

Newsletter Fall 2011

Aging, HIV, and Fracture Risk in Men

By John P. Phair, MD, Principal Investigator, Northwestern University Chicago MACS

Osteoporosis is generally thought of as a women's disease, but what is not as well-known is that over onethird of hip fractures in the general U.S. population occur in men. These fractures not only lead to discomfort, hospitalization, and disability. Additionally, people who have hip fractures are at a greater risk of death compared to otherwise similar people who did not have hip fractures, even up to 10 years after their most recent fracture. What's more is that the risk of death after fracture is even higher among men than in women. Nevertheless, osteoporosis in men remains under-diagnosed and undertreated.

HIV-infected men may be at particularly high risk of fracture, compared to their HIV-uninfected peers. A combination of chronic infection with HIV, the effect of antiretroviral therapy on the bone, and a high prevalence of traditional osteoporosis risk factors (e.g., smoking, alcohol use, low testosterone, and low vitamin D levels) conspire to increase the risk of osteoporosis in HIV-infected persons compared to HIV-uninfected controls. There is emerging evidence suggesting that this increased risk of osteoporosis will translate into an increased risk of fracture. However, with early identification of people at increased risk of fracture, proper preventative measures can be put into place to reduce the risk of fracture.

We typically use dual-energy X-ray absorptiometry (DXA, formerly known as DEXA) to screen people for fracture risk by assessing their bone mineral density. This is a good information about fracture risk, but it doesn't tell you everything. In fact, DXA scanning only explains about 50% of fracture risk. The rest of the risk for fracture is unexplained, and may have to do with other aspects of bone, such as strength, quality, and turnover, as well as non-skeletal factors. These factors have not yet been investigated in HIV-infected men. It's not known how much HIV, the resulting immune activation, and antiretroviral therapies affect these aspects of fracture risk, and how much HIVinfected men differ from HIVuninfected men who are otherwise similar to the HIV-infected men in demographic and behavioral traits.

The MACS has the potential to make a major contribution to our understanding of these issues. We recently received NIH funding to conduct a sub-study to take a comprehensive view of fracture risk in older men in the MACS. Four hundred men (200 HIV-infected and 200 HIVuninfected) will be recruited from the four cities (Chicago, Pittsburgh, Baltimore/D.C., and Los Angeles) to undergo state-of-the-art testing of bone health, including DXA scans, quantitative CT, serum markers of bone turnover, as well as sophisticated measures of muscle and fat (as these latter two factors may influence bone). To study the effect of aging, half of the 400 men will be 50-59 years old, and the other half will be ≥ 60 years old.

Men recruited into the sub-study will also undergo simple tests of strength and balance that will help identify men at increased risk of falling, a major risk factor for fracture that is independent of bone mineral density. We will also recruit additional MACS men ≥ 60 years old to undergo the fall risk assessment. For all men completing the fall risk assessment, we will capture information about

falls in the subsequent 2 years. In this way, we'll be able to tell how well these tools (the simple tests of strength and balance) actually predict the risk of falling.

The information obtained through this substudy could have a major impact on men aging with HIV. For example, if we find that balance and lower extremity function are compromised among older HIV-infected men, these simple tests can be implemented in clinical practice in order to identify patients who may benefit most from physical therapy.

As another example, a finding that inflammation and immune activation are important mediators of bone strength and fall risk would pave the way for investigation of HAART medication which suppress inflammation in addition to suppressing HIV replication, or investigating adjunctive therapy targeting uncontrolled inflammation, with the goal of decreasing fracture risk. We are also partnering with the Women's Interagency HIV Study (WIHS), who have also received an NIH grant to study the same outcomes, so that we can investigate gender differences in fracture and fall risk.

Participating men will be given copies of their DXA reports with interpretation by an expert in the field, and recommendations for referral if needed. Men will be chosen for the study based upon age and several other eligibility criteria. It is important to note that men are specifically chosen through precise criteria for eligibility. Eligible men will be contacted by study coordinators and asked to volunteer for the sub-study. The test-





Newsletter

MACS Participant Spotlight: Q & A

By Amy Miller—HBHC Associate Clinical Coordinator

MACS began recruiting participants in April of 1984. At its peak enrollment, the number of volunteers nationwide reached 6972! Nationwide, there are still around 2050 men still participating, with around 475 still in Chicago! Your dedication to the study after all these years has been truly amazing. We've heard so many inspiring stories: from honoring the memory of friends and lovers who were lost to AIDS, to never letting go of hope for a cure. We asked some of the MACS participants at HBHC to share their stories here, asking:

What motivates you to participate in the MACS year after year?

"In the early 1980s, I, like so many of my friends in the gay community. was stunned, as we felt the impact of this strange deadly disease rampaging through our ranks. I was living in northern West Virginia at the time. and became aware of a new 'study' being hosted by the University of Pittsburgh Medical Center, that was attempting to figure out what was going on, or what was causing this lethal disease, those first Study visits were amazing! Every body fluid and excretion possible was collected in those days. Some dropped out at this point, as providing stool specimens and semen samples were more than they could handle! But as the disease spread and the death toll mounted, this only steeled the resolve of those of us who continued with the Study. Yes, there were fundraisers and education campaigns, but participating in this Study was a very tangible way to do something deeply personal to help combat this horrific mystery disease. Now, almost 30 years later, I still participate

with as much dedication as ever, because a 'cure' has yet to be found, and I owe it to so very many deceased friends, partners, and family, not to let their excruciating sufferings and outrageous humiliations die in vain." - Alan

"The thing that motivates me to participate in MACS year after year is that the research will be able to help in the understanding of our population in the years to come. I also must say that the staff at MACS makes it so pleasant and easy to participate. My past experience with the MACS staff is a big part of why I continue to participate. They're truly amazing.—

Thubten

"I am motivated to participate in MACS because of a question my mother posted 12/25/1996. On Thanksgiving Day 1986, my mother prepared a big dinner for five of my same-gender loving friends at her home. She was happy to meet the men in my life and everybody had a great time. By Christmas 10 years later, all but one of those friends was dead. My Mother (1922-1997) asked why did God spare me, not only to live, but also to be able to show her the annual letters from Howard Brown Health Center saving again and again that I kept testing negative for HIV?!" - Max

"The motivation is to help find a cure to end this wretched disease." - Paul

"I participate in the MACS year after year because I've been in the study since the beginning. I understand that a study involving a number of people over many years can yield some surprisingly important information; some not even imagined when the study began. Also, this is my way to give back to the LGBT community, without which life for me would've

been quit bleak." - Ron

"I volunteered for the MACS in Fall 1984 because I wanted to do something to combat HIV during a very scary time for gay men such as myself. I've kept participating all of these years because MACS continues to be a way that I can both better manage my health care while helping others through the medical research that is supported (in a very small way) by my participation in MACS. We must not forget that HIV is still with us and that many of us continue to live with this 'intruder in our house' every day." - Terry

"What initially prompted me to participate, back when we were SAM, was the idea of getting involved in a small way, that didn't take a lot of time, but could have a significant impact. After my first interview, I thought, 'OMG' (of course, this was back in the late eighties-early nineties, so we all had the time to say the full 'Oh My God'), 'I've done some deliciously trashy stuff. I need to quit. Since that time, what has kept me going is the change in my interview answers (i.e. number of partners, number of intimate encounters while drunk, high, etc.), and it's a nice semi-annual checkup of my own growth as a human being. I also feel a part of history in having helped test the HIV vaccine, and provided valuable behavioral data for social and scientific research. Plus, Nurse Stryker is really cute.—Doug



Newsletter

Fall 2011

Federal Budget Woes

By John P. Phair, MD **Principal Investigator** Northwestern University

Some of you may be asking, "What does the federal deficit mean for the MACS?" The inability of the Congress to agree on a budget for the fiscal year 2010-2011 until April 1, 2011, which was the beginning of MACS wave 55 of data collection, and the resultant reduced federal budget for the remainder of 2010-2011, led to a reduction in the funding for the MACS.

Our fiscal year begins April 1 every year. We were notified that our funding would be reduced to 90% of what we were scheduled to receive this year. Fortunately, sufficient funds were restored in August, to ensure that the three clinics, Howard Brown Health Center, the Ruth M. Rothstein CORE Center (part of the Cook County health system), and Northwestern University's MACS clinic could be fully funded, so that men

in the MACS will see little or no change in their clinic visits.

One casualty of the tight funding situation, however, is the ability to perform the tests for the Human Papilloma Virus (HPV) from anal swab substudy procedures. Those individuals who are due for an anal Pap (cytology) will continue to have their anal swabs on the same cytology schedule (once per year for HIVinfected men and once every other year for HIV-uninfected men). Additionally, those specimens that are collected for cytology testing will be stored in the MACS repository, and pending the procurement of future funding, the HPV testing may be resumed in the future.

Again, cytologic evaluation (anal Paps) will continue unchanged, so that if abnormalities are found, those men will be informed as per the previous protocol and can seek medical attention.

At some sites, such as Howard Brown Health Center, men receiving an anal swab for cytology testing (Pap testing) will be asked to sign an addendum until a new protocol and consent form are approved by the Institutional Review Board (IRB), a committee that oversees the ethical aspects of all research conducted here. After a new protocol and consent form are completed, all participants who had been previously participating will be re-consented.



www.northwestern.edu

Northwestern University MACS Contacts

Theresa Keeley: MACS Research Nurse Phone (312) 695-0186 -Email t-keeley@northwestern.edu

Margarita Aguilar: MACS Research Nurse Phone (312) 695-4997 -Email m-aguilar2@northwestern.edu

HOWARD BROWN HEALTH CENTER

Howard Brown Health Center 4025 N. Sheridan Rd. Chicago, IL 60613

www.howardbrown.org

Kate Lindsay: Amy Miller: Sonia Torres: Michael Maloney:

Howard Brown Health Center MACS Clinic Hours: Mon. 4pm - 6pm | Tues. 9am - 11am | Wed. 8am - 11am

Howard Brown Health Center MACS Scheduling Line: (773) 388-8889 or macs@howardbrown.org

HBHC TOLL FREE (877) 897-2777

MACS Project Coordinator (773) 388-8863 - katel@howardbrown.org

MACS Associate Clinical Coordinator (773) 388-8796 - amym@howardbrown.org

MACS Research Associate (773) 388-8867 - soniat@howardbrown.org MACS Research Associate (773) 388-8683 - mmaloney@howardbrown.org



CORE Center MACS Clinic Hours/Contacts CORE Center MACS Toll Free Number (866) 591-MACS

Tuesday 7:15 am - 11:30 a.m. I Thursday 1:30 pm - 6:30 pm

CORE Center 2020 W. Harrison St. Chicago, IL 60612

Carmon Houston: MACS Project Director (312) 572-4552 - carmonhn@aol.com Landra Tillman: MACS Visit Coordinator (312) 572-4567 - Itillman@aol.com Jessica Alfred: MACS Research Assistant (312) 572-4544 - jalfred@corecenter.org





Newsletter

Why are we doing the "numbers tests" and what do they mean?

By John P. Phair, MD Principal Investigator

At every MACS visit, the volunteers are asked to perform the Trailmaking and Symbol Digit neuropsychological (NP) tests. The results of each test are compared to the previous test results of the same individual; that is, they are comparing each individual participant's score to his own previous scores.

These mini-NP tests screen for change in neurologic function, and can vary for a variety of reasons, including acute illness, such as a cold with fever, fatigue, unrelated concerns, or use of alcohol or drugs in the past 24 hours.

If the Trailmaking and Symbol Digit tests results were lower than would be expected, given how the individual performed in the past, we ask him to complete a longer series of tests of NP functioning. Additionally, individuals who score normally in the Trailmaking and Symbol Digit tasks are still asked to complete this longer NP battery every 2 years in case of any previously undetected neurologic change.

Included in this battery of tests are:

Pegboard task—measures motor
speed, Stroop task—determines if a
person can keep track of more than
one thing at the same time,

CalCAP computer task—evaluates
an individual's reaction time, RAV or

RAVALT—tests the memory for
word recall, and Rey Complex Figure—tests recall of images and
drawings.

The full NP battery takes about 45 minutes to complete these five tasks, so usually we ask the men to return at a later time, at their convenience, to perform them. We also ask all the men in the MACS to perform the complete NP testing every two years.

The clinical significance of a decreasing NP performance, in comparison to a person's past performance, is uncertain. In the MACS, both men who are HIV-infected and HIV-uninfected take these tests. Therefore, we will be able to determine if an individual's change in test results are due solely to aging or to aging plus treated HIV infection.

Howard Brown Health Center MACS Staff Changes

By Kate Lindsay, PhD MACS Project Coordinator, HBHC

It is with great pleasure we announce a more sustainable MACS staffing situation at HBHC that will be optimal for everyone involved with MACS here.

I am still your Project Coordinator, and handle all the higher-up and administrative tasks, lead daily clinic coordination on Wednesdays and Sunday clinic, process substudy results, contact you with concerns about abnormal labs, and a million behind-thescenes scientific and administrative jobs.

Our very own Amy Miller has been promoted to a new position—Associate MACS Clinical Coordinator. Amy will lead the daily clinic coordination (your participant visits) on Monday and Tuesdays, and help coordinate Sunday clinic. Additionally, Amy will enter your primary lab results—T-cells, viral loads,

Decision-Making and Drug Abuse in the Chicago MACS

By Eileen Martin, PhD Professor of Psychiatry and Neurology—UIC

People with current or past drug problems often make decisions impulsively without considering the possible consequences of their actions. The Chicago MACS has been conducting a study of decision-making abilities among HIV-infected and HIVuninfected men who have sex with men and who have used drugs.

The main study measures were computerized "gambling" and "risk-taking" tasks. Data collection was recently completed and the data indicate that the HIV-positive men who continue to use drugs make riskier decisions than HIV-negative men who use drugs in unstructured settings, but take many fewer risks when specific information is available.

and send you those results letters. We are proud to have Amy step into a leadership role!

Sonia Torres, the longest-running staff person at HBHC, is our full-time Research Associate. She is producing scheduling letters, giving you friendly scheduling and reminder calls, interviewing you about medical conditions, and processing serostatus and lipodystrophy/cholesterol results. She'll continue to take great care of all of you at your semiannual visits.

We are **welcoming** to our team Michael Maloney, as a part-time MACS Research Associate. He'll work side-by-side with us all, but especially Sonia, to help with scheduling, reminder calls, and conducting interviews. He's a great addition to the team! Please congratulate everyone on the team for their new roles and welcome Michael to the MACS!