

The WIHS Woman



The Connie Wofsy Women’s HIV Study

Visit 42

Happy Spring!



It’s hard to believe we will begin Visit 42 in April. We don’t have much in the way of changes for this visit, but we want to keep you informed of recent WIHS activities.

Introducing Jenna Burton, Clinical Research Coordinator

Our newest Interviewer, Jenna Burton, joined WIHS in February 2015. In addition to doing interviews and core visits, Jenna is our new CAB Coordinator. We are planning to have our next CAB meeting in May. We hope you can attend, meet Jenna, and get involved with the CAB.

Jenna has a BA in Anthropology from Howard University. With an interest in community health, she started doing community-based work for organizations like Planned

Parenthood, Golden Gate and Congregations Organizing for Renewal. After a few years of working at non-profit organizations, she began working in public health research. Jenna has worked on a number of studies with UC Davis Medical Center, Public Health Institute (PHI) and Kaiser Permanente.

In 2008, she founded a grassroots organization – Red, Bike and Green – in an effort to use bicycling as a way to promote healthy living within the African American community. She has organized tons of community bike rides, and in 2009 rode her bike from San Francisco to Los Angeles as a participant in the AIDS LifeCycle.

Jenna is very excited to join the WIHS community and looks forward to getting to know everyone. Welcome Jenna!



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CAB CORNER



By *Adrienne, NCAB Representative*

I have been with our local CAB for years. For me, the most encouraging part about our group is the educational factor. I have learned so much about women's bodies. Most studies are about men. And we all know we differ in many ways. The CAB speakers have been amazing, and socializing with everyone is always a plus.

I'm also on the NCAB. Every two weeks, we have an Executive Committee conference call to discuss what's new and to make decisions about important health topics under study. The NCAB members from all the different sites also have conference calls to share information about the WIHS sites locally and nationally. The purpose of the NCAB is to inform, educate, and support one another. We also advocate for research funding. The NCAB reps also meet up once or twice a year at the EC meetings to make sure we have a voice to represent women's needs in the study. Please consider joining your local CAB and join the WIHS community. Here's to good health!

New Participant Feedback Survey

We would like to know how we are doing! WIHS has a new participant satisfaction survey and we would appreciate your input. When you come to the clinic, you will be asked to complete a brief anonymous survey to let us know what you like about the study and how we can improve to meet your needs. We truly value and appreciate your time and effort in coming to all of your study visits. We look forward to seeing you for WIHS visit 42!

Fibroscan: A New Non-Invasive Way to Measure Liver Health

By *Linda Nix, Fibroscan Technician*

We are excited to Fibroscan all WIHS women at our site! No longer a sub-study, the first Fibroscan baseline exam is now part of the core visit, with a second follow-up scan about 2.5 years later. The Fibroscan is so exciting because traditionally, liver disease is measured by a liver biopsy and blood tests.

Biopsies can take a long time and can be uncomfortable, while the blood tests measure liver health indirectly and are often not very specific to liver health. The Fibroscan was developed as a non-invasive test, meaning it does not break the skin. The Fibroscan calculates the amount of scarring and fat in the liver in a relatively short amount of time. While liver biopsies are still considered the "gold standard" of liver tests, the Fibroscan samples an area 100 times larger than a biopsy. The idea is that we can reduce the number of biopsies needed by getting regular Fibroscans.

The Fibroscan is a quick test similar to an abdominal ultrasound – but with a little kick to it. You lie on your back with your right arm raised above your head while a probe is placed against your side in-between your ribs. We do use ultrasound gel and try our best to keep it away from clothes, but we recommend not wearing your favorite blouse on the day of your Fibroscan. The operator uses ultrasound to find a spot where she sees liver tissue, then presses a button to take a measurement. This causes a small area of the probe (about the size of a pencil eraser) to poke out and create a wave that travels across your liver. While not painful, this feels like a quick tapping sensation and has been described as similar to a baby kicking. Using ultrasound, the machine determines how

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fast the wave moves and calculates the amounts of stiffness and fat in the liver, expressing them in numbers. We need 10 good measurements in the same spot and take an average for the final score.

Sometimes the test takes less than 5 minutes, but most scans take less than 20 minutes. You don't need to hold your breath—you can even fall asleep! It is important to fast at least 3 hours before a Fibroscan because the extra blood in your liver that helps with digestion will cause an inaccurate reading.

The two things measured by the Fibroscan are fibrosis and steatosis. Fibrosis is the amount of scarring or stiffness in the liver, and a severe amount of fibrosis is referred to as cirrhosis. The technology for measuring fibrosis is called transient elastography. Everyone has some amount of scarring just by being alive, but alcohol, infections like hepatitis B and C, and many medications can cause concerning amounts of fibrosis. Fibroscan values of fibrosis range from 2.5 to 75 kPa (which is a measure of pressure) and the lower the better. While we get immediate results in terms of the median stiffness value, that number does not mean much by itself. A doctor would need to interpret that number along with other tests and consider other infections, such as hepatitis B or C, to accurately judge the number.

Steatosis is the amount of fat in the liver. Non-Alcoholic Fatty Liver Disease (NAFLD) is a huge concern for the American public, since obesity is so common and liver fat often accompanies obesity. The fat measurement, called CAP for Controlled Attenuation Parameter, is a newer feature for the Fibroscan and is currently for research purposes only, so we cannot inform your doctor about the amount of liver fat. The values range from 100 to 400 dB/m, but

there have not been many studies to determine what a cut-off for “normal” or “average” would be. The good news is that we can compare steatosis measurements from scans years apart. By the time we are finished collecting this data we will know more of what those values mean.

The Fibroscan received FDA approval in April 2013 to determine the level of fibrosis in a clinical setting, so we can share this score with your doctor if you grant us permission. Based on previous literature, we have determined 9.3 kPa as the cut off for severe fibrosis, meaning that if the average number of 10 Fibroscan measurements is above that number, we will reach out to your doctor about the score. If requested, we can send this score to your doctor even if it is below 9.3 kPa as well. Feel free to ask any of the staff about scheduling your appointment for the Fibroscan.

What's new for Visit 42?

Women's Adherence and Visit Engagement (WAVE) is a new study to learn more about barriers to engagement in HIV care (including adherence to HIV medications and attendance at HIV care visits) for women and the effects of stigma and discrimination in their lives. We are interested in learning more about how experiences of stigma or discrimination, along with associated stress levels, affect a woman's overall health and well-being. This information will be used to tailor policies and interventions to make sure that they have the maximum benefits for women's engagement in HIV care and associated health outcomes.

If you are eligible for participation, the study interviewer Tessa Napoles will contact you directly to schedule a visit.

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What's continuing in Visit 42?

The Ankle Brachial Index (ABI) measurement will continue. The ABI is a brief measurement of the blood pressure in the arms and legs that provides the WIHS with a measure of large blood vessel disease. Disease in the large vessels of the limbs including arms and legs has been associated with cardiovascular disease, decreased muscle strength and difficulty walking. The ABI will be done every two years and involves a brief interview about physical activity and pain or discomfort you may experience in your legs. This is one of the first large studies of factors related to vessel disease in HIV-infected women and HIV-uninfected women. We hope to use the findings of the study to help with prevention and treatment recommendations for patients and providers.

The Fibroscan and MRI Study is being done to understand how body fat and metabolism are impacted by HIV, Hepatitis C, or obesity and how this affects the health of your liver. A Fibroscan is an ultrasound scan of your liver to check for stiffness (also called "Fibrosis"). The Fibroscan will be done at our Scott Street office. Reimbursement for the Fibroscan is \$5 if you are seen at the Scott Street Clinic. Reimbursement is \$20 if you are coming from the east bay to have a Fibroscan. About 55 women in the Fibroscan study will also be asked to have a Magnetic Resonance Imaging (MRI) scan which is a way to measure the amount of fat in the liver. Your study interviewer can explain more about the study and determine if you are eligible. The MRI will be done at the UCSF China Basin campus. Reimbursement for the MRI is \$50 plus transportation expenses. Mary is the clinical research coordinator for this study.

Please remember to bring your medications in their original bottles, your medi-set, or a list of the medications you have taken since your last visit. If you are taking HIV meds, we'll also need the dosage information. Thank you for bringing your medication information to your interview! It is very helpful for providing us with a complete medical history.

Please fast (don't eat or drink anything, except water, for at least 8 hours) before your WIHS core visit. Although many beverages, such as black coffee, plain tea, and diet sodas don't contain any calories, they do contain other ingredients that can affect some of the measurements. Even sugar free gum has a couple of calories. So, please drink only water for at least 8 hours before your core visit. This is important 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. If you have concerns about fasting or if you have certain medications that need to be taken with food and at certain times, or if you are diabetic, please discuss this with your medical provider.

The Neurocognitive Study will continue. The neurocognitive tasks are administered verbally, using paper and pencil, and a pegboard. 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 component is to look at cognition – that is, mental processes such as memory and learning. It takes about an hour, and you will be reimbursed an additional \$20 at the visit.

The Musculoskeletal (MSK) Study will continue. This study looks at the effects of transition

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to menopause on bone mass and structure, muscle mass and strength, and how changes in fat distribution and immune function. If you agree to participate, you will have some additional tubes of blood drawn at your WIHS visit. You will be scheduled to come back for an additional visit, which consists of a DEXA scan to measure bone density, tests of your muscle strength and function, measures of the curvature of your spine, a questionnaire, and a quantitative computed tomography (QCT) of your spine and hip. This visit takes about 4 hours and reimbursement is \$85. If you also have an MRI, you could earn an extra \$50. If you are eligible for this study, we will offer this study to you when you come in for your WIHS visit. Audrey is the coordinator of the MSK study.

The Pulmonary Studies – TEAL and LEAP will continue. This study involves an interview, lung function test, chest CT scan (for LEAP), and blood draw. All procedures take place at the UCSF Parnassus campus. This study visit takes about 2 hours and you will be reimbursed \$60. Audrey is also coordinating this study and will contact you if you are eligible.

Hair Samples

If you are HIV-positive, we will ask for your permission to cut a small amount of your hair (about 20-100 strands) depending on the type of HIV medication you are taking. These hair samples are being tested for levels of HIV medications. Did you know that we all lose over 100 hairs every day? Having this information is very important to understanding women's response to treatment as new medications become available.

Abbreviated visits will continue for women who are unable to come into the clinic. If you do have an abbreviated visit, we will ask you

questions about your health and medications you are taking.

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 one tube of blood collected at the time of their colposcopy examination.

Women's History Month

March marks the 35th anniversary of Women's History Month. The theme for this year is women who have published, edited, or co-authored books. These works weave women's stories into the fabric of our country's history.

Delilah L. Beasley (1867-1934) Historian and Newspaper Columnist



Delilah Beasley is the first African American woman who regularly published articles in a metropolitan newspaper and the first author to present the history of African Americans in early California. She began her career in 1915 at the Oakland Tribune. Her column, "Activities Among Negroes", would highlight the activities of local churches, literary societies, national politics, and the achievements of African American men and women. She trained herself in archival research and oral history. In 1919 she published a book entitled "The Negro Trail-Blazers of California", which chronicled the lives of black Californians from the pioneer era

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to the early 20th century. She was also the driving force behind the first anti-lynching bill in California.

Gladys Tantaquidgeon

(1899-2005)

Mohegan Medicine Woman, Anthropologist, and Tribal Elder



Gladys Tantaquidgeon grew up in the Mohegan community (Uncasville, Connecticut). She was educated in tribal spirituality and herbal medicine by her tribal “grandmothers”. She completed grade school and had an opportunity in 1919 to attend the University of Pennsylvania where she studied anthropology and was mentored by Dr. Frank Speck. Gladys expanded her knowledge of tribal medicine by researching east coast tribes including Delaware, Nanticoke, Cayuga, and Wampanoag Indians. Her best known publication is “A Study of Delaware Indian Medicine Practice and Folk Beliefs,” which was printed in 1942 and reprinted as in 1972 and 1995 as “Folk Medicine of the Delaware and Related Algonkian Indians”. In 1987 she received an honorary doctorate from the University of Connecticut and another from Yale in 1994.

Gladys, her father and brother co-founded the Tantaquidgeon Indian Museum in 1931 in Uncasville, Connecticut. She shared her brother’s philosophy that education was the best cure for prejudice. “You can’t hate someone that you know a lot about.”

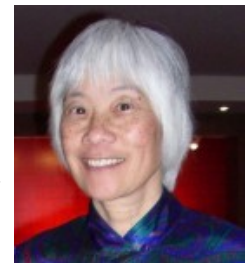
She worked for the Bureau of Indian Affairs for 10 years and in the late 1940s she worked as a full time curator for her family’s museum. She passed away peacefully at home at the age of 106.

**Eleanor Flexner (1908 -1995)
Historian and Independent Scholar**



Eleanor Flexner was a pioneer in women’s studies whose 1959 book, “Century of Struggle: The Women’s Rights Movement in the United States” was ground-breaking. Eleanor researched the labor struggles of women and the women’s suffrage movement of the 19th century. She was surprised to find that no one had ever researched or published in these areas. Harvard University published her early works in spite of the fact that Eleanor had no academic credentials. In the 1970s, Eleanor expanded her “Century of Struggle,” further explaining the women’s movement. She received an honorary doctorate in human letters from Swarthmore College in 1974.

**Judy Yung (1946-Present)
Oral Historian, Author, and Professor**



Judy Yung, professor of American Studies at UC Santa Cruz, is best known for her work in documenting the immigration history of Angel Island and the life stories of Chinese American women. She is a second generation Chinese American and a native San Franciscan.

In her first book, “Island” (1980), she translated the writings found on the walls of the Angel Island Immigration Station. She also collected oral histories from former Chinese detainees. In 1986 she wrote “Chinese Women of America: A Pictorial History”.

In the 1990s, Judy wrote “Unbound Feet: A Social History of Chinese Women in San Francis-

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co" and "Unbound Voices: A Documentary History of Chinese Women in San Francisco." Through oral history gathering, immigration records and personal memoirs, these books show how race, gender, and class shaped the lives of two generations of Chinese American women.

Vicki L. Ruiz (1955 – present)
Educator and Pioneer in Latina History



Vicki Ruiz was the first in her family to receive an advanced degree, earning her a PhD in History at Stanford University in 1982. In 2012 she was the first Latina historian to be inducted into the American Academy of Arts and Sciences in recognition of her pioneering scholarship and leadership in the history of women and workers. She has published over 50 essays and a dozen books including: "Cannery Women, Cannery Lives" and "From Out of the Shadows: Mexican-American Women in 20th Century America". She has edited and co-edited many collections, including a three-volume set entitled "Latinas in the United States: A Historical Encyclopedia." Vicki is currently the President-Elect of the American Historical Association.

Darlene Clark Hine (1947- present)
Historian and Educator



As a historian Darlene Clark Hine explored African American history, but expanded her studies to the history of African American women in our society. Darlene is an expert on the subject of

race, class, and gender in American society and is credited with helping to establish a doctoral field in Comparative Black History at Michigan State University.

"Historians can write a history of anything or anyone," Hine is quoted as saying, "but apparently few considered black women worth the telling." Hine herself had to be persuaded to explore the lives of African American women in Indiana, but soon became convinced that US history was missing an important component in regards to African American Women. Darlene's research on women's roles in churches, and other settings led to brief monograph, *When the Truth Is Told: Black Women's Community and Culture in Indiana, 1875-1950* (1980).

"If I can...impress upon the historical profession" she once insisted, "how important it is to talk to and illuminate the lives of people who did not leave written records, but who also influenced generations of women all over the globe, then I will feel that my career is worthwhile."

Below is a historical timeline of women's rights legislation:

- 1920 - 19th amendment guarantees American women the right to vote
- 1963: Equal Pay Act.
- 1964: Civil Rights Act.
- 1977: Title IX Implemented
- 1981: Congress passed authorized and requested the President to proclaim the week beginning March 7, 1982 as "Women's History Week".
- 1987: After being petitioned by the National Women's History Project, Congress desig-

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nated March as “Women’s History Month”.

- 1988 - 1994: Congress passed additional resolutions authorizing the President to proclaim March of each year as Women’s History Month.
- 1995 on: Presidents Clinton, Bush and Obama have issued annual proclamations designating the month of March as “Women’s History Month”.

Since March is National Women’s History month, we thought you would like to know about some interesting events and birthdays that took place in March.

March 15, 1933 – Birthday of Ruth Bader Ginsburg, Supreme Court Justice.

March 18, 1964 – Birthday of Bonnie Blair, Olympic speed skater. She made US Winter Olympic History by winning 5 gold medals.

March 18, 1970 – Birthday of Queen Latifah, Golden Globe winning actress, rapper, song writer, singer, comedian, and talk show host.

March 20, 1852 – Harriet Beecher Stowe’s novel, “Uncle Tom’s cabin”: is published and becomes the best-selling book of the 19th century.

March 21, 1986 – Debi Thomas becomes the first African American woman to win the World Figure Skating Championship. She won a Bronze medal in the Winter Olympics in 1988. Debi Thomas is an orthopedic surgeon and is currently in private practice.

March 22, 1899 - Birthday of Ruth Page, ballerina. Ruth Page began a career in ballet in 1919 and was the first American to be accepted in the Ballets Russes. Ballet Russes was a ballet com-

pany based in Paris and was widely regarded as the most influential ballet company of the 20th century.

March 23, 1924 – Birthday of Bette Nesmith Graham. Bette was the inventor of Liquid Paper, the correction fluid used in offices worldwide.

March 23, 1857 – Birthday of Fannie Farmer, author of the famous cookbook, “The Boston Cooking School Cookbook”. This is the first time a cookbook included specific ingredient measurements.

March 23, 1904 – Birthday of Joan Crawford, famous actress, whose films have spanned from 1928-1978.

March 25, 1934- Birthday of Gloria Steinem, feminist, journalist, and social and political activist. Gloria was the leader of the feminist movement on the late 1960s and 1970s. She was the founder of MS magazine and was the first woman to speak at the National Press Club.

March 25, 1942- Birthday of Aretha Franklin, “Queen of Soul”, singer and musician. Aretha has won 18 Grammy awards and has sold over 75 million records worldwide. She was inducted into the Rock and Roll Hall of Fame in 1987. She is currently on tour throughout the US.

