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Health WIHS

AUGUST



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CAB CORNER

by Marta Santiago, Chicago NCAB Rep.

Back home, following the International AIDS conference in Barcelona, the Chicago WIHS hosted another workshop luncheon for a conference update. Dr. Mardge Cohen gave a slide presentation – you can get a summary inside this newsletter. The theme of the conference was “Knowledge and Commitment for Action.” The conference highlighted places like Brazil and Thailand where people with HIV and AIDS are getting treatment, and this showed that we can fight AIDS. But it’s also clear that we still have our work cut out for us.

Too many people all over the world are getting HIV and the epidemic is still spreading. And far too many people are dying because they can’t afford the medicines they need. So, we’ve made some progress, but we still have a long way to go.

The National Community Advisory Board had two poster presentations at the conference: Who’s Afraid of Colposcopy? Peers Confront Women’s Fears and Peer Initiatives in the Enrollment of a New Cohort in the WIHS (see pages 2-3).

We are making a conscious effort to relay more information about the research that the WIHS is doing to WIHS participants. WIHS investigators who write manuscripts using WIHS data, are now required to provide lay language summaries that will be posted on the WIHS public website. We will also be featuring these summaries and the poster presentations in upcoming newsletters.

It did me good to hear the new women who were at the luncheon asking what the WIHS was all about. To me, that’s a sign that the new participants are interested in good health, and that the WIHS is having an impact. I hope for more of this trend in the WIHS.

***A special welcome to all the
new women in the WIHS!***

The Chicago WIHS has enrolled 140 new women in the study. This makes a total of 372 participants in Chicago! THANKS for being a part of the WIHS. Your participation is making a difference for all women living with HIV!



WHO'S AFRAID OF COLPOSCOPY? PEERS CONFRONT WOMEN'S FEARS

By Elisa Sanchez-Jenkins and the WIHS NCAB

“I haven’t had a colpo. At first, I was saying, I’m not going to have one. Because you hear horror stories about how it hurts and how uncomfortable it is. So I was afraid. But I really didn’t know much about a colpo. But when I learned about how important it is to have pap smears and if you have an abnormal pap smear that it’s very important to have a colpo because they can tell you so much about cancer and HPV. And it’s really the only way that they can know how to treat. If you have a colpo they can treat you if there’s something wrong. So now, if I have an abnormal pap smear, even though I might not want to do it, I will do it. And I will encourage other people to do it.” —Alice Williams

“When I had a colposcopy the clinician explained to me everything that was going to be done. I got up on the table. There was a nurse to hold my hand. They told me to take a deep breath and they took a pinch of tissue. As the doctors should explain to you, you might have some mild discomfort after the colpo, but it’s just like going through mild menstrual cramps. Getting a colposcopy is no worse than getting the anal exam. If you can handle the anal part of the WIHS exam then you can definitely handle a colposcopy. Just take a deep breath in and relax.” —Kim Kelsey

“It hurt, I have to admit it! I’ve had it twice. It did hurt, and it lasts for a while. It’s kind of like menstrual cramps. The first time the pain lasted for about an hour. The second time, I had cramps for the whole night. But I still think it’s worth it. The short-term pain is worth the long term benefit. A colpo can help you find out if there’s something wrong and if you need early treatment. I advise anybody to do it, if you need it. It’s one little step and it’s over. You do get over it.” —Sidney Green

“My experience was ten years ago. I remember that the clinician guided me through each step. That’s what made me comfortable, and I relaxed. She’d say, now I’m getting ready to do this.....now I’m getting ready to do that. I was fearful but the doctor made me comfortable because she explained each step of the way. And because she was a female that made me even more comfortable. It’s better to go through it than not because it’s better to know than not know. Because I did have dysplasia and the comb biopsy removed the cancer. Now, ten years later I’m still coming up okay. And I’m not even on meds. So it’s best to go ahead and conquer it because you might be lucky enough to nip it in the bud. Push past the fear and do what you gotta do because there’s a good chance you can conquer it.” —Amirah Waleed

“If I was to have an abnormal pap and needed a colpo I wouldn’t want to have one, but I would have one because of the long term benefits. I’m not in the business of dying. I’m in the business of living. The results of a colpo can be beneficial to your overall health. Whatever they find out from a colpo – it doesn’t have to be that serious—or even if it is, you can nip it in the bud right away. That would put you ahead of the game—not behind. In the normal scheme of things, a woman only goes to the gyne once a year. With the WIHS you’re getting a gyne exam twice a year. So if anything does change you’re going to know a lot sooner which is beneficial to your health down the line. And I’ll do what’s beneficial because I love Jeanette first and foremost.” —Jeanette Carter

Peer Initiatives in the Enrollment of a New Cohort in the WIHS

By Alice Kim and the WIHS NCAB

The NCAB, comprised of one to three participants from each of the six WIHS research sites, devised strategies to reach out to and welcome new participants in the study including:

- *a step-by-step guide to the WIHS visit describing the survey and examinations that would take place
- *a “Welcome to the WIHS!” bookmark for participants
- *appreciation gifts
- *focus groups to determine how best to reach potential enrollees
- *a “Welcome Party” including new and veteran participants
- *a buddy system



The NCAB dedicated working meetings, nationally and locally, to discuss and devise strategies to reach out to potential enrollees.

The NCAB felt that it was important to make new women feel welcome—part of a “new family.”

NCAB representatives also helped to enroll new women by distributing recruitment flyers to peers.

Recommendations: The NCAB's strategies were effective in enrolling women in the WIHS and can be used as a model for other research studies enrolling participants who are thought to be hard to reach.

Lessons Learned

1. As veteran participants in the WIHS, their experiences were integral in identifying the needs of a new cohort, making outreach effective and helping recruitment efforts to be well received.

The strategies that they devised were effective in the following ways:

- a.) helping new women understand each step of their research visit
- b.) welcoming new women into the study
- c.) encouraging feedback from new participants about their research visits and healthcare priorities.

2. New participants expressed a desire for more knowledge about their bodies and how to better take care of themselves.

3. The new cohort presents the NCAB with opportunities to expand and rejuvenate the NCAB and local CABS through the involvement of new participants.



Highlights from the 14th World AIDS Conference

Excerpts from Dr. Mardge Cohen's slide presentation at the Chicago WIHS workshop in August.

It is not the lack of knowledge that is the bottleneck. It is the lack of resources ... We must learn that a life from New York or from Mozambique or from China has the same value.

*Irene Fernandez
(Malaysian human rights activist)*

Delaying a response to AIDS for just one year is going to cost another 5 million lives ... The time for excuses has run out ... 3 million people should be in treatment by 2005.

*-Bernard Schwartlander
(Director of Evidence and Policy, HIV/AIDS, WHO, Geneva)*

It is short-sighted to focus only on prevention as healthcare systems struggle with the burden of people already infected -- it is also unconscionable, as it is our lives at stake.

*--Zachie Achmat
(South African AIDS activist)*



Adults and children living with HIV/AIDS (as of end 2001)

North America	940,000
Caribbean	420,000
Latin America	1.4 million
Western Europe	560,000
North Africa and Middle East	440,000
Sub-Saharan Africa	28.1 million
Eastern Europe and Central Asia	1 million
East Asia and Pacific	1 million
South and South-East Asia	6.1 million
Australia and New Zealand	15,000

Total People living with HIV/AIDS	40 Million
New HIV infections in 2001	5 million
Deaths due to HIV/AIDS in 2001	3 million

CHILDREN IN AFRICA. . .

The majority of children infected at birth or through breastfeeding will die before they reach 5 years old

The under 5 mortality rate from HIV/AIDS increased by 20-40%.

Benefits of Anti-Retroviral Therapy in the developed world

One study showed an 89% decline in MAC and an 88% decline in CMV.

Another study showed that there were no important new toxicities related to Anti-Retroviral therapy use in pregnancy.

Chances Missed for Preventing Woman to Infant Transmission

A study of 5,054 HIV exposed deliveries at 6 sites between 1996-2000 found the following:

- 423 HIV infected infants.
- Women taking anti-HIV medicines experienced woman to infant transmission rates of 2.5%. Women taking AZT only experienced transmission rates of 5.4%. Women on no treatment experienced transmission rates of 28%.
- In HIV positive infants, 57% of mothers missed woman to infant HIV prevention



Treatment Response: Differences Between Women and Men

- Women on NFV (nelfinavir) who previously were not on any HIV medications had better CD4 responses, prolonged viral load reduction and time to treatment failure
- At six months, women on HAART have higher CD4 responses than men
- Women do not experience more rapid progress of HIV infection than men at equal levels of viral load.

What is working in the worldwide fight against HIV/AIDS?

1. Making generic antiretrovirals
2. Importing generic antiretroviral drugs
3. Getting cheaper antiretroviral drugs
4. Prevention
5. Where there is political will to treat (Thailand, Brazil)
6. Activism and advocacy

WIHS poster presentations at the conference. . .

Temporal trends and predictors of HAART discontinuation in the WIHS—by LA Grant and others

Increased incidence of cancer among participants in the WIHS—by N Hessol and others

Discontinuing and switching medications in the era of HAART: women tell us why—by A Kim and others

Peer initiatives in the enrollment of a new cohort in the WIHS—by A Kim and others

Who's afraid of colposcopy? Peers confront women's fears—by E Sanchez and others

Trends in complementary/alternative medicine (CAM) use in a large cohort of HIV infected women in the US from 1994-2001—by K Weber and others

Medically eligible women not reporting use of HAART—by M Cohen and others

Initiation of frequent marijuana use among a cohort of women infected with or at risk for HIV in the WIHS—by WH Kuo and others

Prevalence and correlates of neutropenia among a large cohort of HIV infected women and HIV negative women at risk: WIHS—by A Levine and others

Patient satisfaction with care and antiretroviral therapy use among women with HIV/AIDS; which comes first? - by J Burke and others

Decline in a cohort of HIV seropositive women—by J Cook and others

HIV-1 in genital tract and plasma of women: compartmentalization of both viral sequences and coreceptor usage—by K Sherefa-Kemal and others

AIDS morbidity and death by CD4 cell count (CD4) and quantitative HIV-1 RNA (VL) as time varying measurements after HAART initiation—by K Anastos and others

The association of Delayed-Type Hypersensitivity (DTH) with death and incident AIDS-defining illness (ADI) in HIV-1 infected women after HAART initiation—by K Anastos and others

Dynamics of suppression of CXCR4 specific HIV-1 strains by antiviral therapy—by S Philpot and others (ORAL presentation)

Association of CCR5-D32 mutation with Hepatitis C seroprevalence and incidence in a large cohort of women—by V Madhava and others

The potential impact of ART and HIV vaccines on adult HIV incidence: model estimates for a rural population in Rakar District, Uganda—by S Gange / R. Gray and others (ORAL presentation)

Mother's Day is

Greetings with a big hug to all the Chicago Women of WIHS. My name is Nina. I've known many of you for about 12 years. Most of you know me as Marta Santiago's daughter and some of you call me nicknames that you gave me.

I've been fortunate to be among so many extraordinary women throughout my earlier days of growth. You have so much to give. In the past year I have learned with you and beside you. By watching you I've learned to be a stronger woman and a happier woman in loving myself. Most of all I have learned to understand my mom with the virus, menopause, motherhood, loosing one's parent, and parenthood.

We (you and I) have done an enormous amount of good together- at the AIDS walk, the Juvenile Home, the County Jail, the Penitentiary, the Women's Project Kids Group, the TASC Inc., the Women and Children's Program events, and at Conferences, Trainings, High Schools, Television shows, Pride Parade, the lobby at the Capitol and as participants in this study.

I came into this arena as a teenager with fear of not knowing my purpose. All of the wonderful moments that I've shared with you all will continue to be with me forever.

Often I wanted my mom with me at all times for all my engagements. Many of you women gave me the support and encouragement I needed when ma was away at her engagements.

Thank you ladies for being all that you are. Happy Mothers Day! Happy Sisters Day! Every Day!

A Wonderful Night by Leatrice Simpson

I walked along the shorelines with sand in between my perfectly polished purple toes. Watched the sun dance in the sky. Then I came across a message in a bottle. Intensely did I open and read with full amazement in the love that was shared by two. While inhaling the fresh air moving gingerly across my nose. I sit at the beach and enjoy the birds singing to me in harmony, as I continue to let my imagination carry me away to a place I've never traveled to before. Its getting late, nightfall. I'd better walk towards the pier. As I walk long the pier and see the sun dance across the ocean, it shifts from colors of gold to orange. This life is rich with simple pleasures. The seagulls cautiously approach, hoping for a morsel of food. The wind blows through my hair. A few strings sweep across my eyelash as I turn to see. I feel a shiver go through me with chill bumps on my arm. Tenderly I notice eyes glance at mine instantly. Then I meet you...

therefore,

Be still the warmth of my heart from the throws of passion that so anxiously awaits me to bask in!

I beseech thee to be gentle with thy touch, for I am so impressionable to the kindnesses that I desire evermore.

I too look forward to discovering the wondrous excitement and mysteries of a new friendship however long distance it might be.

The day not passes me by fast enough till I get the opportunity to write again and better to hear your voice.

Oh relieve me of my request soon, that I that I might feel the joys deep with in.

Though I tread gently, for I knowest not if thou mightest belongest to another.

In anticipation...

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!

WELCOME to Darlene Joiner, LaShawn Moore and Landra Tillman—new WIHS staff at The CORE Center/Cook County Hospital.

GOODBYE to Rosalie Gibson, Chloe Godwin and Benna Crawford. We'll miss you!

Hello UIC WIHS participants! My husband and I returned home in May with our 2 lovely children from Kazakhstan. They are now 10 months old, healthy, active, and just beautiful! It was an incredible journey, and we're glad to be home, tired, but very happy! Thanks to all of you for your best wishes. I'll have pictures when you come in for your study visit. Speaking of study visits, UIC WIHS started up again in mid June. If you have any questions about when your visit is, please call. See you all soon!! — Doris

Do you want to quit smoking? Are you thinking about it?



*How committed are you to quitting? Commitment is directly related to whether or not one will be successful in quitting

*Fear is often a reason that people do or do not quit smoking. The fear may never disappear, but remember that people often do things in the face of fear.

*Medications for quitting are one of many tools that can be used to quit, but will not work alone.

*If you are not ready to quit completely, cut some cigarettes out of your daily routine. Give yourself credit for cutting down.

After you have done something as many times as you have probably had a cigarette, it's a behavior that can be very difficult to change. Be patient with yourself. You can do it!

To learn more about strategies to quit smoking, call the smoking cessation clinic at (312) 633-7587 or stop by the smoking cessation clinic located in Fantus in the 2nd floor clinic.

If you are interested in participating in a WIHS quit smoking workshop, call Sage Hales at (312) 572-3715.

Distance - a poem by Ellen M. Bruhuke Richard

The distances of one's self
many courses

Can only be determined by
Which is right for you?

Being ruled by no one,

except one's self.

Life has

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 have come up during visit 16:

- ◆ There were many requests for information on “**dealing with stress.**” We are in the process of planning a workshop on this topic for fall or early winter of 2002. Look for a flyer in your mailbox!
- ◆ One participant asked for phone numbers to call when there is a crisis. Here are a few basic Hotline/helpline numbers that you can call if you need information or assistance:
 - National Sexually Transmitted Disease Hotline: 1-800-866-8922
 - Parental Stress Hotline: 312-3-PARENT
 - Friends of Battered Women and Their Children: 1-800-603-HELP
 - Alcoholics Anonymous Greater Chicagoland/Chicago: 1-800-371-1475
 - Hopeline/Illinois (assistance for homeless): 847-228-3463
 - Homelessness 24 hour Hotline: 847-866-7027
 - Warm Line/Parenting Resource Network / Illinois: 847-675-3555
 - Courage Program/Pregnancy: 847.636.5437
 - Planned Parenthood/ Chicago, Illinois: 312-427-2245

