

THANKS FOR JOINING THE MWCCS STUDY

As a participant of the MACS-WIHS Combined Cohort Study (MWCCS) you are part of one of the most important research studies looking at the impact of HIV/AIDS. You should feel proud to join over 4,000 other participants, some of whom have been in the study since the early-1980s.

This welcome sheet has been prepared by volunteer participants who serve on the MWCCS National Community Advisory Board (NCAB). See the article in this flyer about the NCAB.

WHAT TO EXPECT ON YOUR STUDY VISIT?

Study visits are notated by a visit number. Visit 102 begins in October 2021 and should conclude by September 2022.

The design of study visits generally includes two semi-annual visits both likely in-person at your local site. The length of each visit varies by the number of tests scheduled to be performed.

The first activity participants will take part in is the consenting process where participants are made aware what the study process will include and acknowledgement of participation in the study.

The in-person visit has three major components:

- Questionnaires
- Physical & Research (Scientific) Tests
- Blood Draws

While there are several different questionnaires part of this study, to ease the burden on each participant, some are administered at a computer and are done in private; others are administered by a study staff member, and sometimes some are done on the phone.

While some of these questionnaires can get fairly personal with the questions, it's important to answer as honestly as possible. It's critical for the study to have honest and accurate responses. You need not be

embarrassed, the person administering them is a professional and is not making any judgements on you.

The Physical and research (scientific) tests vary by visit and site. Most will participate in a host of core tests including, but not limited to, walking, balance, hearing, physical assessments, frailty, lipodystrophy measurements, muscle strength, neuropsychological tests, an oral exam and, for women, a gynecological exam.

Sometimes there are other special research efforts that require additional tests such as Pulmonary Function Tests (PFT), echocardiogram, and fibro scan. In some cases, you may be asked to come back for a special test that could be performed at another location. Your participation is voluntary, but is important for the general benefit of the study.

Bloodwork is the third important and critical component of the study visit. Blood tests are performed on our samples and the good thing is we are provided with test results. This can include a Complete Blood Count (CBC), HIV test, Viral Load, cholesterol, liver and kidney function, blood sugar count tests. These blood test results are generally made available to participants so we can share the results with our personal physician. Some of the blood is also stored for future research. See the accompanying article to understand why so much blood is drawn.

IT TAKES A VILLAGE...TO RUN AN MWCCS SITE

As a participant, we generally develop a relationship with local site research coordinators/staff via calls, emails and at in-person visits. The coordinator serves as our main point of contact and he or she also is shepherding you through the study visits, and also may administer some of the tests that will be performed.

The exact staffing at each site can vary, but there is an organization of dedicated persons who work behind the scenes at the site to make this historic study run. The number and organization of the study staff varies by the size and organization of each site, but generally the

staffing is composed of research personnel dedicated to the success of the study.

Site staff can include: Principal and Co-Investigators, Clinical Director, Clinical Coordinator, Project Director, Clinical Research Nurses, Research Coordinators, Phlebotomists, Supporting Doctors & Physician Assistants, Midwives, and Laboratory Staff & Technicians.

MWCCS: WHAT'S BEHIND THE NAME

The MACS WIHS COMBINED COHORT STUDY (MWCCS) is a mouthful, but the name reflects its origins and the study's two original landmark studies: MACS and WIHS.

MACS stands for the Multicenter AIDS Cohort Study which began in 1984 as a research study of HIV in gay and bisexual men in the United States. At its highpoint, more than 7,300 study participants were enrolled and were evaluated twice a year in study visits. It's hard to think back to 1984, a time where gay men were becoming sick and dying from a mysterious illness nicknamed the "gay plague" or "gay cancer". We just didn't have the answers of what was happening so this historic study was started, and now over 35 years later, has provided a tremendous amount of research that has helped countless researchers and scientists get to the point where HIV was discovered, antiretroviral therapies were developed and HIV is now treatable disease.

The Women's Interagency HIV Study (WIHS) was organized in 1993 to study the progression of HIV disease, but focused on women. Over 5,000 women were enrolled in WIHS and participated in research topics focusing on the impact of HIV on women's reproductive health, clinical outcomes (for example, cardiovascular disease, diabetes, and others), and the effectiveness of antiretroviral therapy. The WIHS research has made important contributions to medical knowledge and has led to a greater understanding of how HIV impacts the health of women.

In 2021, these two studies were united into the MACS WIHS Combined Cohort Study (MWCCS) and are now managed by a joint leadership organization.

More information about the studies can be found on the MWCCS website:

<https://statepi.jhsph.edu/mwccs/>

WHY IS SO MUCH BLOOD DRAWN?

In the Spring-Summer 2021 edition of the NCAB News! There is an article written by Dr. Beth D Jamieson that explains the importance of studying blood and why the study collects the amount of blood they do during each study visit. You can read the full article and the rest of the newsletters on the NCAB website.

ABOUT THE MWCCS NCAB

The NCAB is a volunteer-led and staffed group of study participants who support the study, its outcomes, and participant interests. The NCAB bylaws state five key goals for the group:

- Identify pertinent research issues not addressed.
- Provide study concerns to MWCCS leadership.
- Provide feedback on proposed research activities.
- Communicate study results to MWCCS participants.
- Support local community advisory boards.

If you are interested in learning more about your local CAB, or volunteering to serve on it, contact your local study staff, or ask about the CAB at your next study visit.

HOW TO CONTACT OR LEARN MORE ABOUT THE NCAB

You can contact the NCAB by sending an email to the NCAB at: mwccsncab@gmail.com



You may also learn more the NCAB on the NCAB website where past newsletters are available for viewing.

<https://statepi.jhsph.edu/mwccs/ncab/>