

*Brought to you by the Chicago WIHS Consortium. . .*

# Health WIHS

Fall 2001



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## CAB CORNER

by Marta Santiago, Chicago NCAB Rep.

Hope everyone is happy, healthy and enjoyed their summers.

For those of us who have been with the WIHS from the start, we thought we were going to be the only ones. But now, the WIHS is enrolling 153 new participants! We'll have new comrades — in a sense, new blood. The family is growing.

With more women in the study, the hope is that researchers will be able to find out even more about the progression of HIV in women.

Life is here for us

to live, and now women are living longer and more productive lives. Over the years, I have learned to take charge of my life. And the rewards have been numerous.

I'm happy to be a part of WIHS. I have found it to be an empowering experience. The WIHS is like family to me. Really, I mean it.

For those of you, who will be new to this family, and for those of you who have been around, we are creating a step-by-step guide to your WIHS visit. The idea behind this bro-

chure is to make sure that everyone woman in the WIHS knows what to expect from beginning to end.

We just had an incredible workshop, "How and When Do you Tell Someone that you are HIV positive?" Women shared their experiences, frustrations and fears about disclosure. I think everyone there got a lot out of it. I know I did.

I'm looking forward to seeing new faces at future workshops!

**WOMEN! The WIHS at The CORE Center is now enrolling new women in the study. We are enrolling women with HIV infection and women at risk for HIV infection to examine how HIV affects women. By taking part in two research visits a year, you can help us further our efforts in fighting HIV disease. See page 3 for more info.**

**For more information  
about enrolling in the WIHS  
call WIHS at (312) 633-5720.**

# The New WIHS Colposcopy Protocol

(from the Southern CA WIHS Newsletter)



Beginning with Visit 13, a new protocol for colposcopy has gone into effect. The protocol should decrease the number of patients who need colposcopy. Here is a summary of when and why you would need colposcopy:

1.) If your pap smear is normal and no areas of the vagina, vulva or cervix have obvious warty lesions, then there is no need for anything until your Pap is repeated at you next core visit.

2.) If your Pap smear result is atypical squamous cells of undetermined significance (ASCUS), or if a wart is seen during your pelvic exam, then you should have colposcopy. If the colposcopy doesn't reveal any abnormalities, then you will just have a repeat Pap at your next core visit.

If an abnormality is found, you will need to have another colposcopy in six months. If you continue to show abnormalities, you will need to have follow-up colposcopy every six months until the abnormality is gone.

3.) If your Pap smear result is a low grade lesion, you should have col-

poscopy performed. If no lesion found, there is no need for anything until your Pap is repeated at your next core visit.

4.) If at any time you have a Pap smear result which is a high grade lesion, or which shows cancer, or which shows atypical glandular cells of undetermined significance (AGUS), you should have colposcopy. Patients with AGUS Pap smears may also need an endometrial biopsy as this result may indicate the presence of abnormal cells from the lining of the uterus.

If no lesion is found, it is advisable that a cone biopsy (a larger part of the cervix is removed for evaluation during a brief operation) be performed to be certain that there is no dysplasia present in the cervix. If you decide not to have a cone biopsy, then colposcopy should be performed again in 6 months.

If a lesion is found at the initial colposcopy, it should be treated with a LEEP (loop electrode excision procedure) or with a cone biopsy. A Pap smear should be repeated in 6 months. If the result is normal, then there is no need for anything until

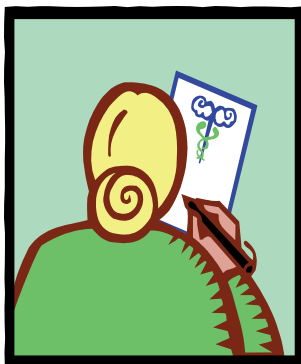
your Pap is repeated at your next core visit. If the result of the Pap smear is abnormal, a colposcopy and biopsy should be performed. If you decide to have no treatment at all for the lesion, then you should have colposcopy every 6 months. You only need to have a biopsy if the lesion or the Pap smear gets worse.

It is important to remember that colposcopy is the next step in finding out why a woman has an abnormal Pap smear.

**By having Pap smears regularly and by having colposcopies when needed, your risk of developing cancer of the cervix is greatly reduced.**

Lesions that may with time become cancerous can be treated when they are first discovered at a much earlier stage.

If you are afraid of colposcopy, talk with your WIHS clinician about your fears. You will find that there is a great deal that can be done to make the colposcopy a better, less frightening and less painful experience.



# Women! You Can Be a Part of the WIHS!



The WIHS is now enrolling new participants in the study. You can be a part of this national study addressing 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.

## Who can participate?

- Women 18 years of age or older who can provide informed consent
- Women who are HIV+ but do not have AIDS
- Women who are HIV – but at risk



## What will be expected of me?

- A baseline visit to review your medical history and enroll in the study if you are eligible
- A confidential interview every 6 months including detailed questions about your health, medications, feelings and experiences
- A GYNE and general exam every 6 months including special procedures if you have an abnormal PAP smear

## How will I benefit?

- Access to support, education and information
- Contribute to a better understanding of HIV in women
- \$30 compensation, a \$10 gift certificate, free transportation and childcare



**For more info,  
Call Alice Kim at  
(312) 633-5720.**

## **A new substudy in the WIHS** by Lori Ackatz

A new report in the Journal of Infectious Diseases indicates that anal human papillomavirus (HPV) appears to be common in HIV positive and HIV negative women who are at high-risk for infection.

Researchers from the University of California at San Francisco studied 251 HIV positive women and 68 women who had similar risk factors but were not

infected with HIV.

Approximately three quarters of the women with HIV and two-fifths of the HIV negative women had anal HPV DNA.

The researchers also discovered that in a subset of 200 women for whom cervical HPV information was also available, anal HPV was much more common.

A substudy in the WIHS looking at anal

HPV will be recruiting women starting in October.

The study will be conducted at The CORE Center, but women from other sites who are interested in participating are welcome.

If you have any questions, please call Lori Ackatz, at 312-572-4546.



# How and When do you tell someone that you are HIV positive?

(excerpts from the Chicago WIHS workshop held in August 2001)

## **Marta's story. . .**

"I want to tell you a little bit about myself and what my issues of disclosure have been. I also want to say that disclosure is not something you have to do. I do highly recommend that you tell your doctors and your dentist. This is very important, especially because interacting medications are very serious. I'm going to go back to '89. That's when I found out that I was HIV positive. At that time I also found out that my son who was not quite eight years old yet was also HIV positive. He is now twenty years old, and he's been living with HIV for twenty years.

"I didn't know how to handle it. At first I figured that this was something I needed to keep to myself. Because people tended to ostracize people with HIV. You must be a junkie or a whore if you had HIV. I felt like it was a disgrace. So I just kept it to myself. At first, I didn't even explain to my son why he was coming to the clinic with me. I didn't know how.

"But eventually my provider helped me out with that. She convinced me to start speaking to groups of people about HIV. I remember thinking, how the hell am I going to go up in front of these people. I was looking to get sunglasses. I was looking for a wig. But we didn't do that. Instead, we came up with a fictitious name—Sonia Ruiz. I was Sonia for the longest time. I thought that I could hide under that name. I started talking to lots of different groups of people, and that was OK. But then after a point, I couldn't remember if I was going out as Marta or Sonia. So I buried her. I don't even remember what the ceremony was like, but I buried her. I sent memos out to most of the people that I worked with—you've known me as Sonia all this time, but just wanted to let you know the real Marta.'



"I've definitely had different experiences. I told my mother almost right away, she understood. I told my brother, who has since died of AIDS, almost right away. I told my daughter at a time I was heavily drinking, so I told her with a bottle of Vodka in one hand and a bottle of orange juice in the other. And I said by the way, you're brother is too. But to this day, I haven't told my father. He's in a different world, and he's in Puerto Rico so it doesn't matter. I remember he was very upset when my brother died, and I didn't like what I heard from him. He put us down, and I don't need to go through that. I also told my older brother, or he kind of figured it out. I had this get together at my house and everybody that came to my house was connected up to AIDS organizations. And he figured it out. He's been OK with it, very concerned.

"But there are still some people that I feel just don't need to know. I'm comfortable with where I'm at; who I divulge to; and what I am doing. And I still talk in front of audiences, audiences that are there to be educated. So I'm still kind of in the closet. And yet I'm 'out' within our underground group here—our special membership."

## **Chinniese's story. . .**

"Hi, I'm Chinniese, and I was diagnosed in '92. When I first found out I was devastated. I couldn't believe what was happening to me. You know, why me? It took me two years to really come to grips with me being positive. I was just holding it inside and crying and going through the denial thing. I was even contemplating suicide and who was going to raise my son and what are people going to think about me. Then finally, I felt like I had to tell somebody. So I told my mom. She was very supportive. I thank God for her. She didn't know what HIV was. She just said, 'Whatever it is, I love you, and I'm there for you.' And I'm very fortunate to have that because I know a lot of people don't.

"We had a bunch of discussions because I wanted to tell Blake, who is my son. My mom didn't want me to tell him, but I felt like he was mature enough to know. At the time he was twelve. Before I told him anything, I asked him if he knew anything about HIV. He said that he had heard about it at school. About two weeks after that— and I just really prayed about it—I took him to the park and told him. I said, 'Remember the conversation we had a few weeks ago when I asked you if you had any questions about being positive? Well, your mom is HIV positive.' And he said, 'For real Mom?' and I said, 'For real.' And he didn't say anything for the longest time. Then I hugged him and he hugged me back. He asked me how I was doing and I said, 'I'm fine, don't worry about me. I'm taking medicines and just taking care of myself.' So from there it was still hard for him. He didn't want to talk about it. I wanted him to know what was going on—how it works in your body and he didn't want anything to do with it. So I just kind of left it at that. I said, 'You just have to deal with it in the way





## HOW and When do you Tell Someone?

that you have to deal with it.' Now, he's fine. He asks me how I am doing, and he wants to hear. And I am just grateful for that.

"But not all family situations are the same. My immediate family knows, but my dad doesn't know. And my dad doesn't know because my mom doesn't want his side of the family to know.

"I do feel like the more you share with people, the freer you are—the more you don't feel burdened or uncomfortable about sharing. I feel like I want to share so that I won't be having secrets and stuff."

### **Vicky's story. . .**

"Hello everybody. My name is Vicky and I was diagnosed in 1990. It's been a tragedy for me because I haven't told a whole lot of people. My mom and my father know. I have two kids. My oldest is eighteen, and I told him. But my baby who was also diagnosed doesn't know because my mother doesn't want to tell him. I want to tell him, but she wants to wait for him to get a little bit older.

"Mostly I have told the people that are on my mother's side of the family but not on my father's side. I didn't tell my mom myself. She found out because she went to see my baby in the hospital one day. And the nurse told my mother what my baby has. And that really tore me up. I felt like that was the worst thing that I could ever go through.

"When I found out what he had, which it was really, really devastating. There wasn't nothing I could do. I just kept on going. At first I did not take the medicine, but now I have been taking the medicine for about eight months. I feel much better.



"I don't talk to a whole lot of people because some people can take it and some can't. So I'm not going to talk to a whole lot of people and tell them what I got. When people know what you got they just throw a lot of things up in your face and make you feel bad. They make you want to cry. But then I just start praying and I ask God to help me. I've been in church all my life, but I was getting high and drinking and all that stuff like that, but now I finally got myself together. I feel a whole lot better.

"Sometimes I feel like I don't care who knows. But then other times I feel like I don't want nobody to know. So it's just an up and down thing. It's a tough thing to go through.

"I really want to tell my baby because I know he wants to start seeing little girls and stuff like this at his school. I don't know when my mama wants to tell him. I don't know how he is going to feel or whatever, but I do want to tell him because he is getting older and he needs to know. And don't nobody at the school know yet because my mom really don't even want them to know at the school either. So that's going to be another big thing for me to go through also.

"I'm just here by the grace of God and I must say that I'm glad with the things I've been through. Sometimes my mom makes me feel bad because she'll say a whole lot of things to me and stuff, but all I do is I start praying. At this point now, I feel good. So that's all I've got to say.

### **Gigi's story. . .**

"I disclosed to the guy I was dating the very same day that I found out. I had become very fond of him, and I had plans. I needed to know whether he was going to be around to care for me if it was necessary.

I told him that I had finally found out what was happening with me. And he wanted to know, because he was as fond of me as I was

of him. I told him that I had HIV and that I was still trying to find out exactly what that meant, but that I wanted him to know first. He said, you find out exactly what it is...and share with me.

Through the peer education program at Cook County, we were educated. I came home with new information and shared everything that I learned. So, he became a certified peer educator through me.

I decided to tell my whole family at once. I just figured it's more cost effective. It was around my birthday so it was nothing for me to invite them over for dinner. At the dinner table I brought up the issue of HIV/AIDS, just to test the water.

They came up with their thoughts, none of which were intelligent. "That's a gay-white-male's disease; those people deserved what they got; and blah, blah, blah." Well, during desert I brought out my little peer education certificate. I clarified that all these things that they had said were myths, lies, total untruths.

When it was time to serve coffee I got up from the table and said, "Those very people that you are talking about, I am one of them." Now my mom was the first one to get up from the table and she comes around and she hugged me, she embraced me and said, 'You're still my daughter.' The rest of them follow suit. Except my oldest brother. He had issues. He was going to find this guy and he was going to kill him. 'How could you accept what he has done?' he asked me. "Do I have an option?" I said, and that's the way I left it. He had to do his own processing.

But as far as disclosing to the general public, no one outside my family mattered to me. I think that the world knows and the world is the



Hello, my name is Anne. My first contact with AIDS was back in 1982. I was working as a Unit secretary in the MICU of a prestigious local hospital. Back then, HIV/AIDS were, to say the least, a tragic bafflement. Little or nothing was known about this disease, but then, as it is now, I saw the “heart determination” of the medical personnel as they rolled up their sleeves and went to battle against this newest of foes. I feel somewhat in awe of those early pioneers. I especially remember with fondness the nurses and doctors who were able to go beyond the clinical detachment that is so necessary when fighting such an enigma. Little did I know that someday I myself would be more deeply involved.

I reentered the world of HIV/AIDS back in '94. Our choices do dictate our lives, and my choices had been so poor that I truly believed that I would test positive. Please believe me when I say that when I received my “results” I was left speechless and uncomprehending—why was I spared? I had been a prostitute, an alcoholic, many of my poor choices also came about due to my “bi-polar” disease. I still don't know why I was spared, but I wanted to help those who had contracted the disease.

During the years I participated in the study I was well aware of the suffering going on and the earnestness of the battle. I felt like a fraud—I was not sick, not suffering. I cared for my father during these years and lost him in '97. WIHS was there to comfort me. Then I slowly slipped into a nightmare which at times I never believed I would survive—crack cocaine. Lost without my father, I gave up the will to live, I refrained from medications that were vital to my mental health.

One day I received a call, you know, that special “Are you coming to your next WIHS visit?” call! I had been receiving these calls for several years—but this call was very different—To me it was a call between life and death. I had never met or spoken to this young woman and yet, somehow she sensed that something was very, very wrong. She kept me on that phone until I had told her the whole brutal and degrading story. It was the first time in six months that I had spoken to someone who cared about me as a human being—and I did not want to ever put that phone down. But then he came home—the man who had me as a sexual prisoner—I knew if I were caught, the beating I would receive would be more than I had already survived. His first punishment would be to demand that I perform even more demeaning sexual acts. In his mind I had been a “pro” so what could be more natural.

It took another 8 months and a beating so bad that now my left hand is somewhat deformed from a brutal break—suffered from the hands of a man who knew that at long last I wanted out. He was not ready to let me go—but my “angel” had empowered me with courage and I knew that even though I was a “crack-head”, she believed that I still had human worth. Three times I ran, twice I was forced back. On my third attempt I made it.

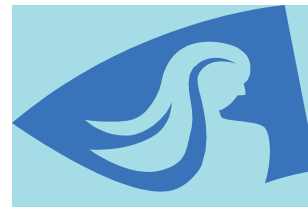
This letter is from the heart. We are blessed, each and every one of us, because we are being cared for by some truly magnificent people.

God bless us one and all,  
Anne



## Announcements from your site. . .

**A list of all WIHS publications is now available.** Call (312) 633-5720 to request a copy.  
**Don't' forget to check out the new Chicago WIHS website!**  
**[www.wihschicago.org](http://www.wihschicago.org)**



### **New Faces and Goodbyes!**

**Welcome to Leticia Martinez and Chloe Godwin**, new research assistants, and **Michele Cumming**, Interviewer and Retention Specialist for The CORE Center WIHS.

“Hi everybody. You can call me **Letty**. Before coming to WIHS I worked at the Howard Brown Health Center as an HIV Testing Counselor. I still volunteer there. And I like Pokemon.”

“Hi, my name is **Chloe**. I just graduated this May from Brown University with a degree in biology (but a passion for health activism). I was drawn to Chicago by this passion (and my new baby niece, Emma 😊). I'm so impressed WIHS and am so happy to be working with all of you.”

“Hi, I'm **Michele**. Before coming to WIHS I was a truancy officer at a public military high school. I was looking for a career change, and I decided to join the WIHS team. I like being around highly motivated, positive thinking people with open minds. And I'm looking forward to meeting all of you.”

**Goodbye from Gabriella Meredith**, Northwestern's site coordinator. Thanks to Gabriella for her commitment and compassion over the years. We will miss you!

“Seven years ago Dr. Pat Garcia gave me the wonderful opportunity to work with her on the WIHS study. While I had some experience with HIV patients as a home care nurse, I knew absolutely nothing about research, and felt quite overwhelmed at first. However, my wonderful participants with their difficult ever-changing lives, made the transition easy; their perseverance in battling this virus, their humor, their spirit, gave me and still give me inspiration and helped me put my personal and professional priorities in order. They inspired me to do and to be the best I possibly could be. So, my thanks for the past seven years not only go to Pat Garcia for putting her trust in me, but also to my clients who have changed my life forever.” Gabriella.

**Congratulations to Brooke Smith**, who will be taking Gabriella's place as the new site coordinator at Northwestern! Brooke has been part of the Data Management team at Cook County Hospital/The Core Center. We look forward to working with Brooke in her new role!

**Welcome back Sandy Micci and Julie Schmidt!** We're glad you're back from your maternity leave!

**Welcome back Kathy Schilder!** We missed you and we're glad you're back.

**Goodbye to Chinwe Oraka**, our CORE Center interviewer who is leaving to attend medical school at the University of Illinois in Champaign. Good luck to you! And much thanks for all your hard work and dedication with the WIHS. You'll be missed by all of us.

**Goodbye to Theresa Dia**, a WIHS research nurse. Theresa will be moving to Senegal with her husband at the end of September. Good luck to you and thanks for being a part of the WIHS team.

#### **A message from Doris at UIC:**

“The WIHS Team at UIC would like to thank all of the women for their continued participation. We look forward to seeing all of you at your next visit! Please note that the WIHS clinic may move from time to time to the 4th floor, Room 4C, instead of our usual clinic on the 3rd floor, 3D, at 1801 W. Taylor. I will call you ahead of time to let you know. Take care and thinking of you.” Doris.

## 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.

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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:*

**The Core Center/  
Luke's Hospital  
Cook County Hospital**  
Mardge Cohen, MD  
Audrey French, MD  
Kathleen Weber, BSN  
Lori Ackatz, RN, MPH  
(312) 572-4546

**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 new Chicago WIHS website!  
[www.wihschicago.org](http://www.wihschicago.org)

## FEEDBACK on YOUR FEEDBACK by Maria Shansky, WIHS Research Assistant

Hi Ladies! Thanks for withstanding the heat this summer to come to your WIHS visit. And many thanks for taking the time to complete your feedback forms. Based on what you've told us, we've been working towards making these improvements to your WIHS visit. . .

- To make your WIHS visit run smoother, we can now conduct your physical and GYNE exam before or after your interview. Previously, parts of the interview had to be completed first. This flexibility should mean **less waiting for you!**
- Many of you want to know more about **what the WIHS has learned so far**. To give you easier access to this information, we have established a local website [www.wihschicago.org](http://www.wihschicago.org) including an up to date list of WIHS publications. AND, current findings will be featured in every issue of *HealthWIHS*.
- We understand that the exam rooms can be chilly due to the air conditioning. We encourage you to bring socks to wear during your exam. We're also looking into providing **disposable slippers** for your use during your visit.
- We want to make sure that you get **enough to eat** on the day of your WIHS visit. We have stocked up on snacks for you. You're welcome to seconds. . .just ask.