

# MACS news

## 25th Anniversary of the Opening of the MACS

### John Phair, MD – Principal Investigator

This spring marked the 25<sup>th</sup> anniversary of the opening of the MACS, recruitment having begun in April of 1984. The anniversary was marked by a gathering in Washington D.C. held in conjunction with the annual MACS/ WIHS meeting. Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Disease, was the keynote speaker for the event at the Carnegie Institution of Science in Washington. He listed the accomplishments of the MACS which have had a major impact on our understanding of the transmission, progression, and management of HIV infection. Other speakers included Christopher Bates, Director of HIV/ AIDS Policy at the Department of Health and Human Services, Jeff Crowley, Director of the White House Office of National AIDS Policy, Richard Kaslow, MD MPH, founding MACS investigator, Gregg Gonslaves, internationally renowned HIV activist, Shannon Hader, MD, MPH, from the District of Columbia Department of Health, and MACS participants from Baltimore, Pittsburgh, Los Angeles and Chicago. Danny Kopelson represented Chicago extremely well, giving a poignant presentation of his experiences with HIV infection and his experience in the MACS at Howard Brown since 1984. In addition, Potomac Fever of the Gay Men's Chorus of Washington D.C. provided a delightful interval of songs. The formal part of the evening was followed by a reception for the speakers and audience. Kate Lindsay, MACS Project Coordinator at Howard Brown Health Center, was an active member of the organizing committee, whose hard work made the evening a success.

Locally, the anniversary was marked by a reception at the Palmer House Hilton in June, to which all MACS participants were invited. Stephen Phelps, Chairman of the Board of Howard Brown Health Center and MACS participant, opened the formal program and welcomed the participants who had gathered for the evening. John Phair, current Principal Investigator (PI) of the Chicago MACS, and David Ostrow, who was honored as the first PI of the Chicago component of the study, gave brief talks, and the closing remarks were given by Michael Cook, President and CEO of Howard Brown Health Center. Participants from each of the three clinics with the Chicago MACS, Howard Brown, Northwestern and the CORE Center attended and enjoyed the refreshments which

followed the formal program. Thanks to Kate Lindsay, Jenny Mack, Paul Fairchild, and other Howard Brown staff volunteers who made the evening possible.

At both the national and local events, a moment of silence was asked for in memory of the participants in the MACS who died as a consequence of HIV/AIDS. All of the speakers at both events emphasized not only how much had been accomplished in the 25 years since the MACS began, but how much more still remained to be accomplished to control this epidemic. The renewal of the MACS offers the opportunity for the participants and investigators to continue the work begun in 1984.



Dr. John Phair (left) and Dr. David Ostrow (right) at the 25th Anniversary of the MACS reception. For more, see pages 6 & 7.

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## What's the T? The Truth About Cholesterol

Raquel Park MBA, BSN, RN

According to the National Center for Health Statistics (2005), about 17% of Americans aged 20 years old and older have high total cholesterol - 240 mg/dL or above. This can be due to many factors, such as diet, activity, medications, smoking, and weight. Before we can discuss the risks of high cholesterol, we must first understand what cholesterol is, and what role it plays in personal health.

"Cholesterol is a waxy substance produced by the liver and found in certain foods. It is needed to make vitamin D and some hormones, build cell walls, and create bile salts that help you digest fat. Your body produces enough cholesterol so that if you never touched another cheese fry, you'd be OK. But it's hard to avoid cholesterol entirely because so many foods contain it" (The Nemours Foundation, 2006).

Every six months (or each wave), the MACS performs a cholesterol screening on its participants. This important test reveals results about:

- **Total Cholesterol:** measures both the HDL and LDL in the body. This determines the level of risk for heart disease and stroke. Atherosclerosis is thickening and/or build-up of fatty plaque in the arteries. This can lead to a heart attack, stroke, and circulation problems in the legs.
- **HDL:** high density lipoprotein is the "good" cholesterol. The HDL decreases your risk for heart attack and atherosclerosis. This is because the HDL carries cholesterol to the liver, where it is then removed from the body (CDC, 2007). So always keep in mind, the higher the HDL the better!
- **LDL:** low density lipoprotein is the "bad" cholesterol. Instead of taking the cholesterol to the liver to be removed, the LDL takes the cholesterol to the bloodstream. In excess amounts, this can increase the risk of heart disease and atherosclerosis. So, lower LDL is better!
- **Triglycerides:** are a type of fat that is formed after the body has converted food into energy. This surplus energy, the triglycerides, accumulates in the body and can lead to heart disease.

### What can I do?

- **Have your cholesterol checked!** The MACS study performs this test every 6 months (every wave). **So, keep current on your MACS visits!**
- **Diet/Weight:** Eat more lean chicken, turkey and/or very lean cuts of beef, olive and/or canola oil instead of lard or animal fats, raw fruits and veggies with every meal, fiber, egg whites/Egg Beaters instead of egg with the yolk, fish instead of shell-fish (shrimp, lobster, etc.). Decrease fast food and fried food intake.
- **Activity:** Walk! Any form of exercise increases circulation in the body and helps prevent and reduce weight gain.
- **Smoking:** QUIT! Howard Brown Health Center's program: ***Bitch to Quit*** is an excellent resource! Contact: Karyn Haney at 773-388-8682.
- **Medications:** If you are on cholesterol medications, it is important to continue taking them. Diet, weight control, and increasing physical activity may not be enough. Dr. David Wohl believes that when it comes to raising cholesterol and triglycerides, not all protease inhibitors are created equal. People respond to HIV medicines in different ways. Some will see an increase in triglycerides, some a rise in LDL cholesterol, and others will have neither. Plus, drugs other than protease inhibitors can raise cholesterol and triglycerides. This is why it is important that all people taking HIV medications make sure to have their cholesterol and triglycerides checked regularly (The Body, 2008).
  - **Always talk with your doctor before deciding to change your medication regimen.**

**There is only 1 butter that should not be used sparingly..... Boy Butter!**

	Normal Value	Treatment	Notes
<b>Cholesterol</b>	<200	Diet & Exercise	
<b>HDL</b>	>40	Quit smoking & exercise	*the higher the better*
<b>LDL</b>	<100	Decrease fat in diet	
<b>Triglycerides</b>	<150	Decrease sugar & carbs Increase exercise	If tri is too high (>1000 mg/dL), this may lead to pancreatitis

## References:

National Center for Health Statistics. (2005). Health, United States, with Chartbook on the Health of Americans. Hyattsville, Maryland: 2004.

Available at:  
<http://www.cdc.gov/nchs/hus.htm>.

CDC. (2007). About high blood cholesterol.

Available at:  
<http://www.cdc.gov/Cholesterol/about.htm>

The Nemours Foundation. (2006). What is cholesterol? TeensHealth.

Available at:  
<http://kidshealth.org/teen/nutrition/general/cholesterol.html>

The Body. (2005). Cholesterol and triglyceride problems: Part of an HIVer's guide to metabolic complications. Body Health Resources Foundation.

Available at:  
<http://www.thebody.com/content/art6890.html>

## RESEARCH OPPORTUNITY!

### C-Talk

**for guys who have used drugs  
and love sex**

**Come to a ten-week group focused on  
healthy sexuality for men who have used  
cocaine and meth.**

**This is a research study conducted by  
the University of Illinois at Chicago (UIC)  
and Howard Brown Health Center,  
which explores if groups such as this one  
can help men develop a healthier sense  
of sexuality that doesn't always  
depend on using drugs.**

**For more information, please contact:  
[nicolep@howardbrown.org](mailto:nicolep@howardbrown.org)  
or call 773-388-8872**

# MACS news

## Recent Publications of Interest from the MACS

**John Phair, MD –  
Principal Investigator**

One of the major issues confronting HIV-infected persons and their physicians is the correct time to begin HAART. Comparisons of differences in disease progression according to stage of disease when treatment is begun is subject to bias if the duration of infection in those who do not start treatment is not known, and if unseen “fast progressors” are missed. The MACS developed a method using information from the pre-HAART era (1984-1995) to estimate duration of infection and unseen events among “fast progressors” (Stat Med 2004; 23:3351). Deferring HAART until the CD4-T-cell number was below 200/ul was clearly detrimental compared to beginning when the count is between 201 and 350. In contrast, starting HAART between 201 and 350 did not increase the risk of developing AIDS as compared to starting with a CD4-T-cell count between 350 and 500/ul. Although this finding has been confirmed in some other studies but not in others, it is not known whether or not continued elevated viral production at high CD4-T-cell numbers is associated with other diseases, especially those associated with aging such as heart and kidney disease. One of the goals of the MACS is to address this question.

Increasing age was most strongly associated with coronary artery calcification for HIV-uninfected, infected HAART-naïve, and HAART-experienced men in the MACS (AIDS 2008; 22:1589). After adjusting for age, race, family history of heart disease, smoking, cholesterol, and high blood pressure, HIV infection and long-term use of HAART tended to increase the presence of calcification

in the coronary arteries as detected by electron-beam computer tomography. Carotid artery (the artery in the neck) lining thickness, as demonstrated by ultrasound, was less among HAART users for more than eight years who were not taking medication to reduce cholesterol and other serum fats (AIDS 2008; 22:1615). The second round of the cardiovascular study has been completed. The Chicago MACS contributed 239 examinations to the first round of the study. The second exam was conducted approximately three years after the first, and should provide information about progression of arterial disease in HIV infection with and without effective anti-viral therapy.

HIV infection was strongly associated with frailty, a measure of aging (Journal of Gerontology, A Biologic Science 2007; 62:1279). Compared to uninfected men of similar age, ethnicity and education, infected men were more likely to demonstrate frailness independent of the duration of their HIV infection. The prevalence of frailness among 55-year old infected men for less than four years was similar to that of uninfected men equal to or greater than 65 years of age. This first analysis was based upon the answers to questions in the interview. We will now include the information obtained from the measure of grip strength and the timed walk.

Waist, chest, hip, arm and thigh measurements have been included in each six month visit in the MACS since 1999. An analysis demonstrated that changes in these anthropometric measures and loss of peripheral fat were more common in HAART-treated infected men than in uninfected participants (Clinical Infectious Disease 2004; 38: 903). Increase in waist was the most common reported fat accumulation inde-

pendent of HIV infection. (The cohort is aging, as are the investigators). Men had lower body weight, smaller waist, hip, upper arm and thigh circumferences and body mass index (a combination of weight and height).

A novel form of fat accumulation was observed in a handful (8) of men MACS-wide (JAMA 2006; 296:766). These eight men had a band-like accumulation of fat extending on both sides symmetrically from the breasts laterally into the axilla (arm pits). None of the men had evidence of endocrine abnormalities, and the fat accumulation was clearly associated with use of HAART.

The MACS joined a collaboration of the various cohorts being studied in North America several years ago. The collaboration, which is funded by the NIH, is called the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD). The purpose is to be able to answer questions which can only be addressed by studying large numbers of persons. Recently the NA-ACCORD published an analysis addressing the question of when is the optimal time to begin antiretroviral treatment. In contrast to current guidelines, the collaboration found that HIV-infected individuals did better when HAART was begun with CD4 T-cells greater than 350/mm<sup>3</sup> (New England Journal of Medicine 2009; 360:1815). Persons who began treatment at a CD4 T-cell count between 350 and 500 were compared to those who deferred therapy. The risk of death was increased 69% in the deferred therapy group. A second analysis compared persons who began therapy at CD 4 T-cell levels greater than 500 with those who deferred therapy. Again, the early treatment group did better in terms of mortality.



# MACS news

## MACS: Past and Future

**John Phair, MD –  
Principle Investigator**

The Multicenter AIDS Cohort Study was initiated in the fall of 1983 and the first participants recruited in April of 1984, concurrently with the confirmation that this illness characterized by progressively severe immunosuppression was due to a newly identified retrovirus. The virus was named the Human Immunodeficiency Virus (HIV) after prolonged negotiation between the American and French investigators who first isolated the retrovirus from patients with the lymphadenopathy syndrome.

In the 25 years since the beginning of the MACS, effective therapy has been developed and introduced widely in 1996. Infected persons are living longer, and therefore becoming subject to chronic disease due to aging, HAART, and HIV itself. However, basic questions about the varying responses to HIV, therapy and immune responses that could confer protection, and aid in the development of a vaccine, remain only partially understood. The MACS is ideally positioned to address these issues because of long-term standardized follow-up, an extensive specimen repository, and an appropriate control group of uninfected men who have sex with men. Additional strengths include following the more than 600 men who developed HIV infection while in the study, experienced investigators, and a broad network of collaborators with expertise in all aspects of HIV disease. To increase the ability of the MACS to contribute to some of the important treatment issues, the investigators have joined with other North American Cohorts in an NIH-funded collaboration termed the NA-ACCORD.

This will bring together data from close to 30,000 infected individuals. Less common events such as heart attacks, which have been relatively rare in the MACS, can be assessed in this collaboration.

To date, the MACS investigators and their collaborators have published more than 1100 papers, have provided information which altered recommendations regarding the ability of infected persons to function in highly skilled occupations, and provided data that was used to develop guidelines to prevent development of opportunistic infections (antibiotic prophylaxis) in persons with severe immunosuppression. The MACS has made major contributions along with collaborators from the Laboratory of Genetic Diversity, the University of Alabama at Birmingham, the Aaron Diamond Foundation, and the University of Washington, toward the understanding of the role of host genetics upon protection from and progression of HIV infection. A recent issue of Science highlighted the MACS as one of three NIH initiatives that provided the highest return for the cost. Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Disease which funds the MACS, stated that the MACS was a gift that kept on giving.

The current cycle of funding of the MACS began on April 1, 2009 and will continue until March 31, 2014. During the next five years, MACS investigators will continue to investigate the biology of HIV infection, the human response to infection, and the clinical outcomes of treated and untreated HIV infection.

The overall goals for the next five years are:

- 1) to better understand HIV/AIDS in aging infected men with extended survival due to effective treatment
- 2) to characterize the biologic changes in response to HIV infection and HAART
- 3) to observe psychosocial responses to prolonged survival and their impact on management of HIV infection, risk behaviors, HIV transmission and the biology of infection.

New initiatives will be presented to the Chicago MACS Community Advisory Boards and outlined in the subsequent newsletters.

# MACS news

## On the Occasion of the 25<sup>th</sup> Anniversary of the Chicago MACS: *"The Work Has Just Begun to Prevent a New Health Crisis in Our Community"*

**David G Ostrow, MD, PhD**  
**First Principal Investigator**  
**Chicago MACS 1983**

On this very important celebration of the 25<sup>th</sup> Anniversary of the Chicago Multicenter AIDS Cohort Study (MACS), we gathered on the evening of June 4th to recognize the contribution to the health of the gay community made by the participants and investigators of this landmark study. I can well remember those significant and disturbing events that marked the beginning of the AIDS crisis in Chicago, and throughout the gay subculture in the early '80s, and the eagerness of the Howard Brown Clinic and Northwestern University to effectively respond to that crisis. One of the reasons that the Howard Brown Health Center (HBHC) was selected to be one of the original sites of the MACS was the trailblazing work that we had already achieved in proving the sexual transmission of hepatitis B among MSM, and the initial trials of the first hepatitis B vaccine. These efforts not only led to the development of the first vaccine against an STI, but also provided many research organizations, including the CDC, to rapidly respond to early reports of Kaposi's sarcoma and opportunistic infections among gay and bisexual men. Also, as a result of the hepatitis B studies and HBHC's role in that research, special legislation was passed that permitted government agencies, like the CDC, to directly fund the efforts of community health agencies, like HBHC, rather than having to channel all their funding through local and state health departments. That important change laid the path for the funding of all the early community-based HIV prevention programs.

But speaking about the early hepatitis B studies at HBHC and the government's involvement in gay community research reminds me of a very sober point. That is, no matter how congratulatory and celebratory we feel about the major accomplishments of the MACS over the past 25 years, we still have a health crisis in our community, and we may be at the start of new health crises. I speak, of course, of the increasing rates of HIV infection among gay men in general, and young and minority gay men in particular, just now being reported by the Chicago Dept. of Public Health (CDPH) in their community-wide HIV risk assessment program just released. That report shows that African American MSM have almost 3 times the HIV prevalence rate of white or Latino MSM in our community (over 30% for African American MSM, as compared to 10-12% of white and Latino MSM), and the role that sex-drug use (stimulants, poppers and erectile dysfunction drugs) are playing in these new infections. Even more shocking is the fact that approximately half of the men who tested HIV+ in the CDPH surveillance study **WERE NOT AWARE OF THEIR HIV+ STATUS!!** So let's celebrate the work that has been accomplished, but also take home the important message that in some ways our work has just begun.

It is a bitter paradox that our success in finding the cause of AIDS and developing highly active anti-retroviral treatments, or HAART, to combat HIV, have contributed to the attitudes and beliefs of some in our community, particularly those who were not "out" or even born at the time when AIDS was a death sentence, that are at the heart of the increasing infection rates among MSM and minority and young MSM

in particular. We can, however, feel positive that the MACS, through the Men's Attitude Survey that was instituted in 1999 and which has been administered every two years since, is a major source of information about the role of changing attitudes towards AIDS/HIV since the introduction of HAART. But recognizing the problem is just the first step to solving it.

I hope that we can all agree that HIV infection is still a great threat to our community, not to mention the potential for the development of HAART-resistant strains of HIV and treatment resistant forms of syphilis, gonorrhea and other STIs, through "barebacking" behavior. Now we need to openly discuss this issue, not only among ourselves, but also in reaching out to the younger and most vulnerable members of our community. Hopefully the MACS will, in the near future, re-open enrollment to younger MSM, particularly newly infected or at-risk minority men, so that they too can benefit from the education and prevention counseling.

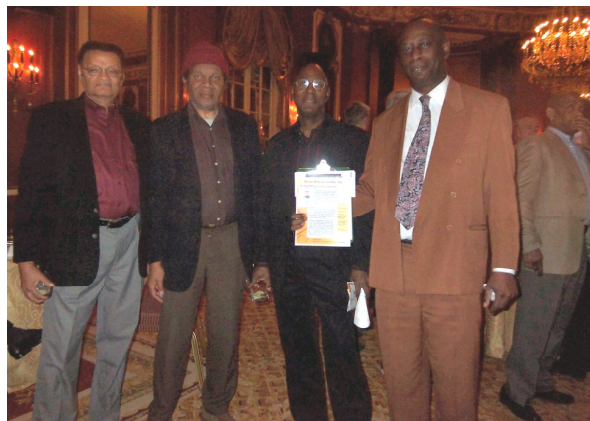
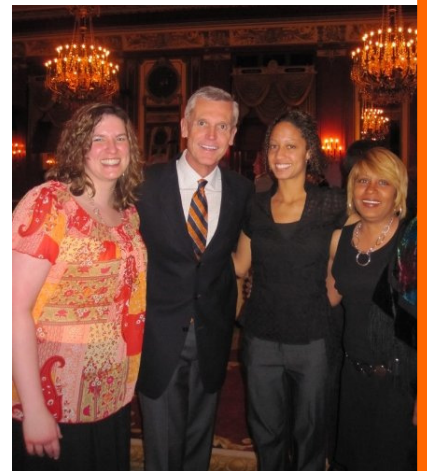
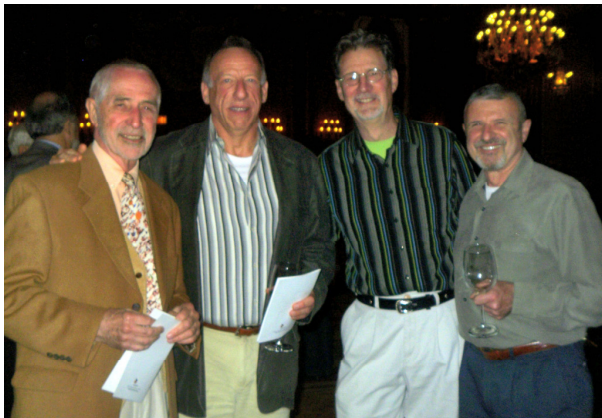
In addition to thanking all of you that have made this event possible, I want to state that as a person living with HIV since 1981, or going on 29 years, I, too, have benefited from the MACS and all of the HIV prevention education and counseling that it has generated and supported. Everyone here is a survivor, whether of HIV, or just living through the AIDS crisis to this point. Let's remember and celebrate our survivorship on this occasion and rededicate ourselves to helping our community avoid another set of health crises in the future.

Thank you for this award on this important 25<sup>th</sup> anniversary of the world's largest and longest ongoing study of both men with HIV infection and those at-risk.



Summer, 2009

# MACS news





# MACS news

## MACS Participant Spotlight

### John Darey

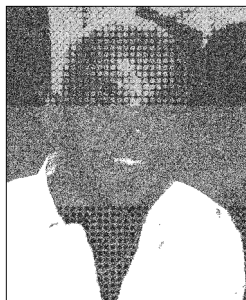
**Margarita Aguilar, RN BSN,  
Research Nurse**

The MACS study has become a rich and intricate tapestry woven in the last 25 years. It has become enriched by our founders, staff, and most importantly, our participants. As we celebrate our anniversary, it is our participants who have given life to this endeavor that began in 1984. Each participant brings with him a unique life experience which creates a wonderful and appreciated contribution to our tapestry of science. One person at Northwestern University comes to mind. John Darey has been a participant for 8 years, and he always comes to his study visits with his welcoming smile and his tales of adventures. He lives life, and celebrates it daily.

John grew up as the fourth child out of five. John and his family lived in LeClaire Courts, one of the first integrated housing projects in Chicago. As an African-American child living in this housing project on the south side of Chicago, John recalls warm memories as a child. He was sheltered from the racial tension of the 1960s by his parents.

As he entered his early teen years, John became aware of his sexual orientation. He embraced it openly, and he lived it without hesitation. His sexual direction surprised his siblings. But with the loving firmness of his mother, each of John's brothers and sisters were told that they were to love and accept their brother. To this day, John is very close to his siblings.

Eighteen years ago, John was diagnosed with HIV after donating to a blood drive at work. In his own words,



John Darey

"I went completely crazy. I thought I had been given a death sentence." For a year, John experimented with alcohol and drugs daily. He then had a moment of clarity and sought medical care at Northwestern Memorial Hospital, where he was treated by Dr. Robert Murphy. He still expresses his gratitude for the non-judgmental and supportive care he received during this difficult time.

Presently, John is doing great medically. Recently, he and his life partner, George, celebrated their thirteen-year anniversary. John lovingly describes George as the most compassionate person he has ever known, and he wishes that he had met him earlier in his life. John and George are now planning their next life adventure.

John and George were present at the MACS 25<sup>th</sup> anniversary event at the Palmer House in June. John appreciated the opportunity to meet the others with HIV that have not only survived but thrived following their diagnosis. It is John's wish that more people realize that a HIV diagnosis is not a death sentence. He expressed his concern about the African-American and Latino community, feeling that their fear and mistrust of the white medical community puts them at a higher risk.

John Darey continues to weave his special pattern of joy and gratitude into our day at Northwestern, which sometimes includes his homemade cookies.

## MACS Clinic Hours:

Monday 4-7 p.m.  
Tuesday 9-11 a.m.  
Wednesday 8-11 a.m.

## MACS Scheduling Line:

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