

## Transcending the Legacy of Silence and Shame Surrounding the Unethical Syphilis Study at Tuskegee

BY DRS. JOAN R. HARRELL, BETTY NEAL CRUTCHER AND WYLIN WILSON

For centuries, many women have endured abuses of power within various spheres of society — familial, economic, social, political and medical. While their silence may seem like a display of their impotence in the face of systems that leave them feeling ashamed and abused, arguably their ability to remain silent until the “right” time, until they have gained courage and prepared to speak up on behalf of others, or to remain silent when speaking up would escalate a situation to dangerous proportions, is a display of great power.

According to the Centers for Disease Control and Prevention, in 1932, the United States Public Health Service (USPHS) began to unethically conduct a syphilis study on an estimated 600 poor African-American men at Alabama’s Tuskegee Institute. This study lasted for 40 years.

In Macon County, Alabama, female descendants of these male subjects are piercing the code of silence and giving voice to their historic narrative of nonidentity, shame and suffering. They are now telling their stories at the right time, after working toward

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— Kimberly Whitley, the great-great-granddaughter of John Goode

healing, reconciliation and hope, both personally and within their communities. Their lives are a testament to the importance of breaking the silence that surrounds abuse and injustice. They stand with many powerful women whom we remember and honor during Women’s History Month.

“We are here. We are alive. We need to be heard, and we are being heard,” said Kimberly Whitley, the great-great-granddaughter of John Goode, one of the human subjects in the syphilis study.

Whitley, a Ph.D. student in integrative biosciences at Tuskegee University, as well as Chanda Faye Moore-Lucien, Whitley’s aunt, and Margaret Benning Moore, Whitley’s mother, expressed concern for the immoral treatment of their ancestors during the 1930s and the health condition of Black women in the area.

After revisiting her 20-year-old copy of the *Ledger Times* from May 17, 1997, when President Bill Clinton formally apologized for the Tuskegee syphilis study, Moore commented, “The morbidity rate was high in the area for Black people when my great-grandmother’s husband, John Goode, was approached to be in the control group in the study. Many of the people in the area were farmers and sharecroppers. They needed healthcare. I can see how the men were misled to be in the study.”

When the study began in 1932, its official name was “Tuskegee Study of Untreated Syphilis in the Negro Male” but citizens of Ma-

con County were kept ignorant about the name of the study. And of course, the wives of the African-American men in the study did not know their husbands were in an unethical, non-therapeutic study.

When she was an undergraduate, Whitley read James Jones’ *Bad Blood: The Tuskegee Syphilis Experiment*, which described how the wife of one study subject asked about her health care. She was told that the study, which she thought offered free ethical health care, only focused on the men. Whitley said, “The wives of the men in the U.S. syphilis study were treated as if they were third-class citizens.”

Through our collaboration and work at the National Center for Bioethics in Research and Health Care at Tuskegee University (<http://tuskegeebioethics.org/>)

focusing on education, narrative ethics, communications ethics

outreach and research, we join with the female descendants of the syphilis study who are determined to break the painful silence through transformative work toward social justice.

We do this on behalf of all vulnerable women and children, many of whom suffer health inequity because of their gender, race, ethnicity and/or socio-economic class. ▣

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From left to right, Kimberly Whitley, Margaret Benning Moore and Chanda Faye Moore-Lucien.