

# The WIHS Woman



## The Connie Wofsy Women's HIV Study

### Changes for Visit 23

by Claudia Ponath, Field Manager

Another six months have flown by and this fall we begin WIHS visit 23. There are quite a few changes this visit, but first I want to thank all the WIHS women for their continuing dedication to this important study! We truly appreciate everybody's unique contribution to the study.

#### *What's different?*

And now for the changes you can expect this visit. First of all, the WIHS investigators have taken a very close look at all the WIHS questionnaires, which have been getting longer and longer, and we have tried to cut out any unnecessary questions. We have also tried to rearrange some questions, so that the questionnaire will be less repetitive and flow better. We have done the same thing with the physical examination. The one change you might notice is that we will have stopped doing the skin fold measurements. So **you will no longer have your skin pinched** during the

body measurements, we will only take the circumferences with the tape measure.

#### *What's new?*

For this visit only, we are adding a short component that looks physical functioning. We will ask you a few questions about your physical activities, and a few questions about activities of daily living. Then we will measure your grip strength in your dominant hand and we will ask you to walk 9 or 12 feet.

#### *What's continuing?*

We will ask you again to complete the 3 short **paper and pencil tasks** that we asked you to do at your last visit. We will continue to ask you to **fast (not eat or drink anything, except water, for at least 8 hours)** before your visit 23 study appointment. The reason for this is to get a more accurate measure of key laboratory tests for things like cholesterol, lipids, and glucose. These blood tests are important markers for diseases that affect women, including diabetes, heart disease, and hypertension (high blood pressure).

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Many of our sub-studies are continuing through visit 23. If you are enrolled in the **Tushie** study, your clinician will ask you the questions from the anal questionnaire and collect an anal pap smear. For the following two studies, your interviewer will ask you a couple of questions at your WIHS visit to determine for which ones you are eligible and she will give you more information about each of these studies:

The **PK study** (or Pharmacokinetic study) looks at HIV medication levels in the blood over a 12-24 hour period.

The **Metabolic Study** involves testing for glucose and insulin and doing a bone density test (DEXA). This visit, we will ask women who first participated during visit 19 to come back in for a follow-up visit.

**Abbreviated visits** for women who are unable to have a full core visit will continue.

For women undergoing colposcopy, we will continue to ask if you want to donate tissue to the AIDS and Cancer Specimen Resource (ACSR). Women do not need to have cancer or HIV to enroll in this sub-study. Women who are eligible and wish to donate tissue to the bank will have an extra biopsy, oral rinse, and blood specimens collected for this study at the time of their colposcopy examination. We have had great response from you to this protocol and we thank you for your help!

### **What's gone?**

The Pregnancy Protocol has been discontinued. The food frequency questionnaire and fitness test study is completed. The ultrasound scans of your neck, done at the San Francisco VA hospital, are finished.

Thank you from everybody in the WIHS team to each of the WIHS women participating in this study. We truly appreciate each and every one of you contributing your time and effort to this very important study. We will continue to do our best to make your study visits as pleasant as possible, and to offer you enrollment in our exciting sub-studies.



## Quality Healthcare Data and You

by Cheryl Conover



What can we do to improve the quality of our own healthcare? Have you ever felt a pain or had something happen and you think to yourself you need to call your doctor. You call your doctor and make an appointment, but when you see your doctor you feel better and wonder if you should have called your doctor at all. You may even forget some of what you experienced that made you call the doctor in the first place. The fact is exactly what you experienced could be very useful information for your doctor. Your doctor has the clinical knowledge to determine if what you experienced is important or not. Early detection of disease is vital to better outcomes of disease. One tip I have is to write down any symptoms and/or reactions you are having as you have them or soon after. Describe your symptoms clearly and briefly. Be sure to include when they start, how you feel, what you think may trigger them, and anything you have done to feel better. I have also found it helpful to make a list of any concerns and questions I have as they come up. I take this list with me to my doctor's appointment. This helps me not to forget to tell my doctor something. The more information your doctor has

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the better care he or she can give you. Also remember, your doctor is your resource. Ask questions. If you don't understand something, ask. Discuss with your doctor any diagnoses and treatment and/or preventative plans he has for you. Always find out the results of any tests you have taken. Quality healthcare begins with quality data. Healthcare data includes facts we tell our healthcare providers during patient care. Remember, you and your doctor are partners in your healthcare. Quality healthcare data depends on you!



## My Trip to Poland

by Ann Kalinowski



My father turned 80 last year, and my mother will turn 80 next month. When they were younger they used to rent a trailer and travel around the US and Canada. But now, because of poor health, they are homebound. My 'baby sister' Joan and I decided that a nice birthday present would be to visit our grandparents' villages in Poland, take lots of photographs, and see if we could find any remaining relatives. No one in our family has been to Poland since our grandparents left prior to World War I.

We flew to Warsaw and took the train to Przemysl (SHEH-mish), which is the closest city to one grandmother's village. The village is 15 miles out of the city, and we took a taxi to get there. It cost us about \$20. The village, Kalwaria Paclawska (kal-VAR-ee-ya pots-WAFF-ska), is only a little over a mile from the border with Ukraine. There are only about a hundred people there, and a couple dozen houses. There is also a monastery with

a few dozen Franciscan priests and seminarians. The houses are old: The house my grandmother was born in is still standing. This part of Poland is in the foothills of the Carpathian Mountains. It is very beautiful, and very remote. The new government of Poland has made this area a National Park.

There is a cemetery behind the church, and there we found the graves of our great and great-great grandmothers, and our great-grandfather. It is a very beautiful cemetery, on a hill with a view of the mountains. We probably have other ancestors buried there, but the old graves were only marked with wooden crosses, and the graves themselves were reused after 25 years or so.

It happens that our cousins from this village had immigrated in 1995 to Brooklyn, NY, but they still came to Poland for the summers. We had always missed each other before. Now we met each other for the first time. They were very generous. They stuffed us full of good hearty Polish food, and kept us full of coffee and tea – and they even lent us their car so we could visit our other grandparents' villages, about 90 miles away! My cousin's husband is 81 years old, but he insisted on washing the car for us before we left on our trip to these other villages.

We were armed with internet maps for roads to the other villages, but little did we know the state of roads in rural Poland. Our cousin's husband pointed out some of the roads on the map and told us, 'Road no good!' but we decided to take them anyway. It looked shorter on the map. Well, soon enough the smooth asphalt petered out to potholes that couldn't be missed no matter how hard I tried. And one road through parkland started as asphalt, turned to gravel,

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and was two dirt ruts by the time we got near the end. But we survived, and had an adventure. It also took us almost 5 hours to drive those 90 miles! However, when we drove the 'good' roads, it still took 4 hours. The main highway was a 2-lane road through the mountains. If you got caught behind a tractor or a horse-drawn wagon in a no-passing zone, you were stuck there for a while. I say 'we.' I drove. My sister forgot her driver's license. But I am still talking to her in spite of that.

My mother's parents came from villages only a mile or so apart. We found out from their marriage record that they were both baptized in the village of Cieklin (CHECK-leen). We found their own villages, but we did not know of any relatives left there. (We also found ourselves on another gravel/dirt road between them!) We hoped that a visit to the church might help us find more records, but the priest was away. So we decided to see if we could find anyone in the cemetery, but the cemetery was not near the church.

We drove around a little bit and found ourselves on the interface of yet another road that was going to be a dirt road, when we saw a woman walking with two little boys down that dirt road. I took out the wedding information, and asked in my best bad Polish if she knew where the cemetery was, because we were from America and thought we had family there. It turned out she had the same last name as my mother's parents! Although we still haven't found out the connection, we are sure we are related. After all, there are only a few hundred people in all three villages. And the cemetery she showed us was full of names from my mother's side of the family. We were so happy! Marya's daughter Anna speaks English, and she translated for us when we visited the priest to ask for

more records. And just on the basis of "we're probably cousins" Marya cooked us a big meal and offered to let us stay the night at her house.

It was fun meeting family, especially making connections after a lapse of almost 100 years. And best of all, my parents loved the photographs, and the hams and candies we brought back from our newfound family.

## CAB CORNER



by Michelle Barry

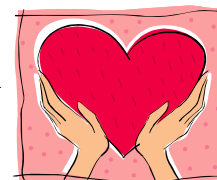
### Good Food, Good Company, and Good Information!

That's what most of the WIHS women say when they go to one of our CAB luncheons. We spoke to several women who attended these luncheons and here's what they had to say:



**Avis:** I really enjoy these luncheons. They are informative and keep me abreast of the new study procedures and tests.

**Shavonn:** These meetings make me feel special and loved. Besides having good food, they are very informative and make me feel like I'm part of a family. I even exchanged telephone numbers with another woman at the last meeting and we have talked since then. It doesn't matter what our backgrounds are or whether we're HIV-positive or HIV-negative; we are all friends supporting each other at these meetings. I feel really close to the other WIHS women



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and believe we give each other strength.



**England:** I enjoy the good food and love being around people. The luncheons are a great way to share ideas and learn new things about the study. I also hope that these meetings will help me to find something that I can do for my community.

**Angele:** The information at the meetings is very helpful for both HIV+ and HIV- women. At the last meeting, I learned about antiretrovirals and how they are being studied as a possible means of protection from sexually transmitted diseases, including HIV. I enjoy learning about new developments in HIV research around the world and hope to volunteer to help other women with HIV in the United States.



**Joyce:** The information at these meetings is very helpful. I enjoy meeting other WIHS women. I would like to thank all the WIHS staff for inviting me and look forward to many more meetings!

**Thank you to these fabulous women who shared their thoughts with us! If you would like to be in our next newsletter, please call Michelle: 415-502-6284. Our next CAB meeting will be in October. If you want to meet other amazing WIHS women and learn more about your bodies, please join us!!**

We would like to give a special thanks to Pat Winston who delivered the food for the last CAB meeting in San Francisco. We had barbecue chicken, ribs, collard greens, coleslaw,

and corn muffins from Big Nate's BBQ. The food was so good that we still can't stop talking about how delicious it was! Pat did not attend the meeting but she did have some thoughts about how wonderful the food smelled!



## DREAMS OF BBQ

by Patricia Winston

Actually, I picked up pans of ribs, chicken, cole slaw, and collard greens; mind you all these items were hot along with corn bread muffins. All of these items had a combined smell like soul food from the South; of which I am not from or familiar. But, the smell got to me so, I drove quickly from south of Market to Divisadero.

As I got closer to the Mt. Zion site, the smell got stronger and stronger. Well, that was because the collard greens juice spilled into the back (cloth) seat of my V.W. Once I arrived the food was quickly carted off by Michelle and food bandits. I rushed in to wash my hands of the aroma. But, once I returned to my V.W. the aroma revealed itself again and I had to roll down the car windows, wash the back seat and only dream of a plate of collard greens, chicken and corn bread.

And to this, may dreams come true.



# Honey

by Phyllis Tien, MD



About six years ago, my husband became interested in becoming a beekeeper. He was fascinated by the whole process of how the bees made honey. We had about 10,000 bees along with a queen bee mailed to our house in a small box. We set up their hive in our backyard and they went to work gathering the nectar from the flowers. We barely notice the bees whizzing around our flowers, but it is amazing how much honey these small creatures can make.



Since becoming beekeepers, we learned that honey has been used since ancient times both as a food and as a medicine. Apiculture, the practice of beekeeping to produce honey, dates back to the days of ancient Egypt about 2000 years ago.



Honey is made naturally by bees as a food source for themselves. The process of making honey begins when the bees collect the nectar from flowers in their mouths. This nectar is then broken down into honey in the bees' saliva. The bees carry the honey back to the hive, where they store it in the honeycombs in the hives. The



fluttering of their wings then reduces the honey's moisture content, making it ready to eat. Honey comes in many different colors and flavors depending on the types of flower nectar from which it was made.

Honey has been used for both internal and external diseases for hundreds of years. Honey was most commonly used to heal wounds. The thickness of honey provided a protective barrier for wounds. Enzymes in the honey from bees were thought to be able to kill bacteria and promote healing.

Honey is also thought to contain antioxidants, which are believed to prevent some cancers and maybe heart disease.



For centuries, honey has also been used as a folk remedy to soothe sore throats and reduce cough.

Finally, some also believe that eating honey that is made from flowers in your neighborhood may prevent allergies.

Very small amounts of the pollen allergens are in the honey, which some believe is just enough to keep the body from developing allergies when exposed to large amounts of pollen.



Honey although often used as an alternative to refined white sugar should still be used with caution in patients with diabetes.



University of California, San Francisco  
Veterans Affairs Medical Center, San Francisco

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We are looking for HIV-negative women for a research study  
on HIV Protease Inhibitors

Participants will be required to:

- Take one dose of a FDA-approved HIV Protease Inhibitor drug and placebo.
- Spend two nights on two separate admissions at the Special Diagnostic and Treatment Unit at the San Francisco Veterans Affairs Medical Center.
- Undergo two sets of studies of metabolism including oral glucose tolerance testing to study diabetes and CT scan of the abdomen and whole body DEXA to measure fat in the body.

Criteria:

- Age 21-72
- Does not have diabetes or heart disease
- May have high blood pressure and/or slightly elevated blood sugar and cholesterol levels
- Waist size greater than 35 inches
- Weigh less than 300 pounds

Volunteers will be compensated \$500

Transportation can be reimbursed

For information, please call:

Grace Lee, M.D.

(415) 750-2005



# WIHS Luncheon

Join us for a free lunch and raffle prizes!

Tuesday, October 21

11am-1pm

WORLD Conference Room

414 13th St. (@ Franklin St.), 2nd Floor

in Oakland

(Near Oakland City Center Bart )

- ⌘ Meet other WIHS Women
- ⌘ Learn about HPV and pap results
- ⌘ Ask us questions or share your thoughts about the study.



**\*\*Please RSVP to Michelle 415-502-6284\*\***

**Directions:** AC Transit Bus Routes **11, 12, 13, 14, 19, 15, 40, 40L, 43, 51, 63, 72, 82, and 88.** Call AC Transit at (510) 817-1717 for updated schedule. Take BART to **12th St./Oakland City Center BART Station.** WORLD is on 13th St. between Broadway and Franklin. Call BART at (510) 465-2278 for updated schedule.

**\*\*We will reimburse transportation costs\*\***