load. Although most of the abnormal “tushpaps” were low grade, we diagnosed high grade anal SIL in several of the women. In our opinion, anal high grade SIL should be treated to prevent anal cancer, just like we treat cervical SIL to prevent cervical cancer. In fact, there is now information indicating that the risk of anal cancer among HIV-positive women is almost 7-fold higher than women in the general population.

So, what’s the “bottom” line? We have much more to learn about anal HPV infection and anal SIL in women. We need to know how anal HPV infection and anal SIL progress over time. We need to know how often a woman will develop high grade SIL, which normally needs to be treated and whether HAART has any effect on preventing development of high grade SIL.

We need to know how HPV infection and SIL of the anus affects HPV infection and SIL of the cervix, and vice-versa. And in the end, we thank you for your contributions to the study - you really are pioneers- And that’s the truth- no ifs, ands or “butts”!





WOMEN, HIV and CANCER

Spring 2002 WIHS Workshop

The topic of this year's first WIHS workshop was "Women, HIV and Cancer." Here are some highlights from Dr. Gail Shiomoto's presentation.

Breast Cancer

- The lifetime risk of developing breast cancer is 1 in 8. However, early detection allows approximately 60% of women to be cured of the disease.
- Doing regular breast self exams, getting regular mammograms after turning 50 and telling your provider about conditions such as breast pain and nipple discharge, are ways to find breast cancer in it's early stages.
- Women with a family history of breast cancer should start to get mammograms 5-10 years before their relative was diagnosed.
- If you have a breast mass, you should still have a biopsy, even if your mammogram is normal because not all cancer's are detected by mammograms.

Lung Cancer

- In the US lung cancer is the most common cause of death among women.
- Lung cancer is also the most deadly of any cancer among women.
- Cigarette smoking increases the risk of developing lung cancer as well as dying from it.

CHICAGO WIHS STATISTICS Women who smoke....

- At Visit 15, 122 of 194 women (or 63% of WIHS pts) reported having smoked since their last WIHS visit.
- Of the 122 smoking women, 15 (or 12% of smokers) reported quitting smoking since their last visit.
- Of the 15 women who quit smoking, 10 (or 66% of quitters) started smoking again.
- Of the 116 smokers who reported their daily smoking routine:
 - 34 (or 29%) smoke a pack or more per day (20 or more cigarettes per day)
 - 36 (31%) smoke more than a 1/2 pack but less than one pack per day (10-19 cigarettes)
 - 15 (13%) smoke 1/4-1/2 pack per day (5-9 cigarettes)
 - 31 (27%) smoke less than a 1/4 pack per day (1-4 cigarettes).

“We’ve learned that if you stop smoking once, you’re more likely to stop smoking the next time and then it takes many many times to stop smoking, so every time someone makes an effort and succeeds, it moves them closer to actually truly stopping. Don’t get upset that you can’t get your risk down to zero after stopping for lung cancer. You can get your risk down to zero for heart disease and other problems that smoking does cause. So, you want your risk lower for the cancers that cigarettes cause and you want your risk to be totally reduced for the other medical problems brought up by cigarettes.”

—Dr. Mardge Cohen, WIHS PI

Colorectal Cancer

- Colorectal cancer is the second most deadly cancer among women.
- Screening for colorectal cancer includes anal pap-smears, anoscopy and colonoscopies.
- Diets low in fat and high in fiber help reduce your risk of developing colorectal cancer.

Cervical Cancer

- Cervical cancer is associated with a history of sexually transmitted diseases including HPV and herpes.
- Because women with HIV are immunosuppressed they have a higher likelihood of having abnormal pap smears.
- The purpose of the Pap test is to detect changes that may lead to cervical cancer long before cancer develops. Pre-cancer of the cervix is easily treated, and almost always prevents cancer from developing.

Women, HIV and CANCER

“The whole thrust to WIHS is to make it easier and easier for you to get your colposcopies as soon as we know that you have abnormal paps... All those calls to get you guys to come in and get those colpos, that’s what that’s all about. It’s really related to you and your health.”

—Dr. Mardge Cohen, WIHS PI

Screening Tests to Detect

Cancer Early

- Mammogram
- Breast self-exam
- Pap smear & colposcopy
- Anal pap smear & anoscopy



Come to our upcoming workshop on “How to Quit Smoking”

Please call us at (312) 572-3715 if you are interested in attending.



Reasons for Quitting (from www.quitnet.com)

- Freedom from nicotine urges and cravings
- Reduced risk of lung cancer, heart disease, emphysema, stroke, and lots of other diseases
- Fewer colds and missed days of school for my kids
- Fewer stomach problems
- Being a good role model for my children
- Fewer sore throats
- No more thick phlegm
- Improved sense of taste and smell
- Sleeping better
- Not needing as much sleep
- Saving money
- No more “smokers’ headaches”
- No more smokers cough
- Having more energy
- Not having to worry about offending or bothering others with smoke
- No more stains on my fingers
- Being able to walk farther and breathe more easily
- No more complaining from my friends and family about my smoking
- Being able to exercise harder and longer
- Being able to breathe more easily
- Longer and healthier life
- Feeling proud
- Feeling good about myself!

Cancer Vocabulary

Biopsy- The surgical removal of tissue so that it can be examined under a microscope to help with diagnosing an illness such as cancer.

Cancer- A group of diseases in which cells grow out of control and spread to other parts of the body. For example, cancer of the cervix develops when cells on the surface of the cervix begin to divide uncontrollably. This eventually produces a large growth, or tumor, which can be seen with the naked eye. However, cancers rarely develop suddenly. In most cases, it takes several years for a group of normal cells to turn into a cancer. During this time period the normal cells undergo changes in which they become progressively more and more abnormal before finally turning into a cancer.

Colposcopy- When abnormal cells are seen on a Pap test, the cervix must be looked at more closely to determine the exact nature of the abnormality. To do this we examine the cervix with a special microscope called a *colposcope*. This examination is called *colposcopy*.

Dysplasia- Abnormal cell growth. For example, cervical dysplasia means disordered growth of cervical tissue.

Lymph nodes- small oval bodies of immune system tissue that help fight infections and also have a role in fighting cancer.

Malignant tumor- A tumor made up of cancer cells of the type that can spread to other parts of the body.

Mammogram - A low-dose x-ray/ picture of the breasts to determine whether abnormal growths are present used to detect breast cancer in its early stages.

Metastasize- When cancer spreads from its first site to another part of the body, for example, breast cancer that spreads to the bone.

Oncology- The study and treatment of cancer. Doctors (like Dr. Gail Shiomoto) who specialize in oncology are called oncologists.

“SUSTA” aka SISTER (or Miss Celie’s Blues)
by Tata Vega from the soundtrack of “The Color Purple”
(lyrics of a song about sisterhood)

“I heard that some of you want to learn the words to the song that has quickly become a kinda’ “Theme Song” for the Chicago Women’s AIDS Project Support (CWAP) Ho’ Group and associated Womyn and their families and friends. The Color Purple came to the theaters, when ever that was, I’ve been singing this song wherever. Womyn gather at every given opportunity. I’m told you haven’t grown tired of it yet. It says so much, so deeply, for and about us. Well, here it is!”

— submitted by Waver

Begin humming to blues tune

Susta, You’ve been on My Mind

Susta, We’re Two of a Kind

Sooo Susta, I’m keepin’ my eyes on you

I betcha Think I Don’t Know Nothin’

But Singin’ the Blues

Oh Susta, Have I Got News For You

I’m Somethin’

I Hope You Think That You’re Somethin’ Too

oohh – Scufflin’ I’ve Been

Up and Down that Lonesome Road

And I Seen a Lot a Sun’s Goin’ Down

Oh, But Trust Meeeeeee – No Low-Life’s

Gonna Run Me Around

So Let Me Tell You Somethin’ Susta

Remember Your Name

No Twistuz’, Gonna Steal Yo’ Stuff Away

My Susta- We Sho’ Ain’t Got A Whole Lot of Time

... Sooo Shake Your Shimmy, Susta

‘Cause Honey This (Shug) Susta’s Feelin’ Fine



Announcements from your site. . .

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

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



New Faces and Goodbyes!

Sage Hales.

Hi, my name is Sage Hales and I started here as the Administrative Assistant in January. I recently graduated from The University of Michigan and moved to Chicago. While working here at WIHS I have found that both WIHS staff and participants are amazing and motivating people. I look forward to meeting you all!

Crystal Barnes

Hello I'm Crystal Barnes, a new Research Assistant for the WIHS. I'm helping with new enrollment efforts and recruiting new women to the study. I'm looking forward to meeting all participants soon!

Piper Davis

I'm Piper and I'm very happy to be with the WIHS study. I have been involved within the area of HIV for about 10 years. I do data management for the oral study and research interviewing at UIC. Hope to meet you soon.

Kelly Mattson

A big hello to all. My name is Kelly and I have recently joined the WIHS team. I have been with the WIHS for almost six months, but still consider myself one of the rookies. I am part of the data management team and work with the daily entry of data, maintaining data quality, and data analysis. I feel very fortunate to be employed for an organization that works toward such a meaningful cause. When I am not working you will most often find me playing soccer or knee deep in my July 2002 wedding plans. If you are in the area, stop by and say hi. I would love to meet you.

Rosalie Gibson

Hi, my name is Rosalie and I am one of the new interviewers at The CORE Center. I have worked in research for several years now and am very excited to now be with the WIHS.

Doris Carroll

Hello from UIC WIHS. Well, If you are wondering if I have returned from my trip to Kazakhstan with my 2 babies, the answer is, NO- I haven't even left yet!! Apparently this happens frequently with adoptions. I am trying to be flexible and positive, but the wait can be frustrating. Since I don't have a travel date, we will start to schedule visits in April. It is still too soon to say whether we will schedule visits in May. I can say that whenever I know my travel date, I will send another letter to all of you with your new appointments. Remember, I will be gone for 2 months. During that time no study visits will be scheduled. However, If you have any female problems, Dr. Vajaranant will be able to see you. Cynthia Stephenson, RN will be working with Dr. V. She can be reached at (312) 996-8337 for any questions you may have. Please know that I may have to leave at the last minute, and end up canceling a study visit until I come back. I hope you understand that I will work very hard to update all of you as soon as I know when I am leaving. Thanks for your patience and support!!



Goodbye to Lori Ackatz! Thanks Lori for all of your hard work. We'll miss you!

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
1900 W. Polk St., Rm. 1240
Chicago, IL 60612
(312) 633-5720 phone

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
Chicago Hospital**

University of Illinois at Chi-

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

FEEDBACK on YOUR FEEDBACK by: Sage Hales, WIHS Administrative 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 15:

- ◆ There were many requests for information on **“dealing with stress.”** In the past, we've had successful workshops on this topic. We'll make sure to plan another one soon!
- ◆ A number of participants asked for free condoms to be distributed at WIHS visits. What a great idea! We'll make condoms available at your WIHS visit.
- ◆ Many participants expressed interest in the WIHS goals, data collected, and outcomes. Reading the WIHS publications is one way to learn more about this. One of the most recent WIHS publications is by our very own principal investigator, Dr. Mardge Cohen on **“Causes of death other than AIDS.”** Please contact us at (312) 572-3715 if you'd like a complete list of WIHS publications or for any copies of specific publications.
- ◆ One participant suggested a **“Q & A”** column for the newsletter. Please feel free to write us with any questions that you have about the study, your body or your health and we will include it in our next newsletter! You can mail your questions to HealthWIHS, Administration Building, 1900 W. Polk St., Rm. 1248, Chicago, IL 60612 or e-mail kima@hektoen.org.

