

Final Report of the Syphilis Study Legacy Committee¹—May 20, 1996

Abstract

From 1932 to 1972, 399 poor black sharecroppers in Macon County, Alabama were denied treatment for syphilis and deceived by physicians of the United 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 unacknowledged 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.

Report

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 this context of doing the right thing, 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

1. 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.

2. No public apology has ever been made

In the aftermath of a Health, Education and Welfare 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.

3. 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.

4. 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.

2. 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.

3. 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 programs 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.

Notes

1. The Committee was established at a meeting at Tuskegee University, January 18-19, 1996. A list of the Committee members can be found below. 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.
4. 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, Evelyn 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:

1. 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;
2. To provide a place for scholars to examine the ethical, legal, and social significance of the Study and other issues in bioethics;
3. To conduct public education on the Study and its legacy in schools, community organizations, and medical institutions;
4. to aid in the production of audiovisual aids for public education that will place the Study within its broadest social and historical context and provide suggestions for transforming its past legacy;
5. to assure the rigorous preservation of presently endangered documents and other records to further encourage studies of race, ethnicity, and medicine;

6. 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
- **Ms. Patricia Clay**
Administrator, Macon County Health Care Authority
- **Dr. James A. Ferguson**
Dean, School of Veterinary Medicine
Tuskegee University
- **Dr. John C. Fletcher, co-chair**
Director, Center for Biomedical Ethics
Cornfield Professor of Religious Studies
University of Virginia
- **Dr. Vanessa Northington Gamble, chair**
Associate Professor of History of Medicine and Family Medicine
University of Wisconsin Medical School
- **Dr. Lee Green**
Assistant Professor
University of Alabama
- **Ms. Barbara Harrell**

Director, Division of Minority Health

Alabama Department of Public Health

- **Dr. Bill Jenkins**

Epidemiologist

Centers for Disease Control and Prevention

- **Dr. James H. Jones**

Professor of History

University of Houston

- **Dr. Ralph Katz**

Professor

Department of Behavioral Sciences and Community Health

School of Dental Medicine

University of Connecticut Health Center

- **Ms. Joan Echtenkamp Klein**

Assistant Director for Historical Collections and Services

Health Sciences Library

University of Virginia Health System

- **Dr. Susan Reverby**

Luella LaMer Professor for Women's Studies

Wellesley College

- **Dr. Reuben Warren**

Associate Director for Minority Health

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- **Mr. Anthony Winn**

Program Analyst

Minority Health Professions Foundation