

Descendants of syphilis study subjects emerging from shadows

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In this 1950's photo released by the National Archives, a black man included in a syphilis study has blood drawn by a doctor in Tuskegee, Ala. For 40 years starting in 1932, medical workers in the segregated South withheld treatment for unsuspecting men infected with a sexually transmitted disease simply so doctors could track the ravages of the horrid illness and dissect their bodies afterward. Finally exposed in 1972, the study ended and the men sued, resulting in a \$9 million settlement. (National Archives via AP)

Decades later, it's still hard to grasp what the federal government did to hundreds of black men in rural Alabama—even if you're among their descendants, lighting candles in their memory.

For 40 years starting in 1932, medical workers in the segregated South withheld treatment for unsuspecting men infected with a sexually transmitted disease simply so doctors could track the ravages of the horrid illness and dissect their bodies afterward.

Finally exposed in 1972, the study ended and the men sued, resulting in a \$9 million settlement. Twenty years ago this May, President Bill Clinton apologized for the U.S. government. It seemed to mark the end of this ugly episode, once and for all.

Except it didn't.

Relatives of the men still struggle with the stigma of being linked to the experiment, commonly known today as the "Tuskegee Syphilis Study." For years they have met privately to share their pain and honor the victims.

And, amazingly, that class-action lawsuit filed by the men in 1973 has outlived them all. The litigation continues to this day, with a federal court currently considering a request that will help determine the study's final legacy.

A key, unanswered question: What should be done with unclaimed settlement money that still sits in court-controlled accounts?

Lille Tyson Head wants you to know that her father, Freddie Lee Tyson, wasn't just a man infected with syphilis.

Once a sharecropper in the fields of rural eastern Alabama, Tyson became a carpenter early in his marriage to Johnnie Mae Neal Tyson. He helped build Moton Field, where the famed "Tuskegee Airmen" learned to fly during World War II, he later worked as a firefighter there, his daughter said. He also worked for the government after it established the Tuskegee National Forest in eastern Alabama. Around 1960, he moved the family out of the Jim Crow South to Connecticut, where he worked in a factory.

"He was a wise man, very gentle. He was a disciplined man. Active in the church, loved his family and his extended family," said Head, of Wirtz, Virginia, one of the Tysons' eight children. "He was a good man. He had a sense of humor, he was a good dancer."

Though he displayed no symptoms, Tyson also was born with [congenital syphilis](#) inherited from his mother, Head said. And that is how he became a participant in "The Tuskegee Study of Untreated Syphilis in the Negro Male."



In this 1950's photo released by the National Archives, men included in a syphilis study pose for a photo in Tuskegee, Ala. For 40 years starting in 1932, medical workers in the segregated South withheld treatment for unsuspecting men infected with a sexually transmitted disease simply so doctors could track the ravages of the horrid illness and dissect their bodies afterward. It was finally exposed in 1972. (National Archives via AP)

Located about 40 miles east of the state capital of Montgomery, Macon County is one of the poorest places in a poor state. In the early 1900s, the majority black county was a hotbed for syphilis, which affected about 35 percent of its residents of reproductive age.

In 1929, government doctors working in conjunction with a philanthropic fund began treating syphilis patients in the county with bismuth and mercury. Few people were cured, according to a summary

from the Centers for Disease Control and Prevention, and some died.

Three years later, the U.S. Public Health Service, working with state and local health agencies, began what was supposed to be a short-lived program in Tuskegee to record the progression of the illness, which begins with a small sore and can progress to open wounds, blindness, deafness, mental illness and death.

Workers initially recruited 600 [black men](#) into a health program with the promise of free medical checks, free food, free transportation and burial insurance in a county where many blacks had never even seen a doctor. The men were tested and sorted into groups—399 with syphilis and another 201 who were not infected.

The disease-free men were used as a control group. Health workers told syphilitic fathers, grandfathers, sons, brothers and uncles only that they had "bad blood."

None of the men was asked to consent to take part in a medical study. They also weren't told that "bad blood" actually was a euphemism for syphilis. Instead, doctors purposely hid the study's purpose from the men, subjecting them during the study's early months to painful spinal taps and blood tests.

Medical workers periodically provided men with pills and tonic that made them believe they were being treated, but they weren't. And doctors never provided them with penicillin after it became the standard treatment for syphilis in the mid-1940s.

The government published occasional reports on the study, including findings which showed the men with syphilis were dying at a faster rate than the uninfected. But it's doubtful any of the men—or their wives, girlfriends or other sexual partners—had any idea what had happened

until an Associated Press story was published nationwide on July 26, 1972.

The next morning, farmer and community leader Charlie Pollard walked into Fred Gray's law office in Tuskegee. Gray already was a civil rights legend by that point: His clients included Martin Luther King Jr. and Rosa Parks following her arrest in Montgomery in 1955 for refusing to give up her seat on a city bus to a white man.

Pollard "came into my office and asked me if I had been reading in the newspaper about the men who were involved in the syphilis tests for 'bad blood,'" Gray wrote in a memoir.

Pollard was among the men in the study, and his visit with Gray led to the lawsuit and the multimillion-dollar settlement reached with the government on Aug. 28, 1975. In all, Gray said in an interview, government documents showed 623 men were involved in the study.

Payments to men and their heirs differed based on whether men were infected or were in the control group, whether they were dead or alive. Living participants who had syphilis got \$37,500; heirs of deceased members of the [control group](#) received \$5,000. Women and children who were infected with syphilis got lifetime medical and health benefits, and a handful still survive, according to the Centers for Disease Control and Prevention.



In this 1950's photo released by the National Archives, a man included in a syphilis study sits on steps in front of a house in Tuskegee, Ala. For 40 years starting in 1932, medical workers in the segregated South withheld treatment for unsuspecting men infected with a sexually transmitted disease simply so doctors could track the ravages of the horrid illness and dissect their bodies afterward. Finally exposed in 1972, the study ended and the men sued, resulting in a \$9 million settlement. (National Archive via AP)

For decades, the study has been widely blamed for distrust among U.S. blacks toward the medical community, particularly clinical trials and other tests. In medical and [public health](#) circles, it's known as the "Tuskegee effect."

Freddie Lee Tyson quit the study during the 1950s after hearing rumblings that "something was wrong," Lille Head said.

Unaffected by the disease despite years of being in the study's syphilitic group, Tyson learned the true nature of the program only when the rest of the country found out, his daughter said. His wife and children all tested negative for syphilis, but Tyson was traumatized and feared the disease would show up somewhere in his family.

"After he found out about it he had to live with it. That could bring a person down if he wasn't strong. He was angry and he was upset," she said.

The lawsuit settled years before, Tyson died in 1988 at age 82 after an automobile accident. Today, the 72-year-old Head chairs Voices of our Fathers Legacy Foundation, a nonprofit organization formed in 2014 by the men's relatives to tell the story of the victims of the Tuskegee study.

Through the decades, their loved ones have been portrayed both as unwitting victims of a horrid experiment and as ignorant hicks who brought trouble on themselves with promiscuous behavior. Many descendants are still steamed over a 1997 movie called "Miss Evers Boys," which they believe cast the men in a bad light. A big part of the foundation's purpose is rounding out the narrative of the men's lives by telling the story of people like Freddie Lee Tyson, Head said.

Descendants of the men began gathering a year or two after Clinton hosted five remaining test survivors in the White House. The meetings are held in conjunction with Tuskegee's National Center for Bioethics in Research and Health Care, established in 1999 to address ethical and human rights issues in science, particularly concerning minorities.

The last man involved in the syphilis study died in 2004 and this year, for the first time, relatives both allowed The Associated Press into their annual gathering and invited the public to a ceremony where they lit candles for the men.

This year's ceremony included about 110 descendants, friends, community members, a gospel choir from Tuskegee University and public officials. There were speeches by Head and attorney Gray and others. The "community day of healing" was a big step for the families, Head said.

"It was important that the people of Macon County knew what the descendants were doing, and it gave them a chance to come out and be a part not only of the healing but also remembering of the men," she said. In the future, she hopes, more descendants "will come out of the shadows and be a voice for their fathers and grandfathers."

Retired public health nurse Amy Pack both visited with men of the study through her job in Macon County and had relatives who were among the test subjects, including great-uncle Seth Barrow. She said the foundation is still trying to find additional descendants; there's a small chance that syphilis dating back to the years of the study could still be in the bloodlines of families who are unaware of their connection to the study, she said.



In this 1950's photo released by the National Archives, a nurse writes on a vial of blood taken from a participant in a syphilis study in Tuskegee, Ala. For 40 years starting in 1932, medical workers in the segregated South withheld treatment for unsuspecting men infected with a sexually transmitted disease simply so doctors could track the ravages of the horrid illness and dissect their bodies afterward. Finally exposed in 1972, the study ended and the men sued, resulting in a \$9 million settlement. (National Archives via AP)

The legal fallout from the Tuskegee syphilis study lives on at the federal courthouse in Montgomery.

Settlement funds were used for decades to compensate study participants and more than 9,000 of their relatives. Court workers were unable to locate other descendants, and some never responded to letters from the

clerk's office, which disbursed millions before the last payment was recorded in 2008.

Court officials won't say how much money is left, but documents indicate the balance is mostly interest earnings from money first paid by the government decades ago. Gray said he's heard it's less than \$100,000.

Some family members say the money should be used for additional funding for medical screenings for the men's families, and others want a long-discussed memorial at the old hospital where the study was run at Tuskegee University.

U.S. District Judge Myron Thompson is currently considering a request Gray filed in August to use the remaining money to fund operation of the Tuskegee Human and Civil Rights Multicultural Center, a combination museum and town welcome center that includes a display about the syphilis study.

The center is located in an old bank building owned by the county, and it's operated by a nonprofit headed by Gray and his daughter; the organization had net assets of more than \$850,000 in 2015, with money coming from grants and donations, tax records show. The names of the men who were involved in the program are etched in a circle on the floor as a memorial.

In his address to descendants during the community service, Gray made what amounted to a closing argument for using the money for the museum, which is open only during the summer because of funding shortages. Gray told descendants that the men of the study—the people he represented after that meeting with Charlie Pollard—wanted a lasting memorial to their legacy, and he has worked for 20 years to make it happen at the center.

A judge refused a similar request from Gray to provide the leftover money to the museum in 2004 after the government insisted it should get the money, records show.

But Pollard's 92-year-old daughter, Ralphine Pollard Harper, said she likes the idea. People need to know what happened, she said, even if her father didn't like discussing the study.

"He'd get mad about it," she recalled. "He said, 'They just took us up here and made guinea pigs of us.'"

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