

The Tuskegee Syphilis Study (1932-1972)

African Americans Distrust of Medical Institutions



The Tuskegee Syphilis Study continues to cast its long shadow on the contemporary relationship between African Americans and the biomedical community.

Numerous reports have argued that the Tuskegee Syphilis Study is the most important reason why many African Americans distrust the institutions of medicine and public health.



<https://uwa-ed504-gr1-tuskegee-syphilis.wikispaces.com/file/view/Original%20Tuskegee%20Experiment%20flier.jpg/488593218/360x266/Original%20Tuskegee%20Experiment%20flier.jpg>

<http://584766978810689455.weebly.com/uploads/6/4/1/1/6411834/508721874.jpg?303>

Contents

- Background information
- Chronology of the study
- Ethical shortcomings
- John Charles Cutler
- Consequences
- Impact on daily life

Syphilis

- Treponema pallidum
- transmission: sexual activity, congenital (pregnancy, birth)
- 4 stages of symptoms:

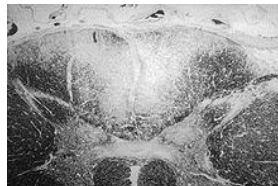
1) Primary: painless, non-itchy skin ulceration



<https://upload.wikimedia.org/wikipedia/commons/thumb/9/91/Ulcus-durum-am-Penis-01.jpg/220px-Ulcus-durum-am-Penis-01.jpg>

3) Latent: little or no symptoms (lasts for years)

Syphilis
cerebrospinalis



<https://encrypted-tbn0.gstatic.com/images?q=tbn:ANd9GcRdIaCh-G9PQVAqf51cS02oaON0gKYSj0QjMDMGBbsTdo02uVhEwg>

2) Secondary: diffuse skin rash on palms of hands and soles



https://encrypted-tbn2.gstatic.com/images?q=tbn:ANd9GcSc0eVibLNJIJgoLIamXk1__66L8K5QEK6YbCICEICYCn8nsF40

4) Tertiary: “gummas” (granulomes), soft non-cancerous growth with neurological and heart diseases

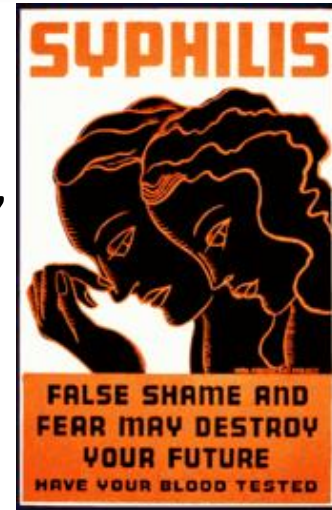


https://upload.wikimedia.org/wikipedia/commons/thumb/5/56/Gumma_of_nose_due_to_a_long_standing_tertiary_syphilitic_Treponema_pallidum_infection_5330_lores.jpg/220px-Gumma_of_nose_due_to_a_long_standing_tertiary_syphilitic_Treponema_pallidum_infection_5330_lores.jpg

Syphilis

- Diagnosis: dark field microscopy, immunfluorescence, PCR (direct)
- Screening: TPHA (4-6 weeks post infection)
 - FTA-Abs-Test (no false-positive results)
- Development: CMT (nonspecific)

- Prevalence (2013): 315,000 infected people worldwide (prostitutes, more men than women)
 - Hygienic measures
 - Use of latex condoms
 - decreased dramatically after availability of penicillin during 1940s
- Therapy: penicillin G (doxycycline)

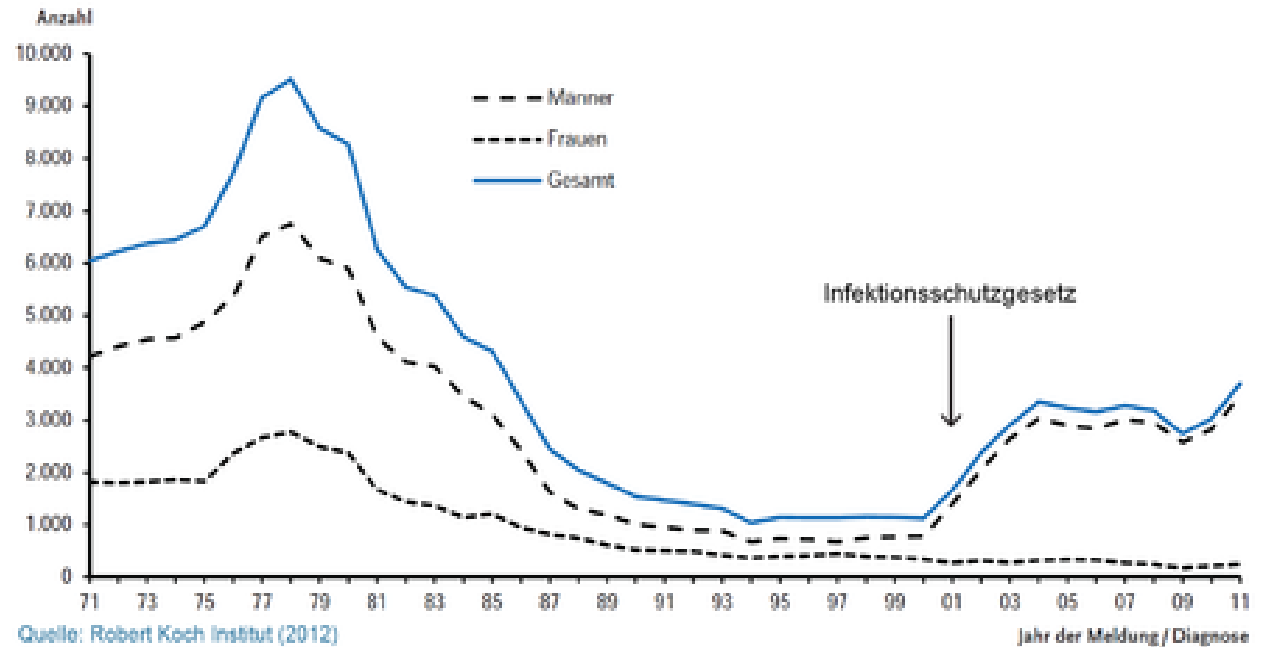


https://upload.wikimedia.org/wikipedia/commons/5/5b/Syphilis_false_shame_and_fear_may_destroy_your_future.png

Syphilis in Germany (2014)

Increase since 1990s

Incidence (2013):
5,017



BLACK TUESDAY

NEW YORK, TUESDAY, OCTOBER 29, 1929

THE STOCK MARKET CRASH OF 1929

BY BARBARA
SILBERDICK FEINBERG

NEW YORK, OCTOBER 29—An other hurricane of liquidation hit the stock market today, as financial uncertainty led on rumor and turned to panic. Frightened investors ordered their brokers to sell at any price, and the stock market crashed. Those on the floor of the Wall Street exchange waded in paper and tried to add up their losses.

It is believed these losses total billions of dollars. Thousands of accounts were wiped out as a record



Crowds Gathered On Wall Street As The Market Went Into Historical Decline

number of shares were traded. Some stocks were almost given away. Millions of shares traded hands.

Brokers on the floor of the Exchange have never seen a day like this. The shock on Wall Street spread to other exchanges and markets. It

was a country-wide collapse of security values in which losses were the most disastrous and far-reaching in the history of the Stock Exchange. There was near-panic on the Chicago commodities exchange. Rumors spread from one end of the United



<http://i.huffpost.com/gen/1432903/images/o-NEW-YORK-STOCK-MARKET-1929-facebook.jpg>

<https://s-media-cache-ak0.pinimg.com/736x/8b/d6/29/8bd629c1cd0e64febcdebc044628c81a.jpg>

Historical Context

- era of unprecedented and especially unprecedentedly lopsided prosperity
 - Extremely uneven distribution of wealth since early 1920s
 - International instability since World War I.
- → Great Depression: stock market crash on Oct 29, 1929
- “hear nothing, see nothing, do nothing policy“ under president Hoover
- 1932: Election of Franklin Roosevelt as new president (regulated state interference in the market, social insurance, wage floor)
- Start of the Tuskegee Syphilis Study

Beginning

- Usual therapy: arsephenamine, mercurial ointments and bismuth (highly toxic)
- 1931: United Public Health Service approached the Tuskegee Institute (located in Macon County) about forming a research group
- 1932: Start of the study in Tuskegee/Macon County, Alabama
- Under direction of John Charles Cutler
- Aim: “healing of syphilis disease” ↔ “study effects of untreated syphilis disease”
- Study collective: 399 infected and 201 non-infected
- Only infected participants suffering from latent form
- Only male black americans (25-60y), mostly sharecroppers



<http://image.slidesharecdn.com/thetuskegestudy-141015214717-conversion-gate02/95/the-tuskegee-study-5-638.jpg?cb=1413409965>

DATA PRESENTED BY DR. B. C. BROWN

Classification of Cases in Tuskegee Study

	Controls	Syphilitic	Total
Classification at initial examination	200	411	611
Cases added in 1938-1939	-	14	14
Total - Original classification	200	425	625
Controls infected during observation	-9	+9	-
Controls reclassified as syphilitic on basis of additional history	-1	+1	-
on basis of treponemal tests	-8	+8	-
Total - Final classification	182	443	625
Known dead - Number	97	276	373
Percent	53.3	62.3	59.7
Remainder - Examined in 1968	85	167	252
Number	36	53	89
Percent	42.4	31.7	35.3

2/4/69: az

https://upload.wikimedia.org/wikipedia/commons/thumb/b/b9/Tuskegee-syphilis-experiment_table-subjects.gif/458px-Tuskegee-syphilis-experiment_table-subjects.gif

Benefits for participants

- Free treatment
- Free treatment of minor ailments
- Free rides to and from the clinic
- free warm meal on examination days
- 50 \$ burial insurance

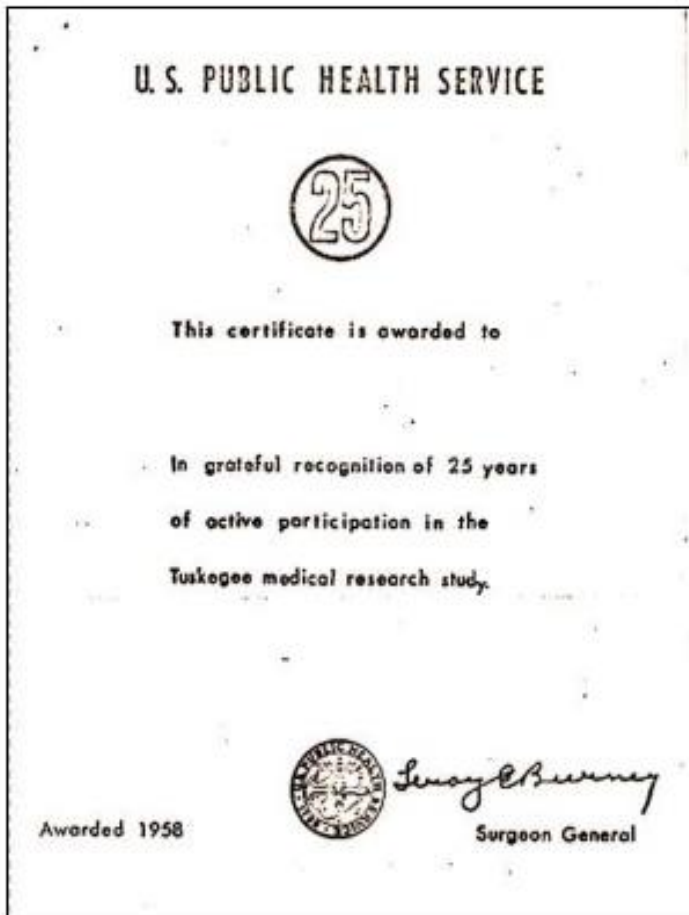
Procedure

- Participants were told to be treated because they have “bad blood”
- Methods: Physical examination, blood test, x-rays, lumbar puncture (incident of neuro-syphilis), every in a 6-months rhythm (epidemiological study)
- Medical examinations only at Tuskegee University Hospital
 - Other doctors were not allowed to examine study participants (participants' lists)
- 1936: first major report: no significant results → also examinations at special local doctors
- By 1947: penicillin became standart treatment for penicillin
→ But treatment was denied

Procedure

- Doctors who treated patients were punished (payment, revoke of medical license)
- Results: no difference in both the nature and extent of the disease among white and african americans
 - not significance or hint for difference
 - assumption regarding biological differences influenced investigators view
(before: claim that blacks suffer more frequently from cardio-vascluar complications while whitse from neurological problems)

Certificate for Participants in the Syphilis Study



In **1958** this certificate was provided to participants in the Tuskegee Syphilis Study after 25 years.

The PHS leaders employed many strategies to keep the subjects happy with their involvement in the study so that as many as possible could be "brought to autopsy." This special certificate was distributed to all surviving participants in 1958, and praises them for their involvement in the "Tuskegee medical research study." Even at this late date the men did not know that the disease for which they were being observed, and not adequately treated, was syphilis.

<http://image.slidesharecdn.com/thetuskegeestudy-141015214717-conversion-gate02/95/thetuskegee-study-12-638.jpg?cb=1413409965>

Ending

- 1965: Irwin Schatz (young doctor from Chicago)
- Oct 1966: Peter Buxtun (Epidemiologist from PHS) found out about the study
 - → not possible to stop it
 - informed Center of Disease Control in 1966
- Everybody assured him that the study had to be kept going until the death of the last patient
- 1972: shared his knowledge with journalist Jean Heller
 - → article in “Washington Evening Star” from July 25, 1972
 - 74 people of the study cohort were still alive

Ending

- Under public pressure: Conference of the PHS whether study should be stopped
 - → after 3 months: ending was confirmed
- lawyer Fred Gray successfully fought for the remaining participants in court → 9 million \$ settlement for medical treatment
 - Wives, widdows and offspring were added

Ethical shortcomings

- Aim of study
- Diagnosis → only „bad blood“
- No Informed consent
 - No communication possible (other subjective-symptoms?)
- Ambiguity concerning number of participants
- Racially motivated, discrimination of blacks
- No defined inclusion and exclusion criteria
- No consistent record of results (published)
- Inaccurate measures of follow-up
- Effective treatment was denied to participants (since 1947)
 - Government violated the constitutional rights of the participants

Isolated incident?

- Guatemala experiments from 1946-1948
- Initiated by PHS, direction: *John Charles Cutler*
- ***Intentionally exposed*** to sexually transmitted diseases (STDs) to investigate the impact of penicillin-therapy
- 1308 infected participants (prisoners, soldiers, psychiatric patients)
 - Transmission through commercial sex workers (for 25 \$ payment)
 - By researchers: toothpick covered with gonorrheal pus directly in urethra
 - only about 50% were treated with penicillin
- 5128 participants (whole group) underwent diagnostic testing (blood sample, lumbar or cisternal puncture)
- 2010: first public apology by president Obama

John Charles Cutler (1915-2003)



<https://nsarchive.files.wordpress.com/2011/04/jcutler2.jpg?w=600>

- 1941: Medical Degree at Western Reserve University Medical School
- 1942: U.S. Public Health Venereal Disease Research
- Tuskegee Syphilis Study
- 1946-48: Guatemala Experiments
- 1954: Experiments on Prisoners at Sing Sing (Effect of Penicillin on syphilis infection)
- 1958: Assistant Surgeon General of the United States
- 1967: Professor for "International Health" at the University of Pittsburgh
- 1968-1969: Dean of the Graduate School of Public Health

John Charles Cutler

- “Unless the law winks occasionally, you have no progress in medicine“ - *1970*
- “ It was important that they were supposedly untreated, and it would be undesirable to go ahead and use large amounts of penicillin to treat the disease, because you’d interfere with the study“
1993 in TV-documentary called “The Deadly Deception“

John Charles Cutler

- 1967: Professor for “International Health“ at the University of Pittsburgh
- 1968-1969: Dean of the Graduate School of Public Health
- 2003: Death
 - not at least one of his obituaries mentioned Tuskegee or Guatemala
 - “. . . led the way in trying to prevent and control sexually transmitted disease throughout the world.“
 - Prof. Sharma (University of Pittsburgh): “...his appreciation of the freedom of people across the world, as well as his efforts to ensure access to reproductive healthcare services for women not only in the US, but also in the developing world.”

→ in honor: Lecture series which was called after him

John Charles Cutler

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Obituaries

<http://snipurl.19wdkn>

Obituary: John Charles Cutler / Pioneer in preventing sexual diseases

Wednesday, February 12, 2003

By Jan Ackerman, Post-Gazette Staff Writer

Long before AIDS became an international health problem, Dr. John Charles Cutler led the way in trying to prevent and control sexually transmitted diseases around the world.

Dr. Cutler, a former assistant surgeon general of the U.S. Public Health Service, was part of a group that in 1944 worked out the ways penicillin could be used to treat syphilis.

As one of the founders of the Family Health Council of Western Pennsylvania in 1971, he worked tirelessly to find better ways to provide affordable ...

<https://coto2.files.wordpress.com/2010/10/cutler-obit.jpg?w=500&h=388>



Delta Omega

Honorary Society in Public Health

<http://www.deltaomega.org/cutler.cfm>

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Honorary Members

John C. Cutler

John C. Cutler was graduated from the Western Reserve University in 1941 with a medical degree. In 1942 he joined the U.S. Public Health Service and spent the next twenty-five years working in the PHS.

In 1967 he was appointed to the University of Pittsburgh as professor. Dr. Cutler began the head of the University of Pittsburgh's population studies program in the 1970s. He also served as the president of AVSC (currently known as Engenderhealth), president of the United Nations Association of Pittsburgh, and president of the World Federation of Health Agencies for the Advancement of Voluntary Surgical Contraception.

He was named professor emeritus in the International Health department of the Graduate School of Public Health at University of Pittsburgh. He retired in 1985 from the University.

<https://coto2.files.wordpress.com/2010/10/cutler-honor-delta-omega.jpg?w=500&h=264>

John Charles Cutler

- 2008: Lectures were stopped because his inhuman conduct in Guatemala was detected
 - no impact on his reputation
- Never called to account (“in his capacity as an official of the US Public Health Service”)
- Did never apologize

Consequences

- Investigators ← Directors (Dr. Cutler) ← PHS ← Government
- No criminal misconduct
- Cutler involvement was in his “capacity as an official of the US Public Health Service“
- Heavily involved: Johns Hopkins Institute, Rockefeller foundation
- 1974: lawyer Fred Gray successfully fought for the remaining participants in court
→ 9 million \$ settlement for medical treatment
 - Wives, widows and offspring were added
- 2012 (Guatemala), 774 plaintiffs: „U.S. District Court of Columbia finding that the goverment has immunity from liability for harm suffered outside the U.S.“
- No cases in which anybody was called to amount or made responsible in any way

- May 16, 1997: public apology of President Bill Clinton

Consequences

- Office for Human Research Protections (OHRP)
 - C.F.R. 45: Institutional Review Board that mirrors FDA-regulations (guidance on research ethics, advises on issues of medical ethics)
- Belmont Report (1979) in Elkridge, Maryland
 - summarized ethical principles and guidelines for research involving human subjects (reference of Institutional Review Board)
 - 3 core principles: respect (protecting autonomy of all persons), beneficence (“do not harm”), justice (reasonable, well-considered procedures)
 - 3 primary areas of application: informed consent, assessment of risks and benefits, selection of subjects
 - allows for a solution to future subjects who are not capable to make independent decisions

Impact on Daily Life

- Impact on contemporary relationship between african Americans and the biomedical community
- Numerous reports and studies argued that the Tuskegee Syphilis Study is most important reason why african Americans distrust the institutions of medicine and public health
 - Critics: already deep-rooted in the institution of slavery

ABNF J. 2012 Summer;23(3):59-62.

Influence of scary beliefs about the Tuskegee Syphilis Study on willingness to participate in research.

Davis JL¹, Green BL, Katz RV.

➔ **Author information**

¹H. Lee Moffitt Cancer Center & Research Institute. jenna.david@moffitt.org

Abstract

OBJECTIVES: To assess whether scary/alarming beliefs about details on the Tuskegee Syphilis Study (TSS) are associated with willingness and/or fear to participate in biomedical research.

<http://www.ncbi.nlm.nih.gov/pubmed/22924230>

Am J Public Health. 1997 Nov;87(11):1773-8.

Under the shadow of Tuskegee: African Americans and health care.

Gamble VN¹.

➔ **Author information**

<http://www.ncbi.nlm.nih.gov/pubmed/9366634>

Thank you for your attention!

Any questions?

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