

# *The WIHS Woman*



## **The Connie Wofsy Women's HIV Study**

### **Changes for Visit 36**

*By Claudia Ponath*

Writing this article always gives me a chance to appreciate the passing of time and how I perceive it. The last 6 months felt both long and short at the same time. Mostly, they were incredibly busy, first moving our office, and then submitting the grant application for WIHS 5. We are now in the last year of WIHS 4. Since we go in 5 year cycles, that means WIHS is about to turn 20! Below is a description of what you can look forward to at your next WIHS visit:

#### **What's new?**

There are new questions about sexual risk behaviors that will only be asked at this visit. The additional questions are for a larger study which is conducted by Dr. Tonya Taylor, who is an investigator with the Brooklyn WIHS site. The study will look at the influence of physical health, mental health, and relationships on sexual behaviors of women with HIV who are over 50 years old. It will use data collected from

WIHS, as well as obtain data from in-depth one-to-one interviews and focus groups (in-depth interviews and focus groups will be done at the Brooklyn, Bronx, and Chicago WIHS sites only). This information will be used to develop a program to reduce risky sexual behaviors of women with HIV who are over 50 years old.

#### **What's back?**

The examination of your feet and ankle reflexes is back for this visit, as are the breast and uterine exams.

#### **What's continuing?**

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 to your study visit. For those of you on HIV meds, we'll also need the dose information. Bringing this information to your interview is incredibly helpful, and it will make your interview go more smoothly. And if you have been bringing this information, please continue to bring it. Both you and your interviewer will be glad you did.

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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. It is also good to know that 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 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. If you have concerns about fasting, for example, 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

If you are HIV-positive, we will ask your permission to cut a small amount of your hair (about 20 strands). These hair samples are being tested for levels of HIV medications. So far, we have looked at levels of Lopinavir and Raltegravir and found that levels of those drugs in hair are a very strong predictor of your response to HIV treatment.

The Neuro-cognitive component of the WIHS will continue during visit 36. If you did the neuro-cognitive assessment 2 years ago, we will ask you to do it again this visit. The neuro-cognitive tasks are administered verbally, using paper and pencil, and using 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 we reimburse you an additional \$20 for your time and effort to complete it.

The Musculoskeletal (MSK) Study will continue during visit 36. This study looks at the effects of transition to menopause on bone mass and structure, muscle mass and strength, and how other factors, such as changes in fat distribution and immune function, might affect these associations. If you are eligible for this study, we will approach you about it before you come for your WIHS visit. If you agree to participate, you will have some additional tubes of blood drawn at your WIHS visit. Then 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. The visit takes about 4 hours and the reimbursement is \$85. There is also an article about the study in the newsletter.

The CIDI study will continue during visit 36. Your interviewer will let you know if you are eligible to participate. The purpose of this study is to learn about women's emotional health and well-being, both now and when they were children. It consists of an interview only, which will be done by either Karen in the East Bay or Alyson in San Francisco. The reimbursement is \$40.

The Pulmonary Study will continue during visit 36 and consists of a blood draw, interview, a lung function test and a chest CT scan. All procedures take place at the UCSF Mount Zion campus. The study visit takes about 3 hours and you will be reimbursed \$60. We have reached our target number and are now doing only follow-up visits on the enrolled women. Most, but not all, women who had an initial

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visit will be asked to come back for a follow-up visit. Heneliaka or Alyson will contact you when it is time for your follow-up visit.

The Fibroscan Study will continue through the end of May. The Fibroscan is an ultrasound scan of your liver to check for stiffness (also called “Fibrosis”). This study is being done to understand how body fat and metabolism relate to HIV, Hepatitis C, or obesity and how this affects the health of your liver. The study visits take place at Moffitt hospital on the Parnassus campus in San Francisco. Your study interviewer will determine if you are eligible. Alyson coordinates this study, and the reimbursement is \$40.

The Pharmacokinetic (PK) study will continue during visit 36 and women who are taking Isentress (Raltegravir) are eligible to participate, if they haven’t already. The PK study looks at factors that influence how HIV drugs are metabolized in your body. For this study, eligible participants bring their medications to the hospital. They 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 Moffitt hospital on Parnassus in San Francisco and the reimbursement is \$150.

Abbreviated visits will continue for women who are unable to have an in-person core visit. If you do have an abbreviated visit, we will now ask you a few short questions about pregnancies.

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 for this study at the time of their colposcopy examination.

### What’s gone?

We have completed the Cardiovascular study. Thank you very much to all who made the trip to the San Francisco VA hospital to have an ultrasound scan done. You made an important contribution.

### In conclusion

I would like to thank all of our study participants for their contribution to this very important study. I want to especially welcome our newly enrolled participants: Thank you for joining the WIHS. We look forward to seeing more of you. I would like to equally express my deep appreciation and gratitude for the continued dedication of our longstanding participants who have been coming to study visits faithfully for many years. We look forward to continue to see you for many more years.



## New Musculoskeletal Study Underway

*Phyllis C. Tien, MD*

A new musculoskeletal study (also known as the MSK) began enrollment at the start of the New Year. This study looks at how getting older and transitioning to menopause affect the health of bones and muscles in HIV-positive and negative women. The main eligibility criteria include being between the ages of 40 and 60 years, being on stable antiretroviral therapy for at least 1 year, and having a T cell count greater

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than 100 cells/ul. The study extends our findings from the Metabolic Study, and women who were in that study will be targeted for enrollment in the MSK study. But other WIHS women can also participate as long as they meet the eligibility criteria.

Participating women will undergo tests at the Moffitt Hospital Clinical Research Center. Similar to the Metabolic Study, women will have a DXA scan performed to measure bone mineral density and body fat, and to assess for fractures in the spine. A number of other tests will also be performed in the Clinical Research Center to measure balance, muscle strength, the curvature of the spine, and how fast and how far women can walk around a hallway.

Women will also be asked to go to our China Basin facility to have a CT scan of the bones and muscles on the same day. There is a shuttle that can take you from Moffitt Hospital to China Basin. Many participants of the Metabolic Study may be familiar with the China Basin facility, because they had a MRI scan done in the past at China Basin to measure liver and belly fat as part of the Metabolic Study.

Women participating in MSK will also have some additional blood drawn at their WIHS Core visit. Blood will be used to test bone-related hormones and markers of inflammation.

Finally, enrollment into the study will be over 2 years from the beginning of 2012 until the end of 2013. Beginning in 2014, women who participated in MSK at the baseline measure will be asked to come back to have the same tests performed. With this information, we will be able to study changes in bone and muscle health over a 2-year period.

Women will be paid \$85 for participating in the

baseline MSK visit and another \$85 2 years later when the second visit is completed. Transportation to and from the Clinical Research Center will be reimbursed at each visit.

If you are approached regarding participation into the MSK, please consider this study. It will help us understand what happens to bones and muscles in HIV-positive and HIV-infected women as they age and enter menopause.



## To the WIHS family,

It is with bittersweet emotions that I inform you of my departure from the Women's Study. In June, I will begin my graduate studies with the UCSF Master's Entry Program in Nursing (MEPN). Over the past 6 years I have truly enjoyed my time working with all of you. It is rare when one finds a combination of supportive, dedicated, compassionate and hard-working group of co-workers. I have been blessed to have this opportunity with the WIHS. When you work with the best, you become the best!

And to the WIHS women, thank you for allowing me to see the world through your eyes. You have given me a unique perspective on life. I have come to know many of you really well. You have shared your lives with me and for that I am truly grateful and honored. I will miss your humor, strength, and tenacity; but most of all I will miss your straightforwardness - where I am from, we call it "keeping it real". My desire is to apply what I have learned from you to help others in need. Thank you!

Sincerely,  
*Heneliaka L. Jones*



## Summary of Recent Research Findings in the WIHS

*By Alyson Holsclaw*

Multi-dimensional risk factor patterns associated with non-use of highly active antiretroviral therapy among human immunodeficiency virus-infected women” by Snow-Jones et al, 2010.

It is important to understand how problems and stress in life can make it less likely that people living with HIV will take their HIV medications regularly. It is not surprising to learn that situations such as low socio-economic status (less education and/or living in poverty) and difficulty accessing medical care or paying for medicine can make it hard to begin and stick with treatment. But we also think that for many people, issues such as alcohol or drug abuse, depression, having unprotected sex, having multiple male partners, and experiencing violence all might be associated\* with problems taking medicine regularly.

To learn more about this, in this study WIHS researchers looked at your answers to the questions on the WIHS interview, as well as your labs and information you gave about your medications. They compared and contrasted information from many WIHS participants until they found a pattern. They found that women who drink heavily (over 13 drinks each week) and women who had recently experienced physical violence (they were physically hurt by a partner, a friend or family member, or a stranger) were at the greatest risk for missing their HIV medication doses or not taking their medication at all. The women who had this problem most tended to be under 40 years old, and race/ethnicity did not seem to make a difference.

Interestingly, the researchers compared what

they found with similar studies done with HIV+ men, and found that their risks were very similar. From this study we learned that we need to understand better why many people who have heavy alcohol use and exposure to violence in their lives, even more than some other life stressors, have difficulty taking medications regularly.

We also learned that women who have been dealing with drinking problems and physical abuse or violence may need extra attention and encouragement when it comes to maintaining their medication schedules. If you or anyone you know fits this description and you are concerned about it, please talk to your healthcare providers, counselors, or trusted friends or family members for support!

(\*Science Note: when scientists say that one thing is “associated with” or “correlated with” another thing, it does not always mean that one causes the other. It does mean that the two things often happen together. This suggests that the two things might be related. This is important because if we do more research and pay special attention to it, we may learn the how’s and why’s of that relationship. Then, in the case of studies like this one, hopefully we can learn ways to keep that relationship from harming those affected by it.)





## Celebrating Black History The Mother of Modern Medicine: Henrietta Lacks

*By: Heneliaka jones*

Walk into any biomedical laboratory in the world and chances are you will find a strain of HeLa cells stored in that lab. You may ask, what are HeLa cells and why are they important? Well, in 1951 HeLa cells became the first human cells to survive indefinitely, outside of the human body, in a cell culture. In science terminology this type of cell is called “immortal” because it will live forever through continuous cell growth. This scientific breakthrough was possibly the most important contribution to modern medicine. Prior to HeLa cells, scientists were only able to perform research on animal cells because human cells survived no more than a couple of weeks in the laboratory. Consequently, more time was spent trying to keep human cells alive in cell culture, than actually being able to do research on them.

Because of “HeLa” scientists were able to learn how human cells work and thus were able to test theories about the cause and treatment of diseases. One of the earliest and most notable uses of HeLa was to develop a vaccine for polio in 1952. Since then, HeLa cells have been continuously used for research in cancer, AIDS, and countless other diseases as well as genetic testing. HeLa cells also lead scientist to develop the basic techniques for cloning and in-vitro fertilization. According to Masters (2002), “Much of what we know today, and much of what we do tomorrow, depends on the supply of HeLa and other cell lines.”

For decades, after the breakthrough of HeLa cells, there was no human face attached to these cells - they were merely a tool used for re-

search. It would take approximately 2 decades before scientists would want to learn more about the person behind the cells. Shocking to some, she was an African American woman named Henrietta Lacks.

While alive, there was nothing significant about Henrietta Lacks. She was a loving wife and mother of five children, who farmed tobacco in southern Virginia. At the age of 30, she was diagnosed with cervical cancer. On October 4, 1951, after several surgeries and months of radiation treatment, she died 8 months after her diagnosis, at the age of 31, in the segregated ward for blacks at The Johns Hopkins Hospital, in Baltimore Maryland. But before she died and without her consent, two samples of her cervix, both cancerous and noncancerous, were given to Dr. George Gey, who was head of tissue-culture research at Johns Hopkins. (Skloot, 2010). The cancerous samples would soon become known within the science community - as the HeLa immortal cell line. HeLa is an acronym of the first and second letters of Henrietta Lacks.

Not only were these cells taken without proper consent, but decades would pass before her family even knew that her cells were being used for research purposes. According to Masters (2000), “When Mrs. Lack’s children eventually discovered - more than 20 years later- what had happened to her tissue, they were shocked that cells from their mother had been distributed worldwide and no one had ever sought their views or permission.” What is even more disturbing is that despite all the contributions Henrietta’s cells have made towards the advancements of science, and despite all the millions of dollars profited from HeLa cells, Henrietta’s own children cannot afford health insurance. If you “Google” HeLa cells, you can purchase a sample, costing anywhere from \$20.00 -

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\$400.00 per vial.

I first learned about Henrietta Lacks after reading *The Immortal Life of Henrietta Lacks*, by Rebecca Skloot. Ironically, I've known about HeLa cells for many years as I was a Biology Major in college. However, after learning about Henrietta's life, family, and the ethics surrounding her legacy, I was deeply touched and found her story to be bittersweet. I tried to imagine how I would have felt if I was one of Henrietta's children - not knowing that a part of my mother was (and still is) being used for science, without my knowledge or her consent. I eventually had to remove that thought from my mind because it became too overwhelming for me to even fathom. Moreover, I began to look at research in a whole new light. The birth of Henrietta's immortal cells is a part of each and every one of us, either directly or indirectly. Many of the vaccines that we use today and many of the anti-cancer and antiretroviral drugs that are being used are studied using HeLa cells. Closer to home, the consent forms we use and the consent process we go through for your study visits, are in part a consequence of the HeLa cell story. We can't change the past, but having knowledge of Henrietta's story allows us to appreciate her legacy. So the next time you go over a consent form or get a vaccine shot or take your HAART medication, remember the woman who unwittingly made it all possible!

#### References:

Masters, J.R. (2002). HeLa cells 50 years on: the good, the bad and the ugly. *Nature Review Cancer* 2 (April 2002), 315.

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*Life, Death, and Life After Death of Henrietta Lacks, Unwitting Heroine of Modern Medical Science*. Retrieved from <http://www/2.citypaper.com/news/story.asp?id=3426&p=1>

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Five reasons Henrietta Lacks is the Most Important Woman in Medical History. (2/5/2010). Retrieved from <http://www.popsci.com/science/article/2010-01/five-reasons-henrietta-lacks-most-important-woman-medical-history>

## March is Women's History Month

This month in Washington DC, the Library of Congress, National Archives and Records Administration, National Endowment for the Humanities, National Gallery of Art, National Park Service, Smithsonian Institution, and United States Holocaust Memorial Museum join in paying tribute to the generations of women whose commitment to nature and the planet have proved invaluable to society. Special exhibits will be seen in these museums.

If you recall there is a different theme each year in regards to women's history. For example, in 2008 we honored women in the arts and in 2009 we honored women who were leaders in the attempt to keep our planet clean. This year the theme is Empowerment.

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Although women now outnumber men in American colleges nationwide, the reversal of the gender gap is a very recent phenomenon. The fight to learn was a valiant struggle waged by many tenacious women – across years and across cultures – in our country. After the American Revolution, the notion of education as a safeguard for democracy created opportunities for girls to gain a basic education – based largely on the premise that, as mothers, they would nurture not only the bodies but also the minds of (male) citizens and leaders. The concept that educating women meant educating mothers endured in America for many years, at all levels of education.

Pioneers of secondary education for young women faced arguments from physicians and other “experts” who claimed either that females were incapable of intellectual development equal to men, or that they would be harmed by striving for it. Women’s supposed intellectual and moral weakness was also used to argue against coeducation, which would surely be an assault on purity and femininity. Emma Willard, in her 1819 *Plan for Improving Female Education*, noted with derision the focus of women’s “education” on fostering the display of youth and beauty, and asserted that women are “the companions, not the satellites of men” – “primary existences” whose education must prepare them to be full partners in life’s journey.

While Harvard, the first college chartered in America, was founded in 1636, it would be almost two centuries before the founding of a college that admitted women – Oberlin, which was chartered in 1833. Even as “coeducation” grew, women’s courses of study were often different from men’s, and women’s role models were few, as most faculty members were male. Harvard itself opened its “Annex” (Radcliffe) for

women in 1879 rather than admit women to the men’s college, and single-sex education remained the elite norm in the U.S. until the early 1970s. As coeducation took hold in the Ivy League, the number of women’s colleges decreased steadily; those that remain still answer the need of young women to find their voices, and today’s women’s colleges enroll a far more diverse cross-section of the country than did the original Seven Sisters. The women listed below were selected as honorees for 2011:

### [Emma Hart Willard \(1787–1870\)](#) - Women Higher Education Pioneer

She fought against the philosophy of ‘finishing schools for girls’ and was instrumental in starting a school in the state of New York for young women.

### [Charlotte Forten Grimke \(1837 – 1914\)](#) - Freedman Bureau Educator

Charlotte was born into an educated and affluent African American family who were abolitionist activists. She was a scholar, teacher, abolitionist, and crusader during the early part of the 19<sup>th</sup> century.

### [Annie Sullivan \(1866 – 1936\)](#) - Disability Education Architect

Annie Sullivan’s story is remembered in the play and movie, “The Miracle Worker.” Annie Sullivan was a pioneer in a kind of education that was in its infancy--No one had ever considered the notion of educating a disabled person.

### [Gracia Molina de Pick \(b.1929\)](#) - Feminist Educational Reformer

Molina de Pick’s community organizing skills developed in high school, where she was in-

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volved in post-World War II peace movements and political efforts to get women the right to vote in national Mexican elections. She moved to the US in the 1960s and received two college degrees in Education. Realizing the critical relationship between parents—especially mothers—and their children's education, Molina de Pick built library resources and created reading opportunities to engage the whole family.

### **Okolo Rashid (b. 1949) - Community Development Activist and Historical Preservation Advocate**

Born in Mississippi in 1949, Okolo Rashid grew up in the tumult of racial strife in the south, and has been a life-long advocate of social justice, multiculturalism, and anti-racism. After earning degrees in economics and public policy, she had a varied career, specializing in project administration with a focus on community development projects, including historic preservation, working primarily with inner city communities and grassroots organizations. Her goals continue to use education to promote tolerance and understanding, even in the most difficult times.

### **Brenda Flyswithawks (b. 1950) - American Indian Advocate and Educator**

Brenda Flyswithawks is one of the first women of the Cherokee nation to receive a Ph.D. As a psychologist, Dr. Flyswithawks works as an advocate for the American Indian community to help ensure that their cultural values are respected. She works within and across cultural circles in support of both mutual understanding and cultural home-coming. She started the SEED (Seeking Educational Equity and Diversity) Project at a community college in Santa Rosa, CA and at Wellesley College in Massachusetts.

## **Here's to Your Health**

### ***The Importance of Physical Activity in Healthy Weight Management***



#### **So Many Reasons to Get Going!**

Along with eating healthy, physical activity is integral to weight management. Research has shown that physical activity helps you to lose weight and keep it off. Not only does it burn calories but there are numerous other advantages of a physically active lifestyle ...

- Helps regulate the appetite
- Helps to boost metabolism
- Reduces stress
- May help with insomnia
- Is associated with a decreased risk for heart disease, type 2 diabetes, high blood pressure, Osteoporosis

#### **What's Considered Physical Activity?**

Physical activity is not always about spending hours at the gym. There are many ways to become more physically active.

#### **Every Day Activities**

- Take the stairs.
- Park at the far end of the parking lot.
- Take a walk at lunch time.
- Walk to the store instead of driving.
- Get up to change the TV channel.

Don't be fooled. The calories burned by being more active in your daily routine will add up.

#### **Recreational Activities**

- Enjoy activity with your friends and family: cycling, bowling, gardening, dancing.
- Join a group to enjoy your favorite activity like a cycling club or swim team.
- Maybe now is the time to join that dance class you've always planned to take.

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**Working Out.** An ideal exercise program includes aerobic exercise, strength training, and flexibility exercises. A good goal is to work up to exercising 4 to 6 times a week for at least 30 to 60 minutes each time.

**Aerobic Exercise** burns calories and strengthens the cardiovascular system.

- **Why?** Elevates heart rate for a sustained period of time.
- **How?** Walking, swimming, bicycling, rowing, running, and aerobics classes.
- **How Fast?** Exercise at intensity where you are able to talk but not sing, and sweat a little.

*NOTE: Start slowly – you may only be able to do 5 to 10 minutes at first. If you are over 35, and have been inactive, see your physician before beginning an exercise program.*

**Strength Training** strengthens muscles, increases lean body mass, and helps to strengthen bones.

- **How?** Calisthenics and weight lifting with free weights, resistance bands, and weight machines.
- **How Often?** Should be done 2-3 times per week. The same muscle group should not be worked on consecutive days.
- **Rate?** Start slowly, with lighter weights.

**Flexibility Exercise** (stretching) keeps muscles flexible and joints healthy.

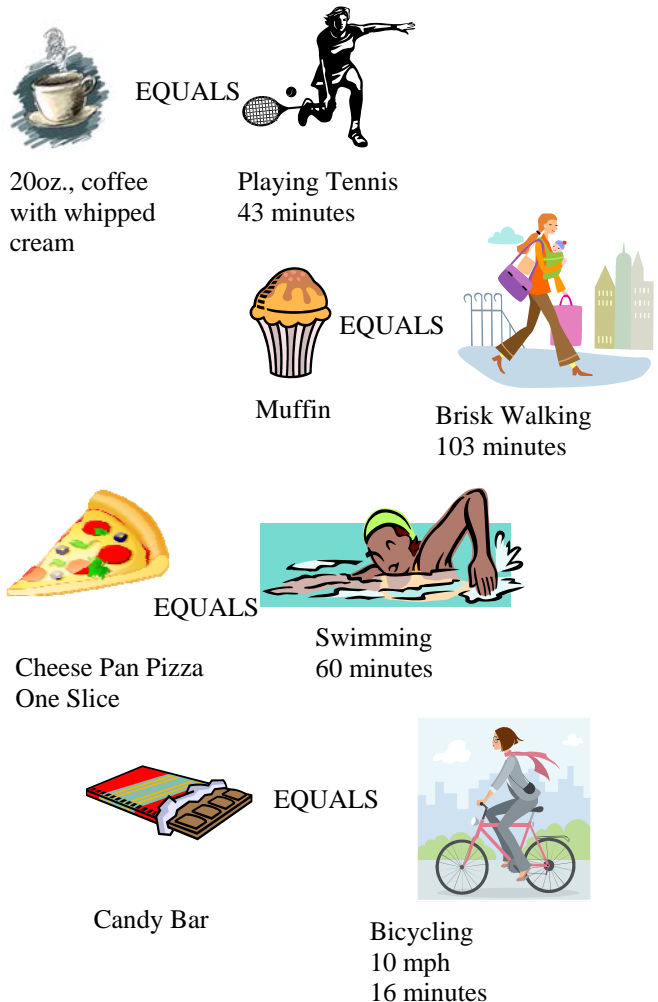
- **When?** Should be done before and after aerobic and strength training exercise, targeting the muscles used.
- **How Often?** Can be done every day to maintain overall flexibility.

*NOTE: Yoga and tai chi also help to maintain flexibility*

## Calories Burned During Specific Activities

### Burning It Off !

The number of calories burned during an activity will depend on body weight, the intensity of the activity and duration. The examples illustrated below is the amount of exercise required for a 150 lb person to burn the calories in some popular foods.



Source: McArdle, William D., Exercise Physiology: nutrition, energy, and human performance/William D. McArdle, Frank I Katch, Victor L. Katch., 7th ed., page 814. Published by Lippincot William & Wilkins, a Wolters Kluwer business, 2010

# CONTRACEPTIVE GEL STUDY



*You can help us learn about how birth control gels affect immune cells in your uterus and cervix.*

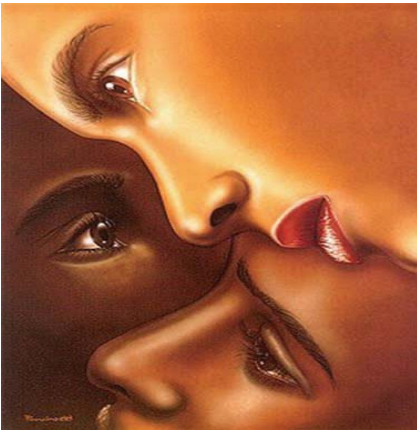
## ***You may be eligible if you:***

- *are 18 to 40 years old and have regular menstrual periods.*
- *are HIV negative and generally healthy.*
- *are not using an IUD, contraceptive gels or hormonal birth control.*
- *are willing to use two different vaginal gels, each for about 10-14 days.*

## ***Study participants will:***

- *be helping in the fight against HIV in women!*
- *come to nine visits at Mt. Zion Hospital (part of UCSF).*
- *be reimbursed **up to \$460** in cash and/or gift cards, plus transportation.*

***Please call Tara at 415-502-8802***



# Join the WIHS

## **What is the WIHS?**

**It is the largest study of HIV among women in the US. The study is being conducted by researchers at the University of California at San Francisco (UCSF) and includes women who are living with HIV and women who do not have HIV.**

## **What will happen if I join?**

**You will have a study visit twice a year including an interview, physical exam and laboratory tests. Study visits will take place in our San Francisco and East Bay Clinics. You will receive \$50 for each study visit, your travel will be compensated, and food and thank-you gifts will be available. All information collected is confidential.**

## **Who can join?**

**If you are an HIV-positive woman and are 30 - 39 years old. Participants will include women of all backgrounds to represent the diversity that the Bay Area is known for.**

## **How do I join WIHS?**

**Call to speak with a member of the WIHS staff. They can determine if you are eligible for the study and answer your questions.**

**PLEASE CALL 415-502-8800 or 510-869-6972**

**Spaces are limited!!!**