

The Tuskegee Syphilis Experiment

"The eight men who are survivors of the syphilis study at Tuskegee are a living link to a time not so very long ago that many Americans would prefer not to remember, but we dare not forget. It was a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy. It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future."

—President Clinton's apology for the Tuskegee Syphilis Experiment, 1997

Overview

For forty years (between 1932 and 1972,) the U.S. Public Health Service conducted an experiment on 399 black men in the late stages of syphilis. These men, for the most part illiterate sharecroppers from one of the poorest counties in Alabama, were never told what disease they were suffering from or of its seriousness. Informed that they were being treated for "bad blood," their doctors had no intention of curing them of syphilis at all. Rather, data for the experiment was to be collected from autopsies of the men, who were deliberately left to degenerate. In this lesson, students will learn about the U.S. government's "Tuskegee Study of Untreated Syphilis in the Negro Male" via class discussion, a Power Point, and reading. After sharing their thoughts regarding how American should atone for such past wrongs, students will create a memorial designed to educate the public regarding the Tuskegee experiment.

Grade

High School

Essential Questions

- What was the Tuskegee syphilis study?
- Who were the subjects of the experiment? What was their position in society and what motivated them to participate?
- What were participants told about the purpose of the study and the health consequences of participating in it, and how did this differ from actuality?
- What impact did the Tuskegee study have on the participants, their families, the African American community, and the American community in general?
- How should our government compensate for past wrongs?

Materials

- The Tuskegee Syphilis Experiment accompanying Power Point;" available in the Database of K-12 Resources (in PDF format) at
 - https://k12database.unc.edu/files/2012/07/TuskegeeSyphilisExperimentPPT.pdf
 - To view this PDF as a projectable presentation, save the file, click "View" in the top menu bar of the file, and select "Full Screen Mode"
 - o To request an editable PPT version of this presentation, send a request to CarolinaK12@unc.edu
- "Ernest Hendon, an unexpected survivor, died on January 16th, aged 96," article attached
- "Remarks by the President in apology for study done in Tuskegee," attached
- "U.S. Apologizes for 'Reprehensible' 1940s Syphilis Study in Guatemala," optional article attached
- "CIA organized fake vaccination drive to get Osama bin Laden's family DNA," optional article attached

Duration

60-90 minutes

Student Preparation

- While this lesson deals with sensitive topics, both in its focus on a syphilis study and on issues of racism and injustice, it is important for students to explore such controversial history in order to have a comprehensive understanding of our nation's past and to be empowered to create a better future. In order to lead this lesson effectively and safely, teachers must have established a safe classroom culture with clear expectations of respect, open-mindedness, and civil conversation. See Carolina K-12's Database of K-12 Resources under the "Activities" section and our Tips for Tackling Sensitive History & Controversial Current Events in the Classroom.
- While an in-depth study of the syphilis disease itself is not crucial for this lesson, an overview of the disease will be necessary. Thus, students should be prepared in advance that they are expected to interact with the lesson's content with respect and maturity. Each teacher should consider their particular school community to determine what type of preparation may be necessary for administrators and parents.
- This lesson is best placed after students have an understanding regarding the Jim Crow Era.

Procedure

Introduction to the Tuskegee Syphilis Experiment

- 1. As a warm up, ask students if they have heard of any medical or health research studies. Have students briefly explain the studies of which they are aware and note these in a list on the board. (Answers may include studies conducted locally, or students may identify larger, historical studies such as Nuremberg or Tuskegee.) If a student brings up Tuskegee, ask the class to share what they already know/think they know regarding this topic. If no one brings up Tuskegee, address it with the class and ask if anyone knows anything about it.
- 2. Inform students that they will be learning about one of the most infamous American studies in the history of public health research, the Tuskegee syphilis experiment. Before going further into the lesson, explain to students that the history they are going to study is sensitive and requires them to be mature and respectful (see "Preparation" above.) Also, let students know that they will possibly find the information they are going to learn shocking, disheartening, and angering, since it involves egregious government abuse. Let students know that the purpose of studying this history, even though it can be emotionally difficult, is to gain a comprehensive understanding of our nation's past, learn from such mistakes, and better ensure the present and future is improved.
- **3.** Before delving into the details of the study, teachers should provide a general overview of syphilis so that students have a very basic understanding of the disease:
 - Syphilis is disease transmitted through sexual contact; it may also be transmitted from mother to fetus during pregnancy or at birth, resulting in congenital syphilis. The signs and symptoms of syphilis vary depending in which of the four stages it presents (primary, secondary, latent, and tertiary). The primary stage classically presents with a single skin ulceration (typically firm, painless, non-itchy), secondary syphilis with a rash which frequently involves the palms of the hands and soles of the feet, latent syphilis with little to no symptoms, and the final stage of syphilis with gummas (non-cancerous growths), neurological, and/or cardiac symptoms. Diagnosis is usually via blood tests; however, the bacteria can also be visualized under a microscope. Syphilis can be effectively treated with antibiotics, most commonly with penicillin, which was discovered and made widely available in the 1940s. (Source: http://en.wikipedia.org/wiki/Syphilis)
- **4.** Next, project <u>slide 2</u> of the accompanying <u>Power Point</u> and explain to students that in1932, the Public Health Service of the American government, working with the Tuskegee Institute, began a study of the effects of syphilis on the human body. Ask students to take a moment and view the poster located on <u>slide</u> 2 and discuss:
 - What do you see/first notice? What information does this poster share?
 - Who do you think created this poster?

- What impression do you have of the Health Department based on the information shared?
- What do you think the purpose of this poster is?
- 5. After discussing, let students know that this was an advertisement distributed by the U.S. Public Health Service, which was actively engaged in public education campaigns designed to encourage diagnosis and treatment of syphilis in the early 1900s, when more discoveries were being made about the disease. For example, in 1906, the first effective test for syphilis, the Wassermann test, was developed. Although it had some false positive results, it was a major advance in the prevention of syphilis. By allowing testing before the acute symptoms of the disease had developed, this test allowed the prevention of transmission of syphilis to others, even though it did not provide a cure for those infected. In the 1930s the Hinton test, developed by William Augustus Hinton, and based on flocculation, was shown to have fewer false positive reactions than the Wassermann test. Both of these early tests have since been superseded by newer analytical methods. (Source: http://www.news-medical.net/health/Syphilis-History.aspx)

"Tuskegee Study of Untreated Syphilis in the Negro Male"

6. Next, as an overview of the Tuskegee syphilis study, go through <u>slides 3-7</u> with students and discuss:

➤ Slides 3-5:

- Why did the volunteers agree to take part in this study?
- How did what the study participants experienced/received differ from what they were expecting and promised?
- Why did the government not treat the patients? Why do you think those conducting the study failed to inform these men regarding their true intentions and the men's actual medical situations?
- Why did the medical officials not treat the men with penicillin once it was discovered as a cure for syphilis in 1947? Had the infected men been treated, what symptoms may have been alleviated and how might their quality of life have improved?
- Overall, how would you describe this study? Does anything shock or surprise you? Explain.
- What is "informed consent?" What roll is informed consent supposed to play in medical studies today? What roll did it play in the Tuskegee experiments?

Slide 6:

- Reconsider the poster pictured. Considering what you have now learned about Tuskegee, does your interpretation of this poster and its purpose change? Explain.
- In what ways does the message of this poster contradict the actions of the US Health Dept. during the study?
 - Ensure students discuss how the poster suggests that the U.S. Public Health Service was engaged
 in discordant activities. While the U.S. Public Health Service was actively engaged in public
 education campaigns designed to encourage diagnosis and treatment of syphilis, it was also
 funding the Tuskegee syphilis study, in which treatment was being actively withheld from syphilitic
 men.

Slide 7:

- Why was Tuskegee compared to Nazi experimentations? What do you already know about this subject?
 - Teachers may want to review some general information with students regarding the experiments on humans conducted by the Nazis:
 - Nazi human experimentations were a series of medical experiments on large numbers of prisoners, mainly Jews (including Jewish children) from across Europe, by the Nazi German regime in its concentration camps during the early 1940s (during World War II and the Holocaust.) Prisoners were forced to participate; they did not willingly volunteer and there was never informed consent. Experiments on twins, freezing experiments, head injury experiments, and bone, muscle, and nerve transplantation experiments were common. Typically, the experiments resulted in death, disfigurement or permanent disability. The experiments are thus considered to have been medical torture. At Auschwitz and other camps, under the direction of

Dr. Eduard Wirths, selected inmates were subjected to various hazardous experiments which were designed to help German military personnel in combat situations, develop new weapons, aid in the recovery of military personnel that had been injured, and to advance the racial ideology backed by the Third Reich that Jews were an inferior race. Dr. Aribert Heim conducted similar medical experiments at Mauthausen. After the war, these crimes were tried at what became known as the "Doctors' Trial," and revulsion at the abuses perpetrated led to the development of the Nuremberg Code of medical ethics. (Source: http://en.wikipedia.org/wiki/Nazi human experimentation)

> Slides 8 & 9:

- What various impacts did this study have on...
 - o the male participants themselves?
 - o their family members?
 - o descendants of the families?
 - o their immediate community and the African American community at large?
 - o the government?
 - o the health care field at large?

(Encourage students to consider all aspects in terms of physical, emotional, psychological, etc., and the ways in which the impact would be long lasting, through generations and even through today.)

- Why do you think the study is cited as leading to public distrust of scientific research, particularly in the African American community and among poor patients? What can be done to regain such trust?
- The advisory board deemed the study unethical. What is ethics? What is meant by "ethical?" What role should ethics play in medical experiments?
- Medical experiments still take place today, and often humans are asked to volunteer for studies, drug trials, experimental treatments, etc. What are the benefits of such practices? What is necessary to ensure such practices are ethical?

A Survivor's Story: Mr. Ernest Hendon

- 7. Next, project <u>slide 10</u> and tell students they are going to learn a bit more about the Tuskegee experiment by reading an article about Mr. Ernest Herndon (pictured on the slide), an unexpected survivor of the syphilis study who passed away in January, 2004. Provide students with the attached article and instruct them to read it (either individually or with a reading partner) then answer the three questions provided. Once students have had time to read, discuss their answers to the questions as a class and further discuss:
 - The author notes that there was "a sense that the doctors cared about the health of poor blacks. At that time, few others did." Considering that this study was started during the 1930s, what is the author highlighting about this particular time period?
 - Spend some time discussing the historical context of the time during which the study was conducted, which was during the heart of the Jim Crow Era. Remind students that between 1877 and the mid-1960s, Jim Crow laws were in effect and represented a series of rigid, unjust laws with the purpose of keeping the races separated (segregation.) Blacks and other minority groups were treated as "second class citizens" and were forced to use separate restrooms, water fountains, restaurants, waiting rooms, parks and swimming pools, libraries, hospitals, bus seats, and even cemeteries. Beyond the unfair laws, there was equally oppressive etiquette and behavior expected of African Americans, based on the misconception that Blacks were intellectually and culturally inferior to Whites.
 - Were you surprised to learn that some of the nurses and doctors involved in the study were also
 African American? Why do you think they may have agreed to participate? (i.e., limited opportunities
 for black doctors and nurses during this time, which would likely contribute to their willingness to
 follow orders without speaking out; fear of repercussions given the Jim Crow mentality if they did
 speak out; lack of information regarding all aspects of the study and the government's primary
 concern in the study; etc.)

Additional information to share with students: "It takes little imagination to ascribe racist attitudes to the white government officials who ran the experiment, but what can one make of the numerous African Americans who collaborated with them? The experiment's name comes from the Tuskegee Institute, the black university founded by Booker T. Washington. Its affiliated hospital lent the PHS its medical facilities for the study, and other predominantly black institutions as well as local black doctors also participated. A black nurse, Eunice Rivers, was a central figure in the experiment for most of its forty years.

The promise of recognition by a prestigious government agency may have obscured the troubling aspects of the study for some. A Tuskegee doctor, for example, praised "the educational advantages offered our interns and nurses as well as the added standing it will give the hospital." Nurse Rivers explained her role as one of passive obedience: "we were taught that we never diagnosed, we never prescribed; we followed the doctor's instructions!" It is clear that the men in the experiment trusted her and that she sincerely cared about their well-being, but her unquestioning submission to authority eclipsed her moral judgment." (Source: http://www.infoplease.com/spot/bhmtuskegee1.html)

How Do We "Right" Such Wrongs?

- 8. Next, ask students to take some time to consider everything they've learned thus far and discuss:
 - How do you imagine you would feel if you were one of the participants or their family member and
 you found out that you had been lied to in this way? (Encourage students to infer such feelings, but
 point out that in truth, we can't possibly know exactly what the level of emotion might be like to
 experience something like this.)
- **9.** Next, either in partners or small groups, instruct students to take a few minutes to consider and discuss the following question. (One student per partner/group should take notes regarding the ideas students have in terms of compensation, apologies, etc.)
 - Given all you have learned, what steps should be taken, and by who, to try and right the wrongs committed during the Tuskegee study?
- **10.** After students have had some time to discuss, open up the discussion to the entire class, allowing students to share their ideas and comparing the various thoughts and approaches raised. Create a master list of student thoughts so that it can be compared to the actual steps for reparation taken.
- **11.** Next, share the information on <u>slide 11</u>, which details the actual reparations offered to those impacted by the Tuskegee study, then discuss:
 - What is your opinion of these reparations? How do they compare with the ideas you noted in our class discussion?
 - You read that Mr. Hendon was given \$37,500 in the settlement. Is this a sufficient amount of money based on the circumstances? Explain.
 - Do you think these steps made any headway in repairing trust in the American government? Why or why not? If not, what could be done to repair the lost trust?

President Clinton's Apology

- 12. Tell students that as they've now learned, one of the ways the government has attempted to "right the wrongs" of Tuskegee is by issuing an apology. In 1997, 65 years after the study was implemented, President Bill Clinton delivered a formal apology for the syphilis study at Tuskegee. The ceremony was attended by the few remaining survivors, patient family members, members of the community, and others impacted. Provide each student with a copy of President Clinton's speech (attached) and instruct them to take notes on the text as they read:
 - Circle any words that are unfamiliar to you.

- Underline any parts of the excerpt that you think are most important or that stick out to you.
- If you are confused by any part of the excerpt, write a question mark by that line or section. You can also write out questions on the text.
- If anything surprises you or evokes a strong emotional response from you, you can write an exclamation mark by the line or section,
- If a particular thought pops in your head that connects to the reading, write it in the margins.
- **13.** Once students are done reading, have them discuss the attached questions in small groups, or engage in a whole class discussion.
 - What does President Clinton mean when he refers to the White House as the "people's house?"
 - Why does President Clinton feel it is important to not forget the Tuskegee syphilis study?
 - President Clinton describes the Tuskegee events as "a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy." What does he mean? In what way was trust broken by the government in the Tuskegee study?
 - How does Clinton describe the men from the Tuskegee study?
 - In what ways did the US government betray these men, their families and community?
 - Is it surprising to hear the President say that the government did something wrong? Why or why not?
 - Why do you think it took the US government so long to apologize (over 60 years)?
 - What impact do you think this apology had on the few Tuskegee survivors still living? On their families? On the African American community?
 - While Clinton acknowledges that "what's done can't be undone," what does he say we can do?
 - President Clinton asks the American people to "resolve to hold forever in our hearts and minds the
 memory of a time not long ago in Macon County, Alabama, so that we can always see how adrift we
 can become when the rights of any citizens are neglected, ignored and betrayed." Why is it important,
 as citizens and community members, to be aware of situations in which people's rights are being
 infringed upon and to speak out against such whether it directly impacts you or not?
 - Clinton notes that the Tuskegee study hurt and divided America, stating that "We cannot be one America when a whole segment of our nation has no trust in America." What does he mean?
 - Summarize the five steps President Clinton outlines for helping to rebuild the lost trust.
 - Of these actions, which do you think is most important, or will be most impactful, and why?
 - Clinton notes that science and technology are progressing, but he says that "with these changes we must work harder to see that as we advance we don't leave behind our conscience." What does he mean and what implications does this have for health and medical research?
 - Do you think you would be able to forgive your government were you in a situation like that of the Tuskegee study? Why or why not?
 - Choose a phrase in the speech that you feel is most powerful. Write it below and describe why you think this particular excerpt is most meaningful.

Design a Memorial for Tuskegee

14. The first step President Clinton outlined in his speech was a planning grant for establishing a center for bioethics in research and health care. "The center will serve as a museum of the study and support efforts to address its legacy and strengthen bioethics training," he stated. Tell students to imagine they have been hired to design a memorial that will be placed outside the center with the purpose of educating people about the Tuskegee study. Provide students with the attached assignment sheet and go over the details of the project. Make sure students understand that their memorial should educate, and should particularly be connected to President Clinton's remarks that, "It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future. And without remembering it, we cannot make amends and we cannot go forward."

- **15.** Teachers should determine whether this assignment will be completed individually, in partners, or in small groups. Let the class know that they can create anything within the realm of a memorial (i.e. a statue, a mural, an interactive exhibit, etc.) but that they must focus on the assigned theme. The assignment sheet doesn't offer any parameters in terms of the size of the sketch required— teachers should determine whether they want this done on regular art paper, or whether they want students to work on a larger scale (i.e. poster paper or poster board.) Let students know the due date of their memorial and if time permits, allow students to begin brainstorming in class.
- 16. On the date monuments are due, allow students to share their work by instructing them to first post their memorial sketches around the room. Allow the class to spend approximately 10+ minutes of class doing a "gallery walk," during which they rotate among all of the sketches and observe them. Teachers may want to number each sketch and instruct students to carry paper and pencil with them, writing down "What they liked and learned" for each sketch, or for a pre-determined number of sketches (i.e., instruct students to review 5 memorials of their choosing.) This can be followed with a class debrief in which students offer feedback to one another. Optionally, the class could also vote on which sketch they feel best educates and makes amends.
- **17.** Close the review of the memorials by discussing:
 - Even though it presents an unflattering picture of the American government and our history, why is it important to be aware of events such as the Tuskegee study?
 - What are the most important lessons our government and nation can learn from this history? How can we take responsibility for past wrong doings?

Additional Activities

- Have students read and discuss the attached article "U.S. Apologizes for 'Reprehensible' 1940s Syphilis Study in Guatemala," which highlights a similar study to that of Tuskegee also conducted by the American government.
- Have students read and discuss the attached article "CIA organized fake vaccination drive to get Osama bin Laden's family DNA." Have students discuss the following questions:
 - Describe the CIA's program. Why did the CIA create this program? Was it successful?
 - O What happened to the Pakistani doctor in charge of the program?
 - o How does this program affect international relations between the US and Pakistan?
 - Do you think that Pakistani parents will be less likely to have their children vaccinated as a result of this
 operation?
 - O What are some similarities and differences between the CIA's program and the Tuskegee study?

Additional Resources

- U.S. Public Health Service Syphilis Study at Tuskegee: http://www.cdc.gov/tuskegee/timeline.htm
- Remembering Tuskegee: http://www.npr.org/templates/story/story.php?storyId=1147234
- Tuskegee Lessons Syphilis Study Leaves Behind Legacy of Mistrust: http://www.npr.org/programs/morning/features/2002/jul/tuskegee/commentary.html
- Bad Blood: The Tuskegee Syphilis Study:
 http://www.hsl.virginia.edu/historical/medical-history/bad-blood/
- The Tuskegee Syphilis Experiment: http://www.infoplease.com/spot/bhmtuskegee1.html

Ernest Hendon, an unexpected survivor, died on January 16th, aged 96

Jan 29th 2004 | The Economist

THEY said Ernest Hendon did not look his age when he stood, two years ago, in front of the Alabama House of Representatives in Montgomery. His back was straight, his eyes bright. He felt good, he told reporters; and better still now that the Alabama House had expressed regret for what had been done to him. "I feel this means that it won't happen again," he said happily.



Limelight was the last thing he had ever expected. He was born a poor black sharecropper's son in Macon County, Alabama, and was a sharecropper himself. Nothing came easily to him or his neighbors. They hoed small plots of red earth in the pine woods, lived in wooden shacks, and picked cotton in the season. There was little money around and small chance of seeing a doctor, though syphilis was more rampant there than anywhere else in the South. From time to time, the Ku Klux Klan lit their fiery crosses in the hills.

Mr. Hendon remembered the day the bus arrived, in 1932. It carried doctors and nurses who had come to do a study among the syphilitic sharecroppers. In exchange for their help they would get free medical examinations, burial insurance, free transport to and from the hospital in Tuskegee and—a rare treat—the chance to stop and shop in town. On the days they were examined, the men got a free hot meal. Along with 398 others, Mr. Hendon, then 24, signed up to take part.

He was already unwell, though he himself, like most of the men, was not sure what was wrong with him. The doctors called it "bad blood", a term that also covered anemia and general weariness. Some of the volunteers were given, for a while, the fierce and ineffective syphilis treatment of the time: injection with arsenic compounds and mercury ointment for the crusted ulcers on their skin. Mr. Hendon, like many of the others, was not. He was given "pink medicine", or aspirin, and "some kinda brown-looking medicine", which was iron tonic. When a "last chance" for free treatment was offered, Mr. Hendon turned up and was given a spinal tap: "They give me a test in the back and they draw something out of me." "They said it would do you good," he said later.

None of it did him good. The doctors and nurses were not there to cure, but to observe the progress of untreated syphilis. Patients who are untreated sometimes develop no symptoms, and sometimes spontaneously recover; but they can also suffer liver deformity, heart damage, paralysis and insanity. Burial insurance was offered because the data for the study was to come from the men's autopsies. But none of this was communicated to them.

For 40 years, the Tuskegee Syphilis Study continued. Mr. Hendon went for his examinations and, after 25 years, got a certificate of appreciation from the surgeon-general. The men especially liked Eunice Rivers, a motherly black nurse who made them feel at home in the hospital. Several of the doctors and nurses were black, and the Tuskegee Institute, which ran the hospital, was a black university. There was dignity in the proceedings, and a sense that the doctors cared about the health of poor blacks. At that time, few others did.

Ignoring penicillin

Yet the study also showed clearly the paternalistic racism of the age. The federal Public Health Service (PHS) wanted not only to compare the effects of syphilis in blacks and whites, but also to stop black "degeneracies" spreading to the white population. It made no secret of this. The Tuskegee study was mentioned in reports and cited at conferences. The fact that it was doing nothing to cure Mr. Hendon or the others was, however, kept quiet.

Certain moments were tricky. In 1942, the army drew up a list of likely recruits from Macon County. Many subjects of the study were on it, presumably including Mr. Hendon, who was the right age. Having seen them, the local recruiting board ordered them to be treated for syphilis; but the assistant surgeon-general intervened to have their names removed from the list.

The next year, penicillin became an effective treatment for syphilis. It was not given to the Tuskegee subjects unless they asked for it. By 1948 the Nuremberg Code, inspired by revelations of experiments in the Nazi death camps, set standards for medical studies on human subjects. In Tuskegee, things went on as before.

No serious questions were asked until 1972, when a whistle-blower from the PHS talked to the Associated Press. Once exposed, the study was ended immediately. That very year, the surviving subjects filed a lawsuit against all the individuals and institutions involved. The government agreed to pay out almost \$10m, of which Mr. Hendon's share was \$37,500, with free health care for life.

He had confounded expectations by living so long. More than 100 of the subjects died of the disease or related complications, together with at least 40 unwitting wives, and 19 children contracted syphilis at birth. A longer-lasting legacy was black distrust, which continues, of government doctors and clinical trials.

Source: http://www.economist.com/node/2383949?story_id=2383949

Please answer:

- 1. Describe Mr. Hendon based on what you read. What is your impression of him? Does anything about his attitude surprise you? Explain.
- 2. What type of life did Mr. Hendon lead?
- 3. Overall, what do you find most shocking or upsetting regarding the Tuskegee syphilis study?

THE WHITE HOUSE Office of the Press Secretary

For Immediate Release May 16, 1997

REMARKS BY THE PRESIDENT IN APOLOGY FOR STUDY DONE IN TUSKEGEE The East Room 2:26 P.M. EDT

THE PRESIDENT: Ladies and gentlemen, on Sunday, Mr. Shaw will celebrate his 95th birthday. (Applause.) I would like to recognize the other survivors who are here today and their families: Mr. Charlie Pollard is here. (Applause.) Mr. Carter Howard. (Applause.) Mr. Fred Simmons. (Applause.) Mr. Simmons just took his first airplane ride, and he reckons he's about 110 years old, so I think it's time for him to take a chance or two. (Laughter.) I'm glad he did. And Mr. Frederick Moss, thank you, sir. (Applause.)

I would also like to ask three family representatives who are here -- Sam Doner is represented by his daughter, Gwendolyn Cox. Thank you, Gwendolyn. (Applause.) Ernest Hendon, who is watching in Tuskegee, is represented by his brother, North Hendon. Thank you, sir, for being here. (Applause.) And George Key is represented by his grandson, Christopher Monroe. Thank you, Chris. (Applause.) I also acknowledge the families, community leaders, teachers and students watching today by satellite from Tuskegee. The White House is the people's house; we are glad to have all of you here today...

The eight men who are survivors of the syphilis study at Tuskegee are a living link to a time not so very long ago that many Americans would prefer not to remember, but we dare not forget. It was a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy. It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future. And without remembering it, we cannot make amends and we cannot go forward.

So today America does remember the hundreds of men used in research without their knowledge and consent. We remember them and their family members. Men who were poor and African American, without resources and with few alternatives, they believed they had found hope when they were offered free medical care by the United States Public Health Service. They were betrayed.

Medical people are supposed to help when we need care, but even once a cure was discovered, they were denied help, and they were lied to by their government. Our government is supposed to protect the rights of its citizens; their rights were trampled upon. Forty years, hundreds of men betrayed, along with their wives and children, along with the community in Macon County, Alabama, the City of Tuskegee, the fine university there, and the larger African American community.

The United States government did something that was wrong -- deeply, profoundly, morally wrong. It was an outrage to our commitment to integrity and equality for all our citizens.

To the survivors, to the wives and family members, the children and the grandchildren, I say what you know: No power on Earth can give you back the lives lost, the pain suffered, the years of internal torment and anguish. What was done cannot be undone. But we can end the silence. We can stop turning our heads away. We can look at you in the eye and finally say on behalf of the American people, what the United States government did was shameful, and I am sorry. (Applause.)

The American people are sorry -- for the loss, for the years of hurt. You did nothing wrong, but you were grievously wronged. I apologize and I am sorry that this apology has been so long in coming. (Applause.)

To Macon County, to Tuskegee, to the doctors who have been wrongly associated with the events there, you have our apology, as well. To our African American citizens, I am sorry that your federal government orchestrated a study so clearly racist. That can never be allowed to happen again. It is against everything our country stands for and what we must stand against is what it was.

So let us resolve to hold forever in our hearts and minds the memory of a time not long ago in Macon County, Alabama, so that we can always see how adrift we can become when the rights of any citizens are neglected, ignored and betrayed. And let us resolve here and now to move forward together.

The legacy of the study at Tuskegee has reached far and deep, in ways that hurt our progress and divide our nation. We cannot be one America when a whole segment of our nation has no trust in America. An apology is the first step, and we take it with a commitment to rebuild that broken trust. We can begin by making sure there is never again another episode like this one. We need to do more to ensure that medical research practices are sound and ethical, and that researchers work more closely with communities.

Today I would like to announce several steps to help us achieve these goals. First, we will help to build that lasting memorial at Tuskegee. (Applause.) The school founded by Booker T. Washington, distinguished by the renowned scientist George Washington Carver and so many others who advanced the health and well-being of African Americans and all Americans, is a fitting site. The Department of Health and Human Services will award a planning grant so the school can pursue establishing a center for bioethics in research and health care. The center will serve as a museum of the study and support efforts to address its legacy and strengthen bioethics training.

Second, we commit to increase our community involvement so that we may begin restoring lost trust. The study at Tuskegee served to sow distrust of our medical institutions, especially where research is involved. Since the study was halted, abuses have been checked by making informed consent and local review mandatory in federally-funded and mandated research.

Still, 25 years later, many medical studies have little African American participation and African American organ donors are few. This impedes efforts to conduct promising research and to provide the best health care to all our people, including African Americans. So today, I'm directing the Secretary of Health and Human Services, Donna Shalala, to issue a report in 180 days about how we can best involve communities, especially minority communities, in research and health care. You must -- every American group must be involved in medical research in ways that are positive. We have put the curse behind us; now we must bring the benefits to all Americans. (Applause.)

Third, we commit to strengthen researchers' training in bioethics. We are constantly working on making breakthroughs in protecting the health of our people and in vanquishing diseases. But all our people must be assured that their rights and dignity will be respected as new drugs, treatments and therapies are tested and used. So I am directing Secretary Shalala to work in partnership with higher education to prepare training materials for medical researchers. They will be available in a year. They will help researchers build on core ethical principles of respect for individuals, justice and informed consent, and advise them on how to use these principles effectively in diverse populations.

Fourth, to increase and broaden our understanding of ethical issues and clinical research, we commit to providing postgraduate fellowships to train bioethicists especially among African Americans and other minority groups. HHS will offer these fellowships beginning in September of 1998 to promising students enrolled in bioethics graduate programs.

And, finally, by executive order I am also today extending the charter of the National Bioethics Advisory Commission to October of 1999. The need for this commission is clear. We must be able to call on the thoughtful, collective wisdom of experts and community representatives to find ways to further strengthen our protections for subjects in human research.

We face a challenge in our time. Science and technology are rapidly changing our lives with the promise of making us much healthier, much more productive and more prosperous. But with these changes we must work harder to see that as we advance we don't leave behind our conscience. No ground is gained and, indeed, much is lost if we lose our moral bearings in the name of progress.

The people who ran the study at Tuskegee diminished the stature of man by abandoning the most basic ethical precepts. They forgot their pledge to heal and repair. They had the power to heal the survivors and all the others and they did not. Today, all we can do is apologize. But you have the power, for only you -- Mr. Shaw, the others who are here, the family members who are with us in Tuskegee -- only you have the power to forgive. Your presence here shows us that you have chosen a better path than your government did so long ago. You have not withheld the power to forgive. I hope today and tomorrow every American will remember your lesson and live by it.

Thank you, and God bless you. (Applause.)

REMARKS BY THE PRESIDENT IN APOLOGY FOR STUDY DONE IN TUSKEGEE Discussion Questions

- 1. What does President Clinton mean when he refers to the White House as the "people's house?"
- 2. Why does President Clinton feel it is important to not forget the Tuskegee syphilis study?
- **3.** President Clinton describes the Tuskegee events as "a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy." What does he mean? In what way was trust broken by the government in the Tuskegee study?
- **4.** How does Clinton describe the men from the Tuskegee study?
- 5. In what ways did the US government betray these men, their families and community?
- **6.** Is it surprising to hear the President say that the government did something wrong? Why or why not?
- 7. Why do you think it took the US government so long to apologize (over 60 years)?
- **8.** What impact do you think this apology had on the few Tuskegee survivors still living? On their families? On the African American community?
- 9. While Clinton acknowledges that "what's done can't be undone," what does he say we can do?
- 10. President Clinton asks the American people to "resolve to hold forever in our hearts and minds the memory of a time not long ago in Macon County, Alabama, so that we can always see how adrift we can become when the rights of any citizens are neglected, ignored and betrayed." Why is it important, as citizens and community members, to be aware of situations in which people's rights are being infringed upon and to speak out against such whether it directly impacts you or not?
- **11.** Clinton notes that the Tuskegee study hurt and divided America, stating that "We cannot be one America when a whole segment of our nation has no trust in America." What does he mean?
- 12. Summarize the five steps President Clinton outlines for helping to rebuild the lost trust:
- 13. Of these actions, which do you think is most important, or will be most impactful, and why?
- **14.** Clinton notes that science and technology are progressing, but he says that "with these changes we must work harder to see that as we advance we don't leave behind our conscience." What does he mean and what implications does this have for health and medical research?
- **15.** Do you think you would be able to forgive your government were you in a situation like that of the Tuskegee study? Why or why not?
- **16.** Choose a phrase in the speech that you feel is most powerful. Write it below and describe why you think this particular excerpt is most meaningful.

ASSIGNMENT:

Design a Historical Memorial Regarding the Tuskegee Syphilis Study

In his 1997 apology for the Tuskegee syphilis study, President Clinton said that that, "It is not only in remembering that shameful past that we can make amends and repair our nation, but it is in remembering that past that we can build a better present and a better future. And without remembering it, we cannot make amends and we cannot go forward."

Keeping this in mind, you are tasked with designing a memorial with the purpose of educating people about the Tuskegee study.

- **1.** Brainstorm ideas for your memorial and consider:
 - What is most important for people to know about the Tuskegee syphilis study? What impact did the study have on the participants, their families, their community, and America at large? Why should people be educated about what took place during the study?
 - How will you design a memorial to educate the public on the Tuskegee syphilis study?
 - How will your memorial assist in healing our nation? How will you illustrate a particular emphasis on "remembering this shameful past so that we can make amends to repair our nation, building a better present and future?"
 - How will your monument encompass and illustrate some of the themes associated with the study (racism, poverty, justice, equal rights, ethics, forgiveness, unaccountable government, etc.)?
- **2.** You may use any creative medium you choose to design your memorial. The memorial can be literal or abstract, simple or complex. Examples may include (but are NOT limited to):
 - art work
 - statues
 - plaques, written descriptions, quotes, or other text displayed in some way
 - structures or buildings
 - symbolic or abstract shapes
 - inclusion of music or voice over's (i.e. you push a button and narration plays)
 - performance art that takes place live at the memorial on a particular schedule
 - a television screen that plays a particular performance clip or narration
 - PICTURE YOUR OWN CREATIVE IDEAS HERE!
- **3.** Once you have thought through your idea, you will create a detailed sketch of your memorial that shows what it will look like when finished and installed in its final location. Your sketch can contain labels, in which you point to certain aspects of the drawing and use text to describe additional details that may not be clear in the visual.
- **4.** You must also turn in a paragraph in which you provide an overview of your memorial, describe what it represents, as well as explain why it is important to remember the Tuskegee syphilis study. You will share your work on the due date.

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U.S. Apologizes for 'Reprehensible' 1940s Syphilis Study in Guatemala

By: Lea Winerman

U.S. officials apologized Friday for unethical medical experiments conducted in Guatemala more than 60 years ago, in which prison inmates were deliberately infected with syphilis.

The experiments were conducted between 1946 and 1948 by Dr. John C. Cutler, a U.S. public health service doctor who was also involved in the infamous Tuskegee syphilis study in the United States.

Secretary of State Hillary Clinton and Health and Human Services Secretary Kathleen Sebelius issued a joint statement apologizing for the experiments:

"The sexually transmitted disease inoculation study conducted from 1946-1948 in Guatemala was clearly unethical. Although these events occurred more than 64 years ago, we are outraged that such reprehensible research could have occurred under the guise of public health. We deeply regret that it happened, and we apologize to all the individuals who were affected by such abhorrent research practices."

The history of the Guatemala study was uncovered by Wellesley College professor Susan Reverby, a medical historian who has written two books about the Tuskegee case, in which black men with syphilis were observed -- but not treated -- by U.S. government researchers for nearly 40 years. Reverby was reading Cutler's papers in an archive at the University of Pittsburgh, looking for references to the Tuskegee study, when she came across descriptions of the experiments in Guatemala.

"So I started to read it, and I said, 'Oh my god,'" Reverby says.

In the study, the researchers were investigating whether penicillin -- which was already being used to treat syphilis -- could prevent the disease if it was administered right after someone was exposed to the bacteria.

The researchers exposed hundreds of people in Guatemala to the disease. Many were men who were prison inmates, others were residents of an army barracks and mental hospital. None of the subjects were asked for their consent. The researchers used visits with prostitutes who were infected with syphilis to expose the men to the disease (such visits were legal in Guatemala at the time). They also, Reverby writes, "used direct inoculations made from syphilis bacteria poured into the men's penises and on forearms and faces that were slightly abraded when the 'normal exposure' produced little disease."

They did treat the people with penicillin afterwards, but, Reverby writes, it's not clear whether everyone was cured, or even whether they received what would have been considered adequate treatment.

The Guatemala experiment differed from the Tuskegee case, Reverby says, because people were actually exposed to the disease and then treated, instead of being denied access to treatment for a disease that they already had, as happened in the Tuskegee case.

Even within the context of the much more lax research ethics standards of the time, Reverby says, the research "fell off the edge" of what was acceptable.

"Even within the context of history, this was something they shouldn't have been doing -- and they knew that," Reverby said. In fact, she cites a letter in which Surgeon General Thomas Parran said "You know, we couldn't do such an experiment in this country."

Reverby presented her findings at a medical history association meeting in May, and also wrote them up for publication -- they'll be published in January in the Journal of Policy History, but a prepublication version of the four-page paper is available on Reverby's website.

The government got involved in the spring, when Reverby showed the paper to David Sencer, a retired director at the Centers for Disease Control and Prevention whom she knew from her research on the Tuskegee experiment's history. Sencer passed it on to current CDC officials, and the agency sent a syphilis specialist to examine the papers in the University of Pittsburgh archive. That specialist confirmed the accuracy of Reverby's report.

Now, the government, in addition to issuing its apology, will also convene a panel of independent experts through the National Academies of Sciences Institute of Medicine to conduct a fact-finding probe of the events in Guatemala.

And Sofia Porres, of the Guatemalan Embassy, told the Washington Post that the Guatemalan government would also investigate. "We of course are very upset about this, and we think it's a very unfortunate event," she said. "We're going to do an investigation as well to see if there are any survivors, family, etc."

Source: http://www.pbs.org/newshour/rundown/2010/10/us-apologizes-for-60-year-old-unethical-syphilis-study-in-quatemala.html

CIA organised fake vaccination drive to get Osama bin Laden's family DNA

By Saeed Shah; The Guardian, July 11, 2011

Senior Pakistani doctor who organised vaccine programme in Abbottabad arrested by ISI for working with US agents

CIA organised fake vaccination programme in Abbottabad to try and find Osama bin Laden. Photograph: Md Nadeem/EPA

The CIA organised a fake vaccination programme in the town where it believed Osama bin Laden was hiding in an elaborate attempt to obtain DNA from the fugitive al-Qaida leader's family, a Guardian investigation has found.

As part of extensive preparations for the raid that killed Bin Laden in May, CIA agents recruited a senior Pakistani doctor to organise the vaccine drive in Abbottabad, even starting the "project" in a poorer part of town to make it look more authentic, according to Pakistani and US officials and local residents.

The doctor, Shakil Afridi, has since been arrested by the Inter-Services Intelligence agency (ISI) for cooperating with American intelligence agents.

Relations between Washington and Islamabad, already severely strained by the Bin Laden operation, have deteriorated considerably since then. The doctor's arrest has exacerbated these tensions. The US is understood to be concerned for the doctor's safety, and is thought to have intervened on his behalf.

The vaccination plan was conceived after American intelligence officers tracked an al-Qaida courier, known as Abu Ahmad al-Kuwaiti, to what turned out to be Bin Laden's Abbottabad compound last summer. The agency monitored the compound by satellite and surveillance from a local CIA safe house in Abbottabad, but wanted confirmation that Bin Laden was there before mounting a risky operation inside another country.

DNA from any of the Bin Laden children in the compound could be compared with a sample from his sister, who died in Boston in 2010, to provide evidence that the family was present.

So agents approached Afridi, the health official in charge of Khyber, part of the tribal area that runs along the Afghan border.

The doctor went to Abbottabad in March, saying he had procured funds to give free vaccinations for hepatitis B. Bypassing the management of the Abbottabad health services, he paid generous sums to low-ranking local government health workers, who took part in the operation without knowing about the connection to Bin Laden. Health visitors in the area were among the few people who had gained access to the Bin Laden compound in the past, administering polio drops to some of the children.

Afridi had posters for the vaccination programme put up around Abbottabad, featuring a vaccine made by Amson, a medicine manufacturer based on the outskirts of Islamabad.

In March health workers administered the vaccine in a poor neighbourhood on the edge of Abbottabad called Nawa Sher. The hepatitis B vaccine is usually given in three doses, the second a month after the first. But in April, instead of administering the second dose in Nawa Sher, the doctor returned to Abbottabad and moved the nurses on to Bilal Town, the suburb where Bin Laden lived.

It is not known exactly how the doctor hoped to get DNA from the vaccinations, although nurses could have been trained to withdraw some blood in the needle after administrating the drug.

"The whole thing was totally irregular," said one Pakistani official. "Bilal Town is a well-to-do area. Why would you choose that place to give free vaccines? And what is the official surgeon of Khyber doing working in Abbottabad?"

A nurse known as Bakhto, whose full name is Mukhtar Bibi, managed to gain entry to the Bin Laden compound to administer the vaccines. According to several sources, the doctor, who waited outside, told her to take in a handbag that was fitted with an electronic device. It is not clear what the device was, or whether she left it behind. It is also not known whether the CIA managed to obtain any Bin Laden DNA, although one source suggested the operation did not succeed.

Mukhtar Bibi, who was unaware of the real purpose of the vaccination campaign, would not comment on the programme.

Pakistani intelligence became aware of the doctor's activities during the investigation into the US raid in which Bin Laden was killed on the top floor of the Abbottabad house. Islamabad refused to comment officially on Afridi's arrest, but one senior official said: "Wouldn't any country detain people for working for a foreign spy service?"

The doctor is one of several people suspected of helping the CIA to have been arrested by the ISI, but he is thought to be the only one still in custody.

Pakistan is furious over being kept in the dark about the raid, and the US is angry that the Pakistani investigation appears more focused on finding out how the CIA was able to track down the al-Qaida leader than on how Bin Laden was able to live in Abbottabad for five years.

Over the weekend, relations were pummelled further when the US announced that it would cut \$800m (£500m) worth of military aid as punishment for Pakistan's perceived lack of co-operation in the anti-terror fight. William Daley, the White House chief of staff, went on US television on Sunday to say: "Obviously, there's still a lot of pain that the political system in Pakistan is feeling by virtue of the raid that we did to get Osama bin Laden, something the president felt strongly about and we have no regrets over."

The CIA refused to comment on the vaccination plot.

Source: http://www.guardian.co.uk/world/2011/jul/11/cia-fake-vaccinations-osama-bin-ladens-dna