

## **The Combined Value of Our Contributions to AIDS Research: A Study Participant's Personal Perspective on Years of Study Participation**

By Marc C.E. Wagner, MACS NCAB member and study participant since 1984

The beginning of the AIDS epidemic came with great uncertainty. All that was being reported is that an ever-increasing number of gay men were coming down with this mysterious disease. They were dying and science was struggling with why. Born out of this chaos was the Multicenter AIDS Cohort Study (MACS) in 1984. The principal investigators faced a daunting task of recruiting men, collecting blood and other samples to probe for answers. Once the causative virus, later dubbed the Human Immunodeficiency Virus or HIV was discovered, then the race began to develop tests to determine who had been infected. If it was not for this effort, many of the early study participants would not have known they were infected, until a commercial test became available. I was later informed by the study that I converted from HIV negative to HIV positive between my first visit in 1984 and my second visit in early 1985.

Technology was not as advanced in the early 1980's, so a very labor-intensive test was used to determine if someone had been infected. The study was tasked to answer the important questions on how the virus is spread, what is the virus doing to the immune system, and how can its spread be prevented.

The Women's Interagency HIV Study (WIHS) came along later in 1993 as by this point the epidemic in the United States moved from just men to also women. In Africa, it was already a disease that affected both men and women. In speaking with Marilyn who is a WIHS study participant since 1993, she had concerns about joining the study because of the Tuskegee Experiment where individuals were left untreated after testing positive for syphilis. This was a barrier, but she joined and has been a faithful participant ever since.

The studies have provided so much value over all these years to each and every participant. Both HIV positive and HIV negative individuals have participated in twice a year visits and a large battery of laboratory tests are done, in addition to many other tests, such as tests for cognitive function. There have been ancillary studies looking at the heart, lungs, and the brain that would not have been done at such early ages. The study made it possible. Many participants were then informed of issues before they became severe. The time spent as a volunteer participant in the now MACS/WIHS Combined Cohort Study (MWCCS) was and remains well worth it. Dr. Fauci reportedly stated that the MWCCS is the study that keeps on giving. The data and samples obtained for the 35 plus years is the cornerstone of its success and it could only be done because of each and every participant's contribution.