

History, Scandals and Tragedies: Beecher, Tuskegee, Willowbrook and the Rest



SUSAN E. LEDERER, PH.D.
UNIVERSITY OF WISCONSIN SCHOOL
OF MEDICINE AND PUBLIC HEALTH
OCTOBER 1, 2014

Disclosure

I have no relationships to disclose, and
I will not discuss off label or investigational use
products in my presentation



SUSAN E. LEDERER, PH.D.



University of Wisconsin
**SCHOOL OF MEDICINE
AND PUBLIC HEALTH**



**U.S. LEGISLATION AS
RESPONSE TO
SCANDAL AND
TRAGEDY**

The Patent Medicine Evil in the Early 20th century



MARIANI WINE

MARIANI WINE Quality Restores
**HEALTH, STRENGTH,
ENERGY & VITALITY.**

MARIANI WINE
FORTIFIES, STRENGTHENS,
STIMULATES & REFRESHES
THE BODY & BRAIN

HASTENS
CONVALESCENCE
especially after
INFLUENZA.

His Holiness
THE POPE

writes that he has
fully appreciated the
beneficial effects of
this Tonic Wine and
has forwarded to Mr.
Mariani as a token of
his gratitude a gold
medal bearing his sig-
nature.



MARIANI WINE

is delivered free to all parts of the United Kingdom by WILCOX & CO.,
85, Mark Lane Street, London, E.C., price 4/- per Single Bottle, 22/- half-
dozen, 43/- dozen, and is sold by Chemists and Stores.



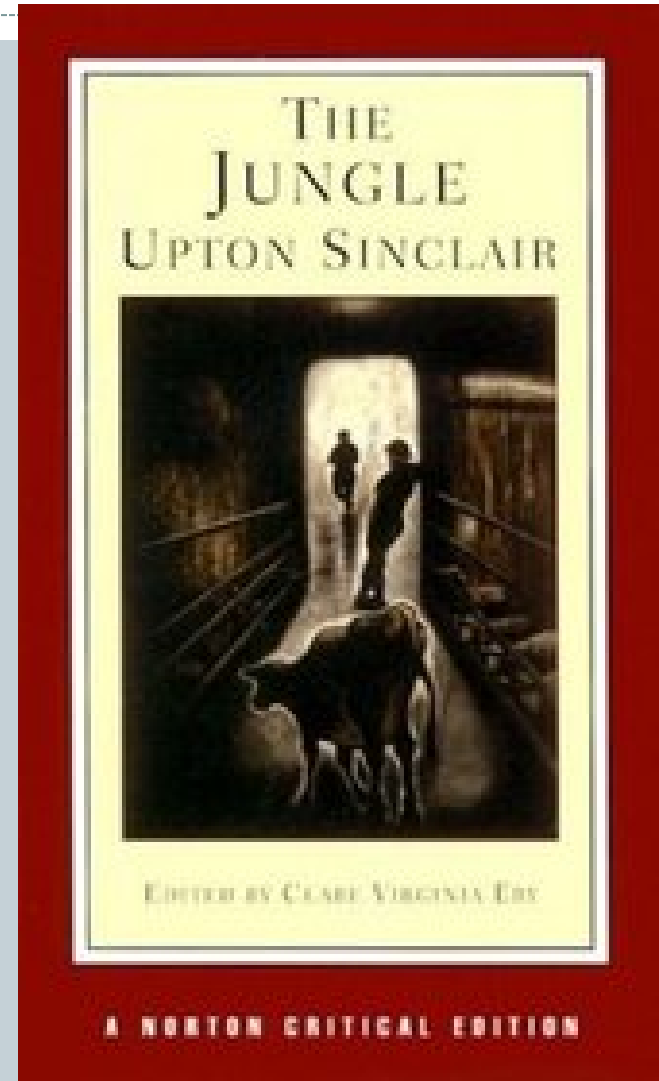
COCAINE
TOOTHACHE DROPS

Instantaneous Cure!
PRICE 15 CENTS.
Prepared by the
LLOYD MANUFACTURING CO.
219 HUDSON AVE., ALBANY, N. Y.
For sale by all Druggists.
(Registered March 1885.) See other side.

Safety of the food supply



Food and Drug Act 1906



Elixir of Sulfanilamide tragedy 1937

107 deaths



Click the "X" in the upper right hand corner of this window to return


ONE GALLON ELIXIR ONE GALLON

SULFANILAMIDE

Each fluidounce represents:
Sulfanilamide, 40 grs.

SUGGESTED FOR THE TREATMENT OF ALL CONDITIONS
IN WHICH THE HEMOLYTIC STREPTOCOCCI APPEAR

Dose, begin with 2 to 3 teaspoonfuls in water
every four hours. Decrease in twenty-four
to forty-eight hours to 1 or 2 teaspoonfuls
and continue at this dose until recovery.



THE S. E. MASSENGILL COMPANY
Manufacturing Pharmacists
BRISTOL, TENN.-VA.

Please do not copy or reproduce this picture in any way.

Diet and cosmetic dangers c. 1930s

dinitrophenol



Food, Drug and Cosmetic Act of 1938



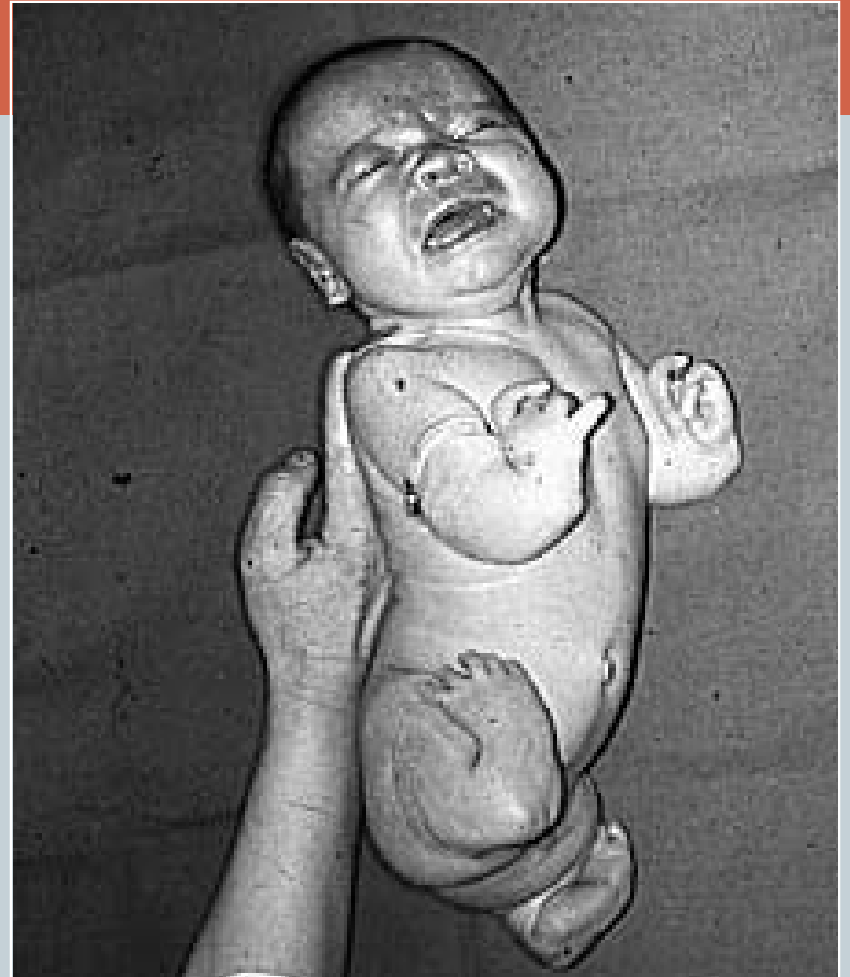
- **Drugs or cosmetics must be tested for toxicity before marketing**
- **Adequate directions for use need to be on package**
- **Some drugs are designated “by prescription only”**

Thalidomide

1960-1961

83 children were born with unusual birth defects, not linked to thalidomide use.

a German scientist makes connections between thalidomide use and thousands of babies born with birth defects.



Kefauver-Harris Amendments to FDA



Drugmakers must establish the effectiveness of drug products before they go on the market, and afterwards report any serious side effects.

Requires clinical studies conducted by qualified experts.

Requires informed consent by study subjects

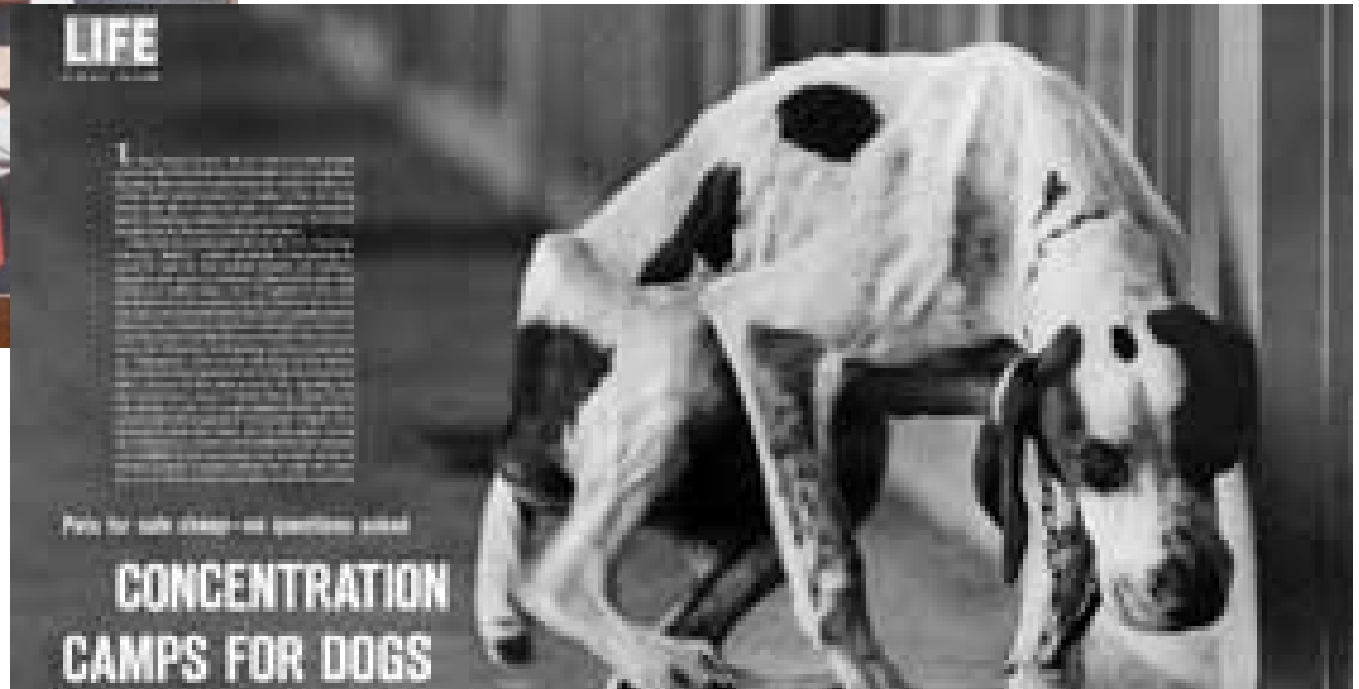
Animal Welfare Act,



1966



LIFE MAGAZINE 1966





**WHY DO WE HAVE
FEDERAL
REGULATIONS FOR
HUMAN
EXPERIMENTATION?**

Scandals and tragedies prompt Congress to pass the National Research Act



1974



**Both the history of human
experimentation and history of
controversy over human
experimentation much older**

United States Congress, 1900



considers Senate bill 3424, a law that

would require investigators to disclose in advance the purpose and procedures of any non-therapeutic experiment involving human beings.

Senate bill 3424



calls for explicit ban on experiments using those persons deemed unable to consent, including
infants,
children under the age of 21,
and pregnant women.

The Yellow Fever Board in Cuba, 1900



Reed and his colleagues introduce written permission forms

available in both
English and Spanish

En una ciudad, *Antonio Benigno*
deve de veinte y cinco años de edad, natural de *Cerceda*
provincia de *Coruña* hijo de *Manuel Benigno*
y de *Josefa Castro* hace saber por la presente que, habiendo
ejercitado su libertad y libre trazo voluntario, consistente en sustracción de los
experimentos que con el objeto de determinar las vías de circulación de
la peste se realizan, desde en su ciudad de *Cerceda* que esta era objeto de
comercio el comercio de la venta de los animales muertos que de su compra
insiste que que se dan en caso de enfermedades, con sus efectos
con las condiciones que están se establece.

El interesado declara haber conocido que en el caso de compra
causar en la de salud pública de los animales de esta zona que se
debe asegurar convenientemente a través de la compra de la venta de
los animales, desde el día, mediante el objeto de circulación de animales
con la finalidad de que se de recibir de la Comisión de Sanidad, que
cualquier sea el objeto de la presente y de los efectos.

Como consecuencia que el interesado hace experimentar, desde de su ciudad
con sus efectos de esta salud, el interesado se de recibir de la Comisión
de Sanidad y que desde de su ciudad de esta de Sanidad, que desde de
esta ciudad su experiencia de esta ciudad, desde de esta
ciudad, desde de esta de 100. --que habiendo, desde de su ciudad y que
desde de su experiencia con objeto de que desde de la Comisión de Sanidad
de esta ciudad, que desde de esta ciudad, desde de esta ciudad, desde de esta
ciudad de esta ciudad.

El interesado se compromete a no salir de sus límites de esta ciudad
dentro de la ciudad de sus habitantes y desde de esta ciudad de esta
ciudad de esta ciudad de esta ciudad.

Y que su ciudad de esta ciudad, desde de esta ciudad, desde de esta ciudad
de esta ciudad, desde de esta ciudad, desde de esta ciudad, desde de esta
ciudad de esta ciudad.

En esta ciudad,
de esta ciudad, de esta ciudad.
Antonio Benigno
Walter Reed
Rep. de esta ciudad

The undersigned understands...



perfectly well that in case of the development of yellow fever in him, that he endangers his life to a certain extent but it being entirely impossible for him to avoid the infection during his stay in this island, he prefers to take the chance of contracting it intentionally in the belief that he will receive from the said Commission the greatest care and the most skillful medical service.

Subjects receive \$100 in gold,
\$200 if death occurs





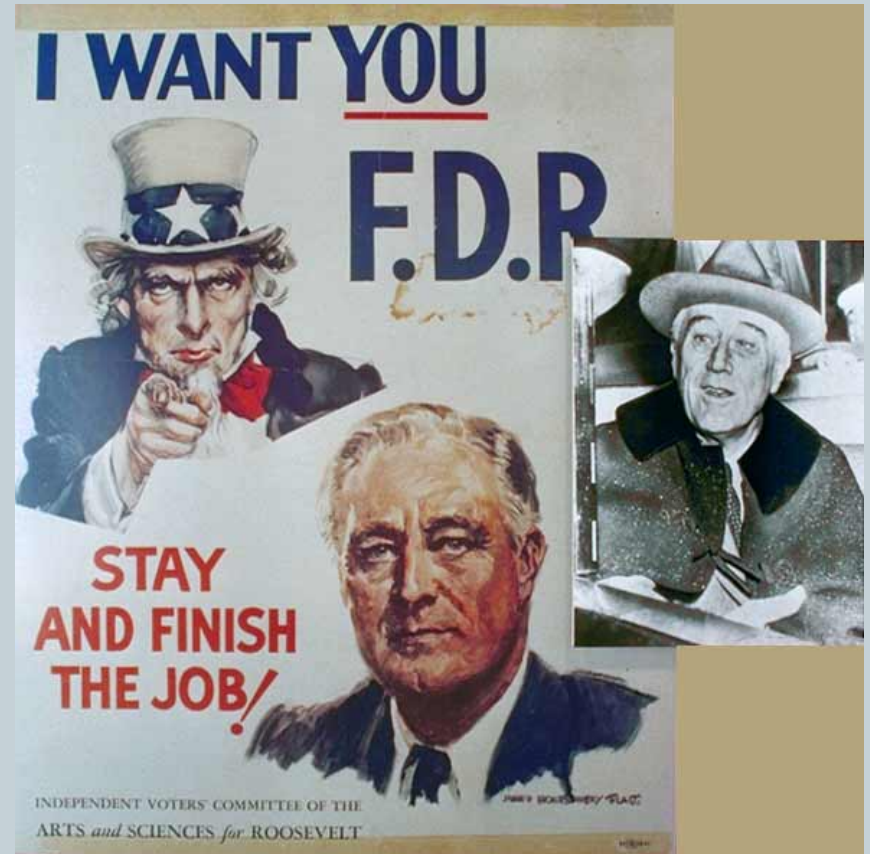
“A written consent was obtained from each one, so that our moral responsibility was to a certain extent lessened. Of course, only the healthiest specimens were experimented upon . . .”
.

Aristides Agramonte

World War II experimentation



- President Franklin Delano Roosevelt establishes the Office for Scientific Research and Development
- Committee on Medical Research
- Unprecedented federal funding for medical research



Research related to war effort



hypothermia

effects of high altitude

de-salination studies

burns/wounds

blood substitutes

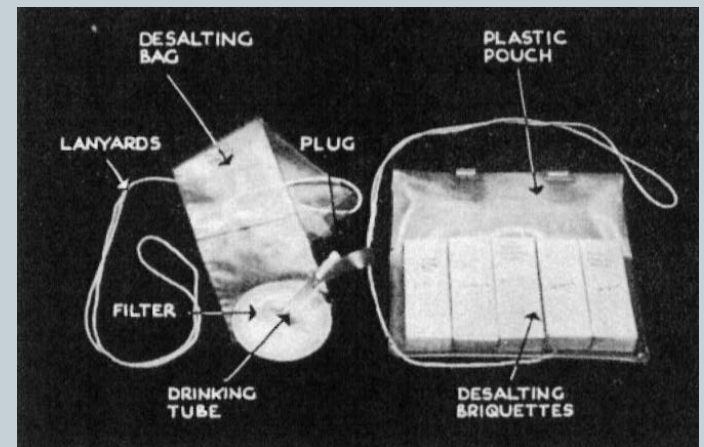
Prevention and treatment of infectious diseases

 malaria

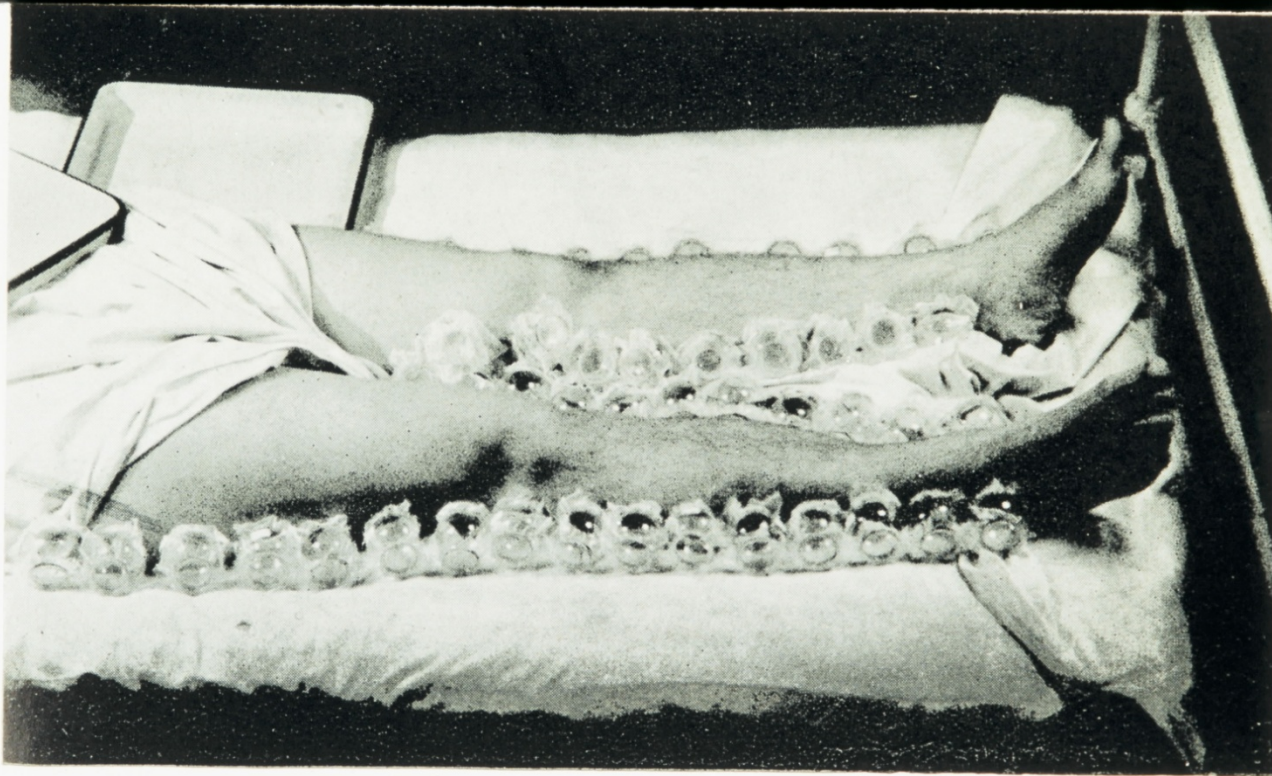
 gonorrhoea

 hepatitis

De-salting sea water



Malaria research



U. S. Public Health Service

Malarial research: infecting mosquitoes by allowing them to bite an infected patient

Nazi war-time medical research agenda



hypothermia

effects of high altitude

de-salination studies

burns/wounds

blood substitutes

vaccines and treatment

 malaria

 gonorrhoea

 hepatitis

Nazi research methods



Dachau Concentration Camp—effects of hypothermia



Dachau Concentration Camp effects of high altitude



Sea water studies



- A Romani (Gypsy) victim of Nazi medical experiments to make seawater potable.



Seawater experiments, Dachau 1944

44 camp inmates ages 16-49)
German, Czech, and Polish
Roma.

“recruited” from Buchenwald
and Auschwitz for a “clean
up work detail”

promised extra rations and
easier conditions

- Group 1 no water at all
- Group 2 fresh water
- Group 3 ordinary sea water
- Group 4 chemically filtered sea water,
- Group 5 sea water with a tomato extract to mask taste (but leaving high salt concentration).

Rudi Taubmann's testimony at the Nuremberg Doctors' Trial



- When test subjects refused to drink any more sea water, they were physically held down, and a red tube placed in their mouth in which sea water was added so that it went to the stomach

- Test subjects undergo:
 - Liver punctures
 - Spinal punctures

Studies of burns and wounds, 1942



- **disfigured leg of a survivor from Ravensbrueck,**
- **scars resulted from incisions made by medical personnel that were purposely infected with bacteria, dirt, and slivers of glass.**

United States v. Karl Brandt et al



Nuremberg Doctors Trial

Prosecution of 23 Nazi medical personnel



Issue for the Tribunal:
what standards to use to judge these
experiments?



Defense attorneys liken Nazi camp experiments to American prisoner research during wartime





Life Photo by Myron Dantz

Malarial convicts contribute to knowledge of the disease

LIFE

TO THE AMERICAN PEOPLE:

Your sons, husbands and brothers who are standing today upon the battlefronts are fighting for more than victory in war. They are fighting for a new world of freedom and peace.

We, upon whom has been placed the responsibility of leading the American forces, appeal to you with all possible earnestness to invest in War Bonds to the fullest extent of your capacity.

Give us not only the needed implements of war, but the assurance and backing of a united people so necessary to hasten the victory and speed the return of your fighting men.

William S. Hoar
Director of War Relocation Authority
Washington, D.C.

JUNE 4, 1945 10 CENTS
 BY SUBSCRIPTION, TWO YEARS \$1.00

PRISON MALARIA

Convicts expose themselves to disease so doctors can study it

! Since U. S. government men who have been captured in various of enemy territory helping out were right war-time enemy of ours. In the U. S. Prisoners in Alaska, the British, French, Russian, and New Jersey State Prisoners, some 100,000 men have volunteered to be infected with malaria in medical experiments for the disease. The experiments, which are directed by the Office of War Relocation and Development, have found prison inmates have contracted malaria with ease. Their subjects will not be used for anything else, but the men have and are used for tests. The prisoners are not considered as possible for admitting to the tests. Prison authorities are making the best use possible to help a great nation medical problem. In the U. S. there are 1,000,000 cases a year. The malaria drug, which is not yet available, and various medical studies has found that it does not bring back after the original infection. The goal of malaria research is to find a way to bring back with the disease, permanent.

American researcher Andrew C. Ivy



- Sent by AMA in 1946 to Nuremberg as medical consultant to the American military tribunal in the Doctors' Trial.
- Self-experimenter in seawater studies, high altitude studies and experiments on volunteers for US Naval research

Permissible Medical Experiments



**COMES TO BE KNOWN
AS THE NUREMBERG
CODE**

First principle



**. THE VOLUNTARY
CONSENT OF THE HUMAN
SUBJECT IS ABSOLUTELY
ESSENTIAL.**

9 additional principles



- **Based on animal experimentation**
- **Must avoid all unnecessary suffering, injury**
- **No reason to think that death will result**
- **Risk should not exceed benefit**
- **Only scientifically qualified personnel**

Outcome of Doctors Trial



**7 ACQUITTED,
7 RECEIVED DEATH SENTENCES,
9 RECEIVED PRISON SENTENCES
RANGING FROM 10 YEARS TO LIFE
IMPRISONMENT.**

Karl Brandt sentenced to death

- Offers his body for experimentation
- US Army rejects the offer
- Executed at Landsberg Prison June 2, 1948



The Nuremberg Code



**MEANING FOR
AMERICAN MEDICAL
RESEARCHERS?**

The Nuremberg Code



Published in Science in 1953

Part of a symposium about the limits and dilemmas posed by experimentation on human beings

- **Adopted by Secretary of Defense Charles Wilson in 1953 for the US armed forces**
- **Classified as Top Secret**
- **Implementation failure**

Would American investigators have met the Nuremberg Code?



NO.

Many American researchers
regarded the Code as unworkable



**WOULD NOT ALLOW
EXPERIMENTS ON
CHILDREN, THOSE IN
INSTITUTIONS, THE
DYING, AND THE
MENTALLY ILL.**

In the 1950s

Medical research in US



- associated with volunteers**
- traditions of self-experimentation**
- anticipated significant advances in medicine**



3/25/52

NYC

TI

Contaminated Blood Injection Kills Youth In Seattle Preservation Research Project

SEATTLE, March 24 (AP)—An 18-year-old college honor student died yesterday of an injection of bacterially contaminated blood given during an experiment connected with war research on blood preservation by the University of Washington.

James Stanley Leedom, a freshman at Seattle University, was one of forty volunteers who participated in the project seeking better ways to preserve whole blood.

He died three days after the injection despite every effort to save his life.

Dr. Robert H. Williams, head of the University of Washington Department of Medicine, said the blood had become contaminated "by some phenomenon" after it had been refrigerated.

"The only way we can explain it," said Dr. Williams, "is that the bacteria was able to grow in some manner while the blood was at freezing temperature and not at body temperature."

Both Dr. Williams and Dr. Clement A. Finch, Associate Professor of Medicine in charge of hematology at the university, said they would "gladly participate in the same experiment tomorrow."

They said the bacteria had not yet been identified, but they believed it to be a saprophyte (any organism living on dead or decaying organic matter) that does not grow at body temperature but



Associated Press Wirephoto
James Stanley Leedom

thrives when chilled. It produces shock and high fever.

The father, Stanley P. Leedom, said he held no one at fault for his son's death.

"I don't blame anyone for this," he said. "I just don't want this tragedy to deter in any way from the blood donor program or these experiments."

The boy had planned to major in medicine.

Polio epidemic c. 1952





PARENTAL REQUEST FOR PARTICIPATION OF CHILD IN POLIOMYELITIS VACCINATION FIELD TRIAL

The National Foundation for Infantile Paralysis, Inc., in cooperation with state and local health, medical and educational authorities, is conducting a nation-wide field study of the effectiveness of a vaccine which may be protective against paralysis due to poliomyelitis. The vaccine consists of chemically killed poliomyelitis virus of all three known types. For purposes of this study, several thousand children will be given three injections of this vaccine into the arm over a period of several weeks; at least an equal number of unvaccinated children will be observed so that a comparison can be made between the two groups. The children in each group, those who are vaccinated and those who are not, are equally important to the study. In certain instances it will be necessary to test small samples of blood at intervals during the study to determine the amount of antibodies against poliomyelitis that are present.

I HEREBY REQUEST that my child, _____, be vaccinated
(first name) (middle name) (last name)
if selected, or otherwise be permitted to participate in the procedures described above without cost to me.

Date _____

Signed _____

Relationship to Child _____
(Must be parent or legal guardian)

School _____

(Street Address or Rural Location)

Grade _____

(City, Town or Township)

(State)

Efforts to create a workable code of ethics for human experimentation



- **To protect human subjects**
- **To enable medical research to advance**
- **Undertaken by the World Medical Association and its committee on ethics**

1964



DECLARATION OF HELSINKI

Recommendations Guiding Doctors in Clinical Research

Declaration of Helsinki (1964)



- Distinguished clinical therapeutic research and nontherapeutic biomedical research.
- Clinical therapeutic research is justified if it improves the well being of the patient.
- Nontherapeutic biomedical research is justified as long as the interest of society does not become more important than the concern for the well being of the patient.
- Permits proxy consent

Declaration of Helsinki Amended



- **29th WMA General Assembly, Tokyo, Japan, October 1975**
- **35th WMA General Assembly, Venice, Italy, October 1983**
- **41st WMA General Assembly, Hong Kong, September 1989**
- **48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996**
- **59th WMA General Assembly, Seoul, Republic of Korea, October 2008**
- **64th WMA General Assembly, Fortaleza, Brazil, October 2013**

Return to US and response to scandal and tragedy



By the 1960s
no longer faith in medical researchers

**Henry Beecher's
bombshell**

**Revelation of
apparent abuses
of human
subjects,
especially the
Tuskegee
Syphilis Study**

HENRY K. BEECHER, M.D.



**Professor of Anesthesia
Research at Harvard
Medical School**

**Convener of the
Harvard Ad Hoc Brain
Death Committee**



The New England Journal of Medicine

Copyright, 1966 by the Massachusetts Medical Society

Volume 274

JUNE 16, 1966

Number 24

Reprinted from pages 1354-1360.

SPECIAL ARTICLE

ETHICS AND CLINICAL RESEARCH*

HENRY K. BEECHER, M.D.†

BOSTON

HUMAN experimentation since World War II has created some difficult problems with the increasing employment of patients as experimental

Experimentation in man takes place in several areas: in self-experimentation; in patient volunteers and normal subjects; in therapy; and in the different

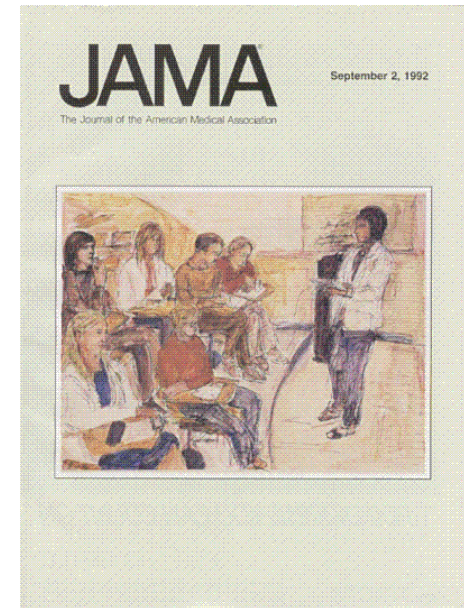
22 examples of “questionable” research practices



**NOT FROM FRINGE BUT
FROM MAINSTREAM
RESEARCHERS AND
INSTITUTIONS**



5



2



5



Prevention of Infective Endocarditis. Guidelines From the American Heart Association. A Guideline From the American Heart Association Rheumatic Fever, Endocarditis, and Kawasaki Disease Committee, Council on Cardiovascular Disease in the Young, and the Council on Clinical Cardiology, Council on Cardiovascular Surgery and Anesthesiology, and the Quality of Care and Outcomes Research Interdisciplinary Working Group

Walter Wilson, Kathryn A. Taubert, Michael Garcia, Peter H. Libman, Larry M. Baddour, Matthew Leisen, Ann Hoge, Christopher H. Cabell, Manoj Jalalodi, Robert S. Fildes, Jane C. Newburger, Diana J. Sones, Floyd Y. Tan, Michael Garber, Robert O. Bonow, Thomas Paluch, Stanford T. Shalton, Anne H. Rowley, Jane C. Thomas, Patricia Carroll, Timothy Gardner, David Goff, David F. Durack and The Council on Scientific Affairs of the American Dental Association has approved this guideline as a guideline to dentistry. In addition, this guideline has been endorsed by the American Academy of Pediatric Infectious Disease Society of America, the In-

The online version of this article, along with updated information and services, is located on the World Wide Web at: <http://circ.ahajournals.org/cgi/content/full/116/15/1736>

Subscription information and advertising in Circulation is online at <http://circ.ahajournals.org/subscribe>
 Permissions: Permissions & Rights Dept., Copyright Clearance Center, a division of Wolters Kluwer Health, 301 River Street, Danvers, MA 01923, 978-750-8400 Fax: 978-750-4744
permissions@copyright.com
 Reprints: Information about reprints can be found online at <http://www.copyright.com>

2

Cover picture: Localization of tropomyosin (green) and α -actinin (red) in cardiomyocytes isolated from a nontransgenic control (left) and tropomyosin overexpressing transgenic (TGT) mouse (right). Control cells show little or no overlap (yellow) between tropomyosin and α -actinin labels in control cells, but the abundant yellow signal in TGT cells indicates abundant colocalization of tropomyosin with α -actinin. See the article by Sessa et al., pp 51-61.

Why HENRY K. BEECHER?



Christian faith?

anesthesia?

**experience with
human subjects
research?**

Beecher concerned about new
researchers who fail to understand
their responsibilities



**BEECHER CONCERN WITH
VULNERABLE RESEARCH
SUBJECTS**

Who were the research subjects in Beecher's 22 examples?

“mentally defective” children

mentally retarded and delinquent children

the very elderly

soldiers in the armed forces

charity patients

the terminally ill

alcoholics

children and newborns

patients at the NIH Clinical Center

Example 16



Willowbrook State School



Willowbrook studies



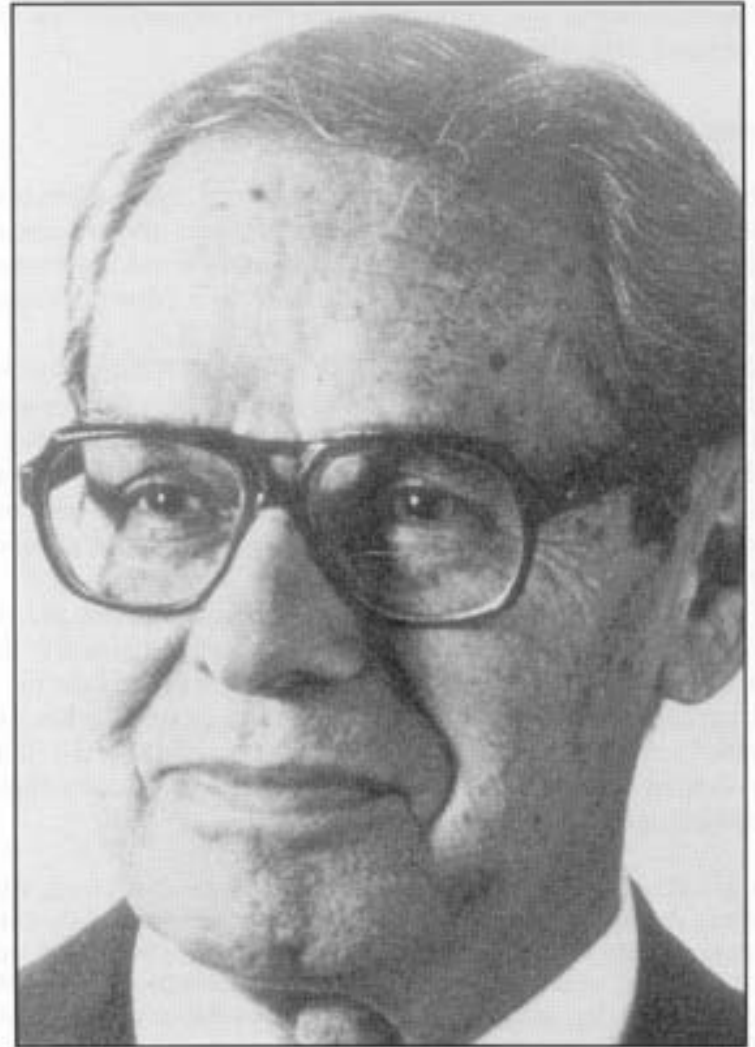
Newly admitted children (whose parents give consent) are given intramuscular injections of hepatitis or “milkshakes” with hepatitis





**Dr. Saul Krugman et al
begin studies to
acquire information
about the natural
history of hepatitis and
work toward vaccine**

Krugman continued to defend the studies but issues persisted about informed consent, coercion, and study design (withholding gamma globulin)



SAUL KRUGMAN, M.D.

Example 17



Jewish Chronic Disease Hospital case

Funded by USPHS and
American Cancer Society

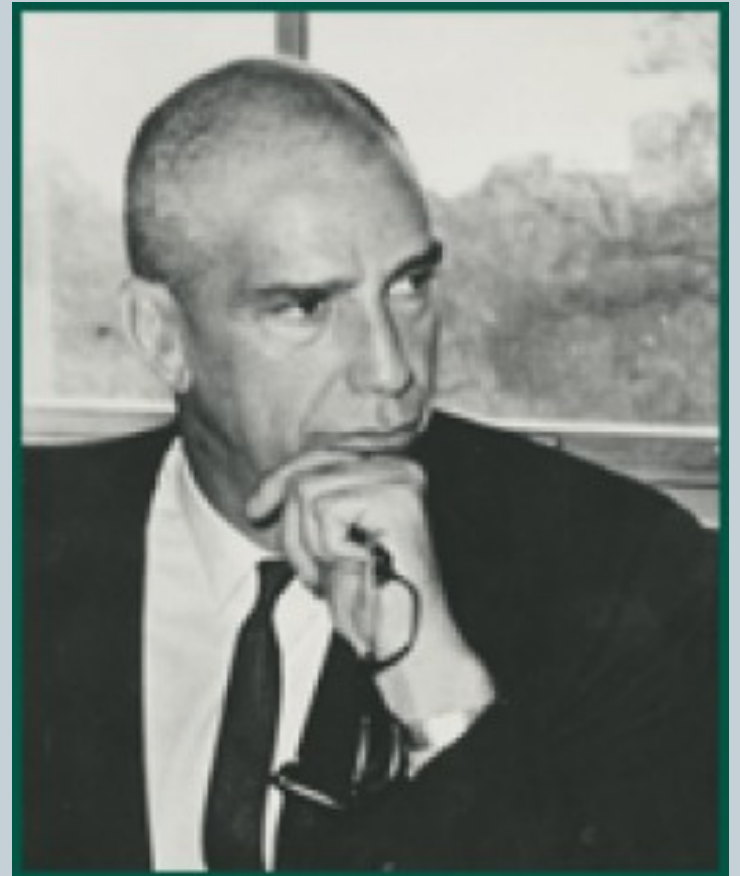
Injections of live cancer cells
into elderly patients
without consent

"did not wish to stir up any
unnecessary anxieties in
the patients" who had
"phobia and ignorance"
about cancer.

Chester Southam, M.D.



Injecting prisoners at OSU



Revelation of the Tuskegee Syphilis Study

July 25, 1972

The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they

have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,



Study begins in 1932



200154129803

(Courtesy National Archives)

PHS Surgeon General Thomas Parran,



Shadow on the Land

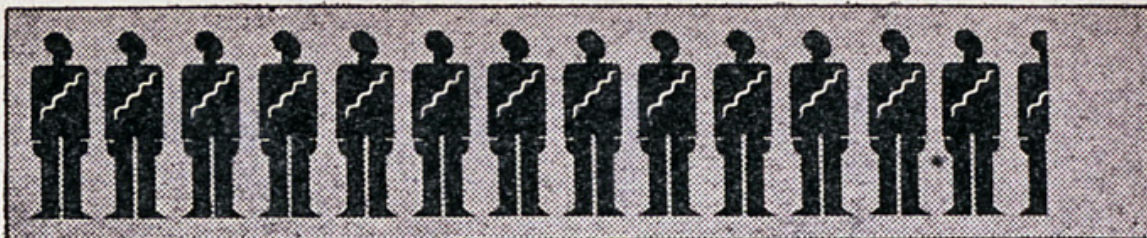
Head of PHS, 1936-
1948



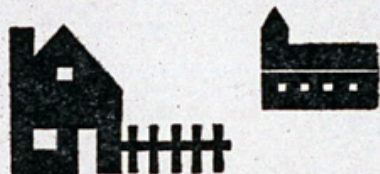
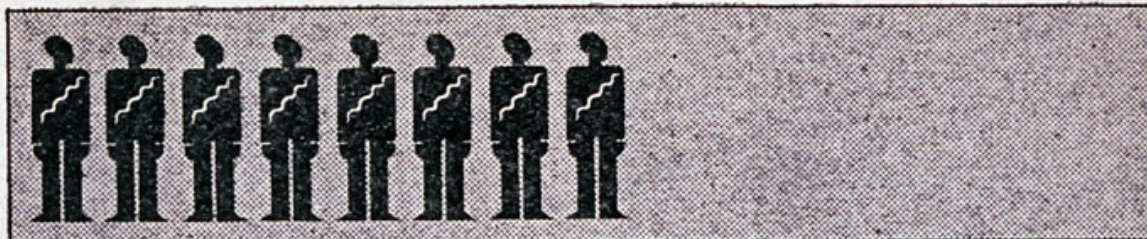
INCIDENCE OF SYPHILIS AMONG NEGROES



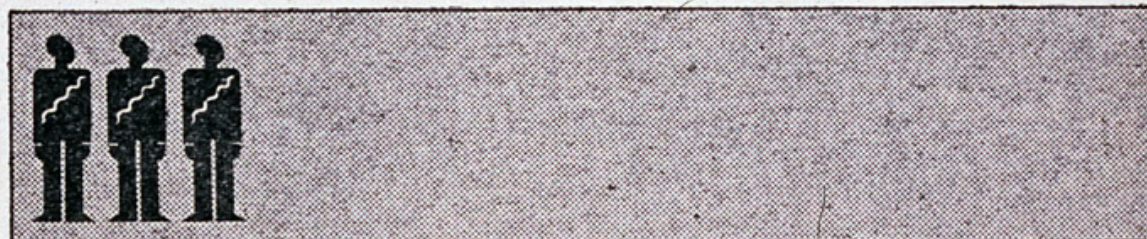
MACON COUNTY, ALA.



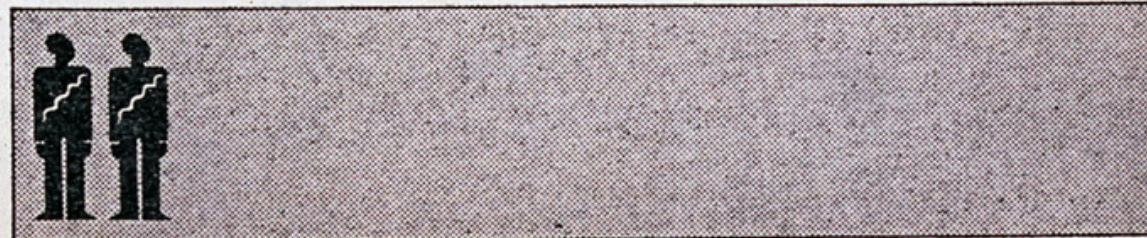
BOLIVAR COUNTY, MISS.




ALBEMARLE COUNTY, VA.



MEHARRY UNIVERSITY, TENN.



Each symbol represents 3% of all Negroes studied

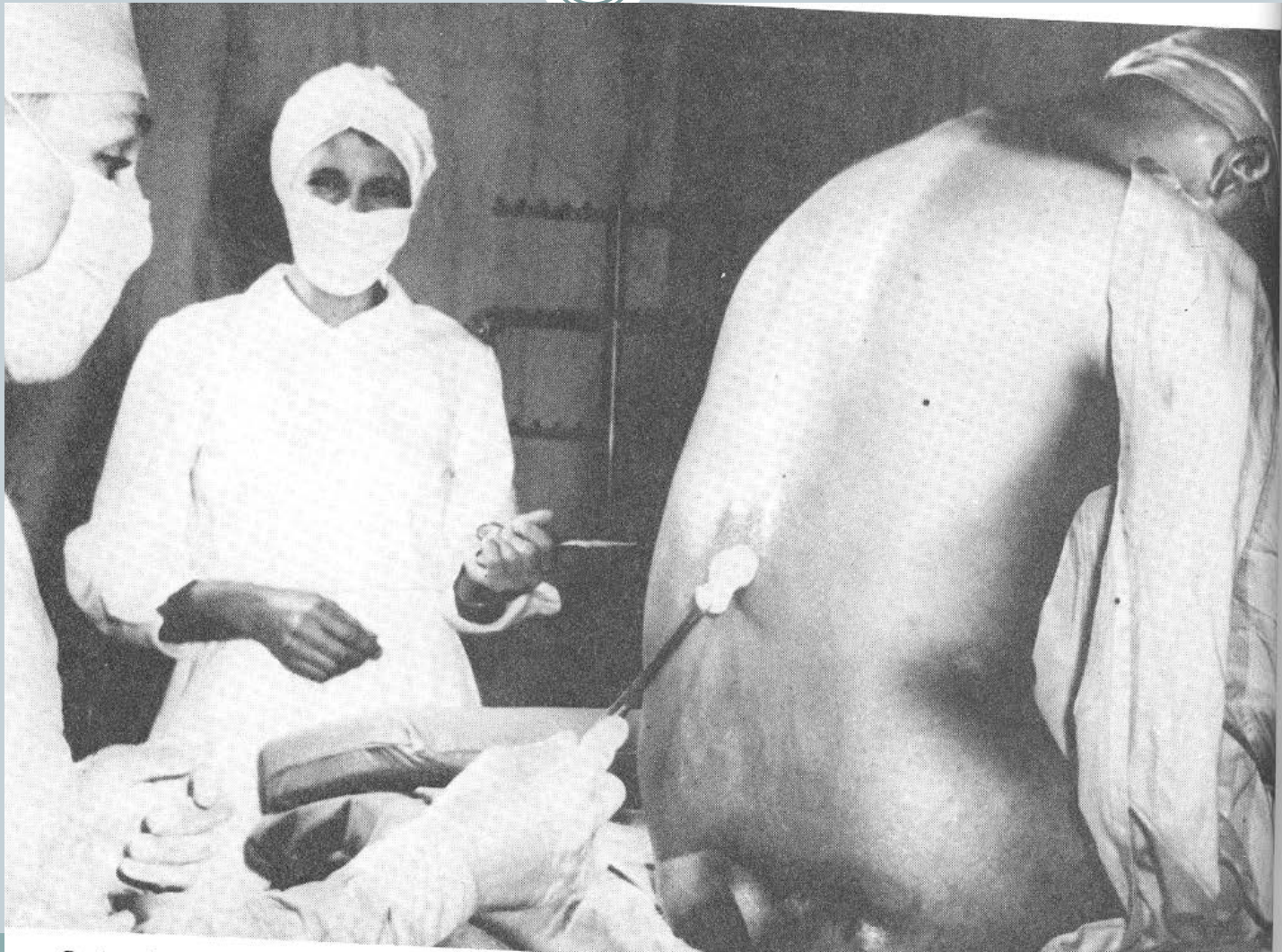
PICTORIAL STATISTICS, INC 

From treatment to “a study in nature”



**Dr. Raymond
Vonderlehr offers
Negro men “last chance
for special free
treatment” for their
“bad blood”**

Lumbar puncture (to obtain spinal fluid for diagnosis)



World War II



- **PHS asks Tuskegee draft board to exempt the men in the study from the draft**
- **They serve in another war**

Nurse Eunice Rivers



Nurse Rivers



**obtains permission
for autopsy**

**easier when a burial
stipend of \$50 is
provided**

**only one refusal in
140 requests**

Figure 3. An unaltered view. Nurse Eunice Rivers measures a participant in the TSUS. Dr. Stanley Schuman records the data. The photograph was taken in the TVAH in February 1952. (National Archives, CDC, East Point, GA)



1954



**„ FOR THE FIRST TIME, MEN
IN THE STUDY IDENTIFIED
AS “VOLUNTEERS WITH
SOCIAL INCENTIVES”**



U. S. PUBLIC HEALTH SERVICE

25

This certificate is awarded to

In grateful recognition of 25 years
of active participation in the
Tuskegee medical research study.



Lesley B. Burreney

Surgeon General

Awarded 1958

1969



- CDC convenes a blue-ribbon panel to determine whether Tuskegee study should continue
- the only physician not familiar with the Study argues that the experiment should end and the men receive treatment
- the Study continues until 1972

Study Revealed July 25, 1972





- **Senator Ted Kennedy holds hearings on human experimentation including the TSS**
- **Legislation passed 1974**
- **National Research Act**

1974 National Research Act



creation of a National Commission to study the moral issues posed by human experimentation

new federal regulations for IRBs and written informed consent

Television

FEBRUARY 16-22



Sacrificed to Science

A Docudrama Reopens
A Cruel Chapter
In the Annals of Race

BY MICHEL MARRIOTT



Persistent stories about the deliberate infection of the men in Tuskegee with syphilis



The AIDS 'Plot' Against Blacks

Bizarre as it may seem to most people, many black Americans believe that AIDS and the health measures used against it are part of a conspiracy to wipe out the black race.

A survey of black church members in 1990 found that an astonishing 35 percent believed AIDS was a form of genocide. A New York Times/WCBS-TV News poll in 1990 found that 1 black in 10 believes the AIDS virus was "deliberately created in a laboratory in order to infect black people" and an additional 2 in 10 thought that might be so. A Gallup/Newsweek poll in March produced similar results.

Even some dedicated black health workers engaged in the fight against AIDS decline to disavow these fears. Testifying before the National Commission on AIDS, one said that "until proven otherwise" she considered AIDS a man-made disease.

Worse yet, the treatments and preventives against AIDS have become suspect. Some blacks believe that AZT, the harsh drug used to combat the disease, is a plot to poison them

... that campaigns urging use of condoms, the best way to prevent sexual transmission, are a scheme to reduce the number of black babies ... that distributing clean needles to slow transmission among addicts is a plot to encourage drug abuse.

At its most destructive, the paranoia causes many blacks to avoid medical treatment. Unless black and Hispanic leaders play a more vigorous role in countering the fears and mistrust, it will become ever harder to slow the epidemic.

The task is urgent because the disease is now spreading most rapidly among minorities. Last year, for the first time, the number of AIDS cases reported for minorities exceeded the number for whites. Most worrisome for the future, blacks account for a majority of AIDS cases in women and children. "AIDS in future generations may be primarily a disease of black people," the New York Department of Health warned last month.

Yet the response to this growing crisis has been sluggish. Financially pressed minority organizations and local governments have little energy for fighting AIDS, especially given the stigma attached to its main victims, homosexuals and drug addicts. But whether financing for minority AIDS programs has lagged behind white programs, as some black leaders charge, is not clear. Federal and state funds to minority AIDS organizations have gone up and the Government's central programs, like counseling and testing services, have huge minority caseloads.

No programs, even if well financed, will succeed without a change in attitudes. Thus it is welcome news that the New York State Health Department, with the help of black politicians and community leaders, has started a media campaign to encourage blacks to mobilize against AIDS.

The campaign rightly stresses that AZT and condoms are not plots against blacks. But it refuses to counteract the paranoia about AIDS as genocide, saying only that no matter

how AIDS got started, there are ways to stop it. Campaign officials reasoned that few blacks would believe government denials anyway. But surely black leaders and public figures with high credibility, such as Magic Johnson, the basketball star, could do much to discredit the pernicious and dispiriting rumors.

Meanwhile, Federal, state and local health officials need a far better assessment of the flow of AIDS money into minority communities and stronger programs to fight the disease there. Costly drug treatment ought to be provided to all who seek it, an investment that would yield dividends far beyond slowing the spread of AIDS. And more vigorous outreach programs might persuade more individuals to avoid risky behavior.

As white Americans, shaken by the riots in Los Angeles, search for ways to help afflicted and distrustful minorities, there's no wiser way to start than AIDS. A failure to treat and prevent AIDS among minorities: That would be the true genocide.

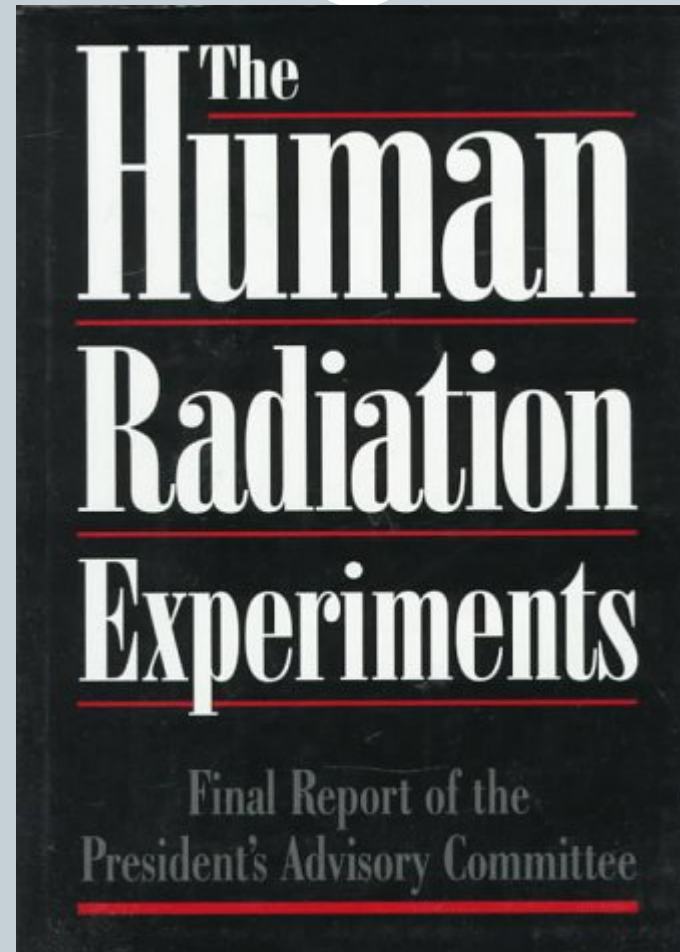
The Plague Spreads

A rising toll among minorities



Centers for Disease Control

Presidential apology 1995



White House Apology for the Syphilis Study,





White House apology ceremony, 16 May 1997. Participants and survivors of the study (first row): Herman Shaw, Fred Simmons, Charles Pollard, Frederick Moss, Carter Howard. White House officials (back row): U.S. Surgeon General David Satcher, President William J. Clinton, Vice-President Albert Gore.

Revelations of scandal and tragedy continue



2010



- **President Obama and Secretary of State Hillary Rodham Clinton apologize to people of Guatemala for studies conducted in 1946-1948**



**US Infected
Thousands of
Guatemalans
With STDs**

Earlier reports said
hundreds were victims

Sep 2, 2011 8:48 AM CDT

John Cutler, STD studies



John C. Cutler
From the National Library of Medicine

- Using prostitutes infected with syphilis and gonorrhea to deliberately infect Guatemalan soldiers and prisoners
- Infecting prisoners manually with STDS

Guatemala, 1946-48



- Infecting inmates of mental hospital with STDS



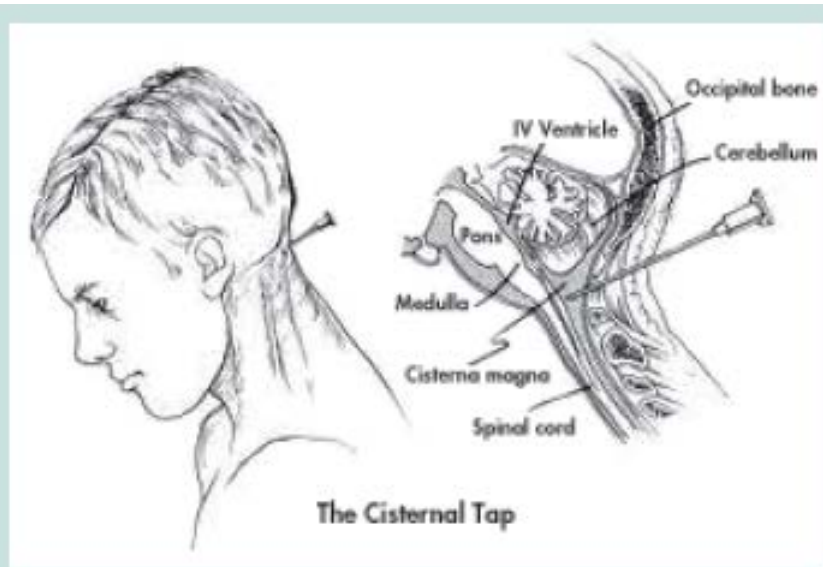
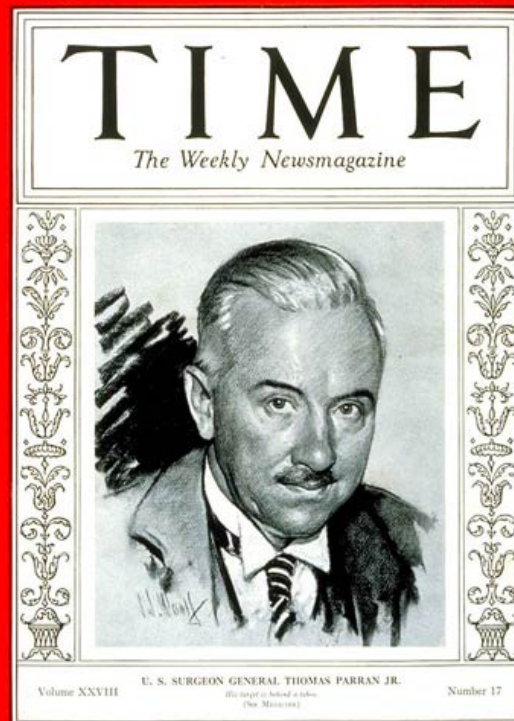


Diagram of a cisternal puncture.
From Alexander G. Reeves, M.D. and Rand S. Swenson,
M.D., Ph.D., "Disorders of the Nervous System"

- experiments in Guatemala that eventually expose 1,308 prisoners, soldiers and patients at a psychiatric hospital to STDs.
- The US team also takes blood from 1,384 orphans and other children to assess STD diagnostic tests.



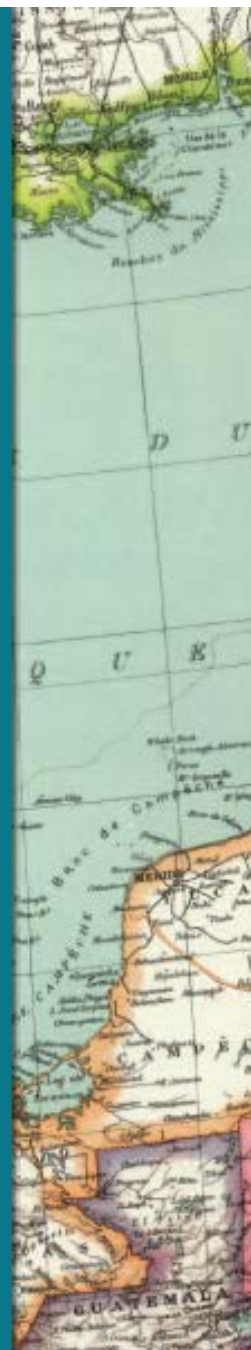
I saw Doctor Parran on Friday and he wanted to know if I had had a chance to visit your project. Since the answer was yes, he asked me to tell him about it and I did so to the best of my ability. He was familiar with all the arrangements and wanted to be brought up to date on what progress had been made. As you well know, he is very much interested in the project and a merry twinkle came into his eye when he said, "You know, we couldn't do such an experiment in this country."



“ETHICALLY IMPOSSIBLE”
STD Research in Guatemala
from 1946 to 1948

Presidential Commission
for the Study of Bioethical Issues

September 2011



Ongoing challenge to protect human subjects and advance medical knowledge

