Remembering Tuskegee - Syphilis Study Still Provokes Disbelief, Sadness

July 25, 2002 --Thirty years ago today, the *Washington Evening Star* newspaper ran this headline on its front page: "Syphilis Patients Died Untreated." With those words, one of America's most notorious medical studies, the Tuskegee Syphilis Study, became public. "For 40 years, the U.S. Public Health Service has conducted a study in which human guinea pigs, not given proper treatment, have died of syphilis and its side effects," Associated Press reporter Jean Heller wrote on July 25, 1972. "The study was conducted to determine from autopsies what the disease does to the human body."

Nurses examine one of the Tuskegee syphilis study participants.

Photo courtesy National Archives

The next morning, every major U.S. newspaper was running Heller's story. For *Morning Edition*, NPR's Alex Chadwick reports on how the Tuskegee experiment was discovered after 40 years of silence.The Public Health Service, working with the Tuskegee Institute, began the study in 1932. Nearly 400 poor black men with syphilis from Macon County, Ala., were enrolled in the study. They were never told they had syphilis, nor were they ever treated for it. According to the Centers for Disease Control, the men were told they were being treated for "bad blood," a local term used to describe several illnesses, including syphilis, anemia and fatigue. For participating in the study, the men were given free medical exams, free meals and free burial insurance.

At the start of the study, there was no proven treatment for syphilis. But even after penicillin became a standard cure for the disease in 1947, the medicine was withheld from the men. The Tuskegee scientists wanted to continue to study how the disease spreads and kills. The experiment lasted four decades, until public health workers leaked the story to the media. By then, dozens of the men had died, and many wives and children had been infected. In 1973, the National

Association for the Advancement of Colored People (NAACP) filed a class-action lawsuit. A $9 million settlement was divided among the study's participants. Free health care was given to the men who were still living, and to infected wives, widows and children.

On behalf of the country, President Clinton apologized in 1997 to Charlie Pollard, pictured here, and other Tuskegee survivors.
Photo courtesy Joan Echtenkamp Klein

But it wasn't until 1997 that the government formally apologized for the unethical study. President Clinton delivered the apology, saying what the government had done was deeply, profoundly and morally wrong:"To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. "What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say, on behalf of the American people: what the United States government did was shameful. "And I am sorry."

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Apology For Study Done in Tuskegee
THE WHITE HOUSEOffice of the Press Secretary

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REMARKS BY PRESIDENT CLINTON
IN APOLOGY FOR STUDY DONE IN TUSKEGEE

The East Room

2:26 P.M. EDT

THE PRESIDENT: Ladies and gentlemen, on Sunday, Mr. Shaw will celebrate his 95th birthday. (Applause.) I would like to recognize the other survivors who are here today and their families: Mr. Charlie Pollard is here. (Applause.) Mr. Carter Howard. (Applause.) Mr. Fred Simmons. (Applause.) Mr. Simmons just took his first airplane ride, and he reckons he's about 110 years old, so I think it's time for him to take a chance or two. (Laughter.) I'm glad he did. And Mr. Frederick Moss, thank you, sir. (Applause.)

I would also like to ask three family representatives who are here -- Sam Doner is represented by his daughter, Gwendolyn Cox. Thank you, Gwendolyn. (Applause.) Ernest Hendon, who is watching in Tuskegee, is represented by his brother, North Hendon. Thank you, sir, for being here. (Applause.) And George Key is represented by his grandson, Christopher Monroe. Thank you, Chris. (Applause.)

I also acknowledge the families, community leaders, teachers and students watching today by satellite from Tuskegee. The White House is the people's house; we are glad to have all of you here today. I thank Dr. David Satcher for his role in this. I thank Congresswoman Waters and Congressman Hilliard, Congressman Stokes, the entire Congressional Black Caucus. Dr. Satcher, members of the Cabinet who are here, Secretary Herman, Secretary Slater, members of the Cabinet who are here, Secretary Herman, Secretary Slater. A great friend of freedom, Fred Gray, thank you for fighting this long battle all these long years.

The eight men who are survivors of the syphilis study at Tuskegee are a living link to a time not so very long ago that many Americans would prefer not to remember, but we dare not forget. It was a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy. It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future. And without remembering it, we cannot make amends and we cannot go forward.

So today America does remember the hundreds of men used in research without their knowledge and consent. We remember them and their family members. Men who were poor and African American, without resources and with few alternatives, they believed they had found hope when they were offered free medical care by the United States Public Health Service. They were betrayed.

Medical people are supposed to help when we need care, but even once a cure was discovered, they were denied help, and they were lied to by their government. Our government is supposed to protect the rights of its citizens; their rights were trampled upon. Forty years, hundreds of men betrayed, along with their wives and children, along with the community in Macon County, Alabama, the City of Tuskegee, the fine university there, and the larger African American community.

The United States government did something that was wrong -- deeply, profoundly, morally wrong. It was an outrage to our commitment to integrity and equality for all our citizens.

To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry. (Applause.)

The American people are sorry -- for the loss, for the years of hurt. You did nothing wrong, but you were grievously wronged. I apologize and I am sorry that this apology has been so long in coming. (Applause.)

To Macon County, to Tuskegee, to the doctors who have been wrongly associated with the events there, you have our apology, as well. To our African American citizens, I am sorry that your federal government orchestrated a study so clearly racist. That can never be allowed to happen again. It is against everything our country stands for and what we must stand against is what it was.

So let us resolve to hold forever in our hearts and minds the memory of a time not long ago in Macon County, Alabama, so that we can always see how adrift we can become when the rights of any citizens are neglected, ignored and betrayed. And let us resolve here and now to move forward together.

The legacy of the study at Tuskegee has reached far and deep, in ways that hurt our progress and divide our nation. We cannot be one America when a whole segment of our nation has no trust in America. An apology is the first step, and we take it with a commitment to rebuild that broken trust. We can begin by making sure there is never again another episode like this one. We need to do more to ensure that medical research practices are sound and ethical, and that researchers work more closely with communities.

Today I would like to announce several steps to help us achieve these goals. First, we will help to build that lasting memorial at Tuskegee. (Applause.) The school founded by Booker T. Washington, distinguished by the renowned scientist George Washington Carver and so many others who advanced the health and well-being of African Americans and all Americans, is a fitting site. The Department of Health and Human Services will award a planning grant so the school can pursue establishing a center for bioethics in research and health care. The center will serve as a museum of the study and support efforts to address its legacy and strengthen bioethics training.

Second, we commit to increase our community involvement so that we may begin restoring lost trust. The study at Tuskegee served to sow distrust of our medical institutions, especially where research is involved. Since the study was halted, abuses have been checked by making informed consent and local review mandatory in federally-funded and mandated research.

Still, 25 years later, many medical studies have little African American participation and African American organ donors are few. This impedes efforts to conduct promising research and to provide the best health care to all our people, including African Americans. So today, I'm directing the Secretary of Health and Human Services, Donna Shalala, to issue a report in 180 days about how we
can best involve communities, especially minority communities, in research and health care. You must -- every American group must be involved in medical research in ways that are positive. We have put the curse behind us; now we must bring the benefits to all Americans. (Applause.)

Third, we commit to strengthen researchers' training in bioethics. We are constantly working on making breakthroughs in protecting the health of our people and in vanquishing diseases. But all our people must be assured that their rights and dignity will be respected as new drugs, treatments and therapies are tested and used. So I am directing Secretary Shalala to work in partnership with higher education to prepare training materials for medical researchers. They will be available in a year. They will help researchers build on core ethical principles of respect for individuals, justice and informed consent, and advise them on how to use these principles effectively in diverse populations.

Fourth, to increase and broaden our understanding of ethical issues and clinical research, we commit to providing postgraduate fellowships to train bioethicists especially among African Americans and other minority groups. HHS will offer these fellowships beginning in September of 1998 to promising students enrolled in bioethics graduate programs.

And, finally, by executive order I am also today extending the charter of the National Bioethics Advisory Commission to October of 1999. The need for this commission is clear. We must be able to call on the thoughtful, collective wisdom of experts and community representatives to find ways to further strengthen our protections for subjects in human research.

We face a challenge in our time. Science and technology are rapidly changing our lives with the promise of making us much healthier, much more productive and more prosperous. But with these changes we must work harder to see that as we advance we don't leave behind our conscience. No ground is gained and, indeed, much is lost if we lose our moral bearings in the name of progress.

The people who ran the study at Tuskegee diminished the stature of man by abandoning the most basic ethical precepts. They forgot their pledge to heal and repair. They had the power to heal the survivors and all the others and they did not. Today, all we can do is apologize. But you have the power, for only you -- Mr. Shaw, the others who are here, the family members who are with us in Tuskegee -- only you have the power to forgive. Your presence here shows us that you have chosen a better path than your government did so long ago. You have not withheld the power to forgive. I hope today and tomorrow every American will remember your lesson and live by it.

Thank you, and God bless you. (Applause.)

http://clinton4.nara.gov/textonly/New/Remarks/Fri/19970516-898.html

The Tuskegee Syphilis Experiment

The U.S. government's 40-year experiment on black men with syphilis

by Borgna Brunner

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clearly racist."

—President Clinton's apology for the Tuskegee Syphilis Experiment to the eight rem
16, 1997

For forty years between 1932 and 1972, the U.S. Public Health Service (PHS) conducted an experiment on 399 black men in the late stages of syphilis. These men, for the most part illiterate sharecroppers from one of the poorest counties in Alabama, were never told what disease they were suffering from or of its seriousness. Informed that they were being treated for “bad blood,” their doctors had no intention of curing them of syphilis at all.

The data for the experiment was to be collected from autopsies of the men, and they were thus deliberately left to degenerate under the ravages of tertiary syphilis—which can include tumors, heart disease, paralysis, blindness, insanity, and death. “As I see it,” one of the doctors involved explained, “we have no further interest in these patients until they die.”

Using Human Beings as Laboratory Animals

Taliaferro Clark, Head of the U.S. Public Health Service at the outset of the experiment.

The true nature of the experiment had to be kept from the subjects to ensure their cooperation. The sharecroppers' grossly disadvantaged lot in life made them easy to manipulate. Pleased at the prospect of free medical care—almost none of them had ever seen a doctor before—these unsophisticated and trusting men became the pawns in what James Jones, author of the excellent history on the subject, *Bad Blood,* identified as “the longest nontherapeutic experiment on human beings in medical history.”

The study was meant to discover how syphilis affected blacks as opposed to whites—the theory being that whites experienced more neurological complications from syphilis, whereas blacks were more susceptible to cardiovascular damage. How this knowledge would have changed clinical treatment of syphilis is uncertain.

Although the PHS touted the study as one of great scientific merit, from the outset its actual benefits were hazy. It took almost forty years before someone involved in the study took a hard and honest look at the end results, reporting that “nothing learned will prevent, find, or cure a single case of infectious syphilis or bring us closer to our basic mission of controlling venereal disease in the United States.”

When the experiment was brought to the attention of the media in 1972, news anchor Harry Reasoner described it as an experiment that “used human beings as laboratory animals in a long and inefficient study of how long it takes syphilis to kill someone.”

A Heavy Price in the Name of Bad Science

> **To ensure that the men would show up for a painful and potentially dangerous spinal tap, the PHS doctors misled them with a letter full of promotional hype: “Last Chance for Special Free Treatment.”**
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> **The fact that autopsies would eventually be required was also concealed.**

By the end of the experiment, 28 of the men had died directly of syphilis, 100 were dead of related complications, 40 of their wives had been infected, and 19 of their children had been born with congenital syphilis. How had these men been induced to endure a fatal disease in the name of science?

To persuade the community to support the experiment, one of the original doctors admitted it “was necessary to carry on this study under the guise of a demonstration and provide treatment.” At first, the men were prescribed the syphilis remedies of the day—bismuth, neoarsphenamine, and mercury— but in such small amounts that only 3 percent showed any improvement.

These token doses of medicine were good public relations and did not interfere with the true aims of the study. Eventually, all syphilis treatment was replaced with “pink medicine”—aspirin.

To ensure that the men would show up for a painful and potentially dangerous spinal tap, the PHS doctors misled them with a letter full of promotional hype: “Last Chance for Special Free Treatment.” The fact that autopsies would eventually be required was also concealed.

As a doctor explained, “If the colored population becomes aware that accepting free hospital care means a post-mortem, every darky will leave Macon County...” Even the Surgeon General of the United States participated in enticing the men to remain in the experiment, sending them certificates of appreciation after 25 years in the study.

Following Doctors' Orders

It takes little imagination to ascribe racist attitudes to the white government officials who ran the experiment, but what can one make of the numerous African Americans who collaborated with them? The experiment's name comes from the Tuskegee Institute, the black university founded by Booker T. Washington. Its affiliated hospital lent the PHS its medical facilities for the study, and other predominantly black institutions as well as local black doctors also participated. A black nurse, Eunice Rivers, was a central figure in the experiment for most of its forty years.

The Veterans' Administration Hospital in Tuskegee, Alabama. Some of the study's post-mortem exams were conducted here.

The promise of recognition by a prestigious government agency may have obscured the troubling aspects of the study for some. A Tuskegee doctor, for example, praised “the educational advantages offered our interns and nurses as well as the added standing it will give the hospital.” Nurse Rivers explained her role as one of passive obedience: “we were taught that we never diagnosed, we never prescribed; we followed the doctor's instructions!”

It is clear that the men in the experiment trusted her and that she sincerely cared about their well-being, but her unquestioning submission to authority eclipsed her moral judgment. Even after the experiment was exposed to public scrutiny, she genuinely felt nothing ethical had been amiss.

One of the most chilling aspects of the experiment was how zealously the PHS kept these men from receiving treatment. When several nationwide campaigns to eradicate venereal disease came to Macon County, the men were prevented from participating. Even when penicillin—the first real cure for syphilis—was discovered in the 1940s, the Tuskegee men were deliberately denied the medication.

During World War II, 250 of the men registered for the draft and were consequently ordered to get treatment for syphilis, only to have the PHS exempt them. Pleased at their success, the PHS representative announced: “So far, we are keeping the known positive patients from getting treatment.” The experiment continued in spite of the Henderson Act (1943), a public health law requiring testing and treatment for venereal disease, and in spite of the World Health Organization's Declaration of Helsinki (1964), which specified that “informed consent” was needed for experiments involving human beings.

Blowing the Whistle

The PHS did not accept the media's comparison of Tuskegee with the experiments performed by Nazi doctors on Jewish victims during World War II. Yet the PHS offered the same defense offered at the Nuremberg trials — they were just carrying out orders.

The story finally broke in the *Washington Star* on July 25, 1972, in an article by Jean Heller of the Associated Press. Her source was Peter Buxtun, a former PHS venereal disease interviewer and one of the few whistle blowers over the years. The PHS, however, remained unrepentant, claiming the men had been “volunteers” and “were always happy to see the doctors,” and an Alabama state health officer who had been involved claimed “somebody is trying to make a mountain out of a molehill.”

Under the glare of publicity, the government ended their experiment, and for the first time provided the men with effective medical treatment for syphilis. Fred Gray, a lawyer who had previously defended Rosa Parks and Martin Luther King, filed a class action suit that provided a $10 million out-of-court settlement for the men and their families. Gray, however, named only whites and white organizations as defendants in the suit, portraying Tuskegee as a black and white case when it was in fact more complex than that—black doctors and institutions had been involved from beginning to end.

The PHS did not accept the media's comparison of Tuskegee with the appalling experiments performed by Nazi doctors on their Jewish victims during World War II. Yet in addition to the medical and racist parallels, the PHS offered the same morally bankrupt defense offered at the Nuremberg trials: they claimed they were just carrying out orders, mere cogs in the wheel of the PHS bureaucracy, exempt from personal responsibility.

The study's other justification—for the greater good of science—is equally spurious. Scientific protocol had been shoddy from the start. Since the men had in fact received some medication for syphilis in the beginning of the study, however inadequate, it thereby corrupted the outcome of a study of “untreated syphilis.”

The Legacy of Tuskegee

In 1990, a survey found that 10 percent of African Americans believed that the U.S. government created AIDS as a plot to exterminate blacks, and another 20 percent could not rule out the possibility that this might be true. As preposterous and paranoid as this may sound, at one time the Tuskegee experiment must have seemed equally farfetched.

Who could imagine the government, all the way up to the Surgeon General of the United States, deliberately allowing a group of its citizens to die from a terrible disease for the sake of an ill-conceived experiment? In light of this and many other shameful episodes in our history, African Americans' widespread mistrust of the government and white society in general should not be a surprise to anyone.

1. All quotations in the article are from *Bad Blood: The Tuskegee Syphilis Experiment,* James H. Jones, expanded edition (New York: