



Summer 2018, Vol. 21, No. 3

[Buy Print Copies](#)Search Periodicals

TABLE OF CONTENTS

[Overview](#)

[From the Editor: Studying the Past to Build a Better Future](#)[Higher Education and a Living, Diverse Democracy: An Overview](#)[Racial Healing Circles: Empathy and Liberal Education](#)[Freedom University: "Where You Walk in Undocumented and Leave Unafraid"](#)[A Legacy of Education for Liberation](#)[The Strength of Our Solidarity: A Student Reflection](#)[Reckoning with Slavery at Georgetown](#)[For Our Ancestors and Our Descendants](#)[Transforming the Negative Legacy of the Unethical United States Public Health Service Syphilis Study](#)[A Descendant's Personal Reflection](#)[Jesuits, Jazz, and Justice: Remembering the Past and Working](#)

Transforming the Negative Legacy of the Unethical United States Public Health Service Syphilis Study

By: Betty Neal Crutcher, Joan R. Harrell and Wylin Wilson

From 1932 to 1972, medical researchers from the United States Public Health Service (USPHS) in Washington, DC, developed and conducted an unethical clinical study in Tuskegee and other locations in Macon County, Alabama. Officially named the Tuskegee Study of Untreated Syphilis in the Negro¹ Male, the study sought to discover how syphilis—the sexually transmitted disease that had spread in an epidemic affecting Black people and White people throughout the United States during the late 1920s and early 1930s—ravaged the human body. The researchers never told the men who were subjected to the study that they had syphilis, never offered them penicillin after it became the standard treatment in 1947, and never gave them the option to leave the study.

The USPHS researchers implemented the immoral public health study at the Tuskegee Institute (now Tuskegee University), a historically Black institution founded sixteen years after the Civil War by Rev. Lewis Adams and Booker T. Washington, two descendants of Black slaves. The researchers lived among the majority African American populations of several rural farming communities in Macon County. Three years after the Great Depression started, the medical investigators recruited more than six hundred Black men—descendants of slaves in the Deep South—at their churches, places of employment, and homes, and offered them the opportunity to receive free health care for themselves and their families, as well as free meals and burial insurance. Research revealed that the original study included six hundred men: 399 who had syphilis and 201 who did not, representing the control group in the study (CDC 2017). By the time the study ended, a total of 623 men had been subjected to this public health medical mistreatment.

The researchers told the men they had “bad blood.” During that time in history, African American citizens in Macon County used the term bad blood for many physical ailments, including syphilis. All men in the study were given spinal taps, ostensibly to treat their condition. A majority of the men and their families welcomed the thought of free health care and the \$25 given to them each time they were subjected to the study. But the men were not offered informed consent when they technically agreed to be guinea pigs in an experiment that was never intended to



DIVERSITY & DEMOCRACY

[About Diversity & Democracy](#)[Current Issue](#)[Previous Issues](#)[Ordering Information](#)[Permissions](#)

RESOURCE HUBS

Resource Hubs

SEE ALL PERIODICALS

[Diversity & Democracy](#)[Liberal Education](#)[Peer Review](#)[Permissions](#)

[for a More Just Future](#)

[Global Indigenous Studies: The Navajo Technical University Experience](#)

[A “Boatload of Knowledge”: New Ideas in a Would-Be Utopia](#)

medically treat them. Additionally, none of the men’s family members received access to the promised free health care (Harrell 2014).

In 1972, an Associated Press reporter, with information from a USPHS employee, blew the whistle (Heller 2017). Macon County and the world were shocked to learn about this tragedy. The federal government ended the study later that year, and the survivors received a settlement of more than \$9 million in 1974.

Building a New Legacy

This infamous study continues to plague the descendants of the 623 men, as well as other members of the Black American community. In an interview with Joan R. Harrell on behalf of Tuskegee University, a granddaughter of one of the men who had syphilis revealed that her grandfather suffered from blindness as a result of not being treated. A great-grandson of another man in the study shared that his family talks about how his great-grandmother died before his great-grandfather because she contracted syphilis from her untreated husband.

According to a report from Johns Hopkins Medicine, “More than three decades after the shutdown of the notorious Tuskegee study, a team of Johns Hopkins physicians has found that Tuskegee’s legacy of Blacks’ mistrust of physicians and deep-seated fear of harm from medical research persists and is largely to blame for keeping much-needed African Americans from taking part in clinical trials” (2008).

In response to this injustice and the need to begin holistically restoring a stigmatized community, physician and medical historian Vanessa Northington Gamble chaired the Tuskegee Syphilis Study Legacy Committee in 1996. The committee declared that the unconscionable medical study should be referred to as the United States Public Health Service Syphilis Study at Tuskegee (USPHSSS), underscoring the fact that the federal government constructed the study. This empowering move catalyzed efforts to examine the history of exclusion in medicine and education and the lived experiences of the survivors and their families, including the issues of racism, sexism, and ethics.

President William Jefferson Clinton made a public apology for the unethical study on May 16, 1997, and announced a \$200,000 grant to Tuskegee University to begin plans for a National Center for Bioethics in Research and Health Care (NCBRH), based on the recommendations of the Legacy Committee members and the university. In 1999, NCBRH opened at Tuskegee University as the only bioethics center in the United States mandated by a US president. Today, NCBRH faculty and staff collaborate with the Voices for Our Fathers Legacy Foundation (VOFLF), which was founded in 2014 and comprises descendants and relatives of the men in the USPHSSS.

Partly inspired by Tuskegee University’s commitment to its bioethics center, VOFLF seeks to assist in the healing process among the descendants and their families, tell the men’s stories, and keep alive the memory of this horrific, decades-long study so that citizens may be alerted to the insidious nature of medical

mistreatment. One joint project between NCBRH and VOFLF was the dedication on March 31, 2014, of a hollow open-ground space at NCBRH to create a Memorial and Inspiration Garden to honor and respect the lives of the 623 men in the study.

Joyce Tyson Christian, secretary of the VOFLF board of directors, told us, “As a daughter of one of the men, I have the opportunity to raise my voice about the USPHSSS and the unethical effects it had on humanity. I hope we can show the ripple effect created by this unjust act, which affected my generation and will affect future generations.” NCBRH continues to work in step with the vision of the descendants through its efforts in education, research, and training. (See Betty Neal Crutcher’s [reflection](#).)

Advancing Ethics and Equity

NCBRH focuses on increasing knowledge and awareness of moral issues underlying biomedical research and the treatment of underserved populations within the health-care system. It also addresses issues of health inequity, among other goals. Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), NCBRH provides ongoing education, training, and research regarding bioethics and public health ethics.

In addition, NCBRH seeks to increase the number of people from underrepresented minority backgrounds trained and working in bioethics. Through the Bioethics Honors–Bioethics Associates Program and Bioethics Minor at Tuskegee University, students are trained to identify, articulate, and analyze ethical issues in biomedical research and to hone bioethical decision-making skills. Bioethics courses and university- and community-wide seminars and conferences address contemporary and historical bioethical violations, as well as ethical issues within the biomedical sciences and public health. Students have a chance to further develop their ethical analysis skills through summer internships at the CDC and fellowship opportunities with NCBRH, working with the majority African American population within the Alabama Black Belt (including in Macon County) to address health disparities.

These programs are open to all students within the university in all majors. Several of the courses, conferences, and seminars are also open to faculty and community members. For instance, in addition to a Special Topics in Bioethics course (an online and face-to-face course that anyone in the United States can take), NCBRH offers a rigorous Public Health Ethics Intensive Course for health-care professionals, medical residents, graduate students, faculty, and community advocates across the nation. Health-care professionals receive continuing education credit, and the course builds competency in the theory and practice of public health ethics, health-care ethics, bioethics, and research ethics. An important feature of the course is its focus on the intersection of the various domains of ethics with race, ethnicity, sex, gender, and class.

Some Tuskegee students in the Bioethics Honors Program are descendants of those subjected to the USPHSSS. For example, Kimberly Carr—a PhD candidate within the Integrative Biosciences Program at Tuskegee, whose research directly

addresses health equity and social justice—is the great-great-granddaughter of John Goode. Carr stated, “Because I am a descendant of John Goode, my career in public health and basic science research is committed and dedicated to fulfilling their dreams deferred. . . . It is my ethical and moral responsibility in my career [to] involve the ethical practices that are critical for humanity” (NCBRH 2018).

Through education, training, and scholarship, NCBRH is transforming the negative legacy of the USPHSS by equipping students, faculty, scientists, and health-care professionals with ethical sophistication that can enhance their daily work toward the health and well-being of underserved communities. In step with the vision of the descendants, NCBRH is working for justice with an aim of keeping the spirit of hope and healing alive.

Note

1. Historically in the United States, people of Black African origin have been ethnically described as “negro,” which means “black” in Spanish. Spanish and Portuguese slave traders used this description during the Atlantic slave trade. “Negro” was later capitalized to denote non-White people. Throughout the Jim Crow era, the term “colored” denoted Black people of African descent in the United States. During and after the Civil Rights Movement, “Black” and “African American” became ethnic descriptors.

References

Centers for Disease Control and Prevention. 2017. “The Tuskegee Timeline.” <https://www.cdc.gov/tuskegee/timeline.htm>.

Harrell, Joan R. 2014. “Why We Are Here: We Are Here Because Communal Bad Blood Perpetuates a Legacy of Mistrust.” *Journal of Healthcare, Science, and the Humanities* 4 (1): 23–31. <http://tuskegeebioethics.org/wp-content/uploads/2016/11/JHSH-Vol-4-No-1-Spreads.pdf>.

Heller, Jean. 2017. “AP Was There: Black Men Untreated in Tuskegee Syphilis Study.” Associated Press, May 10, 2017 (republished from July 25, 1972). <https://www.apnews.com/e9dd07eaa4e74052878a68132cd3803a/AP-WAS-THERE:-Black-men-untreated-in-Tuskegee-Syphilis-Study>.

Johns Hopkins Medicine. 2008. “Trust Between Doctors and Patients Is Culprit in Efforts to Cross Racial Divide in Medical Research.” https://www.hopkinsmedicine.org/heart_vascular_institute/media/press_releases/trust.html.

National Center for Bioethics in Research and Health Care. 2018. “Voices for Our Fathers Legacy Foundation.” <http://tuskegeebioethics.org/about/voices-for-our-fathers-legacy-foundation/>.

Betty Neal Crutcher is Presidential Spouse and Cross-Cultural Mentor at the University of Richmond, and Visiting Scholar at Tuskegee University National Center for Bioethics in Research and Health Care (NCBRH). **Joan R. Harrell** is a Lecturer and

Diversity Coordinator at the Auburn University School of Communication and Journalism, and former Visiting Scholar and Associate Director of Community Engagement at NCBRH. **Wysin Wilson** is a Visiting Lecturer at Harvard University Divinity School Women's Studies in Religion Program, and former Associate Director of Education at NCBRH.

Select any filter and click on Apply to see results

About

Strategic Plan & Goals
Membership
Manage Account
AAC&U Donors
Privacy Policy

Meetings

Annual Meeting
Network Meetings
PKAL Events
Summer Institutes

Research & Publications

Publications
AAC&U News
Liberal Education
Diversity & Democracy
Peer Review
Research

Programs & Partnerships

LEAP
Programs
Partnerships

Press

Press Releases
AAC&U Senior Staff
AAC&U in the News
Liberal Education
News Watch



AAC&U
1818 R Street NW
Washington, DC 20009
information@aacu.org
(202) 387-3760
© 2019 AAC&U
All rights reserved