

The Milbank Memorial Fund's Involvement in the USPHS Syphilis Study at Tuskegee: A Timeline

In 2021, the Milbank Memorial Fund hired Dr. Susan M. Reverby¹ to investigate the extent of its involvement in the United States Public Health Service (USPHS) Syphilis Study at Tuskegee and Macon County, Alabama. The timeline below relies on an amalgam of historical sources, including Dr. Reverby's new research, to recount the events of the study and subsequent developments.

1932

The USPHS begins a syphilis study, with the support of the Tuskegee Institute, to record the progression of untreated syphilis in Black men and determine whether treatment of latent syphilis was necessary. More than 624 subjects and controls were enrolled. The men in the USPHS syphilis study, who were mostly poor farmers, were not asked for consent to be in the study. They were told they were being treated for their "bad blood," a generic slang term that meant syphilis and other diseases. They were given vitamins, iron tonics, and aspirin, and told that a diagnostic spinal tap was a "special treatment." The study continued for 40 years, and the men were not treated, even after penicillin was broadly used as a curative syphilis treatment by the late 1940s.

1935

United States Surgeon General Hugh Cumming, a former member of the Milbank Memorial Fund's advisory board, requests a grant from the Fund to cover the burial expenses of deceased subjects to encourage families to consent to autopsies, which were considered critical to the research. Dr. Reverby notes that, for the study's target subjects, proper burials were "a key point of dignity"; thus, burial stipends were "an important...incentive" for autopsy consent. No consent for the study was required, but by law, consent for an autopsy required the families' agreement in writing.

The Fund agrees to provide \$50 grants per person. After each autopsy, the USPHS notifies the Fund and checks are then sent to the Tuskegee Institute for disbursal. Letters from the Tuskegee Institute treasurer to the USPHS indicate that these funds were disbursed to cover burials of participants (subjects and controls), to obtain the autopsies and to pay the pathologist to conduct them. According to Dr. Reverby, the Fund continued these payments (later raised to \$100) until the end of the study in 1972 and made some final payments in 1973. The number of autopsies conducted is unclear. According to the United States Centers for Disease Control and Prevention (CDC), 234 autopsies were performed as of 1971. Dr. Reverby's analysis of the men's medical reports conducted for her book *Examining Tuskegee* found that by 1973, 353 of the men who had died were autopsied. Government officials updated the Milbank Memorial Fund on the study's progress through grant renewals, letters, and occasional in-person visits.

¹Marion Butler McLean Professor Emerita in the History of Ideas and Professor Emerita of Women's and Gender Studies at Wellesley College and the editor of Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study (2000) and author of Examining Tuskegee: The Infamous Syphilis Study and Its Legacy (2009). She was also a member of the Legacy Committee that successfully lobbied President Bill Clinton for a federal apology for the USPHS syphilis study in 1997.

1937

The best-selling book *Shadow on the Land: Syphilis* by Dr. Thomas Parran Jr. — a public health physician and leading syphilologist, member of the Milbank Memorial Fund Technical Board, New York Health Commissioner, U.S. Surgeon General, and University of Pittsburgh Public Health School dean — is published. The Milbank Memorial Fund provided Parran with \$2,000 to underwrite the book, which was reviewed positively in *The Milbank Quarterly*. According to historical records, in the early 1930s, Parran had an idea for a syphilis study that was similar to the USPHS study prior to its inception. Later, during Parran's tenure as U.S. Surgeon General, he supported the USPHS syphilis study, which had already launched.

1954

The journal article "Untreated Syphilis in the Male Negro: A Prospective Study of the Effect on Life Expectancy" is published simultaneously in the USPHS's *Public Health Reports* and *The Milbank Quarterly*. The Milbank Memorial Fund continues to provide burial stipends for the study participants during the 1950s and 1960s.

1966

Public health services researcher Peter Buxtun raises concerns about the ethics of the study with Dr. William J. Brown, chief of the CDC's Venereal Disease Division, which now leads the study. The agency does not immediately respond to Buxtun's concerns.

1967

Dr. Bill Jenkins becomes one of the first African Americans recruited as an epidemiologist into what was then called the United States Department of Health, Education, and Welfare. Working with others, he starts *The Drum*, a civil rights and Black power newsletter, in which he outlines ethical concerns about the USPHS syphilis study. Dr. Jenkins continues to object to the study and later joins the CDC as an epidemiologist.

1969

CDC director David Sencer convenes an ad hoc panel to review the USPHS syphilis study. Panel participants are primarily CDC researchers, along with other health professionals and academics, including Dr. Clyde Kiser, a Milbank Memorial Fund staff member. Following the meeting, the panel recommends that the study continue, and the CDC heeds this advice.

The Milbank Memorial Fund continues its burial payments.

1972

An Associated Press story by Jean Heller on the study (triggered by a leak from Peter Buxtun) published in July causes public outcry. The article leads Dr. Merlin K. Duval, the U.S. Assistant Secretary for Health and Scientific Affairs, to appoint an advisory panel to review the study. The advisory panel concludes that the USPHS study was "ethically unjustified"; the knowledge gained was sparse when compared with the risks the study posed for its subjects. The panel advises stopping the study, and Dr. Duval announces the end of the study in November.

1973

Tuskegee-based civil rights attorney Fred D. Gray files a \$1.8 billion class action lawsuit, *Pollard v. United States*, against the federal government, the State of Alabama, the State Board of Health of Alabama, the Milbank Memorial Fund, and individual physicians connected with the USPHS syphilis study in July. That year, the Milbank Memorial Fund is dropped from the suit on jurisdictional grounds.

1974

The parties settle the class action lawsuit out of court for \$10 million. This amount is worth approximately \$60.3 million in January 2022 when adjusted for inflation. The Tuskegee Health Benefit Program is established to provide lifetime medical benefits and burial services to all living participants and their wives and children who test positive for syphilis.

Congress passes the National Research Act, aimed at preventing researchers from exploiting human subjects. This law creates the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

The Department of Health, Education, and Welfare (DHEW) adopts regulations that require researchers to obtain voluntary informed consent from all persons taking part in studies conducted or funded by the DHEW. (The DHEW later splits into the Department of Education and the Department of Health and Human Services.) The regulations also require that all DHEW-supported studies using human subjects be reviewed by an Institutional Review Board, or IRB, that decides whether research protocols meet ethical standards.

1979

The DHEW Ethics Advisory Board forms to review ethical issues of biomedical research. DHEW releases the Belmont Report, which summarizes three ethical principles that should guide human research: respect for persons, beneficence, and justice. The report leads to the requirement that any institution conducting biomedical research on human subjects, regardless of DHEW support, must have an IRB to ensure the rights and welfare of the participants are protected.

1981

Bad Blood: The Tuskegee Syphilis Experiment by historian James H. Jones is published. The book mentions the Milbank Memorial Fund's burial payments.

1990s

The Milbank Memorial Fund sharpens its focus on supporting policymakers and other decision makers with "the best evidence and experience." The Milbank Memorial Fund launches the Reforming States Group, which brings together bipartisan leaders to share firsthand experience from the front lines of health care reform.

The Milbank Memorial Fund also promotes the use of reviews of evidence-based research to inform policy and clinical practice.

1993

PBS's NOVA airs an episode on the study called "The Deadly Deception." The Milbank Memorial Fund then president, Daniel M. Fox, a member of NOVA's scientific advisory board, consults with the producers, informs the Milbank Memorial Fund board of the documentary, and recommends writing a paper on the Fund's involvement and holding a public meeting on the issues. The board does not move forward with the paper or meeting.

1994

University of Virginia hosts a conference, "Doing Bad in the Name of Good: The Tuskegee Syphilis Study and its Legacy." Bioethicist Dr. John C. Fletcher is "dismayed and appalled" that there was never an apology from the federal government and declares, "it is never too late to apologize."

1996

Following a conversation with epidemiologist Dr. Ralph V. Katz, Dr. Rueben Warren of the CDC's Office of Minority Health hosts a meeting at Tuskegee University with a group of academics and health professional to discuss a federal apology and how to pursue it. The Tuskegee Syphilis Study Legacy Committee, cochaired by Dr. Fletcher and Dr. Vanessa Northington Gamble, and including Dr. Susan Reverby and Dr. Bill Jenkins, convenes and produces a report that urges President Clinton to apologize for the emotional, medical, and psychological damage of the study. The committee also asks for funding of a bioethics center at Tuskegee. The committee does not ask for apologies from either the state of Alabama or the Milbank Memorial Fund. The Legacy Committee is joined by the Congressional Black Caucus and others in this request to the federal government.

1997

President Bill Clinton issues a formal Presidential Apology for the study during an event in the East Room of the White House in which five of the remaining six surviving men are present. As the Legacy Committee had requested, the Tuskegee University National Center for Bioethics in Research and Health Care is later founded with CDC funding.

2005-2006

In celebration of the Fund's centennial, the Milbank Memorial Fund publishes a report and an article in *The Milbank Quarterly*. Neither piece mentions the USPHS syphilis study.

2009

Historian Susan Reverby's *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy*, which discusses the Milbank Memorial Fund's role in the study, is published.

October 2020

Following George Floyd's death and the nationwide Black Lives Matter protests, the Milbank Memorial Fund staff begins a diversity, equity, and inclusion initiative, which includes an examination of the Fund's history and its involvement in the USPHS syphilis study.

March 2021

Dr. Diane Rowley, a pediatrician and professor of public health at the University of North Carolina and the widow of Dr. Bill Jenkins, asks the Milbank Memorial Fund if the organization has ever apologized for its involvement in the USPHS syphilis study. The Milbank Memorial Fund responds that the organization had not apologized publicly, but that it regretted its involvement.

May 2021

The Milbank Memorial Fund Board of Directors formally discusses acknowledging its involvement in the USPHS syphilis study and instructs an ad hoc committee to:

- Plan for an apology to representatives of the descendants of the men in the USPHS syphilis study,
- Plan for a public apology and disclosure of the Milbank Memorial Fund's involvement, and
- Identify a historian to clarify the record.

June 2021

The Milbank Memorial Fund hires Dr. Susan Reverby to write a history of the Fund's role in the study.

October 2021

Milbank Memorial Fund President Christopher Koller and then board chair Tony L. Milbank send a formal letter of apology to Lillie Head, president of Voices for Our Fathers Legacy Foundation (VFOFLF), a nonprofit organization formed by the descendants of the USPHS syphilis study victims.

January 2022

The Milbank Memorial Fund board approves the Fund's Racial Equity Statement of Purpose, which acknowledges and apologizes for its role in the USPHS syphilis study and outlines its organizational, programmatic, and communications commitments to racial equity. Dr. Susan Reverby produces a report on the Fund's study involvement and the history.

April 2022

The Milbank Memorial Fund and VFOFLF sign a partnership agreement, which includes a gift to VFOFLF to help it achieve its strategic goals.

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