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Health WIHS

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A Tribute to Gigi Nicks: Chicago NCAB Representative

By:
Mardge Cohen

Gigi was a dear friend, patient, colleague, WIHS participant, mother, sister, NCAB member and community advocate. Gigi's contributions to the Women and Children's Program, to WIHS and to the HIV/AIDS community at the CORE Center, in the city of Chicago, and nationally through the AIDS Alliance are far-reaching.

I first met Gigi when she came for care at the Women and Children's Program in the early 1990s. Like many others, she had no health insurance, she didn't really believe her diagnosis, and she felt unsupported and dumped by the physicians she'd seen already. After several appointments, she told me straight out that she could run the office of our program in a much better way than it was being run at that time, and I was ridiculous for waiting one more day to hire her. We hired her in December 1991, and things spiraled upward and outward from there.

She was not the kind of person to stay behind a desk answering phones. She assumed an advocacy role almost immediately as she sought her own support in the weekly support groups, and then mentored other women. With more resources, Gigi became the full time Title IV funded Women and Children's Consumer Advocate. She also helped train and mentor peers in the Maternal Child Health HIV Integration Project, a Special Project of National Significance (SPNS) in the late 1990s. She joined the Board of the AIDS Policy Center for Children, Youth and Families, formed by women and children's Title IV programs all over the country in 1994 as one of the first participating consumers. She was in the first graduating class of the AIDS Policy Center's National Leadership Training Corp in 1999. She also participated in the first Title I Planning Council and many other city projects and groups as well as the local Family Children AIDS Network (FCAN) Board. And as the CORE Center Consumer Advocate for the past 6 years, she was always in some one's face, juggling a very complicated role.

Gigi was a passionate and outspoken advocate for people living with HIV. She was strong and loud and determined to live a healthy and productive life as she courageously fought her own HIV, and moved others to do the same. Some people are convinced that the antiretroviral medications she took so consistently are responsible for her death. They certainly weren't. They did dramatically reverse the course of her HIV infection but they were not responsible for her death. The leading cause of death in women is heart disease, and that is what Gigi died from. I certainly wish she hadn't, but we all have to learn more and do more to prevent others from succumbing to this disease as well. Gigi would want that.

Gigi had a booming voice, an incredible speaking style and a fearless spirit. We argued over how to pursue internal and external politics regularly. She told me to calm down and I told her to keep going—with her gardening, her out of town meetings and speaking engagements. She was truly a mentor and a role model for many of us. It is hard to imagine continuing our work without her. We will miss her tremendously.

Dear WIHS Oral Participants,

Thank you for all your help and attendance at each WIHS oral visit. We would like to extend our gratitude for your contributions and to inform you that effective October 15, 2004, the WIHS Oral Substudy will begin a new phase of analyzing data collected during the past 10 years. Therefore, no more dental visits will be needed. The brief oral screening conducted at your regular WIHS visit will continue. Although the oral visits will stop, you can still continue to receive dental care at the UIC-College of Dentistry, Ryan White Clinic. PLEASE CONTINUE TO COME IN FOR ROUTINE AND EMERGENCY DENTAL CARE WHEN NEEDED.

During your participation, we shared many life changing events such as parenthood, marriage, new jobs and education. We developed a friendship that has blossomed each year. We, the Oral Substudy faculty and staff, have enjoyed knowing you very much. We really do appreciate all you have provided to this phase of the project and encourage you to learn about the Oral Substudy findings through the WIHS. We look forward to seeing you when you come to the UIC Ryan White Clinic for your dental treatment if you decide to continue to receive dental care with us.

We wish you the best in achieving your goals and will always keep you in our heart and thoughts.

Thanks again,

Dr. Mario Alves, Dr. Sunaina Sahgal, Dr. Olga Mendez & Mrs. Marilda Alves

Other Changes in Your WIHS Visit: HIV, Aging and Menopause

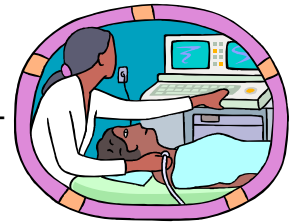
To learn more about how HIV infection, aging, and menopause affect your mood and thinking, we're adding several exercises that will assess your short-term and long-term memory abilities. You'll be asked to complete a few pen and paper exercises as well as a few verbal exercises during your next WIHS visit.

Some of you will also be asked to enroll in a more intensive substudy at University of Illinois at Chicago (UIC) that will look at cognitive function — the way our brains function in everyday life — and menopause that will include brain imaging. Both HIV and aging can affect memory, attention and other mental processes. However, there is little information available about the patterns of cognitive changes among women living with HIV/AIDS as they grow older. As women living with HIV/AIDS live longer, the need to address these issues becomes more urgent. This study will provide information about whether HIV positive women are more vulnerable to cognitive changes compared to HIV negative women which may impact planning for long-term care. The study will also provide preliminary data regarding effects of sex steroid hormones and menopause on cognitive function among women living with HIV/AIDS.

Colposcopy and Cardiovascular Ultrasound Update By Angie Shansky

First of all, I want to mention the progress we have made in our efforts to get more women to come in for colposcopy (or colpo). Our aim is to make this very important procedure easily accessible to those in need. If you need a colpo at your next WIHS visit, Sandy can now do the procedure during your gyne exam. No extra visit and no waiting! We will also have more flexibility in scheduling your colpo. Besides Dr. Cejtin's regularly scheduled colpo clinic, we can schedule more slots on different days here at WIHS. More colpos have been performed since our newfound flexibility. We hope to see this trend continue in the future. The hard-working colpo team — Sandy Micci, LaShawn Moore, and Crystal Barnes — and those of you who come regularly deserve BIG KUDOS for your efforts.

Secondly, the Cardiovascular Disease (CVD) substudy is up and running. Since we didn't begin this study till mid May, some of you may not be familiar with it. The purpose of the substudy is to detect atherosclerosis (plaque build up in the arteries), cardiovascular disease risk factors and cardiovascular disease events, like heart attacks among WIHS women. Cardiovascular health is very important. Cardiac disease is the number one killer of women today. The substudy procedure consists of an ultrasound examination that will take pictures of the arteries in your neck using sound waves. Your heart rhythm and blood pressure will also be measured. For those who have not done so, please remember to fast for your next WIHS visit to obtain fasting blood samples for the study.



What is that Big Blue Machine and why is it beeping at me?

By Karlene Schowalter

When you come in for your next WIHS visit we will be wheeling in brand new blood pressure equipment. This state-of-the art instrument is called a DINAMAP. It automatically inflates the cuff and senses your blood pressure and pulse without so much as a stethoscope! WIHS is replacing its old blood pressure machines at all the sites because the new equipment greatly increases the accuracy of the blood pressure measurement.

Why the focus on blood pressure? High blood pressure is a major risk for heart attacks and strokes (cigarette smoking and diabetes are the other two major risk factors). You may have noticed that many of the new components of the WIHS study are related to heart disease. We ask you about your diet and exercise habits. We've sent you to Rush to have the arteries in your neck visualized via ultrasound. Measuring your blood pressure accurately is part of this focus. On top of that, the definition of high blood pressure is changing. There are new guidelines which set a stricter standard for what is normal blood pressure.

In the past, anything below 130 over 85 was considered normal. That's no longer considered good enough to prevent heart disease. Under the new guidelines, your blood pressure is normal only if it is below 120 over 80! Now blood pressures in the range of 120 to 139 over 80 to 89 are called PREHYPERTENSION because blood pressures in this range tends to progress to outright hypertension over time.

What do you do if you are told you have prehypertension? Do you need to take medicine? Fortunately, you don't need to take medication for blood pressure in this range. That does not leave you off the hook, though. There is a lot you can do to help lower your blood pressure and keep it from turning into outright hypertension.

- #1 If you smoke, stop! High blood pressure and smoking are a deadly combination.
- #2 Maintain a healthy weight.
- #3 Exercise, exercise, exercise!
- #4 Reduce the sodium/salt in your diet.
- #5 Eat fresh fruit and vegetables at every meal and for snacks too.
- #6 Limit your alcohol consumption (one drink a day for women).

Highlights from the 15th International AIDS Conference in Bangkok, Thailand

Global Statistics

People living with HIV	38 million
New HIV infections in 2003	5 million
New HIV infections a day	14,000
Deaths due to AIDS in 2003	3 million

* More than 95% of all new infections are in low and middle income countries.

* Almost 2000 new infections are in children under 15 years of age.

* About 12,000 new infections are in persons age 15 to 49 years. Almost half of these new infections are women. And almost half are 15-24 years old.

On Friday, September 10, Dr. Bonnie Lubin of Hektoen Institute for Medical Research gave a report back from the International AIDS Conference for WIHS participants.

Feedback from the WIHS.....

"I was glad to hear about the array of anti-HIV medicines that now exist and the research into microbicides. It was refreshing to hear that there's a ray of light still out there. And that there are still possibilities of hope out there, especially for the poorer countries that are really in dire, dire need."

~ Marta Santiago, WIHS participant



Facts about Women and HIV/AIDS

In the early days of the epidemic, men vastly outnumbered women among people infected with HIV. In 1997, women made up 41% of all people living with HIV.

Today, nearly 50% of women are infected globally—close to 60% in sub-Saharan Africa.

Women are more physically susceptible to HIV infection than men—male-to-female transmission during sex is about twice as likely to occur as female-to-male ones.

In the United States, approximately half of the 40,000 new infections annually are among African-Americans—women account for an increasing proportion of these infections.

AIDS is also the leading cause of death for African-American women aged 25-34.



"What is needed is positive change that will give more power and confidence to women and girls....what is needed is education of girls. Only when societies recognize that educating girls is not an option but a necessity will girls and young women be able to build the knowledge and self confidence and the independence they need to protect themselves from HIV/AIDS."

~ Kofi Annan, United Nations, Secretary General

WIHS Presentations at the International AIDS Conference



Awareness of Hepatitis C Status and Access to Care among Women with and at risk for HIV in the United States by Mardge Cohen

Co-infection with Hepatitis C Virus (HCV) and HIV-1 is common in U.S. women. Management guidelines for co-infected persons were issued in June 2002. At the 2003 WIHS research visit, we looked at participants' awareness of their hepatitis C status, referrals for and attitudes toward liver biopsies and HCV treatment. We found that 32% of WIHS women were HCV antibody positive. About 72% of WIHS women with HCV were aware of their diagnosis. About half the women whose providers recommended liver biopsy actually got one. We found that one quarter of women with HCV in this cohort may not be aware of their diagnosis. HIV infection, poverty and race influenced referral patterns, but of women referred for specialty care or liver biopsy more than half followed the recommendations. More information and education about HCV diagnosis and treatment may benefit women with and at risk for HIV.

Menopause in Women in the WIHS by Helen Cejtin

A woman's menopausal status determines her need for contraception and risk for diseases such as osteoporosis and coronary artery disease. The timing of menopause has not been well described in HIV-infected women, and it may be difficult to ascertain for a number of reasons. The purpose of this study is to characterize HIV-infection among WIHS women and to compare menopause between HIV-positive and HIV-negative women. WIHS women were included in this study if they were not pregnant or on steroid hormones, 55 years age or less, and with an intact uterus and ovaries in the year 1997. We found that the average age of menopause is 47 years in HIV positive and negative women. **We also found that** HIV infection is not associated with menopause. Other than age, low body mass index (BMI) and a report of illicit drug use are associated with menopause. Advanced HIV infection is not associated with early menopause.

Assessment of Menopausal Status Among Women in the WIHS by Helen Cejtin

For HIV positive women, it is often difficult to distinguish menopause from not having menstrual periods (also known as amenorrhea) because of other reasons. The purpose of this study is to determine how accurately women and their providers determine if women are experiencing menopause. To do this, both participants and their providers were asked to assess a woman's menopausal status after a gynecological exam. Their answers were compared to the women's follicle stimulating hormone (FSH) levels. Overall, premenopausal women were correctly identified about 95% of the time by themselves, and 98% of the time by their providers. Menopausal HIV negative women were correctly identified by themselves about 70% of the time and by their providers 50% of the time. Menopausal HIV positive women were correctly identified by themselves 58% of the time and by their providers only 37% of the time — mostly due to underreporting of menopause in HIV positive women. Menopausal women are more likely to correctly assess their menopausal status than are their providers, especially if they are HIV positive.

The Prevalence of Cigarette Smoking and Interest in Smoking Cessation among Women Enrolled in the WIHS by Alice Kim

Women with HIV infection are living longer and thus the effect of cigarette smoking is more likely to negatively impact their quality of life and longevity. In both HIV-infected and uninfected individuals, smoking increases the risk of morbidity and mortality. Nationally, 45% of HIV+ and 50% of HIV- women were smokers. Smokers were more likely to be African American, less educated, older, not married, unemployed, depressed, current and past IV and hard drug users, drinkers of alcohol (more than 3 to 4 drinks a week), without children under 18 years old and have lower income. HIV+ smokers were more likely to have detectable viral load and CD4 count under 200 than HIV+ non-smokers. Of 96 current smokers in the Chicago WIHS who were offered referral to an on-campus smoking cessation clinic in 2003, 33 (one-third) agreed to make appointments. There were no significant differences between smokers who expressed a desire to quit and those who did not. HIV+ smokers who expressed a desire to quit were more likely to be unemployed than HIV- smokers. In conclusion, facilitating access to smoking cessation interventions among women smokers may positively impact the health of women with and at risk of HIV.

“What the WIHS Means to Me...”



Jeez, where does the time go? It's amazing, I can't get over how fast these past ten years have flown by. Seems like I was just sitting in a meeting when Dr. Cohen announced the new women's

HIV study, the first of its kind. 2600 women from six different sites across the United States, one third of which needed to be HIV negative.

The study sounded so humongous I was not sure just how everyone was going to keep track of all the study participants let alone the study results. I have been part of the National Community Advisory Board (NCAB) since the beginning and I am the last of the original members.

The NCAB has had many 'wise women' on board that I have had the pleasure of knowing. A few of those women lost their battle to HIV and I miss them. I personally think that the project directors, executive members, our NCAB facilitators, the various minute keepers, and of course the many NCAB representatives throughout this decade have made such a contribution to this phenomenal women's' study. Oral, natural history, menopause, anti HIV drug effects, smoking, and illicit drug use are just a few of the many avenues that this wonderful study has taken us through.

~ by Marta Santiago,
Chicago NCAB Representative

I talked to a lady last week about HIV and STD's last week. She was a prostitute and she wanted to turn a date with me. I gave her \$10, I don't know what she did with it. I hope she got something to eat. But I used that opportunity to talk to her and she was willing to listen. And I gave her the phone #'s to Haymarket and The CORE Center. She said that no one had ever taken the time to even care enough to talk to her. She said that she didn't want to be a prostitute but she didn't know how to stop. So, that was deep.

Being a part of the WIHS and the NCAB has made me care a lot more about reaching out to people I don't know. People aren't educated. They don't know they have options. It's also made me care not just about my own health and my family's health but about other people who are strangers. I like to share the information that I've learned and I'm still learning now.

I've also learned to meet people on their level and not to think I'm better. I've learned to have compassion, I guess. When you're a real private person, it takes a long time to get your voice out. But once you do, it's hard to stop. The only way you really keep you knowledge is by sharing it. I learned that one of my gifts is talking to children. I was invited to speak at a high school. They wanted me to push abstinence and I did but I talked to the kids on their level. It was so cool. They wanted to have someone to talk to.

I really like being part of an organization that pushes you to speak out. Speaking in public, that's something I want to get better at.

~ by Alice Williams,
Chicago NCAB Representative



Remembering Gigi — in her own words. . .

"Savoring the Day"

By Gigi Nicks

"I spell Aids in lowercase," says Gigi Nicks, "because I try to keep it from claiming too much power in my life, and I want to show that." Here are other reflections from Gigi, on pursuing joy no matter what."

It is possible to live a happy life with Aids despite the pain and chaos surrounding it, despite the things I want for me that elude me, despite the people around me whose lives seem to say I can't be happy. But though it may not be the perfect picture that I envision, I can live a life that is just enjoyable.

When I feel unhappy, it's because I disagree with what's taking place in my life. I have mental pictures of how my life should be - of the career I should have built, the perfect partner I should have. I have strong ideas about who my children and their mother should be and how they should behave. Even though the life I think I should be living may only be based on my delusions, I still feel unhappy when my reality falls short.

I can't wait for everything in my life to be as I wish it were before claiming my happiness. There are so few moments when I feel that everything is going well. And realistically, no one has all that she wants. That's life with or without Aids. I can't help but wonder, if I felt completely satisfied, what would my purpose be? What would I think about? What would I plan and strive for? I don't believe I will ever know the joy of living if I wait for others, reality to mirror all my dreams and goals.

I know that the threat of loss will always be present in my life. Crossing the street, flying in an airplane or debilitation of my health are risky. A natural disaster can leave me homeless and jobless all in the same day. No place or anyone in this world guarantees my safety. Nothing outside of my being will give me more than fleeting moments of security or joy.

Life with Aids is not easy, but it's a blessing. I am God's beloved child, and the spirit's favor is with me. I am an expression of God. The living dynamic spirit that created all life is alive as me. It is in this truth that my security lies. I am here with Aids because God called my spirit forth, and when my work is done, I will leave. Breath is the gift of life I try to experience the joy of living with Aids in each breath.

Being alive with Aids means dealing. As long as I am here, painful things will happen. To resist them is to resist life. Painful or unpleasant experiences aren't necessarily bad ones, so I shouldn't react as I've been taught, shouldn't let life push my buttons. No matter what is happening around me, I will strive to stay centered. I can handle any difficulty. If I stay strong in my spirit, I will always find my way.

Life is a perceptual experience. The ability to think and feel are gifts that can be both creative and destructive. My life is as good as I think it is. I make it a habit to being each day affirming that God is great and that life is a blessing even with AIDS. I choose each day to savor the precious, moment-to-moment joy of living with Aids.

