

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

# Health WIHS

**Fall 2005**



A patient at the WE-ACT clinic in Rwanda

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## **Women Helping Women in Rwanda: Another World is Possible**

Last year, WIHS Principal Investigators, Dr. Mardge Cohen and Dr. Kathy Anastos, answered an international call by Rwandan women's associations to aid women who had been raped and infected with HIV. Together with other American and Rwandan women and WE-ACTx (Women's Equity in Access to Care and Treatment), they opened an HIV clinic and research project designed to address the needs and issues of Rwandan women who survived the genocide but were infected with HIV as a consequence.

By March of this year, the clinic had treated 900 patients, including 150 men, and more than 400 people have been started on antiretroviral medications or ARVs, as reported in article about the new clinic, "Fighting Genocide's Deadly Legacy," in the Chicago Tribune Magazine.

Earlier this year, at a WIHS workshop, Dr. Cohen talked to WIHS participants about the plight of women living with HIV in Rwanda and the new clinic and research project there. With a slide presentation, Dr. Cohen described the horrific genocide that took place in Rwanda eleven years ago and the ongoing poverty that Rwandans suffer. She explained that nine to ten percent of the Rwandan population is infected with HIV, that's 600,000 to 800,000 Rwandans living with HIV. She talked about a special population of women in Rwanda who were rape victims during the genocide who were infected with HIV ten years ago and are now beginning to develop symptoms and die from AIDS. It is estimated that 250,000 women were raped during the course of the genocide.

But thankfully, there has been a response to this tragedy. Dr. Cohen described the work of Rwandan women's associations and WE-ACTx in setting up an HIV clinic and research project in Kigali, the capital of Rwanda. It was clear that her presentation had made an impact on WIHS women here in Chicago. As soon as Dr. Cohen's presentation came to an end, participants wanted to know how they could help the women in Rwanda.

"We need to send them something from us," someone answers before Cohen can," writes reporter Don Terry in the Chicago Tribune Magazine. "Toothpaste, towels, food. The suggestions start flying. One woman stands and says they should hold a fundraiser. 'We have so much that they don't have. We're some of the blessed women. We should share it.' As these women struggling with HIV in Chicago worried about poor and sick women struggling with HIV in Africa, Cohen didn't say a word. She didn't have to."

Since then, WIHS women have taken the initiative to set up a fundraising initiative called, "The CORE Connection to Africa," to raise funds for people living with HIV in Africa. In these pages, you can learn more about this initiative and the ongoing work in Rwanda, including an article written by Dr. Cohen, Anne-Christine d'Adesky and Kathryn Anastos entitled "Women in Rwanda: Another World is Possible" published in the *Journal of the American Medical Association* (JAMA).

Dear Ladies,

The hand of care is spread out - finally - to Rwanda. How long ago was it that the world knew that there was a crisis in Africa? Now, we're beginning to take responsibility to stem this epidemic. The Chicago WIHS Community Advisory Board has made a commitment to help women and their families living with HIV in Rwanda.

I for one am glad to be making a difference - instead of listening to the problems and knowing about the problems but not doing anything. One of our initiatives, which you'll read more about in this newsletter, is a fundraising program called "The CORE Connection to Africa." Both patients at The CORE Center and staff can donate to this program and all funds raised will go towards helping people living with HIV in Africa.

We're going on eleven years of the WIHS! And we're still stronger than ever. Sometimes I wonder if there are any nooks and crannies left for the doctors and the clinicians to investigate! I just did that MRI thing - and let me tell you it scared me! I didn't know I would get claustrophobic and I wouldn't let the assistant leave the room as I was lying in the big tube. But I was able to listen to music through headphones - which was calming and gave me something to focus on. So, I pulled through!

Personally, I've been taking steps to improve my health. I've been talking about working out forever and I finally took the plunge and called a personal trainer (who I happened to find through another body fat study that

I'm involved in) to help me figure out what I needed to do and to help me stay motivated. When my son moved out, he left me a bench press and weights. I already had a standard exercise bike and an ab cruncher. I've been meaning to make use of them for years. Last month, in July, I finally dusted them off.

I'm making a habit of working out every day. I've only missed four days since July. My work out sessions last anywhere from an hour and a half to two hours. I only saw my trainer twice - but I'm in contact via phone a lot with him. I'm determined to keep with it, which I know is hard to do. But this is something that I'm doing for myself - not for anyone else. The WIHS NCAB is writing an abstract called "Who's in charge: Decisions on how to live healthy with HIV/AIDS." So, I'll be writing about my new exercise regimen.

Lastly, I'm honored and pleased to introduce Veronica Montgomery to all of you as our new NCAB representative. I've known her for fifteen years and she's always been someone special who has been very involved with the HIV community. She's already made such a huge difference organizing fundraisers for The CORE Connection and just bubbling with energy and fresh ideas.

I'm eagerly waiting for the doctors and scientists to come up with one pill a day and no side effects. In the mean time, I wish all of you good health!

~ Marta Santiago  
Chicago NCAB Rep.



Hello Ladies,

My name is Veronica Montgomery, formerly Veronica Brown. I recently married a handsome gentleman from Florida; I met and fell in love with last year on the Alaskan Cruise for positive individuals. I am currently working as a Program Coordinator for Midwest AIDS Training and Education Center (MATEC) here in Chicago. I've worked in HIV/AIDS since 1994 when I was diagnosed. I received my Master's of Public Health in May. I am also a planning council member and advocate for people living with HIV/AIDS.

I have been a WIHS participant since the beginning of the study and am grateful for making the choice to be a part of history. Today, I know that WIHS is one of the 1<sup>st</sup> national studies that are monitoring how the virus is affecting women bodies. The information we are collecting at WIHS will save someone or make someone's struggle a little easier. The project itself has made my life a little easier. I have learned a lot from the WIHS study visits and have decided to stay in it for the long haul. I'm so proud of our Rwanda project. It gives me a chance to help other women like myself struggling with this disease several worlds away. Struggle is struggle, however these women don't have the tools that we have here in the United States and so often take for granted. So that's why it is imperative that we do whatever we can to help them.

I do not expect everyone to do what I am doing. I am doing what God put in my heart to do. I have learned that God gives you dreams that he knows you can attain if you are willing. I am grateful for him seeing me worthy to be used as a vessel to be a blessing to someone else. So that is how I came up with the idea to raise money for the women in Rwanda. To this day we have about \$1500.00 and I plan to raise at least \$1000.00 more before Mardge goes back in September. We're having our "Night at the Races "on August

25<sup>th</sup>, 2005 at Maywood Park. Tickets are \$20.00, \$10.00 of which will go to the WIHS Women in Rwanda. For \$20.00 you get a buffet of Surf and Turf, and an evening of fun.

WIHS participants who would like to help women in Rwanda can give \$1.00 at your study visit. In Rwanda, \$1.00 goes along way. If you want, you can give \$1.00 at your WIHS visit, write a special note, take a Polaroid picture of yourself to send to Rwanda and you can make a difference in someone's life. This would give them something extra to look forward to. We'll send cards for them to write us back. After a while, you will have a friend in Rwanda to share, encourage, and love. These women have been through so much. They have so little and I know we can make a difference. So, if you would like to share in the joy of knowing you helped another "Sista" struggling with HIV/AIDS, please join us in the 'WIHS " Just A Sista Away " project. \$1.00, 1 card, and 1 photo are all it takes.

~ Veronica Montgomery  
Chicago NCAB Representative



# The WE-ACTx Clinic in Rwanda





# THE CORE Connection to Africa

Out of growing concern for people living with HIV/AIDS in Africa, patients at The CORE Center are making a difference. WIHS women came up with The CORE Connection as a way to connect with and support people living with HIV/AIDS in Africa. Through The CORE Connection, WIHS participants — and patients and staff at The CORE Center — can raise funds to go towards the struggle against HIV/AIDS in Rwanda and Kenya.

## How does The CORE Connection work?

You can write letters and take Polaroid pictures at WIHS workshops and WIHS visits to send to Africa.

You can donate to The CORE Connection's matching fund to help support people living with HIV/AIDS in Africa. Every \$1 donated by patients will be matched by \$5 donated by CORE Center staff! You can contribute to The CORE Connection at your WIHS visit.

All the funds raised by The CORE Connection will go to the WE-ACTx Clinic in Rwanda and/or the KAIPPG Project in Kenya.

**WE-ACTx (Women's Equity in Access to Care and Treatment)** is an organization that supports access to HIV treatment for women and girls. They aim to empower women and educate women to confront the challenge of surviving HIV.

**The KAIPPG (Kenya AIDS Intervention and Prevention Project Group)**, a community based volunteer organization located in Mumias, Kenya, is dedicated to preventing and ameliorating HIV/AIDS, poverty, malnutrition and lack of education and healthcare.

## Look at what your donation can provide!

\$5 provides transportation for 10 patients to go to the clinic

\$10 provides minor surgery for 1 patient

\$15 provides morning meals for all patients attending the clinic for one day

\$25 provided one month of anti-fungal cream for the entire clinic

*Checks can be made payable to Hektoen Institute Fund #92451. Write CORE Connection in the memo line. Mail to: Hektoen Institute, 2100 W. Harrison St, Chicago, IL 60612.*

# WIHS Updates to your Research Visit!

## WHAT'S ALL THE HUB? By Angie Shansky, Site Operations Manager

Greetings. . . Just want to talk a little bit about what's been happening before, during and after your WIHS core visits. Visits have been a little longer and we've had the wonderful opportunity of seeing our WIHS ladies more than twice a year. Which is wonderful! Six months is too long to go without seeing your beautiful faces. So we've been loving it!



We're finishing up Visit 22 and getting ready for Visit 23! I'm sure you noticed that the **neurocognitive** component of the interview was administered at your last visit again. Most of you have been very cooperative and have even enjoyed the neurocognitive tasks. Another addition which is very interesting and important is the **physical functioning** component of the visit. We ask you additional questions about your physical activity and abilities. You are also asked to participate in a physical functioning assessment, which measures your grip strength and walk-gait. If time permits a **Mental Health Survey** will be administered. You will be asked some additional questions about your mood and mental health. Women are also making appointments to complete **Mental Health Surveys**. The purpose of these tests is to look at the effects of aging and of the medications used to treat HIV on mental function over time.

Some of you may have noticed additional activity during clinic hours. Women have been coming back to participate in some new sub-studies. By participating in the **Metabolic Substudy** you may learn if you are developing diabetes or osteoporosis. Results from this study may benefit women by providing important clues about the role of diet and physical activity in the health of women with HIV. We also hope to gain knowledge about the effects of antiretroviral therapy on women's metabolisms.

Very soon we will be starting a **Smoking Substudy** that will look at the behaviors of smokers. This is an issue that many WIHS participants have been concerned about — quitting smoking. All WIHS participants who smoke will have the opportunity to participate in this study which will involve sessions with an **interactive computer program** that asks you questions about your smoking. This study will take place here at The CORE Center.



Thank you all for your ongoing participation in the WIHS! If you have any questions or suggestions about your WIHS visits or any of our substudies, please don't hesitate to give Angie a call at (312) 572-4596.

## WIHS Announcements

**Welcome Erica Clift, the new WIHS Assistant Project Coordinator, at The CORE Center.** Erica is originally from Aloha, Oregon, a suburb of Portland. She completed her undergraduate degree in May 2003 at the University of Southern California in Los Angeles with a major in Health Promotion and Disease Prevention Studies. She then moved to Chicago to begin graduate coursework in the Community Health Sciences division at the University of Illinois at Chicago. She recently graduated with a Master's degree in Public Health, concentrating specifically on behavioral sciences and health promotion. Her main public health interests include HIV/AIDS prevention and education, minority health, and women's health issues. Outside of work, she enjoys reading and exercising.

**A big thank you to all of our research interns — Camille Altay, Melanie Andrews, Liza Lichtenfeld, LaMargaret McMiller, and Kari Weber — for all your help this summer.** Good luck in school. We'll miss you!

**Congratulations to WIHS staff person, Kelly MacKenzie and her husband Mike, on the arrival of their baby boy Liam on June 10, 2005!** Kelly has decided not to return to WIHS but rather to stay home with baby Liam in these precious early years. We thank her for her years of helpful service in the WIHS data office. Best of luck, Kelly! Enjoy your growing family. You will be missed!

**Congratulations to Crystal Barnes — now Crystal Winston — on your marriage to Eric Winston on July 16!** We're so happy for you and wish you both happiness and health.

**A reminder to all WIHS women — to show our appreciation for making your appointment on time, we'll give you an extra gift certificate!**

## Cinnamon Raisin Bread Pudding submitted by Marta Santiago

Here's a recipe from the WIHS Cookbook brought to you by Chicago WIHS women. Extra copies of the cookbook are available. Call 312 864-4838 if you'd like an extra copy.

*"This is a delight for anyone who has a year round craving for sweet munchies!"*

1 loaf cinnamon raisin bread	1 egg
15 oz can cream of coconut	1 stick melted butter
10 oz crushed pineapple (drained)	1 tsp vanilla extract
12 oz can evaporated milk	

Preheat oven to 350 F. Spray a 9 x 8 x 2 baking pan with PAM or light oil. Tear bread into 1/2 inch pieces and place in pan. Mix all other ingredients in a blender and pour over bread. Bake uncovered 30-45 minutes or until top does not jiggle.

\* Sneak more fruits into your day with this dessert!

# Health WIHS

**Health WIHS** is a newsletter for, by and about WIHS participants and 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.

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*The purpose of the Women's Interagency HIV Study (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  
Cook County Hospital**  
Mardge Cohen, MD  
Kathleen Weber, BSN  
Angie Shansky, BA  
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(312) 695-1663

**University of IL at Chgo Med Center**  
Ronald Hershow, MD  
Doris Carroll, BSN  
(312) 413-1366

## Coping with HIV: Women, HIV, and Mental Health



Ever feel down or depressed? Or feel like you're just having a hard time coping with life? You're not the only one. It happens to all of us. Come to this workshop for an open conversation about coping with HIV and the special issues facing women living with HIV. Plus, find out what we've learned in the WIHS about mental health and HIV.

**Speakers:** Dr. Judith Cook, PhD, WIHS Investigator  
Rebeka Shephard, Psychiatric Nurse Practitioner  
Kathleen Weber, WIHS Project Director

**Date:** Friday, November 18  
**Time:** 12 noon—2PM  
**Place:** Leona's Restaurant  
1936 W. Augusta (1 block east of Damen)

Lunch will be served. Childcare and CTA passes are available. This workshop is for WIHS participants only. **RSVP by Wednesday, November 16 by calling (312) 864-4838.**