Tuskegee Syphilis Study – (1932-1972)

July 25, 1972: story broke in *Washington Star*

- 600 low income African-American males from rural Alabama with a high incidence of syphilis infection were monitored for 40 years to observe course of disease.
  - Given free medical exams but they were not told that they had syphilis
  - Cure (penicillin) became available in 1950s
  - Participants and families denied treatment
Tuskegee Syphilis Study – (1932-1972)

Newspaper headlines

- “A Violation of Human Dignity” (Houston Chronicle, Aug. 5, 1972)
- ”An Immoral Study” (St. Louis Post-Dispatch, July 30, 1972)
- “Inhuman Experiment” (Oregonian, July 31, 1972)
- “Blot on Humanity” (Chatanooga Times, July 28, 1972)
- “Cruel Experiment” (South Bend Tribune, July 29, 1972)
- “A Shocking Medical Experiment” (New Haven Register, July 29, 1972)
- “Humans as Guinea Pigs” (Richmond Times Dispatch, Aug. 6, 1972)
- “Official Inhumanity” (LA Times, July 27, 1972)
- “Horror Story” (Providence Sunday Journal, July 30, 1972)
- “Nightmare Experiment” (Raleigh News and Observer, July 28, 1972)
- “They Helped Men Die” (Milwaukee Journal, July 27, 1972)
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<tr>
<th>Date</th>
<th>Event</th>
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<tr>
<td>Jul 25, 1972</td>
<td>Story breaks in <em>Washington Star</em></td>
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<td>Aug 24, 1972</td>
<td>Ad hoc panel created at PHS to review experiment</td>
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<td>Oct 1972</td>
<td>Panel recommends ending the study</td>
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<td>Feb-Mar 1973</td>
<td>Edward Kennedy begins Senate hearings</td>
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<td>Mar 3, 1973</td>
<td>HEW Secretary (Weinberger) orders treatment for subjects in study</td>
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Tuskegee Syphilis Study

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<th>Year</th>
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<td>July 1973</td>
<td>$1.8 billion lawsuit filed by patients and families</td>
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<tr>
<td>1974</td>
<td>new guidelines for human subject experiments</td>
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<tr>
<td>Dec. 1974</td>
<td>government settles lawsuit ($37,500 to each living survivor and $15,000 to heirs)</td>
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<td>1975</td>
<td>government extended treatment to wives and children who had contracted syphilis</td>
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<td>1997</td>
<td>Clinton apologizes in person to 4 of the 8 survivors</td>
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Tuskegee Syphilis Study

overall question:
-How could it have happened?

Q. How did it get started?
Q. When did study actually begin?
Q. Who proposed it?
Q. Why?
Q. What was goal of study?
Q. Were there precedents?
Q. Did anyone else approve the study?
Q. Any difficulty securing subjects?
Q. When was “one-time” study extended?
Q. How was time extension possible?
Q. How could treatment of subjects be prevented?
Q. How did study continue after 1945 and discovery of penicillin?
Q. How was the project finally ended?
Tuskegee Syphilis Study: FAQ

Overall question: How could it have happened?

- That as late as 1972 four hundred blacks were part of a government-run experiment, part of which was to withhold known treatment of syphilis?

Tuskegee Syphilis Study: FAQ

How did it get started?

- Like most research, for noble reasons. It followed studies in late 1920s to test & treat those least able to get diagnosis and treatment for syphilis: rural blacks.
  - Pilot program in Miss. run by federal Public Health Service and Rosenwald Fund (foundation created explicitly to help blacks, later changed its focus to concentrate on health)
  - Expanded in 1930 to other locations, including Macon Cty. Ala. (30 mi. east of Montgomery, 80% black). Tuskegee Inst. there, plus a veterans hospital. All black with 22 doctors.
    - 1st stage: 7,000-10,000 people tested; 36% tested positive (very high)
    - 2nd stage was treatment with Salvarsan and mercury; 1200 treated by fall of 1930. After another year, high cost and limited effect made Rosenwald announce end of program. State of Ala. could not pick up cost; nor could PHS (until 1934).
Tuskegee Syphilis Study: FAQ

When did study actually begin?
“Tuskegee Study of Untreated Syphilis in Negro Male” began between 1931 and 1934.

Who proposed it?
Taliferro Clark, a PHS worker who came to Ala. during Rosenwald study

Why?
Preferred to treat but no funding for it. Clark noted that of initial 1400 admitted for treatment, only 33 had undergone any previous treatment.

Goal of study?
To learn about effects of syphilis on blacks; to see if it was different than on whites [racist assumption?]

Were there precedents?
Only anecdotal observations of blacks. Nothing systematic or large scale. But in 1928 an article in a German journal was published with results of a Norwegian study of several hundred untreated patients between 1891-1910. Of note were great frequency in cardiovascular damage, and only rare neurological damage. Common assumptions was that in blacks there was higher frequency of neurological damage. (NOTE: Norwegian study was done before even salvarsan, let alone penicillin was available.)

Did anyone else approve the study?
Yes.
- Discussed with PHS colleagues, all approved
- Ala State Bd of Health approved, on condition that all were treated. No problem since Clark initially proposed a 6-8 month study; treatment, when funds available, took a year. Ala. also wanted local doctors to participate
- Tuskegee hospital medical director agreed to be local medical participant.
- Protocol submitted to Johns Hopkins Medical School doctors, who suggested study of males, over 25, 2-300 size of sample, insure no previous treatment.
Tuskegee Syphilis Study: FAQ

Any difficulty securing subjects?

• No, because it was deliberately confused with earlier testing and treatment.

When was time of study extended?

• By April 1933 results showed little neurological damage. Idea was first suggested that for little expense, subjects could be observed for 5-10 years to produce more information. Subjects already identified and participating.
• June 1933 Clark retired and was succeeded by new PHS doctor, Raymond Vonderlehr. He proposed to follow subjects to autopsy, because so much more info could be learned.

How was time extension possible?

• Little question about it. Most important was agreement of local doctors, because they would not provide treatment. Most subjects were indigent.
• Nurse Eunice Rivers hired, crucial to keeping men in program. She assured them and suggested “burial stipend” as incentive. (funded by Milbank Memorial Fund).

Tuskegee Syphilis Study: FAQ

How could treatment be prevented?

• In 1937 Rosenwald finally renewed funding of treatment program; in 1939 a mobile PHS treatment program was assigned to Macon Cty.
• Nurse Rivers screened men, saying they were under study; several men prevented from treatment 1939-41. Her justification: doctor’s orders and treatment had side effects. After 1942 draft physicals given (pos. tests required treatment; Vonderlehr got exemptions).

How did study continue after 1945 and penicillin?

• As new officials came across the study and raised questions (1948, 1951, 1952), other PHS officials regarded it as a “never to be repeated opportunity”; 20 years invested in experiment.
Tuskegee Syphilis Study: FAQ

How was the project finally ended?

- All along articles were published on results. As late as June 1965 a doctor in Detroit hospital (Irwin Schatz) read a 1964 article and sent a letter to PHS (“I am utterly astounded by the fact that physicians allow patients with a potentially fatal disease to remain untreated when effective therapy is available.”) It was filed in CDC with note it was first such letter. No reply written.

- Peter Buxtun first heard of Tuskegee when hired at SF VD clinic in Dec. 1965. Curiosity and required paper made him research Tuskegee articles (sent by CDC). Based on his reading Buxtun sent a letter in Nov. 1966 questioning the study. No reply, but a CDC official visited him over Christmas to talk to Buxtun, and he was invited to Atlanta for a meeting a few months later. But no change in CDC policy.

- Nov. 1967 Buxtun resigned from VD clinic; fall 1968 he entered law school in SF; Nov. 1968 he wrote another letter to CDC. Now (post MLK assassination riots) it got attention. Feb. 1969 an ad hoc committee met at CDC, serious debate about ending experiment, but in the end it decided to continue. Also, consent to continue was asked from Macon Cty. Medical Society (now mostly black). The men still alive (56 with syphilis and 36 control) would be monitored until their death.

- CDC wrote this back to Buxtun who was still in law school. He talked to a few colleagues (one suggested the ACLU file a suit), but Buxtun left it until he mentioned it to a friend who was a reporter for the AP, who became very interested. It was Feb. 1972. Another reporter, Jean Heller, in Washington got the assignment and the story broke on July 25, 1972.

- An assistant secretary of HEW responded he was “shocked and horrified” at the report. Another ad hoc panel was immediately created (Aug. 24, 1972); Feb. 1973 Sen. Kennedy began hearings.