

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

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

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.

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.

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**

- **Mr. Anthony Winn**

Program Analyst

Minority Health Professions Foundation