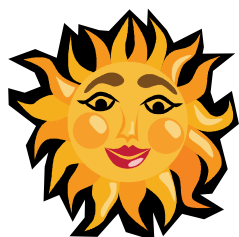


Brought to you by the Chicago WIHS Consortium. . .

Health WIHS

Summer/



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CAB CORNER

by Alice Williams,
Chicago NCAB Rep.

Hello and happy summer! I would like to share with you two very exciting events that I have attended as part of the WIHS. The first event was this year's National Community Advisory Board (NCAB) meeting, which took place this past May in Washington, D.C. For four days I had the great opportunity to attend this conference, where I participated in meetings with NCAB Representatives from WIHS sites all around the country. It was great to meet these women, who came from as far as San Francisco and Brooklyn, and to discuss with them issues that the WIHS was facing on both a national and local level. Also at this conference, I was able to sit in on presentations given by doctors who spoke about the current research that they were doing. Though most of the presentations were, at times, rather hard to follow - with lots of "doctor talk" -- they were still very interesting.

The meeting was going extremely well until we learned that the funding was cut for the NCAB's Conference of Choice as a result of overall budget cuts. Every year, the NCAB chooses one 'conference of choice' to attend, learn about HIV, meet other PWA's, and share our experiences. This news surprised many of us and caused quite an uproar. The chair of the NCAB, Kimberley Kelsey, was asked by the rest of us to communicate our huge disappointment to the Executive Committee the next day, but since she was unable to stay until the end of the conference, I was asked to give this speech instead. I was very nervous about speaking in front of so many people, but I overcame this fear, and in the end, the investigators made a commitment to come up with the money to let us all attend our Conference of Choice. This was a huge accomplishment for all of us.

On a lighter note, the second event was the WIHS trip to the *Vagina Monologues*. It, too, was a big success. Many women took advantage of the free tickets provided by WIHS. Personally, I was interested in attending this event because of the name of the play. I had no idea what to expect. The play turned out to be funny, educational, and a little shocking! It amazed me how three ladies could sit on stage and get so personal! My favorite scene was the one where the woman got onstage and showed us different types of moaning - it was hilarious. I want to encourage women to see this play and attend other events like this that the WIHS sponsors.

In closing, I'd like to thank Mardge Cohen and Alice Kim for asking me to be on the NCAB. It has been a very fulfilling experience. It has given me a lot of knowledge that I most likely would not have learned otherwise and the chance to meet many wonderful people.



New WIHS Substudies...

Intensive PK Study

This substudy looks at what happens to HIV meds once they're inside your body. Medications act differently in different people. Why do some women respond better than others? How are the medicines absorbed, distributed, metabolized and eliminated?

WIHS women who are currently taking kaletra/ritonavir, viracept/nelfinavir, viramune/nevirapine or sustiva/efavirenz are eligible for this substudy. Participants take part in a 12 or 24 hour research visit. (Participants taking sustiva are eligible for the 24 hour visit. Others are eligible for the 12 hour visit.)

An intravenous catheter is placed in the participant's arm to draw blood periodically. The participant also takes part in a brief interview. Participants are reimbursed \$100. Childcare and transportation arrangements available. Eligible participants must be scheduled to come in for their substudy visit within 6 weeks of their core WIHS visit.

Sex Steroids Study

This substudy looks at how HIV affects menstruation in general and how HIV affects women who are entering the "change of life" or menopause.

Do women living with HIV experience their periods and/or menopause differently?

Women who have not had a hysterectomy or entered menopause are eligible for this substudy. Participants need to come in to the clinic for a blood draw two to four days after the first day of their period.

Childcare and transportation provided. Participants are reimbursed \$25.

Feedback on your feedback!

By Angela Shansky, Site Operations Manager

Ladies, because of your feedback, WIHS has adopted a new procedure for pregnancy tests. Study participant Gloria S. pointed out that during her visit a pregnancy test was not performed.

The number of participants has increased. Our clinic days are much busier. To avoid errors we have adopted the following: Clinicians will now perform the pregnancy test. When you are escorted

to the exam room, your urine specimen will accompany you. The test will be done in your presence and results given before you leave the exam room.

Research mandates that data be captured correctly and consistently to measure true outcomes. WIHS's commitment and adherence to gold standard data collection methods are further enhanced with your interest and participation.

Thank you!

BRING TO YOUR WIHS VISIT!

- All of your medications.
- A recipe for the first-ever WIHS cookbook.



A Plug for Hair

Monica Gandhi MD, MPH

Why hair? As you may have noticed, the WIHS is starting to collect hair samples as of our last visit. This collection involves the snipping off of a small thatch of hair (only 10-20 strands!) from the back of the head. You have probably heard this is to 'check HIV medication levels' in the hair, which is true . . . but why hair, exactly?

The problem is this: We are now seeing that these HIV medications are not the magic solutions to HIV we thought they were at the beginning. Many patients 'fail' these therapies for one reason or another and still more people have side effects with these medications. In fact, many patients have to stop their HIV medications because of these side effects, which include nausea, vomiting, diarrhea, liver problems, high cholesterol, etc. We know that part of the reason these medications fail is because some patients have a hard time taking some of the complicated HIV regimens in the right way. However, we think that a big reason some patients may fail therapy (meaning, their HIV virus load does not go down to an "undetectable" level on therapy) is because different people absorb or break down the medications differently. This means that not everyone gets the same effect from the same HIV pill because each person has different genetics – some people absorb a lot of the drug, some people absorb a little bit, some people break down the medication very quickly, some people break down the medication very slowly, etc. One way to figure out how much medication a patient actually gets in her system is to measure the level of that medication in her bloodstream. That way, we can get a rough idea of how much drug the HIV virus is actually seeing once the medication hits the bloodstream.

Doctors in Europe are looking at blood levels of HIV medications more than we are in the US to figure out how to adjust HIV therapy – a patient with very high blood levels of HIV medications and side effects from the medicines may need a lower dose, for instance. We are also looking at blood levels of these medications as part of the WIHS study. However, medications get into the bloodstream quickly and leave quickly and a single blood level can only tell us what medication the patient took over the past 24 hours. Thus, the interest in measuring drug levels in hair.

HIV medications accumulate in hair more slowly than in the bloodstream, over a period of weeks to months, in fact. Hair levels tell us how much drug the patient has been seeing over a long time period, which may tell us more about why she is not doing well on the therapy or why she is having side effects on the therapy. Hair is also easy to collect since it requires just a small amount to measure drug levels. Different cosmetic treatments of hair (bleaching, perming, dye procedures, etc.) may affect drug levels in hair but we are working on techniques to adjust for those procedures so that our levels will be accurate. Hopefully we will be able to *one day* tell you, just by analyzing a small piece of hair, how much HIV medication your body is actually seeing and help you adjust your medication doses to best suit your body. For now, we need the hair to help us figure out these techniques! Thanks, as always, for your participation in the study.



Protect Yourself!

By Jeanette Carter, Brooklyn WIHS NCAB Representative

Sex! Safer sex was not a priority for me before HIV. The only priority I had back then was not getting pregnant. Since I found out that I was HIV+, I've been forced to think about sex differently. At the beginning of my diagnosis I had all kinds of feelings about sex. The major one was whether or not I should I tell any of my partners about my HIV status. If I divulged my status, what would they think of me, and how would they feel towards me then? There were a lot of "what ifs." So, in the beginning, when I first learned about my diagnosis I didn't tell anyone that I was HIV+. However, I did encourage any sex partner that I had to use a condom. If they questioned condom use, I just told them that I was not on the pill and did not want to become pregnant. And that worked pretty damn good.

But as time went on and I became more educated about HIV and its transmission, the "what ifs" started again. What if the condom breaks? What if the condom comes off? And so on. The "what ifs" started giving me a feeling of guilt. I didn't want to be the reason for someone else's HIV status.

So for the past seven years, I have had one main partner who knows I'm HIV+. And we use condoms all the time. In the beginning he told me things like, "I don't care what you have." He didn't know what he was saying. He just didn't want to use condoms. But I convinced him otherwise. Not just for his safety, but for mine.

You can't look at people and tell who has what. You only know what they say when you ask them. But what I know is this: **protect yourself!**

What if my partner and I were both HIV+, then would we have unprotected sex? NO! I most certainly would not. Why? Because when two HIV+ people have sex, they run the risk of altering whatever strain of the virus they already have. This changes your virus and alters it, making it harder to treat with known antiretroviral medications. You may become resistant to antiretroviral medications, leaving you with no treatment options at all.

Ok! Let's talk about low viral load and sex. Just because one or both partners have a low viral load does not mean that you are virus free. Transmission is still possible. Don't be fooled by Magic Johnson's looks and his low viral load. Make no mistake. He is not virus free. Low viral load only means based on the tests currently being used to measure viral load, the virus can't be detected. This does not mean that you have no virus in your body. Once you are HIV+ you will remain HIV+ until a cure is found. Period.

Please note: To date there is no cure for HIV or vaccine available to prevent HIV.



Control your future!
Practice safe sex!

Use condoms all the time, every time!
The Power is Yours.



My Story of Safer Sex

By Elisa Sanchez-Jenkins, Los Angeles NCAB Representative

This is my story of safer sex. When I first found out about my status, I didn't have a problem telling my partner that I was HIV positive. I would tell them up front. I then let them choose if they wanted to use a condom or not. Most men that I dated did not want to use a condom. They felt that because they were fifty years old or older and had lived a full life already, they didn't care if they got anything or not. Plus, I found that most men this age didn't like to use a condom.

I too did not like to use a condom. So, at the beginning, most of the time I didn't. Back then, I didn't care if I got anything else or not, I just wanted to have sex. I never even thought of the possibility of getting re-infected by having sex with someone else who had HIV/AIDS. I thought that if we both had HIV/AIDS it was safer and we both felt more comfortable about it. Now I know that my way of thinking at the time was wrong, and that I was really hurting myself. So, for the first seven years of having HIV, I did not protect myself or others. But then in my seventh year, when I started to get a lot of infections, I knew that it was time to start taking care of myself. If I didn't, no one else was going to do it for me. So, in the year 2000, I decided to stop having sex. And for the last two and a half years I have been abstinent.

Now I'm doing so much better. I don't get any infections any more. Plus, I have a lot less stress to deal with in my life now that there's no man in my life AND no more sexual infections. Before, when I gave speech on HIV/AIDS I would tell the students at the schools I taught at to practice safer sex. I was telling the students that abstinence was always best, but I wasn't abstinent. I wasn't practicing what I was preaching because I thought it was safe to be with someone else who also had HIV/AIDS. This is where I was wrong. Now when I talk about safer sex to others, since I am abstaining from sex I can now say that. The only way for completely safe sex is by not having any sex, period. And if I were to meet a special man now, I would use a condom. I would use it for myself, to keep me safe. If he didn't want to use a condom then I would say no to sex because I can't deal with all the stress of infections anymore. As I said before, I have to care for myself because I know that he sure won't take care of me.



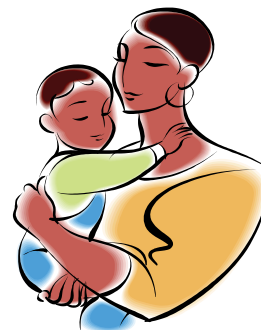
"My name is Julie and I'm a 44 (soon to be 45) year old wife and mother of two (my son 10, my daughter 7). I first found out of my HIV status when I was pregnant with my son. I don't need to tell any of you that have been there the heartfelt pain and hopelessness I felt. First, I came from the western suburbs and my OB/GYN said he wasn't equipped to treat an HIV pregnancy. He gave me a list of 5 doctors in Chicago and Evanston. I chose the only female (Patricia Garcia). From my first meeting with her and all the staff (from the receptionist, the dietitian, the nursing staff) I knew I had made the right choice.

At the time of my pregnancy (11 years ago) AZT and pregnant women was new and all the results which we now have weren't in yet, so I opted not to and rely on my strong faith instead. Pat took such good care of me and my son was delivered 1/26/92. Through the pregnancy and the two years after to wait until I could see if my son was HIV positive was stressful and anxiety causing. I cried and prayed. When all turned out, well, I rejoiced!

By the time my son was five I wanted another child, but knew I couldn't go through with another anxiety ridden couple of years. So my husband and I looked into adoption and on March 21st, 1998 we adopted a three year old girl, our daughter. She is ever much a part of us as our natural born son.

I try my best to keep myself healthy, because my new worries include living long enough to see my children grow and not being there for them. The WIHS Study and all the staff here in the program have helped me do that. I feel very blessed to be part of such a wonderful program and whom I consider friend and family.

I would encourage other moms or moms to be to practice healthy habits, be with your children, and to look into adoption as a viable way to love a child."



Excerpts from *How I See the World* by Pam

The perspective I have with which I view the world is almost like being in a coma. I don't seem to be able to wake up. I find myself lying there helplessly by as the world unfolds around me. It's like a waking dream but something completely unlike daydreaming. I experience dreams and nightmares. I wonder if I'll ever wake up to the "real" world rather than the one that just keeps unfolding within my head.

I believe the body and mind work together; the problem is convincing my brain, yes, everything is in our minds. The whole universe exists within us all. I do believe we have the power inside us to control most of our mental and physical problems. Thoughts control our mind, body, and the world in which we live. In my own small world, I am afflicted with a virus that can wipe me out at any moment. I've been living with the depression, despair and fear that surrounds this disease for more years than I can remember. Although I may be small and kind of insignificant. I see suffering far beyond my personal inner strengths.

Currently I have a hope, and I'm working toward that end in school, that I may help others by simply visiting with a lonely person who may enjoy some company, telling a few jokes, brightening up someone's day just by listening to them talk, or making similar, small positive efforts just by being who I am.

Announcements from your site. . .

New Faces, Goodbyes...

A big thank you to Sasha Swartzman, our summer intern, for all your help and especially for kicking off the first ever WIHS cookbook. Good luck to you in school!

We've had a few changes in the Chicago WIHS....

We'd like to say goodbye and the best of luck to Zyra Gordon-Smith, Research Nurse; Julia Sone, WIHS anoscopist; Ruth Davis, Rush Site Coordinator; Brooke Smith, Northwestern Site Coordinator; Sage Hales, administrative assistant; and Mariela Romo, research assistant.

A warm welcome to Hanako Johnson and Rachel Cassidy, WIHS research assistants; Joan Swiatek, the new Rush site coordinator; Joyce Fitzgerald, WIHS research nurse, and Robert Saquaton, the new WIHS anoscopist.

Congratulations to Kathy Schilder on her second baby boy.

Mothers 2 Mothers 2 Be...

Monday, September 15, 1 PM,

The CORE Center, Conference Rm. A-B

Come and learn first hand about this innovative South African peer support network that trains HIV+ mothers as mentors for newly diagnosed HIV+ pregnant women.

Guest speakers visiting from South Africa: Dr. Mitch Besser, founder and director of Mothers 2 Mothers and Sodwa Emelda Ndlovu, Site Coordinator and Peer Leader.



Excerpts from *I Am Alive!* by Pam

I am alive! It has been over ten years since that day I will never forget. I took and AIDS test with two of my friends and I was not worried. The news was on every night talking about new cases of AIDS and how it was spreading. I was not a gay man and I never injected drugs and I did not have a blood transfusion. September 4, 1991 changed my life forever. I went with my best friend and another friend was going to meet us there for our results. My friend Diane was nervous. She went into the room first and came out and gave the thumbs up sign. I was next; I went in with little worry and to my shock I was positive! My future was wiped out with just the word—"You are positive." I could not hear what the doctor was telling me. It seemed, he was giving me a death sentence. I walked out of the room and looked at my friends and they saw the look of horror on my face. My friend Eileen did not even want to go in the room to get her results because she wanted to comfort me. She went in and was negative.

Presently I am working on getting a job and working on going to graduate school. I still have some problems with the anxiety, which is a very difficult challenge for me. I hope my new therapist that does a method called EMDR can help me get rid of the anxiety. I feel good and strong and healthy, mentally and physically. I no longer feel different like a leper because I have AIDS. I made peace within myself.

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.

WIHS
Administration Building
1900 W. Polk St., Rm. 1240

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) 572-4596

Rush Presbyterian—St.

Beverly Sha, MD
Joan Swiatek, RN
(312) 942-6017

Northwestern Memorial Hospital

University of Illi-

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

Do you have a favorite recipe? A dish that you like to cook as a special treat? A dish that you like to eat when you have a cold? When you're feeling blue? Share your recipe with other WIHS women in the first ever...



WIHS COOKBOOK!

With sections to include:

- Sweets and treats
- Healthy food that's not rabbit food
- And more!



Submit your recipes today!

Mail to: Alice Kim

**1900 W. Polk Rm 1248
Chicago, IL 60612**