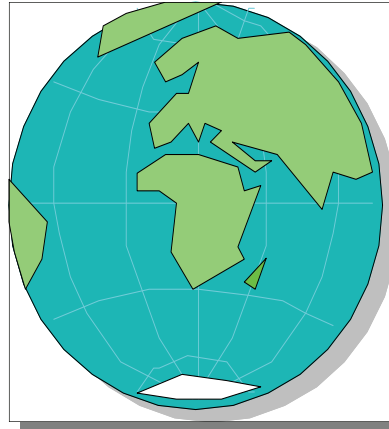


# Health WIHS

Summer / Fall 1998



**“We hope to be a bridge between the optimism HAART (highly active anti-retroviral therapy) proclaimed two years ago, and the immense scale of the pandemic. . . .”**

— Bernard Hirschel and Robin Gorna,

## Bridging the Gap: The 12th World AIDS Conference

***The slogan for the 12th World AIDS Conference in Geneva, Switzerland this past July was “Bridging the Gap.”***

As studies revealed the devastating nature of the AIDS epidemic in the developing world and the lack of resources made available to treat the growing number of people infected with HIV, the conference served as a vehicle for international communication, advocacy and networking.

“We hope to be a bridge between the optimism of HAART [highly active antiretroviral therapies] proclaimed two years ago, and the immense scale of the pandemic, which will be the focus [of the next international AIDS Conference] in Durban [South Africa] in 2000,” said conference organizers Bernard Hirschel and Robin Gorna.

The conference was organized along four tracks: 1.) Basic Science, 2.) Clinical Science & Care, 3.) Epidemiology, Prevention and Public Health, and 4.) Social and Behavioral Sciences.

Within these tracks the conference focused on Gender, Policy, Youth, and Human Rights issues. In general, the conference attempted to address concerns in both resource-rich and -poor areas of the world.

For example, several sessions addressed the prevention of mother-to-child HIV transmission including special attention to several relatively low-cost interventions.

**The Women’s Interagency HIV Study (WIHS), representing the largest cohort of women studied in the U.S., contributed 25 presentations to the**

### **AIDS UPDATE**

(through 1997)

- Worldwide, 30.6 million people are infected with HIV.
- In North America, 860,000 people are infected with HIV.
- In the U.S., 641,086 people are infected with HIV.
- In the U.S., the occurrence of AIDS-defining illnesses and deaths has dropped by 25 percent.
- In Sub-Saharan Africa, 21 million people are infected with HIV.
- In South & South-east Asia, 5.8 million people are infected with HIV.
- Since the beginning of the epidemic, 11.7 million people have died of AIDS-related illnesses.

Conference.

Ten of the WIHS presentations were prepared by Chicago investigators. (See pages 4 - 5 for a detailed report ). WIHS researchers and peer representatives participated in an important exchange of ideas and research.

At the same time, controversy over “how to bridge the gap” was visible throughout the conference. Protesters calling for an African Solidarity Fund and greater access to HIV treatments in developing countries interrupted the conference a number of times during the week.

Touched by the stories of representatives from the developing world and the staggering statistics reported at the conference, many delegates supported the spirit of the protests.

### **INSIDE: A Special Report on the 12th World AIDS Conference . . . .**

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## 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.

If you have a personal story, poem or any other creative work that you would like to share with readers of Health WIHS please submit to:

**WIHS - Cook County Hospital**  
1900 W. Polk St., Rm. 1246  
Chicago, IL 60612

We reserve the right to edit all submissions. 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.

Questions and comments are welcome.  
Call Alice Kim, Newsletter Editor,  
at (312) 572-3741.



### 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:

Cook County Hospital  
(umbrella site for Chicago)  
Mardge Cohen, MD  
Audrey French, MD  
Kathleen Weber, BSN, Project Director  
(312) 572-3740

Northwestern Memorial Hospital  
Patricia Garcia, MD  
Gabiella Meredith, RN, Site Coordinator  
(312) 908-2643

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

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

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## The 12th World AIDS Conference: A Wake-

**AIDS has become a disease that strikes the world's poor.** This was an unmistakable conclusion of studies released at this year's World AIDS conference.

In the U.S. and Western Europe, less than one percent of the population is infected with HIV, and the number of deaths from AIDS each year has continued to drop.

But the picture is very different in poor areas of the world. Of the 30.6 million men, women and children infected with HIV, 90 percent live in the developing world.

### **1 IN 4 INFECTED IN ZIMBABWE**

In the African countries of Zimbabwe and Botswana, up to one-quarter of the adult population is infected. Life expectancy in Botswana has dropped from 68 years into the mid-40s.

AIDS is hitting Africa so fiercely that researchers say it rivals the Black Death of the Middle Ages — epidemics of the bubonic plague which wiped out one-quarter of Europe's population.

These facts contributed to a sober mood at the conference — especially in contrast to the last international conference held two years ago in Vancouver, British Columbia.

Then, researchers presented study results which showed that protease inhibitors used in combination with earlier treatments suppressed the presence of HIV in the body. The mainstream media even began to talk about "the end of

AIDS."

### **16,000 NEW INFECTIONS EVERYDAY**

With nearly 16,000 new infections occurring every day — a new person contracts the virus every five seconds — the AIDS epidemic is far from over. The full combination of anti-retroviral therapy costs about \$15,000 a year. Compare this figure to the \$10 per person spent on health care in countries like Kenya. Clearly, these treatments are not affordable for the overwhelming majority of those infected with HIV.

Even in advanced countries like the U.S., there are big gaps in who gets the drugs that fight HIV. **National studies conducted by WIHS showed that African American and Latino women were less likely to be taking the most advanced medications.**

On top of that, women remain the fastest growing population of people with HIV while AIDS is becoming a leading killer of African Americans. It is no coincidence that women, especially poor women, as well as African Americans do not have access to decent healthcare.

While 11.7 million people have died of AIDS related illnesses, pharmaceutical companies continue to make enormous profits off the exorbitant costs of the drugs.

### **TREATMENT FOR ALL**

AIDS treatments should be made available to all who

# “The Geneva Experience”

by Marta Santiago, Chicago NCAB Representative

**Hello Ladies,**

I would like to take this opportunity to share with you my experience at the World AIDS Conference in Geneva, Switzerland.

What stands out in my mind is all the different people that I was able to meet from all over the world — especially those who were from developing countries.

I learned that we in the United States have access to treatments, education and resources that many people from poor countries only hear about — if that.

I met a PWA from Mexico who told me that there was still nothing for people with HIV in his home town just outside of Mexico City.

A woman from India told

***“I learned that we in the United States have access to treatments, education and resources that many people from poor countries may only hear about — if that.”***

me that little girls were being sold into marriage by their parents who were so poor they felt they had no other choice. If she became infected with HIV — most likely by her husband — she would be ostracized by the community and returned to her original family once she showed any signs of illness.

In many African countries there is no money for any kind of treatments or even HIV testing. Delegates from an African country told me that they felt lucky because they could afford to offer a little education and counseling. They

were more than happy to take copies of our newsletter to distribute in their communities. (*Health WIHS* was passed on to AIDS advocates in Israel, India, the United Kingdom, and Africa!)

**I presented a poster presentation at the conference about the WIHS National Community Advisory Board. It was called, “Personal Stories of Women Infected and Affected by HIV in the WIHS National Community Advisory Board.”**

The presentation told the stories of women living with HIV whose lives had been transformed by their experience advocating for other HIV positive women.

What really moved some of the observers of the presentation were the photographs of women on the NCAB who had been living with HIV for over ten years.

I believe that this presentation gave a message of hope to women all over the world — that their lives could change for the better.

At the conference, there was an atmosphere of openness — that’s for sure. Each morning of the conference, I felt eager to learn and meet more people — even though it took me a cable car, bus and a train ride to get to the convention site.

But I made use of this travel time to talk to other participants of the conference who had to travel the same as me. The conference opened my eyes to all the things I have taken for granted in my life here: my job, my doctors, my medication, my car and everything.

I look at what I have and what I do not have and realize that there’s so many others who don’t have even the basics.

I think of it like this. I may have problems with my plumbing but I have water. In a lot of other countries, people don’t even have water!

***“The conference opened my eyes to all the things I have taken for granted in my life: my job, my doctors, my medication, my car,***

**All this has made me realize that I have a lot to be grateful for AND that we still have a really long way to go.** How many more people will become infected? We already are experiencing 16,000 new infections every day! In some places in Africa, one out of every four people are infected!

The pressure is on. The next International AIDS Conference is going to be held in South Africa in the year 2000. We need to strive for another breakthrough by the time of this conference. The last breakthrough was protease inhibitors. Now, we need to get the medications to everybody. Personally, I feel that there is hope.

**One of the girls,  
Marta Santiago  
Chicago NCAB Rep.**

# CHICAGO WIHS at the 12th WORLD AIDS CONFERENCE!

Here are summaries of the abstracts presented by Chicago investigators. . .

## Child Care Arrangements of Children Whose Mothers Have Died of AIDS

This study looked at the current living situation and custody status of children whose mothers were deceased participants of the WIHS in Chicago.

Between March 1995 and January 1997, 24 HIV positive participants who had children under 18 years of age died, leaving a total of 53 children.

Half of these women (50%) were African American, 42% were white, and 8% were Hispanic. The majority of these women were single, had an average household income less than \$1000/month, and had some history of using crack, cocaine or heroin. Less than one-third of these women did not have a high school education. The average age of the women at death was 36.3 years.

The large majority (91%) of children resided with family members. For nearly half of these children, grandparents had become their primary caregiver. The remainder were divided fairly evenly among grandparents, biological fathers and aunts or uncles.

Only 9% of children were with non-family members and 4% were in foster care. Less than 25% of these arrangements were formalized through legal procedures prior to the mothers' deaths. In this sample, grandparents in particular kept their families together and prevented the orphans from entering the child welfare system.

In conclusion, formalized planning may assist HIV+ mothers

in arranging optimal future care for their children. Many grandparents and family members may also require local, state and federal resources to assist them in raising children who have lost their

## Sources of Dissatisfaction with Health Care Among HIV+ Women in the Chicago WIHS (Jane Burke, M.S.)

mothers to the AIDS epidemic.

The purpose of this abstract was to identify any reasons why women in the Chicago WIHS consortium who are HIV positive may be dissatisfied with the health care they are receiving.

Results showed that 47% of the women were dissatisfied with their ability to get health care; 28% of the women were dissatisfied with the quality of care they were receiving; and 59% were dissatisfied with their interactions with providers.

The particular health care site (e.g. public hospital vs. private hospital) was related to dissatisfaction with ability to get health care. Employment and depression were factors related to dissatisfaction with the quality of care. Depression was also related to dissatisfaction with provider-patient interactions.

The results suggest that various factors influence patient satisfaction or dissatisfaction with HIV care. Also, the quality of the provider-patient interaction appears to be an important aspect of patient satisfaction.

In conclusion, identifying the sources of dissatisfaction and factors related to dissatisfaction could help to improve care for women living with HIV.

## Adherence with Colposcopy Among Women in the WIHS (Helen Cejtin, M.D.)

This abstract looked at factors related to why women in WIHS do not show up for their colposcopy exam.

The results showed that 300 of 450 women (67%) showed up for their colposcopy exam. Of 394 women who were HIV positive, 259 women (66%) showed up for their exam. Of 56 women who were HIV negative, 41 women (73%) showed up for their exam.

Viral load, CD4 count, disease stage and use of antiretroviral therapy did not affect whether or not HIV+ women showed up for their exam. Women who reported crack or cocaine use; were unable to seek medical care due to illness; or experienced domestic violence were more likely to miss their exam than women who did not experience these events.

Women who were actively recruited by WIHS staff or who indicated concerns about not being able to take care of their children were more likely to come to their colposcopy exam. Signs of advanced HIV disease and therapy did not significantly affect the rate that women showed up to their exam. However, chemical dependency and domestic violence seem to be factors related to why women do not show up.

Supportive study personnel and concerns about raising one's children appear to be positive factors related to adherence with research-related procedures like colposcopy.



Ten researchers from the Chicago WIHS presented abstracts at the Geneva Conference. The research presented used data collected from your WIHS visit. Once again, the WIHS would like to extend a big THANK YOU to

**Penetrance of Combination Antiretroviral Therapy into the WIHS (Mardge Cohen, M.D.)**

This abstract described the ways in which combination antiretroviral therapy is used by women in the WIHS who are HIV positive.

Combination antiretroviral therapy means taking more than one drug to treat HIV infection. It is currently the best available treatment for HIV/AIDS. Combination anti-retroviral therapy includes combinations of AZT, ddC, d4T, 3TC, ddI or the new Protease Inhibitors.

Results showed that the use of monotherapy (one-drug treatment) declined while the use of two- and three-drug combinations increased as the study progressed. The use of protease inhibitors (PI) increased from 1% at the beginning of the study to 31% by the end of Year Two.

Many women reporting PI use had CD4 counts under 200. Women reporting PI use also tended to have higher incomes, health insurance, fewer symptoms, and more education. On the other hand, women who were African American or used IV drugs were less likely to report PI use. Also, women who used outpatient health services were more likely to use combination therapy than women who used the emergency room.

In conclusion, women who are HIV+ are taking combination antiretroviral agents. Women who are poor, do not have health insurance, use IV drugs and are African American are less likely to use combination antiretroviral use. Understanding the rate at which new treatments are used and what factors affect use may enhance women's likelihood of receiving the best care.

**Predictors of Combination Antiretroviral Therapy Use in WIHS (Judith Cook, Ph.D.)**

This abstract looked at the national WIHS data to see if HIV positive women who take combination antiretroviral therapy are different from HIV positive women who do not.

We specifically looked at differences — other than level of sickness — between women taking the combination therapy and women not taking combination therapy.

The results showed that almost half of the HIV positive women (46 percent) in the national WIHS cohort reported taking combination antiretroviral therapy. Results also showed that women who had fewer doctors visits, more emergency room visits, were of a minority race/ethnicity, or used injection drugs were less likely to be taking combination therapy than other women.

These results point out that there are identifiable groups of women who are not receiving the best available treatments for reasons other than how sick they are. In particular, better access to these treatments are needed for minority women and for those who use injection drugs. Better access is also needed for women who do not have regular health care access (those with fewer doctor visits and more Emergency Room

**Association of Vitamin A Deficiency with Cervical Dysplasia (Audrey French, M.D.)**

visits).

There are conflicting reports in the medical literature about whether low levels of vitamin A are associated with Pap smear

**Health WIHS**

abnormalities and cervical cancer.

To look into this question, we measured vitamin A levels in women from the Chicago WIHS. We found that 19% of the women had low levels of vitamin A in their blood and 14% had abnormal Pap smears. Having an abnormal Pap smear was associated with a CD4 count less than 200, a detectable viral load, having human papillomavirus infection (the virus that causes genital warts) and vitamin A deficiency.

We will be looking at this association in more WIHS women to see if we can confirm the results of this small study.

**Factors Associated with Sexual Abstinence in the Chicago WIHS (Alice Kim, M.A.)**

In this abstract, sexual abstinence was defined as not having had a sexual encounter for the six months prior to a WIHS participant's study visit.

The first part of this abstract looked at how many Chicago WIHS HIV positive women said that they were sexually abstinent. To see if there were changes over time, data from Visit 1 and Visit 5 were compared. At Visit 1, 33% of HIV positive women (92 out of 279) reported sexual abstinence. At Visit 5, 38% of HIV positive women (72 out of 189) reported not having sex.

The second part of the analysis looked at what characteristics of women were related to not having sex. Results showed that women with AIDS, depression and a poor quality of life were less likely to have sex. Women who were not using hard drugs were less likely to have sexual encounters.

The third part of this abstract reported what Chicago WIHS women have said about not having sex in letters to the newsletter and in discussion groups. The following feelings were said about not having sex: empowerment, independence, contentment, sexual dissatisfaction,

*(Continued on page 8)*

# *Personal Stories of Women in the WIHS National Community Advisory Board (NCAB)*

*A poster presentation at the Geneva Conference.*

**MARTA SANTIAGO,  
CHICAGO**

"When I first learned of my status in 1989, I also acquired anonymity as a big part of my newly found life. I felt the need to shield myself and my son (now seventeen years old!), who is also infected with HIV, from the many closed-minded people that were and still are stigmatizing people who are HIV positive.

"In November of 1992, I was asked to join the WIHS NCAB and did so under the alias of Sonia Ruiz. This name was conjured up in 1990 soon after I learned of my status. I stuck with this name until December of 1996. I had reached a point where I felt I could not handle the duo — Sonia, my HIV positive face, and Marta, my nobody knows face, — anymore.

"I needed a cleansing and my assumed name was the first thing on my list that needed to go. The women of the NCAB helped me through this process. I have heard their personal stories — how they have helped themselves and other women. The NCAB has been one of my routes to a healthier life. **The NCAB has helped me come to terms with HIV and Marta as one and the same.**"

**ELISA SANCHEZ,  
LOS ANGELES**

"I have been in the WIHS since it first started in 1994. I just went for my eighth visit. I'm now the NCAB advocate for the Southern California Consortium.

"This study has helped me to understand a lot about HIV and AIDS. Access to education that could help me live longer was my main reason for joining the WIHS. I have a large family that I love dearly, and I feel that I need to help find a cure for the children of the future.

"That's why I do as much as I can to educate others. I do HIV public speaking in my area, and I assist in facilitating a

**AMIRAH WALEED,**

heterosexual support group with a focus on drug use and HIV at the American Recovery Center."

"I have been living with this virus for nine years. I'm a peer educator for Life Force Women Fighting AIDS. I go out to jails, clinics and drug programs

to educate my community on HIV prevention. I run a support group for people with AIDS for women of color called 'Sister to Sister'.

"I have also been part of this study from day one. I was one of the Bronx site's first participants. I started going to their meetings and became the local CAB chair, then I became their alternate on a national level. From there, I was voted in as their voting member and now I'm the co-chair on the National CAB. The WIHS has given me so much

**MAUREEN DEELY,**

information about HIV and what's going on with my body."

"At first, the thought of being in a 'study' made me think of scientists ghoulishly looking at my blood and tissue and not caring about me, my thoughts, feelings, beliefs, past experiences, present or future goals. I was proven wrong.

"As a member of the NCAB and current chair of the NCAB, I have learned that the researchers and doctors care about the women in the study. They listen when we speak. We remind them of things they either totally didn't think about or had put aside for 'later thinking.' We remind them later is now. And they listen.

"We tell them what can and cannot be tolerated by us physically and emotionally, what we think should be studied and they listen. We are living with this disease, and we are affected by this disease. We want to know

*(Continued on page 7)*

## Health WIHS

When my doctor would tell me information about my HIV status, I used to accept whatever he told me. In 1996, I got involved with the WIHS NCAB. Through the years of being with the NCAB, I have learned

CAROL SIPOREN,

how HIV affects a woman's body, how to educate and advocate for myself and other women who are HIV+ or at risk."

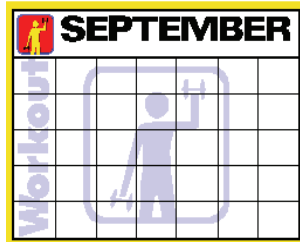
"For three years, I struggled with how to tell my children that I have the virus. Now I help other women figure out how to tell their families. Life has been full of surprises in the last seven years. I just turned 50, got a boyfriend, and now I'm a grandmother!

"Today I am also one of two co-chairs for the WIHS NCAB. I am a staunch member of the Endocrine Working Group, and guess what we are still trying to find out? The effect of HIV on the endocrine system of women, Hormone Replacement Therapy and HIV,

# WIHS Workshop:

## Nutrition & Exercise:

What can you do to improve your health?



**Friday, September 25th at 11:30 AM**

**Leona's Restaurant**  
1936 W. Augusta  
(just east of Damen)

All WIHS participants are welcome! A lunch buffet is provided. Childcare is available. Please call (312) 572-3741 by Wed, Sept. 23 to make your reservation and for childcare.

*(Continued from page 6)*

JACQUELINE SMITH,

why certain things are happening to us and our loved ones. I believe in changing the system from within — finally, someone is listening."

"Originally, I enrolled myself in the WIHS to give something back to society. When I was diagnosed with HIV, I was using drug, selling myself, and never practicing safe sex.

"Through the WIHS, I became involved with the NCAB and since then, I have learned how to advocate for myself and others. I have become more involved with community-based organizations, gaining as much knowledge as I possibly can and passing it on to other women and people in my community."

KIMBERLY KELSEY,

"In 1995, I made up my mind that I was going to start taking charge of my life and get educated about HIV/AIDS. I started reading the information in the waiting rooms.

NILDA RODRIGUEZ,

menstrual irregularities, and the adrenal system and the metabolic system. Being on the NCAB helps me to stay in the forefront of women-specific research."

"I was diagnosed HIV+ in 1988. My passion is to work with women of all ages who are HIV+, to show them there is life after HIV.

"As a Spanish-speaking Latina, I have been a part of both

participation on the NCAB has transformed and enhanced their lives.

Through the NCAB, some of these women have learned to advocate for themselves and others; some have been able to overcome lives of anonymity, isolation and addiction; and still, others have been able to defeat feelings of fear, hopelessness and powerlessness.

In conclusion, CABs can empower individuals and ensure that a study remains responsive to the needs of its target population. By building knowledge and solidarity, the WIHS NCAB has helped women become advocates for themselves and other women

### **HIV Research and Women: What Influences Attrition? (Kathleen Weber, BSN)**

infected with and affected by HIV.

This abstract looked at what factors are related to women in WIHS missing their visits or leaving the study. Of 2,412 women, 348 women (14%) were lost to follow-up. Lost to follow-up meant missing two or more visits in a row or being disenrolled from the study.

The results showed the following: women who were HIV negative; had not participated in any research studies before WIHS; reported crack, cocaine, heroine or injection drug use; did not have a primary care provider when they enrolled in the study; and had higher viral loads showed a higher rate of loss to follow-up than other women.

Even though retention rates in the WIHS remain high (86%), identifiable behaviors and characteristics may predict why women in WIHS miss visits or leave the study. These include chemical dependency, advanced disease, no primary provider, and no prior research experience.

Interventions and retention strategies for participants with these characteristics may improve the rate of follow-up in studies of women with HIV infection.

*(Continued from page 5)*

low self-esteem and loneliness.

In conclusion, providers should be aware of how sexual abstinence is an important part of women's lives, and is related to their physical and emotional health. More studies on sexual abstinence may improve women's treatment.

This abstract looked at the relationship between brain

### **Neurocognitive Function Predicts Employment Status in HIV+ Women (Eileen Martin, Ph.D.)**

impairment and employment in the Chicago WIHS cohort. Of 101 women, the results showed that HIV+ women and 8% HIV - women displayed signs of brain impairment. Only 4% of HIV+ women with brain impairment were currently employed compared to 25% of HIV- women and 26% HIV+ without brain impairment.

No significant difference was found in a comparison of CD4 counts, educational levels, and the rate of use of antiretroviral therapy between HIV+ women with brain impairment and HIV+ women without brain impairment. Similarly, rates of substance abuse and depression were very high but did not differ significantly between these groups.

In conclusion, brain impairment

is more likely among HIV+ women than HIV- women, even though both groups show high rates of depression and substance abuse. Brain impairment seems to be a stronger predictor of current employment status than disease progression, although further research is necessary.

### **Personal Stories of Women Infected and Affected by HIV in the WIHS National Community Advisory Board (Marta Santiago, NCAB Rep.)**

The NCAB is made up of representatives who volunteer their time to provide input into developing the WIHS research agenda and serve as the study's link to the HIV affected community at large.

NCAB representatives are active in all levels of the study including participation on all working group conference calls and the Executive Committee meetings. The NCAB also has its own monthly calls and semi-annual meetings to discuss the study protocols and ensure community access to research results.

In achieving our goals, the WIHS NCAB has served as an engine of growth, change and healing for the women who have participated on it. Stories of NCAB representatives illustrate the ways in which