



# Women at the 2006 World AIDS Conference

by Cathy Christeller

HIV positive women agreed: it's time to deliver on women's rights.

Women now account for nearly half the 40 million cases of HIV worldwide. Young women make up sixty percent of 15-24 year olds living with HIV. More than three-quarters of all HIV positive women live in Sub-Saharan Africa, where the epidemic is primarily heterosexual. In Asia and the Caribbean the growing epidemic is changing from drug users (IVDU) and sex workers to women infected by their hus-

bands.

Women's voices were heard loud and clear: speaking on panels, demonstrating, challenging drug companies and governments, and networking. We heard from young drug users, mothers, grandmothers, widows, sex workers, refugees and immigrants. All agreed that the right to HIV treatment, care, prevention, sexual autonomy, freedom from violence and the right to go to school and earn a living are the basic human right of all

women and girls.

Before the conference even started, there was a demonstration calling for universal access to treatment — highlighting the need for affordable generic drugs.

For women  
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Women demonstrating at the July 2006 World AIDS Conference in Toronto, Canada.

## Rejuvenate, Revitalize and Remember: Highlights from the 10th Annual United States Conference on AIDS

By Veronica Montgomery, MPH

Over the past ten years, there has been a revolution in the treatment and care of people living with HIV/AIDS in the United States. Complex treatments have become

available. Now, we're preparing people to understand their choices. And many of us are faced with battle fatigue. For example, one issue that we're dealing with is trying to

manage the side effects of our medications.

We've also learned that living longer and living well is more than medical

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# Women at the 2006 World AIDS Conference

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around the world, the stigma of living with HIV is a huge problem. A young Indonesian woman, Frika Chia Iskandair, spoke at the opening ceremony. She talked about how she was infected from drug use and stressed the need to organize for the rights of people living with HIV/AIDS and to involve young people in our organizing efforts.

Bill and Melinda Gates spoke about the importance of new prevention methods for women including microbicides, vaccines and pre-exposure medication. Women kept saying, “We don’t even have access to the current methods, such as treatment for pregnant women.”

Speakers at the women’s rally talked about the need for sexuality education for youth and for more prevention options. Activists from Africa stressed the need for girls to go to school and for economic rights for women (because lack of food and early marriage puts women at risk). Over and over again, we heard that the Bush administration’s approach to prevention — ABC: Abstain from sex as your first option; Be faithful if you can’t abstain; use Condoms as a last resort) — doesn’t work for young women in Africa. For many women, marriage is what puts them at risk. “I was abstinent and faith-



A group of Indian women who provide HIV testing for women in south India.

ful, and now I have HIV,” many women said.

One powerful voice for women living with HIV is Stephen Lewis, the United Nations Envoy to Africa for AIDS. Lewis continues to be outraged at the toll that AIDS is taking on women. He brought African grandmothers to Toronto to make the world pay attention to their heroic effort at raising orphans with no support. He is calling for a UN agency devoted to ending gender inequality and closed the conference with a call for the UN to appoint an African woman to replace him when he steps down.

While some of us were at the conference, another powerful voice for people living with HIV/AIDS, Zachia Achmat, from the Treatment Action Campaign, was being arrested in South Africa while protesting the lack of antiretroviral treatment for prisoners. His actions bring us to ask what we are doing to challenge the inequalities of care and prevention here in our own country. What about women in the

south, in prison and jail? What about undocumented women with HIV?

We can take action to end the global AIDS crisis by fighting to change U.S. policy, specifically the administration’s abstinence only restrictions and the “war on drugs” imposed by Bush. Women can join the International Community of Women Living with HIV. We can fight for universal access to health-care. We can support women advocates in Africa with our fundraising efforts here. We can become microbicide advocates by getting trained to be a tour guide for the photo exhibit “In Women’s Hands” which shows why women need microbicides. The training will take place at CWAP, 1817 E. 71st St., 1-4PM. Call Minerva at (773) 271-2242 to sign up.

Together, we can make a difference in the lives of women here in the U.S. and around the world.

— Cathy Christeller is the Executive Director of the Chicago Women’s AIDS Project. This article is based on a presentation that Cathy gave at a recent WIHS workshop.



# Rejuvenate, Revitalize and Remember

(Continued from page 1)

care. We need to know the value of sound nutrition. We need to explore alternative therapies — like acupuncture, yoga, massage and herbal therapy— and integrate these into our lives. We’ve also learned that our spiritual well being is critical to our physical well being. And lastly, we’ve learned that we need emotional support and that we need to pay attention to our mental health.

In addition to medical care, our survival strategies have got to address making sure we have a roof over our heads — that we’re able to maintain housing. We need to make sure that we’re able to utilize existing support services. We also need to continue to educate our communities about HIV and AIDS. The youth in our communities need us to have honest conversations about HIV and AIDS.

Women — especially young women— are still becoming infected with HIV. That’s why we need to think about the future of prevention strategies. We need to develop strategies that take into account the economic situation of at-risk women and girls.

We can’t just tell women not to sleep with men, especially if that’s how they’re feeding themselves and their children. We need to consider the educational levels of at-risk women and girls and we need to consider if they have access to care. In other words, prevention strategies and interventions need to be realistic.

*“While we’re living our lives to the fullest, we should remember that we’ve come a long way but we still have not ARRIVED.”*

So, we still need to mobilize our communities and to use the media to get our message across. We need to continue to advocate for care and prevention. We can do this by getting involved with various Community Advisory Boards and having peers lead the way. We’ve also found that telling our stories can create change. It’s an effective prevention tool and it means that we are educating our peers.

We need to take the time to revitalize ourselves by:

- meditating
- Taking long baths
- Using aromatherapy
- Laughing (often!)
- Sharing regularly
- Pampering ourselves
- Doing things for ourselves every chance we get

While we’re living our lives to the fullest, we should remember that we’ve come a long way but we still have not ARRIVED. People living with HIV/AIDS are educators. That makes us unique and powerful. We’re essential to reducing the spread of this disease, and that puts us in a position to change the world!

— Veronica Montgomery is the WIHS Chicago National Community Advisory Board Representative. This article is based on a presentation that Veronica gave at a recent WIHS workshop.

## A SPECIAL THANK YOU TO MARTA SANTIAGO!

For twelve years, Marta has been a National Community Advisory Board Representative for the Chicago WIHS. Marta is one of the women who has been with the WIHS from the very beginning — when it was just an idea! She’s now passing the NCAB torch to others. Thank you Marta for all that you’ve done for women in the WIHS!

Here’s a shout out from Veronica Montgomery, the current Chicago WIHS NCAB Representative. . .

**To Marta, my big sister in the struggle.**

**Thank you for carrying the torch all those years, setting the pace, and showing us how it’s done. We love you. We especially thank you for all the energy and for showing up for us when we couldn’t.**

**We want you to know we hope we can do half the work you’ve done. We’ll keep trying!**



## Notes from Kigali, Rwanda—October 2006 by Mardge Cohen

Dear friends

I've been in Kigali for the past 2 weeks. With the Ronald McDonald Charity Fund footing the bill, the WE-ACTx Family Program staff has completed over 240 visits to families with children with HIV.

The staff usually travel by moto (motorcycle taxis) and then walk over hills along dirt paths to get to homes that are really very far away from both of our clinics. They ask questions about food, shelter, clothes, school attendance and how the children are doing psychosocially. They give each family a voucher to pick up a food package the next time they go to the clinic. *Listening to their stories*, I realized how empathetic the staff is and how moved they were by these experiences.

Most of the children in these families are between the ages of seven and ten years old. Poverty is clearly the biggest issue; half the parents say they won't be able to pay the rent in the next six months, two-thirds of the kids don't have enough to wear and half of them only eat one meal a day. Of the children over the age of seven, one in five is not going to school, usually because there isn't enough money for school fees.

According to their parents, most of the kids take their medications and get along well, and enjoy school. But about 20% are sad, irritable,



don't get along with others and are considered depressed by their parents.

Families are struggling over disclosure. Parents are reluctant to tell their kids they are infected in part because they want to protect them, in part because they don't tell children most things here. They are also afraid of their child's reaction and anger toward them, and the possibility of the child telling others in the community. Strikingly, the counselors tell us that just visiting some of the families has decreased the stigma, as their neighbors see that people are coming to them and caring about them.

I went on two home visits. The first was to a forty year old woman with two children: a five year old daughter with HIV and a fourteen month old whose infection status will be determined in a couple of months. The mother found out she was infected after the second child was born and stopped breast feeding as she

was instructed at that point. The father had deserted the family, and the mother was very worried about supporting the children, both of whom are taking medicines. The older daughter was in her best dress (a pink party dress with Barbie on the front) and smiled at me many times during the interview.

The house was like others I'd been in — dark mud walls, no electricity or running water, or furniture. We sat on mats rolled out on the dirt floor. The mother was thin and very sad the whole visit. When she walked us to our parked taxi — about a fifteen minute walk over hills with an amazingly beautiful view — she told us that it takes about three hours to go down to get water and bring it back to the house.

A thirteen year old girl joined us and directed the taxi driver to the second family, which included herself, her grandmother, and her ten year old sister with HIV.

This house was also very isolated and bleak, with basically nothing in it. The grandmother was talkative and energetic. At seventy-two years old, she talked about feeling strong emotionally and physically as she cared for her daughter's (who had died of AIDS) children. She wanted them to do well in school (we looked at their notebooks) as she had never gone to school, nor had her daughter.

She talked about

## Notes from Rwanda (continued)

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stigma, about transmission, about what a horror this disease was. I asked her how she knew about AIDS in Rwanda, and Africa and elsewhere. And she pointed outside her door and said once in the last couple of years, there was a counselor who talked about HIV and offered testing. Also she said that when she goes to the clinic she learns from the nurses and counselors.

I was moved by this woman's deep knowledge of so many things—a woman who can't read, has no radio, TV, internet. Her thoughts were laced with proverbs and hope, and we talked about starting a grandmothers' group for others like her. She said she'd facilitate the group at the clinic. It takes her over two hours to walk to that clinic where her granddaughter gets her medical care from WE-ACTx staff.

The director of the WE-ACTx Family Program is a Rwandan psychologist. Her parents died during the genocide and she is responsible for her six younger siblings. During a staff meeting, she told a story to explain what multidisciplinary care teams really mean here in Rwanda.

There was a woman, who twelve years ago when she was fifteen years old, was hidden during the genocide by an older man. Things were fine at first, but then he began raping her and continued this until

even after the war was over. She finally escaped. Then ten years later she complained of severe stomach aches and had many tests and treatments, none of which helped. Finally the counselors and psychologists and the medical doctors talked together and things became clearer, and the trauma history was considered in her care.

*"The genocide is always with people here."*

The genocide is always with people here. I've spent more time this visit with Dr. Evode, one of the doctors working with WE-ACTx as we negotiate contracts for antiretrovirals with the public sector and PEPFAR through Columbia University. We have a joke going about how he is related to everyone we run into, either by family, school, or from the RPF military (Rwanda is really a small country).

But one of the times we laughed about someone who really was his wife's cousin, he got quiet, and began talking about his family being displaced to the Congo because of early fighting in Rwanda in



the 1950s and 60s. He was the last of nine children, his mother died soon after he was born, and he was brought up by his sisters, never meeting his father until he was 16. He went to medical school in the Congo. He visited his aunt in Rwanda in 1988 and saw for the first time the hostility. He joined the RPF and during the war he carried heavy loads up and down the hills and hurt his back.

He told me some of the horrible things he saw along the way. All of his aunts and uncles were murdered during the genocide. His wife's family had lots of money and hid in the Mille Collines Hotel. Paul Rusesabagina was not a hero according to Dr. Evode, echoing the current sentiment in Rwanda about this "western-made hero". Dr. Evode has four children now, all under eight years old.

It's pretty amazing that he's on our WE-ACTx team, fighting for ARVs. And then in other ways, it's not amazing at all.

Thanks again for all your support,  
Mardge

P.S. If you live in Chicago, the WE-ACTx Rwandan dolls are in Barneys' window again.

# WIHS Updates and Announcements

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## **ABOUT YOUR WIHS VISIT.....from Angie Shansky, Chicago WIHS Operations Manager**

We are already into the middle of November and I don't know where the time has gone! This could be because we've all been so busy. Research staff have been re-administering Genetics questionnaires, although some of you are doing this for the first time. It's the questionnaire that asks you all those questions about your family tree. Researchers want to know whether genes (a gene is a set of instructions each cell carries that you have inherited equally from your mother and father) are associated with mood, the stress response and risk for drug dependence, including alcohol, street drugs and tobacco, play a role in depression and/or worsening of HIV disease. Pretty interesting! Many of you are doing this at your core WIHS visit, which is really appreciated. Thanks to everyone involved. Some of you returning smokers are now doing 2nd and 3rd visits with the CES (Computer Expert System). We are trying to accommodate you and have been administering this study also during your WIHS visit. We have had some reported successes. We are still gathering the data. More to come, so stay tuned. We are continuing to screen participants for varied neurological testing that we are participating in. Some women who participated in the Cardiovascular substudy are being asked to come back for a second scan of their carotid arteries. We also want to commend all the women who are having their much needed colposcopies. The colpo staff is doing a tremendous job. Everyone keep up the good work. We have been busy, WIHS participants have been busy. Thank you so much for your participation. Your dedication and hard work continues to make the WIHS the incredible program that it is.

## **Goodbye!**

Dear Ladies, Can I say how great it has been to work with all of you for the last eleven years! In January, I'll be moving on to another position, but I wanted to let you know that I'm so grateful for having had the opportunity to get to know and work with all of you for all these years. Your participation in the WIHS is making a difference (more than you know!) I'll miss seeing all of you at the workshops, but I know that our paths will keep crossing!

Lots of love, Alice Kim

## **“Portraits: Stories of Hope and Survival”**

### **A project of What Will It Take? Building the Safest State for All Women and Girls**

Submit your story to this special project, “Stories of Hope and Survival.” By telling your story, you can help break the barriers of silence that women and girls often face, especially those who have experienced violence. Submitted stories will be considered for publication in a book of essays and a special performance. Submissions must be about violence against women and girls, and they must have an anti-violence message; 3-5 double-spaced pages with 12 point typeface; include a brief biography or resume; and specify the writers' name, race or ethnicity, age, address, email and all phone numbers.

Submissions to “Portraits must be received by December 31, 2006 at [stories@cfw.org](mailto:stories@cfw.org) or mailed to Ms. Hesa Duncan, Portraits Director, Chicago Foundation for Women, 1 E. Wacker Dr., Suite 1620, Chicago, IL 60601 postmarked by December 31, 2006.

Visit [www.cfw.org](http://www.cfw.org) for more information. If you want help writing your essay, call Angie at WIHS, (312) 572-4596 and we'll do our best to help you out.

## **25 Years of HIV/AIDS: Local and Global Steps for Action**

Speakers include: Cathy Cohen (University of Chicago), Keith Green (Black Gay Men's Caucus), Debra Fleming (Local HIV Activist), and Mardge Cohen (The CORE Center and WE-ACTx).

Tuesday, December 5 at Roosevelt University, Congress Lounge, 430 S. Michigan Ave.

Reception from 5:30pm-6:30pm and Panel from 6:30pm-8:00pm

## WIHS Chicago 2006 Publications

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Thanks to all the WIHS women, Chicago investigators have been able to publish the following findings about women and HIV.



**Al-Harathi Lena**, Voris J, Du W, Wright D, Nowicki M, Frederick T, Landay A, Kovacs A. **Evaluating the Impact of Hepatitis C Virus (HCV) on Highly Active Antiretroviral Therapy-Mediated Immune Responses in HCV/HIV-Coinfected Women: Role of HCV on Expression of Primed/Memory T Cells.** *Journal of Infectious Diseases* 2006; 193(9):1202-10. Epub 2006 Mar 17.

**Cook Judith A**, Grey DD, Burke-Miller JK, Cohen MH, Anastos K, Gandhi M, Richardson J, Wilson T, Young M. **Effects of Treated and Untreated Depressive Symptoms on Highly Active Antiretroviral Therapy Use in a U.S. Multi-Site Cohort of HIV-Positive Women.** *AIDS Care* 2006;18: 93-100.

**Massad L Stewart**, Evans CT, Minkoff H, Watts DH, Greenblatt RM, Levine AM, Anastos K, Young M, Seifer DB, Golub E, Cohen M. **Effects of HIV infection and its treatment on self-reported menstrual abnormalities in women.** *Journal of Women's Health* 2006;15:591-8. PMID: 16796486



**Burke-Miller Jane K**, Cook, JA, Cohen MH, Hessol, NA, Wilson, TE, Richardson, JL, Williams P, Gange, SJ. **Longitudinal Relationships Between Use of Highly Active Antiretroviral Therapy and Satisfaction with Care Among Women Living with HIV/AIDS.** *American Journal of Public Health* 2006; 96(4):1044-1051.

**French Audrey L**, Evans CT, Anastos K, Greenblatt RM, Huebner R, Augenbraun M, Young M, Hershov R, Lopez-Gatell H, Passaro DJ. **Incidence of Tuberculin skin test conversion among HIV-infected and uninfected women: results of a 6 year study.** *Journal of AIDS* 2006;42:592-596.

**Spear Greg T**, Alves M, Cohen M, Bremer J, Landay A. **Relationship of HIV RNA and Cytokines in Saliva and Plasma from HIV-infected Persons.** *FEMS Immuno/Micro.* In press.

French Audrey L, Operskalski E, Peters M, Strickler HD, Tien PC, Sharp GJ, Glesby MJ, Young M, Augenbraun M, Seaberg E, Kovacs A. **Isolated Hepatitis B Core Antibody is Associated with HIV and Ongoing but not Resolved Hepatitis C Infection in a cohort of US Women,** *AIDS.* In press.



If you'd like a copy of any of the following articles, please call (312) 864-4853.





## HEALTH WIHS

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

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

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

Mardge Cohen, MD  
Kathleen Weber, BSN  
Angie Shansky, BA  
Karlene Schowalter, NP  
(312) 572-4596

### Rush Presbyterian-St. Luke's

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

### Northwestern Memorial Hospital

Sarah Sutton, MD  
Donna McGregor, MSN, ANP  
(312) 695-5063

### University of Illinois

Ronald Hershow, MD  
Doris Carroll, BSN  
(312) 413-1366

We're on the web!

<https://statepiaps.jhsph.edu/wihs/>

## 2006 WIHS Holiday Luncheon

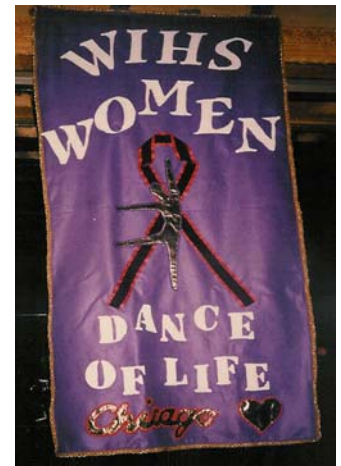
Let's celebrate another year of the WIHS this holiday season. Please join us to enjoy good food, a raffle, appreciation gifts and each other's company!

Date: Friday, December 8

Time: 12 noon—2:00pm

Place: Connie's Pizza

2373 S. Archer Ave. (east of Halsted, south of Cermak)



To RSVP, please call (312) 864-4838 by Wednesday, December 6. WIHS participants are invited to bring one guest only. Childcare and CTA passes are available.