

Brought to you by the Chicago WIHS Consortium. . .

Health WIHS

Spring, 2001

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CAB CORNER

by Marta Santiago, Chicago NCAB Rep.

Like many of you, I just completed Visit 13 recently. Although I've been through 12 previous visits, I found myself full of questions. As I sat down to get my blood drawn, there were seven, or maybe nine, vials set out in front of me — staring me in the face. I realized I had forgotten what each vial was for.

It had been so long since I had thought about the various parts of my WIHS visit, I felt completely in the dark.

Even though I have been Chicago's National Community Adviso-

ry Board Representative since the beginning of WIHS, I realized that I still needed and wanted much more information about the study. And I felt determined to seek answers to my questions.

Other women in the study have also asked me what happens to all the information the WIHS collects from us at each study visit.

Personally, I've decided to revisit my health history—to learn everything about my health. I have also proposed the idea of a very detailed step-by-step bro-

chure outlining exactly what happens at a WIHS visit and why. This will definitely be on the agenda at the upcoming WIHS NCAB and Executive Committee Meetings.

I thoroughly enjoyed our most recent WIHS workshop on Menopause and HIV presented by Dr. Helen Cejtin. She broke it down so that everybody could understand the issues. I'm looking forward to more workshops like these in the future.

Remember, we're always learning.

Feedback on your Feedback!

By Maria Shansky, Research Assistant

Thanks as always for completing the feedback forms at your visit! Your input is invaluable to this study. Here's a few issues that have come up. . .

- There were some requests for a **shuttle system** to the dentist at the University of Illinois at Chicago (UIC). Unfortunately, we're not able to accommodate this. We do want to express our thanks for all who brave the distance to UIC. The **oral study** is a vital part of WIHS. Inside this newsletter, Dr. Alves shares what we have found so far about Gum Disease and HIV.
- Some women requested **speedier registration** upon arrival for your visit. We are currently discussing ways that we can expedite the process and make sure your visit runs smoothly overall.
- For participants who would like to see **more monetary compensation**—we added a \$10 gift certificate from Jewel, Cub Foods, or Target—you choose!
- Lastly, **thanks for all your compliments** to the staff. Many of you write that the staff is the best part of your visit! This means a lot to us—we'll keep doing our best.



WIHS AUTOPSY CARDS: What are they and Why Do We Need Them?



“An autopsy will insure the most knowledge about the effects of the disease on a particular woman.”

The WIHS National Community Advisory Board (NCAB) felt that it was important for our study to be able to study all aspects of the effects of AIDS. This includes studying a woman’s body after death, which can be done through an autopsy.

An autopsy will insure the most knowledge about the effects of the disease on a particular woman. An autopsy can determine the actual cause of death. Yes, someone may have been infected with HIV, but just what stopped that person from continuing to live? What part of their body failed due to HIV disease? Or, was it a combination of factors?

A specialized physician, called a pathologist, who has advanced education in the

study of the tissue and cells can determine these questions by performing an autopsy.

A WIHS participant can decide if she would like a pathologist to perform an autopsy upon her death. This is really a wonderful thing for the advancement of medical science and the purposes of the WIHS — to help improve the health of women with HIV.

The NCAB has devised autopsy cards — enclosed with this issue of **HealthWIHS** — that indicate one’s wishes for an autopsy. To be useful, these cards should be carried with you at all times along with your driver’s license. The card includes the name and telephone number of a WIHS contact.

You also need to

let your family know that you would like an autopsy with consent of organ donation and tissue samples given to the WIHS. Let them know how important this is to you and how important this is to finding a cure for HIV. Ask them to make sure your wishes are honored.

Lastly, it’s very helpful if you draw up a Living Will or a Power of Attorney for Healthcare that also states your decision. (See below for information about free legal assistance.)

If you have any questions, please don’t hesitate to ask your WIHS clinician or interviewer. We will help guide you in this process in every way that we can.

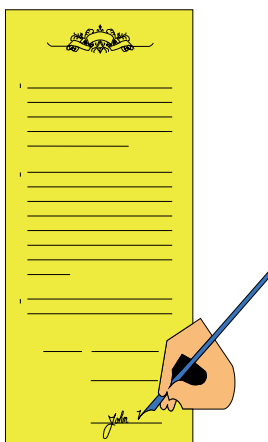
(Thanks to Elisa Sanchez-Jenkins, the Los Angeles NCAB Representative for many of these suggestions that were printed in the

RESOURCES FOR YOU: The AIDS Legal Council of Chicago

The AIDS Legal Council can help you with your Living Will or Power of Attorney for Healthcare. Their mission is to preserve, promote and protect the legal rights of men, women and children in the metropolitan Chicago area living with or perceived to be living with HIV/AIDS. The Council provides direct legal services, education about HIV-related legal issues, and advocacy to protect the rights of people with HIV.

You can call them and request a free booklet called “Will, Powers of Attorney, and HIV” or check out their website: www.aidslegal.com

AIDS Legal Council of Greater Chicago. 188 W. Randolph St., Suite 2400, Chicago, IL 60601-3005. Telephone 312/427-8990. Fax 312/427-8419.



Changes in Your Body Shape: What's Happening? A substudy by Jessica Justman, Bronx WIHS Investigator

The use of Protease Inhibitors has been associated with dramatic improvements in AIDS-related illnesses.

As is true for many strong medications, there may also be side effects for some people. Protease inhibitors can be associat-

ed with changes in the shape of a person's body, or weight.

Women have reported an increase in breast size, a larger abdomen, or a hump on the back of the neck.

There have also been reports of insulin re-

sistance and cases of newly diagnosed diabetes.

By collecting fasting blood samples and body measurements, we hope to describe the possible metabolic side-effects that may occur when women take protease inhibitors.



Why Fast Before Your WIHS Visit? By Lori Ackatz, Chicago Project Director

We hear that many of you have questions about why you are being asked to fast before you come to your WIHS visit (if scheduled for a morning appointment).

Blood drawn at your WIHS visit will be tested for glucose (sugar) and something called hemoglobin A1C, insulin and lipid levels.

Hemoglobin A1C allows us to see whether your glucose levels have been normal over a peri-

od of time and can tell us whether you may be at risk for developing diabetes.

Insulin is a hormone in your body that is important for regulating the amount of glucose in your blood, and lipids are important fatty compounds, not only because of their high energy value, but because absorption of certain vitamins is associated with them.

Eating before your visit may change the re-

sults of some of these tests, but blood will be drawn for them whether you fast or not.

Remember that fasting is not eating or drinking (not even coffee or tea!) after midnight before your WIHS visit. You can have water if you feel thirsty!

If fasting interferes with you taking your antiretroviral or diabetes medicine, do not fast.

Those of you who do fast will have a snack waiting for you!

“Eating before your visit may change the results of some of these tests, but blood will be drawn for them whether you fast or not.”

Your Body Measurements—What Do They Mean?

In response to many requests by participants, we will be taking several steps to provide you with more information about your body measurements.

Clinicians will have body circumference measurements (arm, hip, leg, chest, waist) from the previous visit and then give the current measurements

for comparison. You will know whether the measurements are smaller or larger than six months ago.

Regarding the Bioelectric Impedance Analysis (BIA) measurements, the clinicians will be providing you with reports that show body composition results.

Lastly, clinicians

will determine your Body Mass Index (BMI) through a mathematical formula that correlates somewhat with body fat — a ratio between weight and height.

If your BMI is high, you may have an increased risk of developing certain diseases, including hypertension and Cardiovascular Disease.



Menopause: What is Happening to Our Bodies?

A Summary of Dr. Helen Cejtin's presentation
at the WIHS Workshop on Friday, March 30.

What is menopause? Menopause is defined as having no period for one year. The hard thing about menopause is that you only know you've gone through it once you've been through it. When you miss a period, you don't know if it's the start of menopause or if you're just skipping a period. You might think you're pregnant or sick. And that's what makes the whole transition phase really difficult.

How long does menopause last? Perimenopause refers to the time when you first miss a period or start having irregular periods and when you first experience menopausal symptoms like hot flashes and vaginal dryness. The average age of perimenopause is 51 years old. This period can range from 2 to 7 years.

At what age do women go through menopause? Almost all women have gone through menopause by the time they are 55 years old. But there is a wide range of ages that menopause begins and ends for different women. For example, smokers usually go through menopause a couple years earlier than most women.

Why does menopause occur? Your ovaries produce estrogen, progesterone and a small amount of the male hormone, testosterone. Menopause occurs when your ovaries produce less hormones because the number of follicles in your ovaries decreases as you get older. Women are blessed with about 400,000 follicles at birth. But when you go through puberty, every month you release an egg and follicles die off. As the follicles die off, you make less and less estrogen. By the time you reach your mid-forties, you have less than 100 follicles left. Also, when you stop releasing eggs, you stop making progesterone.

Some changes that women experience result from the decrease in estrogen and progesterone levels. Other changes occur when the ovaries stop producing estrogen and progesterone all together. After three years of menopause, the ovaries stop producing testosterone as well.

Can a health care provider tell you if you are going through menopause? A blood test can measure your Follicle Stimulating Hormone (FSH) level. FSH levels go up as estrogen levels go down. If your FSH level is really high, then you are going through menopause. However, many women begin to experience symptoms before their FSH level increases.

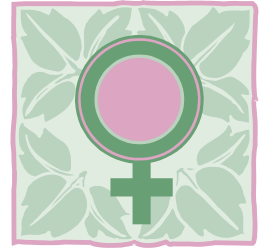
What are the symptoms, and what can we do about them?

- **Hot flashes** are the most common symptom that women going through menopause experience. Hot flashes can last for several months to one or two years. Hot flashes are related to the decrease in estrogen that your body is experiencing. Caffeine, hot drinks, stress, and even spicy foods can trigger hot flashes — so try to avoid these if you can. You can also take small doses of estrogen to prevent hot flashes. It has also been found that soy products (like tofu) can help prevent hot flashes. Clonidine, a prescription medication that is used for high blood pressure, can also help alleviate symptoms.
- **Mood Changes** are experienced by about one-third of women who are going through menopause. But the sadness doesn't seem related to a decrease in estrogen levels. Instead, the sadness seems to be related to the changes that a woman may be experiencing (e.g. lots of symptoms or a long menopausal period). Women who have a history of depression also seem to be more prone to mood changes.
- **Aches and Pains** are also common symptoms which are probably related to the age of the women going through menopause. Sometimes aches and pains go away with small doses of estrogen.
- **Vaginal Changes** like dryness and itching in the vaginal area are related to a loss of estrogen. For some women the dryness interferes with having sex. And some women experience a decrease in sexual desire. A small amount of testosterone can help with this. But most women report that their sexuality is about the same before and after menopause. **The best thing to help the vagina stay soft and elastic — to keep the blood flowing—is to have lots of sex!**

What about HIV and menopause? It can be much harder for women who are HIV+ to sort out if they are experiencing menopause because symptoms like hot flashes and night sweats may be due to infections. Also, irregular periods are more common among HIV+ women who are ill. We still need to learn more about the relationship between hormones and HIV infection. With the help of WIHS women, we are examining this relationship further.

DID YOU KNOW . . .

Back in the 1700s, it was generally believed that when a woman had her period it was to get rid of poison in her body. So, when a woman went through menopause — she would be terrified. How was she going to rid her body of the poison? Women often resorted to blood letting, or cutting their vaginas, to rid their bodies of “toxins.” **We’ve come a long way since then in our understanding of women’s bodies!**



Initial Evaluation of Gum Disease of the WIHS Women

By Dr. Mario Alves, Chicago WIHS Dentist

Gum (periodontal) disease is the general name for a group of diseases affecting the gums (gingiva) and the bone that supports the teeth (alveolar bone). Symptoms can include bleeding gums to losing teeth.

Gum disease is one of the most common diseases of the mouth — second only to tooth decay. It affects 85% of the population in one of its forms. It is a very complex disease caused by the reaction of the body to the microbes from the dental plaque, glued to the teeth, close to the gum line.

Although gum disease is not completely understood, we do know that gum disease is preventable and can be controlled by education and oral hygiene. Gum disease can influence one’s quality of life and can be influenced by one’s general health. Gum disease is influenced

by dental decay, faulty fillings and caps, and bad fixed and removable dentures. It is also influenced by the effects of smoking, drug use, dry mouth and thrush (Candidiasis).

Other changes in one’s general health like menopause, pregnancy, birth control, allergies and diabetes can also influence gum disease.

The WIHS looked at all the information on gum disease collected from WIHS visits during the last six years to evaluate the impact of HIV on gum disease.

The method used to collect this information is similar to a routine 45 minute visit to the dentist, when a series of tests and measurements are made to see if the salivary glands are working (they produce spit), to detect if there is dental plaque on the teeth, to check if the gums are inflamed, to indi-

rectly measure the level of the bone that supports the teeth we measure how deep the pockets of the gums around the teeth are.

The initial evaluation of the data shows that: A) the bone that supports the teeth of the HIV+ persons is behaving the same way as of the HIV– persons. B) the gums of the HIV + persons presented more inflammation than the gums of the HIV– person. C) the HIV+ persons had a little bit more dental plaque than the HIV – persons.

Our initial conclusions are that HIV+ women should have better home care of their mouth and should see the dentist more frequently to prevent losing teeth, due to gum disease.

“Women living with HIV should take better care of their mouth and teeth and should see the dentist more frequently to prevent gum disease.”



The Gifts of AIDS By Waver L. Franklin

For many of us affected by the AIDS pandemic, the grief and the loss is often times overwhelming. However, if we can look beyond our tears and our rage, we may find some gifts glittering in the shadows of our suffering.

INTIMACY. Think of someone who has been drawn into your life, or you into theirs, as a result of AIDS. Think of the sharing that has occurred...including the tears, the fear, the pain...how the façade was stripped away and the human-ness of each of you made vulnerable and available to the other. Has the gift of intimacy opened your heart to greater acceptance of yourself and others.

SURRENDER. Think of some instance where you had to let go of your need for control. Perhaps it was letting go of denial and surrendering to the painful truth of the diagnosis in someone you love. Perhaps you also had to surrender the need to change or fix or cure that person. Perhaps you also had to surrender the need to change or fix or cure that person. Perhaps you had to surrender to a changing relationship or let go of it altogether. Or it may have been letting go of caring for another, or yourself. How has the gift of surrender given you the opportunity to relax a little more deeply into the mystery of life?

COMMUNITY. Think of a bridge that has been built in your life as a result of AIDS. Perhaps it connected you with a support group, a service organization or healing circle. Perhaps it was reaching out to a new ethnic group, learning about a different spiritual tradition, or reconnecting with a family member. The gift of community has grown out of our common cause and our compassionate response. How has the gift of community expanded your sense of connectedness?

SERVICE. Think of something you do for another or allow another to do for you as a result of AIDS. The gift of service melts giving and receiving into one act of love. Receiving is giving and giving is receiving. How has the gift of service opened you to greater appreciation of our interdependence?

WISDOM. Think of something you have learned because of AIDS. Perhaps it is something about the miraculous complexity of our bodies. Perhaps it is something about courage and endurance, about love and relationships, about ethics and values. How has the gift of wisdom expanded your awareness?

PRESENCE. Think of some moment where you were with yourself or with another as a result of AIDS where you were totally present. Where the intensity of the moment moved you so deeply that past and future suddenly faded away and all of you responded, resonated with the power of that moment. How has the gift of presence enabled you to live more completely in the now?

MEANING. Think of some aspect of life that has new meaning for you as a result of AIDS . . . Relationships . . . Career . . . The arts . . . Political process . . . Spirituality. How has the gift of meaning changed your values, your perspective of life, including death?

LOVE. Think of some expression of love as a result of AIDS that moved you. Some unexpected evidence of above that surpassed all of our expectations. Perhaps it was something that swelled up within you or it may have been something that flowed to you in a sharing or gesture. Perhaps it is the compassion and the creativity so evident in our response to the epidemic. How has the gift of love touched you at the core of your being?

INTIMACY. SURRENDER. SERVICE. WISDOM. PRESENCE. MEANING. LOVE.

Gifts for our compassionate and caring friends and family members, partners and patients, colleagues and clients, neighbors and strangers . . . Courageously living and courageously dying.

Announcements from your site. . .

A New WIHS Substudy: The Virologic Rebound and Resistance Study (VRS)

Some of you may be familiar with this study already. It is a new WIHS substudy that is trying to answer the question of why HIV medicines work better in some women than others. WIHS staff began to enroll eligible women at the start of visit 13 and some women have been in for their first substudy visit already! The study will be going on for two years and study visits include up to four blood draws, observed dosing of HAART medicine (taking your medicine while WIHS staff watch), and an interview. Of the 33 Chicago women eligible for this substudy, 21 have agreed to participate!

The Memory Study and Intercurrent Illness Substudy have ended. Thank you to all the women who took part in these substudies. We will have more information about the results of these studies soon!

New Faces at The Core Center/Cook County Hospital

Hello, my name is **Brooke Smith** and I am the new research assistant in data management. I am currently training to be a Cook County back-up interviewer; I look forward to the chance to work with the women in this study. I graduated from Western Michigan University with a BA in Women's Studies and Sociology. I have always had an interest in women's health and related issues, so WIHS is exactly what I've been looking for.

Hi Everyone, I'm **Zyra D. Gordon-Smith**, a Family Nurse Practitioner, and I've been working with WIHS since June, 2000. On Mondays and Tuesdays I'm here with you at the CORE. I'm also on faculty at Rush University's College of Nursing. I've been married to Kenneth for close to 17 years and we have two girls, Ivory who's 9 and Rachel who's 7. In regards to educational background, I received my BSN from Loyola and recently completed my Nursing Doctorate. I've met quite a few of you, and welcome the opportunity to meet the rest. I'm sort of bad with names, so work with me on that. See you soon!

My name is **Karlene Schowalter** and I am happy to be here at the CORE Center working with WIHS. I started in February and have met some of you and am looking forward to meeting the rest of you soon. I have been a family Nurse Practitioner for 15 years, working at Winfield Moody Health Center, a community clinic on the Near North side of Chicago. I am a graduate of the University of Illinois and Rush University. I have two teenage daughters, Carrie and Rachel who keep my life interesting when I am not working.

Congratulations to **Sandy Micci** who had a healthy baby boy, Dominic Vincenzo, 7lbs 0 oz, 20.5 inches, on February 9, 2001 and to **Julie Schmidt** who had a healthy new baby boy, Mason Henry, 7lbs, 6 oz, on February 26, 2001!

Goodbye **Kathy Pietrusiewicz**, who was the nurse practitioner for WIHS. We wish her well at her new job with a Methadone Clinic in Lincoln Park.

Rush would like to thank all the dedicated women in WIHS. We know that making the time and effort to come in for your WIHS visits can be a challenge, but we appreciate the effort. As always, if there is anything we can do for you between visits, don't hesitate to call Ruth Davis at 312/942-6017.

Health WIHS

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.

Readers are encouraged to submit personal stories, poems and other creative work. To submit a story or if you have any comments or questions, please contact Alice Kim, Newsletter Editor.

WIHS
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What is WIHS?

The purpose of WIHS is to learn about the effects of HIV infection on the physical, emotional and social health of women. The results of this study will be used to help improve the health of women with HIV. In Chicago, four hospitals take part in WIHS:

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

Rush Presbyterian—St.

Beverly Sha, MD
Ruth Davis, RN
(312) 942-5865

**Northwestern Memorial Hospital
Chicago Hospital**
Patricia Garcia, MD

University of Illinois at Chi-

Ronald Hershow, MD

**Check out the WIHS national website!
www.statepi.jhsph.edu/wihs**

WIHS Publications!

You can get a complete list of WIHS publications! In the last several years, WIHS investigators have been busy analyzing the data we have collected from your WIHS visits. Many of our findings have been published in medical and scientific journals. Here are a few titles that have been published by Chicago investigators.



"Prevalence of Domestic Violence and Childhood Sexual Abuse in Women with HIV Infection and Women at Risk for HIV" by Dr. Mardge Cohen

"Adherence to Colposcopy among Women with HIV Infection" by Dr. Helen Cejtin

"Hepatitis C Virus Infection in Chicago Women with or at Risk for HIV Infection" by Dr. Ronald Hershow

"Body Composition in HIV-infected Women" by Barbara Swanson

To get a complete list of WIHS publications, call (312) 633-5720.