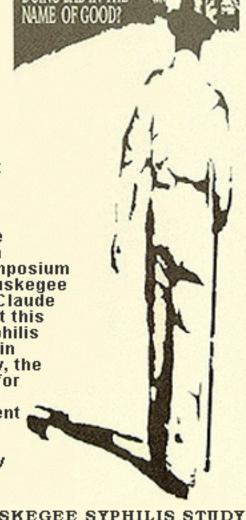


witness the apology.

THE TROUBLING LEGACY OF THE TUSKEGEE SYPHILIS STUDY

For forty years, from 1932 to 1972, 399 African-American males were denied treatment for syphilis and deceived by officials of the United States Public Health Service. As part of a study conducted in Macon County, Alabama, poor sharecroppers were told that they were being treated for "bad blood." In fact, the physicians in charge of the study ensured that these men went untreated. In the 25 years since its details first were revealed, the study has become a powerful symbol of racism in medicine, ethical misconduct in human research, and government abuse of the vulnerable.

The 1990s has been a time of reflection upon the Tuskegee Study and its troubling implications. In February 1994, the issue was addressed in a symposium entitled "Doing Bad in the Name of Good?: The Tuskegee Syphilis Study and its Legacy" convened at The Claude Moore Health Sciences Library. The discussion at this gathering led to the creation of the Tuskegee Syphilis Study Legacy Committee which met in Tuskegee in January 1996. In its final report the following May, the Committee urged President Clinton to apologize for wrongs of the Tuskegee Study. The Committee's work bore fruit on May 16, 1997 when the President apologized on behalf of the United States government to the surviving participants of the study. These men and members of the Legacy Committee were invited to the White House to



THE TUSKEGEE SYPHILIS STUDY AND ITS LEGACY

Although the President's words formally closed this ignoble chapter in the history of American public health, the Study's repercussions are still felt in African-American communities and the bio-medical professions. In keeping with the goals of the Legacy Committee, this exhibit aims to preserve collective memory of the Tuskegee Study and the ongoing transformation of its legacy.

Overview of the symposium, "Doing Bad in the Name of Good?" February 23, 1994

The final report of the Tuskegee Syphilis Study Legacy Committee, May 20, 1996

The Presidential Apology, May 16, 1997

NPR Story July 25, 2002, "Remembering Tuskegee: Syphilis Study Still Provokes Disbelief, Sadness"

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Claude Moore Health Science

1300 Jefferson Park Avenue

PO Box 800722

University of Virginia Health System
Claude Moore Health Sciences Library
1300 Jefferson Park Avenue
PO Box 800722
Charlottesville, VA 22908-0722
(434) 924-5591



Coming to Terms with the Legacy of the Tuskegee Syphilis Study

An important starting point for the renewal of dialogue about the Tuskegee Syphilis Study was the symposium "Doing Bad in the Name of Good?: The Tuskegee Syphilis Study and its Legacy" convened on Wednesday, February 23, 1994 at The Claude Moore Health Sciences Library. The five-hour symposium undertook to apply historical perspective on the Tuskegee Study to the current problems of cultural difference in perceptions of health care workers and the appropriate nexus of scientific research and human rights. Summaries of the talks are provided below.



From left to right: Dr. James Jones, who reported on the Study for the New York Times in 1972; Symposium co-ordinator Joan Echtenkamp Klein of The Claude Moore Health Sciences Library; Dr. Vanessa Gamble, chair of the Tuskegee Syphilis Study Legacy Committee; and Dr. Susan Reverby, Luella LaMer Associate Professor in Women's Studies at Wellesley College.

February 23, 1994 "DOING BAD IN THE NAME OF GOOD?: THE TUSKEGEE SYPHILIS STUDY AND ITS LEGACY" -- A SYMPOSIUM

Speakers:

• JAMES H. JONES, PH.D. University of Houston

Dr. Jones is the author of *Bad Blood: The Tuskegee Syphilis Experiment* (New York, Free Press, 1993). He provided an overview of the origins and progress of the Tuskegee Syphilis Study over four decades. The interest which greeted the symposium gave credence to the 1932 statement of one of the Study's creators who predicted of the Study: "It will either cover us with mud or glory when completed." (Jones, *Bad Blood*, 1993, 112)

• VANESSA NORTHINGTON GAMBLE, M.D. University of Wisconsin School of Medicine

Dr. Gamble spoke of the distrust many African Americans feel toward physicians, and the role the Study has played in perpetuating this problem. She stressed that this distrust is ingrained in African-American society and reinforced by oral tradition. A suspicion of the medical profession is found in urban and rural settings, in poor and affluent communities, and among highly educated as well as less-educated African Americans.

FILM: Bad Blood

This English film, first shown on BBC and A&E, presents interviews with survivors of the Study, physicians responsible for its oversight, and contemporary white residents of Macon County, Alabama. The interviews are interspersed with archival photographs and footage of U.S. Public Health Service venereal disease campaigns and civil rights demonstrations.

• SUSAN M. REVERBY, PH.D. Wellesley College

Dr. Reverby spoke about the varied intepretations of Nurse Eunice Rivers, an African American nurse who served as a liaison between government officials and the Macon County men. Without her assistance, the Study would not have been successful. There have been numerous attempts to "write Nurse Rivers," including several plays; each attempt at biography is affected by the view of the person doing the "writing."

 PATRICIA A. SULLIVAN, PH.D. University of Virginia

Dr. Sullivan provided an overview of the political climate of the Deep South during the last two decades of the Study, which encompassed the years of the Civil Rights movement. She noted the irony that Macon County was both the site of the Study, which relied on compliance and docility,

and a center of civil rights activism.

PAUL A. LOMBARDO, J.D., PH.D. University of Virginia Health System

Dr. Lombardo addressed some of the legal aspects of the Tuskegee Syphilis Study, noting the parallels between it and experiments conducted on mentally deficient subjects and campaigns of forced sterilization.

JOHN C. FLETCHER, PH.D. University of Virginia Health System

A former bioethicist at the National Institutes of Health, Dr. Fletcher addressed the institutional culture that permitted the creation and long-term pursuit of the Tuskegee Study. Fletcher argued that these organizations encourage their workers to believe that they are exempt from the rules of society at large. He drew ethical parallels between the Study and the Nuremberg trials.

• GERTRUDE FRASER, PH.D. University of Virginia

Dr. Fraser provided an anthropological analysis of the Study and its participants. She suggested that in a rural, impoverished society such as Macon County, people would be aware of men receiving treatment, especially since this happened with regularity for decades. She also speculated that the men in the study and their families must have sensed, at some level, that they were colluding with unusual forces in their efforts to find relief from illness.

A question and answer session concluded the program.

The Legacy Committee Report

BLOOD

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A Request for Redress of the Wrongs of Tuskegee

In January 1996, the Tuskegee Syphilis Study Legacy Committee met at Tuskegee University to explore how the government and the nation could publicly address the Tuskegee Syphilis Study and its impact. The final report of the Committee from May 20, 1996 is abstracted and presented in its entirety below:

Abstract of the Syphilis Study Legacy Committee Final Report of May 20, 1996

From 1932 to 1972, 399 poor black sharecroppers in Macon County, Alabama were denied treatment for syphilis and deceived by physicians of the Unites States Public Health Service. As part of the Tuskegee Syphilis Study, designed to document the natural history of the disease, these men were told that they were being treated for "bad blood." In fact, government officials went to extreme lengths to insure that they received no therapy from any source. As reported by the *New York Times* on 26 July 1972, the Tuskegee Syphilis Study was revealed as "the longest nontherapeutic experiment on human beings in medical history."

The Study continues to cast a long shadow over the relationship between African Americans and the biomedical professions; it is argued that the Study is a significant factor in the low participation of African Americans in clinical trials, organ donation efforts, and routine preventive care. In view of this unacknowleged wrong and the damage it has caused, the Tuskegee Syphilis Study Legacy Committee pursues two inseparable goals:

- 1) to persuade President Clinton to apologize to the surviving Study participants, their families, and to the Tuskegee community. This apology is necessary for four reasons: the moral and physical harm to the community of Macon County; the undeserved disgrace the Study has brought to the community and University of Tuskegee, which is in fact a leading advocate for the health of African-Americans; its contribution to fears of abuse and exploitation by government officials and the medical profession; and the fact that no public apology has ever been made for the Study by any government official.
- 2) to develop a strategy to redress the damages caused by the Study and to transform its damaging legacy. This is necessary because an apology without action is only a beginning of the necessary healing. The Committee recommends the development of a professionally staffed center at Tuskegee for public education about the Study, training programs for health care providers, and a clearinghouse for scholarship on ethics in scientific research.

[The report follows in its entirety, followed by two appendixes. Endnotes are indicated by the numbers 1-16.]



Report of the Tuskegee Syphilis Study Legacy Committee [1] Final Report--May 20, 1996

In 1932, the United States Public Health Service (USPHS) initiated the Tuskegee Syphilis Study to document the natural history of syphilis. The subjects of the investigation were 399 poor black sharecroppers from Macon County, Alabama, with latent syphilis and 201 men without the disease who served as controls. The physicians conducting the Study deceived the men, telling them that they were being treated for "bad blood."[2] However, they deliberately denied treatment to the men with syphilis and they went to extreme lengths to ensure that they would not receive therapy from any other sources. In exchange for their participation, the men received free meals, free medical examinations, and burial insurance.[3]

On 26 July 1972, a front-page headline in the *New York Times* read, "Syphilis Victims in U.S. Study Went Untreated for 40 Years." [4] The accompanying article publicly revealed the details of the Tuskegee Syphilis Study--"the longest nontherapeutic experiment on human beings in medical history." [5] In the almost 25 years since its disclosure, the Study has moved from a singular historical event to a powerful metaphor. It has come to symbolize racism in medicine, ethical misconduct in human research, paternalism by physicians, and government abuse of vulnerable people.

The Tuskegee Syphilis Study continues to cast its long shadow on the contemporary relationship between African Americans and the biomedical community. Several recent articles have argued that the Tuskegee Syphilis Study has predisposed many African Americans to distrust medical and public health authorities.[6] The authors point to the Study as a significant factor in the low participation of African Americans in clinical trials and organ donation efforts and in the reluctance of many black people in seeking routine preventive care. As one AIDS educator put it, "so many African-American people that I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee experiment. It is like ... if they did it then they will do it again."[7]

The Tuskegee Syphilis Study Legacy Committee is dedicated to preserving the memory of the Study while moving beyond it, transforming the legacy into renewed efforts to bridge the chasm between the health conditions of black and white Americans. To this end, the Committee is pursuing two inseparable goals:

- 1) to persuade President Clinton to publicly apologize for past government wrongdoing to the Study's living survivors, their families, and to the Tuskegee community, and
- 2) to develop a strategy to redress the damages caused by the Study and to transform its damaging

legacy.

In his recent apology for the government's role in human radiation experiments (1944-1974), President William J. Clinton claimed that "the American people ... must be able to rely upon the United States to keep its word, to tell the truth, and to do the right thing," and that "when the government does wrong, we have a moral responsibility to admit it."[8] President Clinton is not alone in his belief that an apology for past wrongs is "doing the right thing." Recently, the Southern Baptist Church apologized to all African Americans for its stand on slavery during the Civil War and the Prime Minister of Japan similarly apologized to all the people of the United States for the attack on Pearl Harbor.[9]

And yet, these apologies do not merely acknowledge wrongdoing: they act as a first step toward healing the wounds inflicted. President Clinton, for example, saw his apology as "laying the foundation stone for a new era" in trying to regain the trust of the country. [10]

It is within the context of doing the right thing that, redressing past injuries, and regaining trust, that the Committee adamantly believes that a Presidential apology to the victims of Tuskegee is critical to heal the devastating wounds that remain from this shameful episode in the history of medical research.

1. A Presidential Apology for the Tuskegee Syphilis Study

Moral and physical harms to the community of Macon County

It is clear that the U.S. government scientists irreparably harmed hundreds of socially and economically vulnerable African-American men in Macon County, their family members, and their descendants by deliberately deceiving them and withholding from them state of the art treatment. When the Tuskegee Study began, the standard therapy for syphilis consisted of painful injections of arsenical compounds, supplemented by topical applications of mercury or bismuth ointments. Although this therapy was less effective than penicillin would prove to be, in the 1930s every major textbook on syphilis recommended it for the treatment of the disease. After penicillin became available, the researchers withheld its use as well. Published medical reports have estimated that between 28 and 100 men died as a result of their syphilis.[11] Due to a lax study protocol, we cannot be sure that all the men had latent syphilis. It is therefore entirely possible that the infected men passed syphilis to their sexual partners and to their children in utero.[12] Thus the physical harm may not be limited just to the men enrolled in the Study.

• No public apology has ever been made

In the aftermath of a Health, Education and Welfare Task task force report, a Senate hearing, and an out of court legal settlement, the U.S. government provided economic compensation and continues to give free health benefits to the surviving subjects and their families. However, no public apology has ever been offered for the moral wrongdoing that occurred in the name of government medical research. No public official has ever stated clearly to the nation that the

Tuskegee Syphilis Study was morally wrong from its inception, and no public official has ever apologized to the survivors and their families. Yet, an apology is sorely needed. The Committee believes that an apology from the President could facilitate the healing of the victims and the nation.

• The harmful legacy of the Study

The historical record makes plain that African American's distrust of the medical profession predates the revelations of the Tuskegee Syphilis Study and involves a myriad of other social and political factors. Nevertheless, the Study has become a powerful symbol for the fear of exploitation in research and the deprivation of adequate medical care that is widespread in the African-American community. Recent articles argue that Tuskegee has created a climate of suspicion that taints the relationship between many African Americans and the medical profession. The Tuskegee Study is offered as the reason why few blacks participate in research trials,[13] why the need for transplant organs by African Americans widely surpasses the supply,[14] and why African Americans often avoid medical treatment.[15] It is also offered as an explanation as to why rumors about genocide persist in the African-American community, ranging from the notion that AIDS is a plot to exterminate black people to the idea that needle exchange programs fuel a drug epidemic that disproportionately affects black neighborhoods.[16] For many African Americans, the fact that the Tuskegee Study occurred at all proves that black life is not valued. The Committee believes that an apology combined with a strategy for addressing the damages of the Tuskegee legacy would begin the process of regaining the trust of people of color.

• The harm done to the community and the University

Because the name of the study points to Tuskegee Institute (now Tuskegee University) rather than the United States Public Health Service, it clouds the funding and responsibility for the Study. Although facilities and staff of the Tuskegee Institute were involved, primary direction came from the government under the auspices of the USPHS. The notoriety of the Study obscures the achievements of the Tuskegee Institute in improving the health care of African Americans. These achievements include initiating National Negro Health Week, building the John A. Andrew Hospital, creating the John A. Andrew Clinical Society, establishing a nurse training school, and organizing a school for midwives.

1. The Apology: Context and Opportunity

The Committee urges President Clinton to apologize on behalf of the American government for the harms inflicted at Tuskegee. The apology should be directed to those most directly harmed: to the elderly survivors of the Study, to their families, and to the wider community of Tuskegee and its university. Also included within the apology should be all people of color whose lives reverberate with the consequences of the Study.

As the highest elected official of the United States, the President should offer the apology for the Study which was conducted under the auspices of the United States government. The significance of a presidential apology was recognized recently when the President apologized to those harmed by Cold War radiation experiments as a way to regain confidence of the American people. In the context of President Clinton's stated desire to bridge the racial divide, this apology provides the opportunity to begin to heal the racial wounds that persist in this country.

Given the ages of the living participants and the period of time since the Study was disclosed, we believe that the apology should be offered swiftly. There are only eleven survivors; a twelfth died as recently as March 3, 1996. We recommend that the government issue the apology from Tuskegee University, perhaps linked with an early meeting of the new National Bioethics Advisory Commission (NBEAC). Because the Tuskegee study is a starting point for all modern moral reflection on research ethics, a meeting of the NBEAC at Tuskegee in conjunction with a Presidential apology would be an ideal new beginning.

2. Transforming the Legacy

Although a public apology is necessary to heal the wounds of Tuskegee, it alone would not be sufficient to assure the nation that research like the Tuskegee Syphilis Study will not be duplicated. Despite the significance of a Presidential apology, it must not be an isolated event. Consequently, the Committee also recommends the development of a mechanism to move beyond Tuskegee and to address the effects of its legacy. The Committee strongly urges the development of a professionally staffed center at Tuskegee University, focused on preserving the national memory of the Study and transforming its legacy.

Regret for past mistakes must be accompanied by a determination to prevent future wrongs. Until now for black Americans the legacy of the Tuskegee Syphilis Study has been a negative one--a symbol of their mistreatment within American society. The proposed Center could help transform the legacy of Tuskegee into a positive symbol for all Americans by demonstrating the importance of acknowledging past wrongs, rebuilding trust, and practicing ethical research.

The new center's mission would be to preserve the national memory of the Syphilis Study for public education and scholarly research, and to analyze and disseminate findings on effective and ethically acceptable ways to address the profound mistrust that is the tragic and enduring legacy of this Study, especially among African Americans and other persons of color. (See Appendix 1.)

Although the Committee sees the creation of a Center as the most valuable attempt to redress the damages of Tuskegee, we envision several possible concurrent programs. These include:

- 1. a Minority Health Initiative, similar in scope to the newly established Women's Health Initiative;
- 2. training porgrams for health care providers to better understand the social and cultural issues of providing health care and of conducting research in communities of color;

3. a clearinghouse to help investigators conduct ethically responsible research.

The Committee recommends that funding for the Center must combine government and private funding. The announcement of a federal challenge grant would be very useful as a catalyst for future fundraising efforts. It is undeniable that the Tuskegee Syphilis Study has adversely affected the attitudes that many African Americans hold toward the biomedical community and the United States government. But despite the long shadow that it casts, we now have an opportunity to challenge this legacy and create a more beneficial one.

The Presidential apology



Notes

- 1. The Committee was established at a meeting at Tuskegee University, January 18-19, 1996. A list of the Committee members is attached. The Committee wishes to thank Judith a Houck for her assistance in the preparation of this report.
- 2. The term "bad blood" encompassed several conditions including syphilis, anemia, and fatigue.
- 3. For a complete history, see Jones, James H., *Bad Blood: The Tuskegee Syphilis Experiment*, new and expanded ed., New York: Free Press, 1993.
- Jean Heller, "Syphilis Victims in the U.S. Study Went Untreated for 40 Years," *New York Times*, 26 July 1972: 1, 8. The story first broke the previous day in the *Washington Star*.
- 5. Jones, Bad Blood, 91.
- 6. See, for example, Asim, Jabari, "Black paranoia far-fetched? Maybe, but understandable," *The Phoenix Gazette* February 23, 1993 Op-Ed: A13; Karkabi, Barbara, "Blacks' health problems addressed," *The Houston Chronicle* April 10, 1994 Lifestyle: 3; "Knowledge, attitudes and behavior; conspiracy theories about HIV puts individuals at risk," *AIDS Weekly*, November 13, 1995.
- 7. Thomas, Stephen B. and Quinn, Sandra Crouse, "The Tuskegee Syphilis Study, 1932-1972: Implications for HIV Education and AIDS Risk Programs in the Black Community," *Am J. of Pub Health*. 1991; 81: 1503.
- 8. President William J. Clinton, "In Acceptance of Human Radiation Final Report," Washington D.C., October 3, 1995.

- 9. See, for example, Niebuhr, Gustav, "Baptist group votes to repent stand on slaves," *New York Times* 21 June, 1995: A2; and Watanabe, Teresa and David Holley, "Japan Premier offers apology for WWII role," *Chicago Tribune* 15 August 1995: A10.
- 10. Clinton, 3 October, 1995.
- 11. Jones, *Bad Blood*, 2.
- 12.Hammonds, Evelynn M., "Your silence will not protect you: Nurse Eunice Rivers and the Tuskegee Syphilis Study," in *The Black Women's Health Book: Speaking for Ourselves* ed. Evelyn C. White, 2nd ed., Seattle: Seal Press, 1994: 323-331.
- 13. Gamble, Vanessa, "A Legacy of Distrust: African Americans and Medical Research," *Am J. of Preventive Medicine*, November/ December 1993: 35-38.
- 14. "Fear Creates Lack of Donor Organs Among Blacks," Weekend Edition, National Public Radio, 13 March 1994.
- 15. See, for example, Voas, Sharon, "Aging black sick, scared; past abuses, tradition keep them from clinic," *Pittsburgh Post-Gazette*, August 27, 1995: B1.
- 16. Bates, K.G., "Is it Genocide?" *Essence*, September 1990: 76; Thomas, Stephen, and Quinn, Sandra, "Understanding the Attitudes of Black Americans," in Stryker, J. and Smith, M.D., eds. *Dimensions of HIV Preventions: Needle Exchange*, Menlo Park: The Henry J. Kaiser Family Foundation; 1993: 99-128; Kirp, David and Bayer, Ronald, "Needles and Race," *Atlantic* July 1993: 38-42.

Appendix 1

Possible functions for a Tuskegee research center:

- to create and maintain a public museum in Tuskegee, Alabama, to preserve the memory of the Study and to provide a focal point for efforts to transform its negative legacy;
- to provide a place for scholars to examine the ethical, legal, and social significance of the Study and other issues in bioethics;
- to conduct public education on the Study and its legacy in schools, community organizations, and medical institutions;

- to aid in the production of audiovisual aids for public education that will place the Study within its broadest soical and historical context and provide suggestions for transforming its past legacy;
- to assure the rigorous preservation of presently endangered documents and other records to further encourage studies of race, ethnicity, and medicine;
- to offer support for medical researchers seeking ways to conduct research in diverse populations that is both scientifically sound and ethically responsible.

Appendix 2

TUSKEGEE SYPHILIS STUDY LEGACY COMMITTEE

Ms. Myrtle Adams Chairman, Macon County Health Care Authority 704 Patterson St. Tuskegee, AL 36088

Ms. Patricia Clay Administrator, Macon County Health Care Authority PO Drawer 180 Tuskegee, AL 36088

Dr. James A. Ferguson
Dean, School of Veterinary Medicine
Patterson Hall
Tuskegee University
Tuskegee, AL 36088

Dr. John C. Fletcher, co-chair Director, Center for Biomedical Ethics Cornfield Professor of Religious Studies University of Virginia Box 348 HSC Charlottesville, VA 22908

Dr. Vanessa Northington Gamble, chair Associate Professor of History of Medicine and Family Medicine University of Wisconsin Medical School 1300 University Avenue Madison, WI 53706 Dr. Lee Green Assistant Professor University of Alabama PO Box 870312 Tuscaloosa, AL 35487

Ms. Barbara Harrell Director, Division of Minority Health Alabama Department of Public Health 434 Monroe St. Montgomery, AL 36130-3017

Dr. Bill Jenkins Epidemiologist Centers for Disease Control and Prevention 1600 Clifton Road, NE, MS-E02 Atlanta, GA 30333

Dr. James H. Jones Professor of History University of Houston 2202 Swift Road Houston, TX 77030

Dr. Ralph Katz
Professor
Department of Behavioral Sciences and Community Health
School of Dental Medicine
University of Connecticut Health Center
Farmington, CT 06030

Ms. Joan Echtenkamp Klein Assistant Director for Historical Collections and Services Health Sciences Library, Box 234 University of Virginia Health System Charlottesville, VA 22908

Dr. Susan Reverby Luella LaMer Professor for Women's Studies Wellesley College 106 Central St. Wellesley, MA 02181 Dr. Reuben Warren Associate Director for Minority Health, CDC Centers for Disease Control and Prevention 1600 Clifton Road, NE, MS-D39 Atlanta, GA, 30333

Mr. Anthony Winn Program Analyst Minority Health Professions Foundation 20 Executive Park Drive, #2021 Atlanta, GA 30333

For a current bibliography on human experimentation, go to **Ethical Issues in Research Involving Human Participants**, posted by the National Library of Medicine.

The Presidential apology



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The Presidential Apology

On May 16, 1997, the surviving participants of the Tuskegee Syphilis Study and the members of the Tuskegee Syphilis Study Legacy Committee gathered at the White House and witnessed the President's apology on behalf of the United States government.

President Clinton's full remarks are available at the National Archives.

After brief remarks by Vice President Al Gore and Dr. David Satcher of the Center for Disease Control, the President was introduced by one of the study's survivors, Macon County resident Herman Shaw. Mr. Shaw expressed his approval of the President's action, saying, "in my opinion, it is never too late to work to restore trust and faith." But Shaw also called for a permanent memorial so that future generations might learn about what happened. "We were treated unfairly, to some extent like guinea pigs," Shaw said. "The wounds that were inflicted upon us cannot be undone."

President Clinton recounted the injustice done to the study participants and concluded, "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."



Herman Shaw, Tuskegee Study participant, after the White House ceremony.



Charlie W. Pollard, Study Participant.

The President also praised the survivors for their spirit of forgiveness, saying, "Today all we can do is apologize but you have the power. Only you have the power to forgive. Your presence here shows us that you have shown 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." President Clinton announced government bioethics fellowships for minority students funded by the Department of Health and Human Services. He also proposed a \$200,000 planning grant for a bioethics center at Tuskegee University, which was not affiliated with the study but whose reputation has been tarnished by it.

Survivors of the Study at Tuskegee:

Sam Doner
Ernest Hendon
Carter Howard
George Key
Frederick Moss
Charlie W. Pollard
Herman Shaw
Fred Simmons

PROGRAM

Remarks by:

The Vice President

Dr. David Satcher, Director, The Center for Disease Control and Prevention

Mr. Herman Shaw

The President

Members of the Tuskegee Syphilis Study Legacy Committee. Clockwise from right: Joan Echtenkamp Klein is greeted by President Clinton; Committee members (from left to right) Patricia Clay, Anthony Winn, and Dr. Vanessa Gamble, Committee Chair; Dr. Jim Jones, the author of *Bad Blood*, the authoritative work about the Tuskegee Syphilis Study. Clinton photo courtesy of the White House.







This exhibit was designed the Historical Collections Department at The Claude Moore Health Sciences Library. For more information or permission for use of its contents, contact <u>Joan Echtenkamp Klein</u>, Assistant Director for Historical Collections and Services.



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Remembering Tuskegee

Syphilis Study Still Provokes Disbelief, Sadness

Read a commentary by Tuskegee Legacy Committee Chair <u>Dr. Vanessa Gamble</u>.

(1) Listen to <u>Alex Chadwick's report.</u>



Nurses examine one of the Tuskegee syphilis study participants. Photo courtesy National Archives



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

Echtenkamp Klein

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."

The next morning, every major U.S. newspaper was running Heller's story. For *Morning Edition*, NPR's <u>Alex Chadwick</u> 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.

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."

In Depth

More NPR stories on the Tuskegee Syphilis Study.

More Resources

- Transcript of <u>President Clinton's 1997 formal apology</u> to study members.
- Centers for Disease Control (CDC) Tuskegee study Web site .
- A CDC <u>timeline</u> on the Tuskegee study.
- CDC factsheet on syphilis.
- 1996 report by the <u>Tuskegee Syphilis Study Legacy Committee</u> on how the public response to the Tuskegee study.
- Background on the Tuskegee study, from the <u>Tuskegee University</u> National Center for Bioethics.
- <u>Tributes</u> to Herman Shaw, who died Dec. 3, 1999, and Fred Simmons, who died Feb 5, 2000.

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Apology For Study Done in Tuskegee

THE WHITE HOUSE Office of the Press Secretary

For Immediate Release

May 16, 1997

REMARKS BY THE PRESIDENT 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.)

Presidential Remarks

Conference on Hate Crimes

Outreach Meeting

Remarks By The President at Ecumenical Breakfast

President with Tom Joyner's Morning Show

Candlelight Vigil Honoring the Little Rock Nine

Race Advisory Board Meeting

Addressing Students and Others of the Akron Community

Town Hall Meeting on the Initiative

PIR Town Hall Meeting

The American Society Of Newspaper Editors

86th Annual Holy Convocation

Affirmative Action

On Race Relations

40th Anniversary of the Desegregation of Central High

National Association of Black Journalists

Remarks at NAACP Convention

Apology For Study Done in Tuskegee

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Timeline

The Tuskegee Syphilis Study: A Hard Lesson Learned

The Tuskegee Syphilis Study, carried out in Macon County, Alabama, from 1932 to 1972, is an example of medical research gone wrong. The United States Public Health Service, in trying to learn more about syphilis and justify treatment programs for blacks, withheld adequate treatment from a group of poor black men who had the disease, causing needless pain and suffering for the men and their loved ones.

In the wake of the Tuskegee Study and other studies, government took a closer look at research involving human subjects and made changes to prevent the moral breaches that occurred in Tuskegee from happening again.

The Study Begins

In 1932, the Public Health Service, working with the Tuskegee Institute, began a study in Macon County, Alabama, to record the natural history of syphilis in hopes of justifying treatment programs for blacks. It was called the "Tuskegee Study of Untreated Syphilis in the Negro Male".

The study involved 600 black men—399 with syphilis and 201 who did not have the disease. Researchers told the men they were being treated for "bad blood," a local term used to describe several ailments, including syphilis, anemia, and fatigue. In truth, they did not receive the proper treatment needed to cure their illness. In exchange for taking part in the study, the men received free medical exams, free meals,

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and burial insurance. Although originally projected to last 6 months, the study actually went on for 40 years.

What Went Wrong?

In July 1972, a front-page New York Times story about the Tuskegee Study caused a public outcry that led the Assistant Secretary for Health and Scientific Affairs to appoint an Ad Hoc Advisory Panel to review the study. The panel had nine members from the fields of medicine, law, religion, labor, education, health administration, and public affairs.

The panel found that the men had agreed freely to be examined and treated. However, there was no evidence that researchers had informed them of the study or its real purpose. In fact, the men had been misled and had not been given all the facts required to provide informed consent.

The men were never given adequate treatment for their disease. Even when penicillin became the drug of choice for syphilis in 1947, researchers did not offer it to the subjects. The advisory panel found nothing to show that subjects were ever given the choice of quitting the study, even when this new, highly effective treatment became widely used.

The Study Ends and Reparation Begins

The advisory panel concluded that the Tuskegee Study was "ethically unjustified"—the knowledge gained was sparse when compared with the risks the study posed for its subjects. In October 1972, the panel advised stopping the study at once. A month later, the Assistant Secretary for Health and Scientific Affairs announced the end of the Tuskegee Study.

In the summer of 1973, a class-action lawsuit filed by the National Association for the Advancement of Colored People (NAACP) ended in a settlement that gave more than \$9 million to the study participants. As part of the settlement, the U.S. government promised to give free medical and burial services to all living participants. The Tuskegee Health Benefit Program was established to provide these services. It also gave health services for wives, widows, and children

who had been infected because of the study. The Centers for Disease Control and Prevention was given responsibility for the program, where it remains today in the National Center for HIV, STD, and TB Prevention.

Timeline

- **1895** Booker T. Washington at the Atlanta Cotton Exposition, outlines his dream for Black economic development and gains support of northerner philanthropist including Julius Rosenwald (founder of Sears).
- **1900** Tuskegee experiment gains widespread support. Rosenwald Fund provides monies to develop schools, factories, businesses, and agriculture.
- **1915** Booker T. Washington Dies, Robert Motin continues work.
- **1926** Health is seen as inhibiting development and major health initiative is started. Syphilis is seen as major health problem. Prevalence of 35 percent observed in reproductive age population.
- **1929** Aggressive treatment approach initiated with Mercury and Bismith. Cure rate is less than 30 percent, treatment requires months and side effects are toxic, sometimes fatal.
- 1929 "Wall Street Crash" Economic Depression begins.
- **1931** Rosenwald Fund cuts support to development projects Clark and Vondelehr decides to follow men left untreated due to lack of funds to show need for treatment program.
- **1932** Follow-up effort organized into study of 399 men with syphilis and 201 without. The men would be given periodic physical assessments and told they were being treated. Motin agrees to support study if "Tuskegee gets its full share of the credit" and Black professionals are involved (Dr. Dibble and Nurse Rivers are assigned to study).

- **1934** First papers suggest health effects of untreated syphilis.
- **1936** Major paper published... Study criticized because it is not known if men are being treated. Local physicians asked to assist and asked not to treat men. It was also decided to follow the men until death.
- **1940** Efforts made to hinder men from getting treatment by military draft effort.
- 1945 Penicillin accepted as treatment of choice for syphilis.
- **1947** US PHS establishes "Rapid Treatment Centers" to treat Syphilis, men in study not treated, but syphilis declines.
- **1962** Since 1947, 127 Black medical students are rotated through unit doing the study.
- **1968** Concern raised about ethics of study by Peter Bauxum and others.
- **1969** CDC reaffirms need for study and gains local medical societies support (AMA and NMA chapters officially support continuation of study).
- **1970** First news articles condemns studies.
- 1971 Congress holds hearings and law suit initiated.
- **1972** Study ends and participants compensated with cash and continued medical treatment.
- **1997** May 16th President Clinton Apologizes on behalf of the Nation.
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