

The WIHS Woman



The Connie Wofsy Women's HIV Study

Changes for Visit 30

By Claudia Ponath, Field Manager

Visit 29 went by very quickly and I can't believe it's time for the next visit. Site visits were performed during visit 29, in which the folks from the WIHS Data Management and Analysis Center at Johns Hopkins University in Baltimore came to all the WIHS field sites to make sure procedures are done correctly. Some of you participated in these site visits, and we thank you. Below are the major changes you can expect for visit 30.

What's New?

There is a new component to the WIHS visit and consists of a number of mental tasks. The tasks will be administered verbally, using paper and pencil, and using a peg board. You will be asked to read words, recognize shapes, solve problems, memorize things and engage in other mental tasks. Some of the tasks will be familiar from previous WIHS visits and some will be new. The purpose of this new component is to look at the effects of HIV and its treat-

ment, substance abuse, mental health (depression, stress etc), menopause and aging on cognition. We expect that this new component will take 45-60 minutes to complete, and we will reimburse you and additional \$20 for your time and effort. About one quarter of the participants will be asked to complete this additional component at each visit, so that over the course of four visits all participants will have completed this component.

Related to this new component, there are some additional questions about childcare and employment in the interview. We will also be asking you some questions about the flu again. Outside of that, we have really made an effort to keep the interview as short and tight as possible.

A new sub-study is starting up; it's called the Pulmonary Study. It consists of a blood draw, interview, a lung function test and a chest CT scan. All procedures will take place at the UCSF Mount Zion campus. The study visit will take about 3 hours, and you will be reimbursed \$60. Heneliaka will be the coordinator for this

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study and if you are eligible your WIHS study interviewer will refer you to her.

What's Back?

As we did during a prior physical examination, your WIHS clinician will ask you some questions about pain in your feet and legs and test your knee and ankle reflexes with a reflex hammer. She will also test the nerves in your feet with a tuning fork. It's a very brief and painless exam.

The **PK study**, which has been on hiatus for several visits, is coming back for visit 30. Women who are on Isentress (Raltegravir) will be eligible to participate. The PK study looks at the different factors that influence how HIV drugs are metabolized in women. For this study, eligible participants bring their medication to the hospital, then have their blood drawn once before they take their dose and then 11 times after they take their dose over the course of 12 hours. It takes place at the main UC hospital on Parnassus. The reimbursement is \$150, and Heneliaka will coordinate this study.

What's Continuing?

It is extremely helpful if you can **bring either your medications in their bottles, your mediset, or a list of the medications you have taken since your last visit to your study visit. For those of you on HIV meds, we'll also need the dose information.** Those of you who have been bringing this information can attest to the fact that it makes the interview go much more quickly and smoothly. So, if you have been bringing this information, thank you very much! Please continue to bring it. If you have not been bringing it, please strongly consider bringing it in for your next visit. Both you and your interviewer will be glad you did.

The **Metabolic Study** started up again during visit 29 and will continue for visit 30. Your interviewer can determine if you are eligible and refer you to Heneliaka, who coordinates this study. For the metabolic study, you come to Moffitt hospital on Parnassus for a Glucose tolerance test and a bone density scan. The visit is about three hours long and you will be reimbursed \$50.

The **Cardiovascular Study** also started during visit 29 and will continue during visit 30. Eligible women will be seen for ultrasounds at the VA medical center in San Francisco. Your interviewer can tell you if you are eligible and put you in touch with Heneliaka, who coordinates this study as well. The visit takes about an hour, consists of an ultrasound of the right side of your neck and reimburses \$40.

Please **fast (don't eat or drink anything, except water, for at least 8 hours)** before your WIHS visit 30. This is crucial for getting an accurate test result for your cholesterol, lipids, and glucose. These blood tests are important markers for diseases that affect women, including diabetes, heart disease, and high blood pressure. So please try to fast 8 hours before your next core WIHS visit.

For those of you taking HIV medications, we will ask you to give us a small **hair sample** (about 20 strands), as we have at previous visits. The hair samples you have given us in the past are being tested for levels of HIV medications. The results are very promising and we hope some day to be able to use the levels of HIV medication in hair to adjust medication dosage accordingly.

Abbreviated visits will continue for women who are unable to have a full core visit. For women undergoing colposcopy, we will continue to ask if you want to **donate tissue** to

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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 one tube of blood collected for this study at the time of their colposcopy examination. We continue to have a great response from you to this protocol and we thank you for your help!

What's Gone?

The short hair questionnaire has been completed. Thank you for answering the questions about your hair. The vaccination cards have been discontinued. We would like to thank those of you who brought them back to their study visits.

In Conclusion

We will do our very best to make your WIHS visits as pleasant as possible. We have many exciting sub-studies going on during visit 30, and we will do our best to refer you to the sub-studies. We are starting visit 30 in a little over 2 weeks: that means we've been working on the WIHS for 15 years and I applaud you. This is a very important and unique study, and the best part of it is you – the women who come in visit after visit, year after year and answer our questions and donate the specimens. We really appreciate your continued dedication to the WIHS, and your willingness to make time for study visits. THANK YOU SO MUCH!!! We truly look forward to seeing you at your next study visit. Take good care of yourselves.

The National Institutes of Health (NIH) and the American Recovery & Reinvestment Act (ARRA) of 2009

Summarized by Nancy Hessol, Project Director

The American Recovery and Reinvestment Act of 2009 (Recovery Act) was signed into law by President Obama on February 17th, 2009. It is an unprecedented effort to jumpstart our economy, create or save millions of jobs, and put a down payment on addressing long-neglected challenges so our country can thrive in the 21st century. The Act is an extraordinary response to a crisis unlike any since the Great Depression, and includes measures to modernize our nation's infrastructure, enhance energy independence, expand educational opportunities, preserve and improve affordable health care, provide tax relief, and protect those in greatest need.

The NIH is well positioned to fund the best science in pursuit of improving the length and the quality of the lives of our citizens, while at the same time stimulating the economy. The NIH conducts and supports outstanding biomedical and behavioral research, through more than 3,000 institutions across the country – institutions that have a direct impact upon the local economies in their towns, cities, and states.

NIH Funding

The Recovery Act provides a total of \$10.4 billion, all available for two years – through September 2010. The NIH expects to spend as much as possible in FY 2009. Below is a summary:

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- \$8.2 billion in support of scientific research priorities
- \$1 billion to support Extramural Construction, Repairs, and Alterations
- \$300 million Shared Instrumentation and other capital equipment
- \$500 million for NIH buildings and facilities
- \$400 million for Comparative Effectiveness Research (CER)

Many types of funding mechanisms will be supported, but, in general, NIH will focus scientific activities in several areas:

1. The NIH will choose among recently peer reviewed, highly meritorious Investigator Initiated R01 applications and similar mechanisms capable of making significant advances with a two-year grant. R01s are projects proposed directly from scientists across the country. The NIH will also fund new R01 applications that have a reasonable expectation of making progress in a two-year grant.
2. The NIH will accelerate the tempo of ongoing science through targeted supplements to current grants. For example, the NIH may competitively expand the scope of current research awards or supplement an existing award with additional support for infrastructure (e.g., equipment) that will be used in the two-year availability of these funds.
3. NIH anticipates supporting new types of activities that fit into the structure of the Recovery Act. It will support a reasonable number of awards to jump-start the new NIH Challenge Grant program. This program is designed to focus on health and science problems where progress can be expected in two years. The number of awards and amount of funds will be determined, based on the scientific merit and the quality

of applications.

4. NIH will also use other funding mechanisms, as appropriate.

The Process

NIH is working closely with the HHS Recovery Act Implementation team to ensure transparency and accountability for their Recovery Act funds. As NIH Spend Plans are approved through this process, NIH will post information about these critical projects and their impact on the economy on www.hhs.gov/recovery.

The impact is expected to extend beyond the immediate scientists who will receive funds, to allied health workers, technicians, students, trade workers and others who will receive the leveraged benefits. The NIH understand to accomplish the goals of the Recovery and Reinvestment Act, it will take the help of the entire scientific community. Beyond the immediate economic stimulus, the long-term impact from the science funded by the Recovery Act will have a positive impact upon the health of the nation for years to come.

How does this impact the Women's Inter-agency HIV Study (WIHS)?

The NIH is the funding agency for the WIHS. Over the years, the amount of money available to WIHS-funded projects has not remained the same – meaning that some years there is more money and other years less money. For the last several years there has been less money because the NIH's budget has had less money. So the fact that NIH has more money to spend is potentially good for the WIHS in two ways; 1) it may mean that our annual budgets will either increase or remain the same and not be cut and 2) it offers opportunities to get additional grant funded support for new projects. These new projects can cover a broad spectrum of initia-

tives from testing existing WIHS specimens to recruiting new women to participate in the WIHS. Although it's too soon to tell if the new funds the NIH has received will have an impact on the WIHS, the potential is certainly there and we will definitely keep you informed on how this all works out.

CAB CORNER



New WIHS sub-study

By: Heneliaka L. jones

Hello WIHS women!

I am pleased to inform you that we are beginning a new sub-study in the WIHS, called the *Prevalence and Pathogenesis of Pulmonary Disorders in a Large Multicenter HIV Cohort*, also known as the Pulmonary Study. The purpose of this study is to find out how often emphysema (a lung disease that causes shortness of breath) occurs and what the risk are for emphysema in HIV positive individuals.

Who can participate?

Any WIHS study participant who is eligible and willing to partake in this study can participate. For those who are interested, you will be asked a few screening questions at your main WIHS visit to determine your eligibility. If you are eligible then one of the field staff will contact me, Heneliaka – study coordinator, and I will schedule an appointment with you.

What will happen at my visit?

The first part of your visit will consist of a **fasting blood draw** and a **short interview**.

The second part of your visit will consist of a **Lung Function Test**. The purpose of this test is to measure how much total air you can blow out and how fast you can blow that air out. You will simply blow into a tube that is connected to a machine that measures air volume and air-flow. This will take approximately 1 hour.

Finally you will have a **CT chest scan** that will take about 15 – 30 minutes. The purpose of the CT chest scan is to check for emphysema. For the CT chest scan, you will lie on a table with your arms above your head. Your head and chest will be inside a large doughnut-shaped machine. The table will move and the machine will take pictures of your chest. You will be asked to hold your breath at certain points as the CT is performed.

Will I be compensated for my time and participation?

You will get paid \$60.00 for your participation and reimbursed for your travel expenses. The total study should take approximately 3 hours to complete.

Where will this dynamic study take place?

The study will take place at Mt. Zion hospital in San Francisco.

What if I have more questions?

Please call Heneliaka “Ladybug” jones at 415.502.6284. I’ll be waiting for your call!

Lets Welcome Nilda Rodriguez!

By: Heneliaka jones

I would like to take this time to welcome Nilda Rodriguez as our new NCAB voting representative. I have had the pleasure of working with Nilda for the past year, as she has served as our Second NCAB representative. What has impressed me the most about Nilda is her drive and willingness to learn as much as she can about HIV/AIDS. Recently, Nilda submitted a short write-up of why she has continued to stay with the WIHS for so many years. I must admit that when I read her write-up I was moved and felt inspired. I can say a lot of great things about her, but her write-up says a lot about who she is as a person. I asked her if I can include it in this edition of the newsletter and with her permission, here it is:

Before I conclude, I would also like to thank Sheila Bryant for taking on the role as our NCAB voting representative for the past 4-years. Although Sheila is stepping down as the voting representative, she will still serve as one of our NCAB representatives, so you will still see her smiling face at our CAB events and read her heartfelt and informative newsletter articles. Thank you Sheila for your time, dedication and service to the WIHS, we appreciate all that you have done and continue to do!

I look forward to working with both of you this year.

"I have been going to WIHS visits since the first visit. I started in Los Angeles and now I go to the East Bay AIDS Center in Oakland, CA. I have not missed a visit and I'm so proud of myself. I keep going because I feel that I must do it for me and many, many women out there that are infected for a long time or just a few weeks. This is the only study of its kind. I have been in many studies that are short or maybe last two or three years. I have a lot to share with in this study. I have met many wonderful participants and belong to a great CAB and NCAB that allows me to be more involved. I get to go to EC meetings that share such important findings and such crucial information. It's about women for women. I pray that the WIHS continues for many, many years to come. I believe I will pass on before there is a cure or that there will be medications that will be less and less dangerous and toxic. This study will help us find out more about us as HIV/AIDS Positive women. I want to be part of the breakthroughs and successes. I will keep going to my visits until I can no longer go or we don't need to any longer."

- Nilda Rodriguez

March is National Women's History Month

President Obama paid tribute to women who helped preserve and protect the environment. President Obama was quoted to say: "With passion and courage, women have taught us that when we band together to advocate for our highest ideals, we can advance our common well-being and strengthen the fabric of our Nation. Each year during Women's History Month, we remember and celebrate women from all walks of life who have shaped this great Nation. This year, in accordance with the theme, *"Women Taking the Lead to Save our Planet,"* we pay particular tribute to the efforts of women in preserving and protecting the environment for present and future generations."

Rachel Carson, Marine Biologist and Naturalist.



Rachel brought even greater attention to the environment by exposing the dangers of certain pesticides to the environment and to human health. Her landmark 1962 book, **Silent Spring**, was fiercely criticized for its unconventional perspective. As

early as 1963, however, **President Kennedy** acknowledged its importance and appointed a panel to investigate the book's findings. **Silent Spring** has emerged as a seminal work in environmental studies. Carson was awarded the Presidential Medal of Freedom posthumously in 1980 by President Jimmy Carter. Thanks to Rachel Carson, the insecticide, DDT along with several other synthetic pesticides were recognized as agents that contributed to the declin-

ing bird population. Her work also made us aware that what we put into the environment can enter our food chain and we would consume it. Rachel Carson met with a lot of opposition to her work, but with perseverance and true dedication her book, **Silent Spring**, will always be considered one of the most important publications in the area of ecology.

Laura Capon Fermi, Science Author and Community Activist.

Laura Fermi was a writer and political activist. She was born in Rome where she met her husband, Enrico Fermi, the famous Nobel Prize Physicist. Laura Capon Fermi joined with other women to form the Cleaner Air Committee of Hyde-Park Kenwood (CAC), near the University of Chicago. From 1959 to 1972, the CAC lobbied and educated the public about the dangers of pollution from coal-burning furnaces and cars.



Lois Marie Gibbs, Executive Director, Center for Health, Environment & Justice, Virginia.

In 1978, a young housewife named Lois Gibbs discovered that her child's elementary school was built on top of a toxic-chemical dump. Determined to do something, she organized her neighbors into the Love Canal



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Homeowners Association, which worked for more than 2 years to have the community relocated. She led her community in a battle against the local, state, and federal governments. After years of struggle, 833 families were eventually evacuated, and cleanup of Love Canal began. National press coverage made Lois Gibbs a household name. Her efforts also led to the creation of the U.S. Environmental Protection Agency's Comprehensive Environmental Response, Compensation and Liability Act, or Superfund, which is used to locate and clean up toxic waste sites throughout the United States.

In 1980, Gibbs formed the Citizens' Clearinghouse for Hazardous Waste, later renamed the Center for Health, Environment and Justice (CHEJ), where she currently serves as Executive Director. CHEJ is a grassroots environmental crisis center that provides information, resources, technical assistance and training to community groups around the nation. CHEJ seeks to form strong local organizations in order to protect neighborhoods from exposure to hazardous wastes

Jane Goodall, Wildlife Researcher, Educator, and Conservationist.

Jane Goodall is best known for her study of chimpanzee social and family life. In 1960, a young Jane Goodall went to Tanzania to study chimpanzees and soon became their leading crusader. Her research work expanded to include numerous conservation efforts in

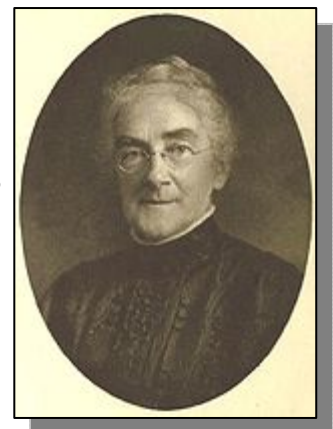


Africa and worldwide. Her global nonprofit, Goodall Institute empowers people to make a difference for all living things, by creating healthy ecosystems, promoting sustainable livelihoods and nurturing new generations of committed, active citizens. Her institute has 19 offices around the world and is widely recognized for innovative, community-centered conservation and development programs in Africa and a global youth program, Roots & Shoots, which currently has over 8,000 groups in over 100 countries. Today, Goodall devotes virtually all of her time to advocacy on behalf of chimpanzees and the environment, traveling nearly 300 days a year.

One of Goodall's major break-throughs in her studies was the discovery of tool-making among chimpanzees. Though many animals had been clearly observed using 'tools', previously, only humans were thought to make tools, and tool-making was considered the defining difference between humans and other animals. This discovery convinced several scientists to reconsider their definition of being human.

Ellen Swallow Richards

is known to have been the first woman in the United States to be accepted at the Massachusetts Institute of Technology in 1873 and went on to become a prominent chemist. Her graduate work was focused on analyses of various metals. At first MIT refused to award her a doctoral degree because of her gender and then 1886 they awarded Ellen her hard earned PhD.

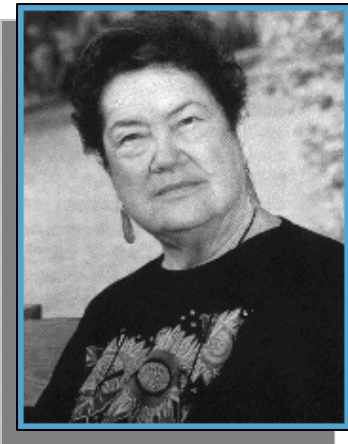


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From 1884 until her death, Ellen Richards was an instructor in the newly founded laboratory of sanitary chemistry, the Lawrence Experiment Station, which was the first in the United States and headed by her former professor William R. Nichols. In 1887, she conducted a survey of water quality in Massachusetts for the State board of Health. As a result, Massachusetts established the first water-quality standards in America, as well as the first modern sewage treatment plant, in Lowell, Massachusetts. This study, the first of its kind in America, led to the Nation's first state water-quality standards.

Her interest in the environment led her in 1892 to introduce into English the word ecology which had been coined in German to describe the "household of nature".

Grace Thorpe, Environmental Advocate.



Until 1991 Grace Thorpe, the daughter of legendary Olympic athlete Jim Thorpe, enjoyed a pleasant, low-key retirement, doing what she calls "typical grandmother stuff." Then she read an alarming newspaper story. It explained that 17 American Indian tribes - including her own, Oklahoma's Sac and Fox nation - had applied for \$100,000 grants from the Department of Energy to consider their reservations as sites for nuclear-waste storage.

Sac and Fox leaders told her that their tribes "could use the money." But Thorpe, a longtime activist on behalf of Native Americans, feared

exploitation. Radioactive waste, she explains, "is the most lethal poison known in the history of man." The prospect of a "monitored retrievable storage" (MRS) facility on what little remains of her ancestral land seemed unthinkable.

In 1992, she launched a successful campaign to organize Native Americans to oppose the storage of nuclear waste on their reservations, which she said contradicted Native American principles of stewardship of the earth. She also proposed that America invest in alternative energy sources such as hydroelectricity, solar power, and wind power.



Hello everyone in the WIHS,

This is a poem that my almost 12 year nephew wrote for a homework assignment for his English class.

I fell in love with it (not coming from a prejudice aunty), and thought it would be wonderful to share with you all.

Enjoy,

Sincerely Sharon Alpert
(on the WIHS team)



MY NEIGHBORHOOD

By Soli Alpert

My neighborhood

To me

Is not what it would be

To others

Trees replace the houses

Cats and skunks replace the cars

And a rabbit

Is the rare Ferrari

I may not live there

But it's my home

As holy as any temple

As humble as any shack

The San Bruno Mountains

Is what I'm talking about

With its paths so known to me

As if they were carved into my hands

I know more people there

Than I do on my block

Jim, Carmelita, Isabella and more

They all come from the mountains

With my swords and staves

Daggers and wands

I vanquish evil monsters and samurai

All on a two-mile hike

Even before I could walk

I strolled those paths

Learning the way of the forest

And the spirit of the mountain

Trouble Keeping Your Thoughts Straight?

Are you HIV+ and over 60 years of age?

Let us keep an eye on your memory!

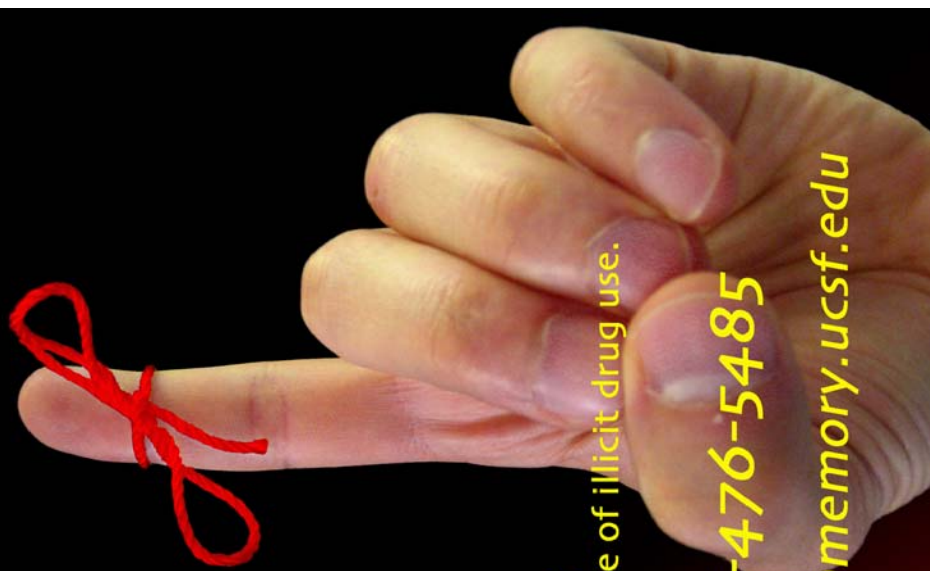
**THE MEMORY AND AGING CENTER,
UCSF,**

*is currently offering free neurological
and cognitive assessments for eligible
study participants.*

Get paid \$50 for each completed visit (2 visits in year 1)

Must be on stable HAART, Hepatitis C negative, and free of illicit drug use.

Call for a short screening: 415-476-5485
Or Email: InsulinStudy@memory.ucsf.edu





Attention WIHS Women!



Scientists have recently learned that immune cells in the intestines and lining the uterus are more affected by HIV than we previously knew.

More information about this could help researchers develop new tests and treatments.

You may be able to help UCSF researchers learn more about this important development.

We may contact you to ask if you want to participate in this study.

Participants will have two visits at Mt. Zion Hospital in San Francisco and will be reimbursed up to \$150 plus transportation reimbursement.

**If you are interested,
please call Jane at 415-353-9767**