

Health WIHS

December, 2000

CAB Corner: A South African Experience!

by Marta Santiago, Chicago NCAB Representative

The 13th World AIDS Conference was held in Durban, South Africa this past summer. I wish I could have been there in person, but I was able to get a flavor of it through the WIHS workshop last month where Mardge Cohen, MD and Bonnie Lubin, Ph.D. presented a slide show about HIV in South Africa and the global epidemic.

They told us about the devastation taking place in Africa and other parts of the world that are underdeveloped. It truly humbled me. When you think about people living with this disease who don't even have running water - never mind healthcare facilities or HIV medications - it's hard to have complaints about our situation here.

At the same time, the dire situation in Africa raised some serious questions for me. Why aren't the pharmaceutical companies and the rest of the

world doing more? How can we help make a difference? That's what I want to know.

That's also why I'm really grateful to be a part of the WIHS. We are making a difference through our participation in this study. It wasn't too long ago that AIDS was mistaken as a gay disease here in this country. It wasn't too long ago that treatment for people living with HIV scarcely existed. And it wasn't too long ago that we, too, were an invisible community here. Because people came together, we were able to get AIDS education, research and treatment. We certainly have come a long way. But we still have a long way to go.

This holiday season the WIHS will be celebrating our research efforts along with other research studies on Friday, December 15. There will be a luncheon at The Core Center (2020 W. Harrison St.) at 12 noon. I hope all of you can come!

I would also like to welcome Leatrice Simpson, who is a WIHS participant at Rush, to our National Community Advisory Board (NCAB) team. As an alternate NCAB representative, she will help to represent the experiences and needs of WIHS participants.

Thanks for being a part of WIHS, and thanks for listening to me. Hope your holidays are healthy and happy!

WIHS Holiday Luncheon

Friday, December 15th

The Core Center

2020 W. Harrison St.

12 noon - 2PM

Local Community Advisory Board

Planning Meeting

Tuesday, January 16th

The Core Center

12 noon - 1:30PM

INSIDE:

Resources for You

p. 2

Changes in Your WIHS Visit

p. 3

An Introduction to the Global Pandemic

p. 4-5

Letters from the Heart

p. 6

Health WIHS

Health WIHS is a publication of the Women's Interagency HIV Study (WIHS) in Chicago.

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.

Please submit personal stories, poems and other creative work to Health WIHS!

**WIHS - Cook County Hospital
Administration Building
1900 W. Polk St., Rm. 1240
Chicago, IL 60612**

You can use your real name or an assumed name for publication, but please include your name and phone number with your submission so that we can call you to discuss your work.

Non-commercial distribution of articles in this newsletter is encouraged.

Any questions or comments, call Alice Kim, Newsletter Editor, at (312) 633-5720.



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 Center / Cook County Hospital
Mardge Cohen, MD
Audrey French, MD
Kathleen Weber, RN, BSN
Lori Ackatz, RN, MPH
(312) 572-3715

Northwestern Memorial Hospital
Patricia Garcia, MD
Gabriella Meredith, RN
(312) 908-2643

Rush Presbyterian - St. Luke's Hospital
Beverly Sha, MD
Ruth Gilmore, RN
(312) 942-5865

University of Illinois at Chicago Hospital
Ronald Hershaw, MD
Doris Carroll, BSN
(312) 413-1366

This publication is made possible by
the National Institute of Health, Grant No. 5 U01 AI 34993.

RESOURCES FOR YOU! DEPRESSION: YOU ARE NOT ALONE

Even though the holidays are supposed to be a joyous time, they can be trying times for some of us. Some people become depressed around the holidays. Common symptoms of depression include sadness, sleeplessness or oversleeping, chronic fatigue, anxiety, shortness of breath, and addictive behaviors. Don't blame yourself. Depression is a health problem — not a personal weakness.

At least one in six people go through a serious episode of depression during his or her life. Approximately 25% of women will suffer from depression. Things like chemical imbalances in the brain, heredity, and stress are common causes of depression. Unfortunately, it's not always easy to recognize depression.

If you think you could be suffering from depression, there are a wide range of coping strategies available. Working with a trusted health professional (primary care physicians, psychiatrists, psychologists, clinical social workers, etc.) can promote effective treatment. Try taking a walk. Exercise has a significant mood-elevating effect. Get involved in group therapy. There are support groups throughout the city of Chicago and the suburbs focusing on depression. Find creative outlets. There are various ways to express your feelings. Learn about effective medications. Medications can sometimes help reduce symptoms.

If you detect depression in a loved one, there are things you can do to help. Reach out with affectionate notes and invitations. And please, take depression seriously, especially talk of suicide. If you are having thoughts of suicide, act now and get help! Call the National Suicide Crisis Hotline toll-free at 1-888-SUICIDE.

Support Groups and Mental Health Services:

Brass Foundation
773 869 0301

Howard Brown Health Ctr.
773 388 1600

Chase House
773 374-0422

NMH - Asher Depression Ctr.
(312) 695 4745

Core Center (HIV+ only)
General info call 312 572-4756

Ravenswood Mental Health Ctr.
773 463 7000

CareMed Chicago
312 738 8622

Rush Mental Wellness
(888) 969 7874

Chicago Women's AIDS Project
North Side
773 271 2070

Southeast Mental Health Ctr.
773 747 0881

South Side
773 863 8711

UIC - Community Outreach
773 561 3777

Community Counseling
Centers of Chicago

773 769 0205

Englewood Mental Health
312 747 7496

**WE ALL DESERVE TO
LIVE HEALTHY AND
PRODUCTIVE LIVES!**

Changes in your WIHS Visit!

Some of you have been in for your Visit 13 WIHS visit and may know about some of the changes going on, but others may not. We'd like to quickly review what's happening for this visit cycle.

Additional \$10 Food Voucher! Since you all have been participating in the WIHS since 1994 or 1995, WIHS staff would like to acknowledge your continued participation by providing you with a ten dollar Jewel food store voucher. You will receive this voucher in addition to the cash amount you already receive at each WIHS Core study visit.

New Substudy! A small group of women will be eligible for participation in the WIHS Viral Resistance and Rebound substudy. This study hopes to learn about how well women on HIV medications (HAART) do over a long period of time. Women who are eligible for the substudy will be approached at their Visit 13 study visit. FYI: The NIDA HCU substudy, a small interview given during your WIHS visit, is no longer being conducted. Any questions? Ask WIHS staff at your next visit.

Fasting before your visit! All WIHS women are now being encouraged to fast (not eating or drinking) after midnight prior to coming in for their WIHS visit. Please remember that you **can** drink water prior to your visit (no coffee or tea), and snacks will be provided after your blood is drawn. If fasting is going to interfere with you taking your antiretroviral medication or with medication taken for diabetes, we would not want you to fast. Blood will be drawn whether you fast or not and testing will be done in the future to look at levels of glucose (sugar), lipids and insulin.

Colposcopy. . . We have heard you !!! We will do less !!! We have changed the procedure so that the need for colposcopy (and biopsy) will be less frequent. This means that we will focus attention on new changes or abnormal findings of greater significance. We will continue to "harass you" when you do need a colposcopy because we want to protect you Early detection is the best answer to cancer prevention. Our goal is that at least 80% of the WIHS women with abnormal pap smear results come in for a better look with colposcopy. Right now, less than 60% of WIHS women come in for their colposcopy.

More to the WIHS. . . After many requests from women and physicians across the country, the National Institutes of Health (NIH) accepted applications from WIHS sites to expand the number of women enrolled. This new effort will take a closer look at issues related to HAART therapy such as changes in health (viral load, CD4 counts, cervical diseases), long term effects including treatment toxicities, and changes in sexual behavior and pregnancy decisions. If all goes well, we hope to begin enrolling women in Chicago as early as July. Women interested in participating should leave a message at (312) 633-8321. We'll put you on our call back list once we receive funding. How's that for positive thinking !

Feedback on Your Feedback! by Maria Shansky, Research Assistant

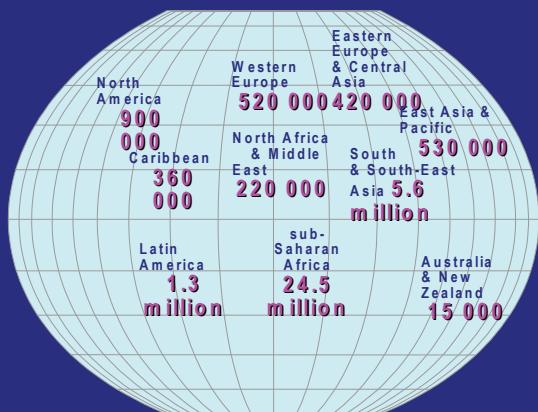
Thank you everyone for taking the time to fill out your feedback forms at your visits. We value your input and do our best to meet your needs. In response to your feedback, here's a few things that are in the works. . .

- In response to many requests for more money, participants are now receiving an additional \$10 food voucher at their visits. In January you'll get to choose a certificate from Jewel, Cub Foods, or Target.
- Many of you have asked for more food or a hot lunch at your visit. We're looking into ways that we can provide a better meal for you.
- Many of you also said the exam rooms were too cold. Unfortunately, The Core Center has a central heating system that can't be controlled individually in each room. But we plan to provide paper slippers to cover cold feet. We'll do the best we can to keep you warm!

A South African Experience: An Introduction to the Global HIV Pandemic

Renslow Sherer, MD - Rush Medical College, The Core Center
Mardge Cohen, MD - Cook County Hospital, WIHS Principal Investigator
Bonnie Lubin, PhD - Hektoen Institute

Adults and children estimated
to be living
with HIV/AIDS as of end 1999



Total: 34.3
million

UNAIDS. Report on the global HIV/AIDS epidemic. June 2000

Extreme poverty is the world's biggest killer and the greatest cause of ill-health and suffering across the globe.[Africans] are confronted by a health crisis of enormous proportions.

Thabo Mbeki, President, South Africa



Poverty the biggest killer:
290 million Africans
live on < than \$1/day

This Activism and Hope poster is on the wall of an elementary school.



People Newly Infected with HIV in 1999

Adults	4.7 million
Women	2.3 million
Children under 15 yrs.	620 thousand
Total #	5.4 million

AIDS Deaths in 1999

Adults	2.3 million
Women	1.2 million
Children under 15 yrs.	500 thousand
Total #	2.8 million

Number of People Living with HIV/AIDS

Adults	33 million
Women	15.7 million
Children under 15 yrs.	1.3 million
Total #	34.3 million

AIDS Deaths since 1981

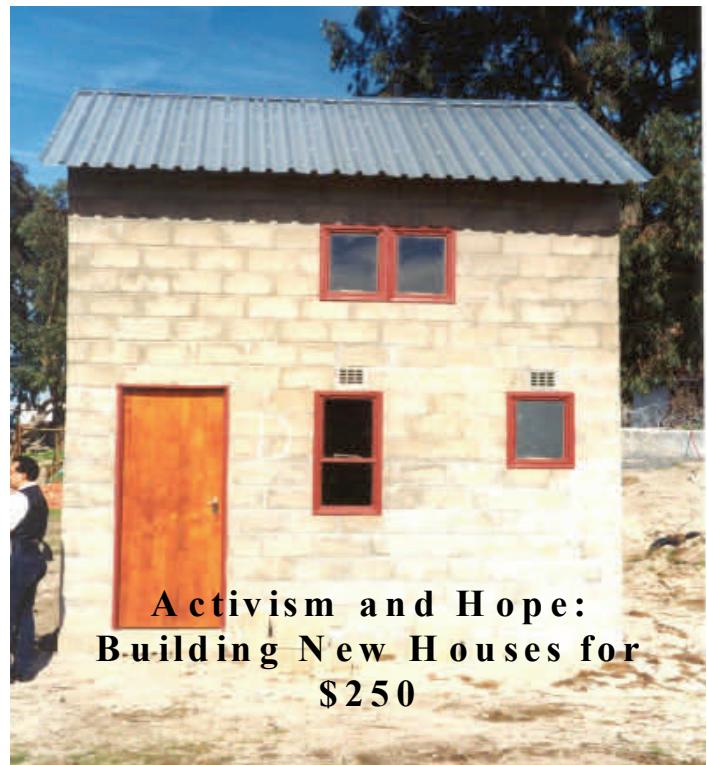
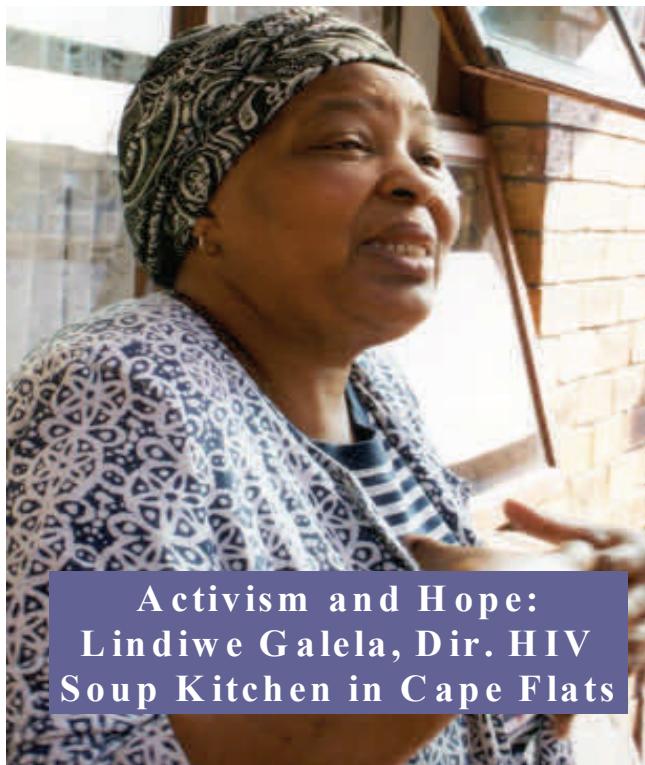
Adults	15 million
Women	7.7 million
Children under 15 yrs.	3.8 million
Total #	18.8 million

Economic, Social and Cultural Realities in Sub-Saharan Africa

- 290 million Africans subsist on less than \$1 per day.
- The majority of people living with HIV seek care from local healers.
- In some areas, condom use is thought of as a practice promoted by whites to diminish Black populations.
- Many countries, and many areas of more affluent countries, lack infrastructure for systems of care, prevention, and education.
- 6 % of women in one cohort were infected solely due to the belief that sex with a virgin will cure HIV.
- In South Africa, 1 of every 2 women has been raped.
- Women who do not breastfeed are assumed to have HIV and are shunned by villagers.
- 5000 babies are born with HIV infection in South Africa every month. At present, the government is declining free Nevirapine to prevent Mother to Child Transmission out of concern for more orphans.

WHAT WILL IT TAKE FOR DEVELOPING NATIONS TO SURVIVE THE HIV PANDEMIC?

- | | |
|------------------|--------------------------------|
| • Resources | Activism and Global Solidarity |
| • Infrastructure | Food |
| • Education | Clean Water and Sanitation |



Letters from the heart.

Want Advice? Need to vent?
Any words of wisdom? Can
you relate?

Hi, my name is Angela and I'm currently at Logan Correctional Center in Lincoln, Illinois. I'm also a participant in the WIHS study. I have done many things as far advocating for women with HIV along with being in various support groups and relapse prevention groups. Being an addict with HIV is a hard thing to deal with on a day to day basis.

When I relapsed, it hit hard. I got no support from my support groups. And, you see, the Department of Corrections does not offer support, or any valuable information on HIV. I came to Logan in July of 1998. I didn't have a problem with telling people my status, although there is still a lot of ignorance to this disease here.

I asked if I could do peer-education at the jail, but I wasn't the right color. When a spot opened up, I was passed up. They had no person of color on this team. Then a woman came from Springfield, and asked me if I would be interested in coming to a support group. I said yes. The first meeting had a few women. I knew there were others because the prison guards would bring HIV meds to our units where everyone can see.

When I approach these women about joining the support group, they were afraid to come. Others were still in denial of their disease. Others didn't want to talk about it. The medical staff didn't want to get involved for

whatever reason. So a year later it stopped.

I wrote to different places but couldn't get the educational materials I needed. All mail first goes to the warden, and the warden didn't want anything to do with this subject.

Then I started getting sick. We had no HIV specialist here and it was hard. I went back and forth to the doctor. I was denied blood pressure medication called Clinidine because of my addictions. I stayed in the health care unit for four days out of the week from January to April of 2000.

I needed information about HIV meds. But they don't have any resources for us down here, and they really don't care. The books that were in the library were taken out. Why, I don't know.

I really thank God for WIHS. Of all the letters I wrote, they are the only ones who sent me the information that I needed and sent me cards too. And I got the chance to get to know Chinwe Oraka. She is truly a blessing.

Down here if you don't have someone on the outside to call, in most cases, you will not get help. But WIHS sent me the information I needed.

Also, I thank Dr. Mardge Cohen for calling. She saw the letters I wrote to WIHS and helped me. After her phone call to Logan, I was finally given proper medical treatment. That's when I found out that I

was being under medicated and my viral load was going up. Then my meds were switched and I was being over medicated.

You see, in prison, they don't tell what to look for and if you don't have your own information you're shit out of luck.

Since I've been here, I have completed a 9-month Gateway program. I'm now in Business Management. I have my certificates. I am currently taking my associates level class, although I will be home before I complete it. But I must thank God for WIHS because they have really been here for me when others haven't.

Through this whole experience, I learned that help was not where I thought it would be. It can come from the most unexpected places and people. I also learned to watch my expectations — which was a painful lesson. I'm healthier and happy. And I know that I'm not alone.

Love,
Angela

announcements from your site. . .

The Core Center / Cook County Hospital

Welcome to our new staff, Kathy Pietrusiewicz and Maria Shansky . . .

Hello WIHS! My name is Maria Shansky and I am a new addition to the Data team. I joined WIHS in early September and am enjoying meeting everyone. Many of you may know my mother, Angela Shansky, who is an interviewer with our program. I am a student currently pursuing Biology at Harold Washington College in the Loop. My office is located in the Administration Building, so I look forward to the Holiday party and the WIHS workshops to be able to mingle with all of the CORE participants. Happy Holidays to All!

Dear WIHS Women, For those of you who have not already met me, my name is Kathy Pietrusiewicz and I am the new Nurse Practitioner for the WIHS program at the CORE Center. I am very excited about my new role and in getting to know each of you. I graduated from the University of Illinois at Chicago last spring and am getting ready to certify in the specialty area of Family Practice. In addition to completing the WIHS exams, I am also following the colposcopies for our patients. So, if you are in need of a colpo and have not been in yet, Amy Berrios, LPN will be contacting you shortly. I am available to all WIHS patients by pager at 312-556-5557 if you should have any questions or concerns about your WIHS visit, colposcopy exam or other health concerns.

Good-bye to Monica Delgado! After five years as part of the Data Management Team, she will definitely be missed by all of us! Congratulations on your new position as a health educator/case manager at The Core Center.

Saturday December 16th, 2000 10AM - 12 PM There will be a Core Center Christmas party! Bring your children for free gifts, food, and fun! For Core Center patients.

Northwestern Memorial Hospital

The address for Gabriella Meredith's office has changed to 680 Lake Shore Drive, Suite 1106, Chicago, IL 60611. The phone number is still (312) 908-2643. The fax number is (312) 908 5820. Patients are still seen in the HIV clinic in the Galter Pavilion.

Rush Presbyterian St. Luke's Hospital

Please remember to fast before your visit, if possible. And thank you to all the women in WIHS for your dedication to the WIHS.

University of Illinois at Chicago (UIC) Hospital

Happy Holidays!

**Express Yourself! Write for Health
WIHS!**

Share your personal stories, poems and other creative work
with WIHS women.

WIHS / Administration Building

**Know Your Body!
Keep a look out for
information that we will
soon be sending you on**

You are invited to . . .

A Holiday Luncheon

to celebrate RESEARCH at The CORE CENTER!

Date: Friday, December 15th

Time: 12 noon - 2PM

Place: The Core Center
2020 W. Harrison St.

The Core Center would like to wish you and your loved ones
a very happy and healthy holiday season. Over the years, we
have truly learned that what we do makes a difference.
Thank you for helping to make a difference.

Please join us this holiday season for a very special
luncheon with raffle prizes, entertainment and
appreciation gifts just for you!

Childcare, CTA passes and parking will be available.
Any questions, please call (312) 633-5720.