Committee on Human Gene Editing: Scientific, Medical and Ethical Considerations
Washington, DC
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RACE AND GENETICS IN U.S. HISTORY

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SYMPHILIS VICTIMS IN U.S. STUDY WENT UNTREATED FOR 40 YEARS

By JEAN HELLER

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,
Fannie Lou Hamer, “Mississippi appendectomy”
STERILIZATION
OF MOTHERS
VIOLATES U. N. CHARTER
ART. 25, SEC. I & II
VOTE NO HOUSE BILL 20
EUGENICS BOARD

State action led to the sterilization by choice or coercion of over 7,600 people, 1933-1973. Met after 1939 one block E.
Following reports of forced sterilization of female prison inmates, California passes ban

By Hunter Schwarz  September 26, 2014

California Gov. Jerry Brown (D) signed a bill Thursday prohibiting forced sterilization in prisons. A report last year said that female inmates at facilities were being coercively sterilized as recently as 2010.

Nearly 150 female inmates were sterilized between 2006 and 2010 by doctors under contract with the California Department of Corrections and Rehabilitation, according to the Center for Investigative Reporting. A May state audit reported that some of the tubal ligations in that time were done illegally without informed consent, according to Justice Now, an advocacy group.

"Pressuring a vulnerable population into making permanent reproductive choices without informed consent is unacceptable, and violates our most basic human rights," said state Sen. Hannah-Beth Jackson (D), the bill’s sponsor, in a statement.

Kelli Dillon, a Los Angeles domestic violence counselor, said she experienced forced sterilization when she was 24 years old in a California prison and said the bill “will protect the rightful reproductive capacity of women inside prison.”

“No one should have their opportunity to be a mother taken away or decided for them,” she said in a statement.

The bill prohibits sterilization as a form of birth control except for certain medical emergencies and was passed unanimously by the California Senate and Assembly.
Indian Tribe Wins Fight to Limit Research of Its DNA

Edmond Tilousi, 56, who can climb the eight miles to the rim of the Grand Canyon in three hours. More Photos »

By AMY HARMON
Published: April 21, 2010
6. WE WANT COMPLETELY FREE HEALTH CARE FOR ALL BLACK AND OPPRESSED PEOPLE.

We believe that the government must provide, free of charge, for the people, health facilities which will not only treat our illnesses, most of which have come about as a result of our oppression, but which will also develop preventative medical programs to guarantee our future survival. We believe that mass health education and research programs must be developed to give all Black and oppressed people access to advanced scientific and medical information, so we may provide ourselves with proper medical attention and care.
Health Care Priority and Sickle Cell Anemia

Robert B. Scott, MD

Health care priority for sickle cell anemia (SCA) should be based on its prevalence, severity, and on a standard of support set for similar conditions. Sickle cell anemia occurs in about one in 500 Negro births and median survival is still only 20 years of age. In 1967 there were an estimated 1,155 new cases of SCA, 1,206 of cystic fibrosis, 813 of muscular dystrophy, and 350 of phenylketonuria. Yet volunteer organizations raised $1.9 million for cystic fibrosis, $7.9 million for muscular dystrophy, but less than $100,000 for SCA. National Institutes of Health grants for many less common hereditary illnesses exceed those for SCA. Prevalence data in cities with sizeable black populations show that SCA is a major public health consideration. More appropriate priority for SCA depends on improved public and professional understanding of its importance.

groes. Childhood diabetes and leukemia occur more often among white persons, and muscular dystrophy is believed to occur with equal frequency in both races. Health professionals have generally failed to recognize sickle cell anemia as a major community health concern, and consequently the public has been poorly informed. A recent survey revealed that only three out of ten adult Negroes had ever heard of the illness.

The treatment of patients with sickle cell anemia remains a difficult clinical problem, since there is no cure and no truly effective management.

Although longevity has no doubt
JUNE 24, 1972 - 2:00 P.M.
OAKLAND AUDITORIUM
THE BLACK PANTHER PARTY'S
ANTI-WAR - AFRICAN LIBERATION -
VOTER REGISTRATION - SURVIVAL CONFERENCE
SPEAKERS:

ELAINE BROWN
MINISTER OF INSTRUCTION, BLACK PANTHER PARTY

REV. CECIL WILLIAMS
MINISTER, UNITED CHRISTIAN CHURCH

BOBBY SEALE
CHAIRMAN, BLACK PANTHER PARTY

RON DELUMS
CONGRESSMAN, REPRESENTATIVE, 8TH CONGRESSIONAL DISTRICT

FR. EARL A. NEIL
ST. ANDREW'S EPISCOPAL CHURCH

10,000 FREE FULL BAGS OF GROCERIES
(with a dozen large grade AA eggs in every bag)

10,000 SICKLE CELL
ANEMIA TESTS

TOP ENTERTAINMENT

2,500 PAIRS OF BRAND NEW WOMEN’S SHOES
FROM THE DAVID HILLARD

VOTE FOR SURVIVAL
BOBBY SEALE FOR MAYOR
ELAINE BROWN FOR CITY COUNCIL!
Sickle Cell Anemia has claimed countless Black lives. We will accept this no longer.
INTRODUCTION

I

This is an action to prevent the allocation of approximately $1,000,000 of taxpayers' monies by the California Council for Criminal Justice and the State of California to the proposed Center for the Study and Reduction of Violence at UCLA (hereinafter "Violence Center"), unless and until it is clearly established that (1) this Violence Center will operate under enforced...
Brooklyn Man Is Exonerated After 25 Years in Prison for Murder

Andre Hatchett, 49, with his great-nephew K’mel Hawkins outside the courtroom where he was exonerated after serving 25 years in prison. Bryan R. Smith for The New York Times
a genetics “halo effect”

PAT

I’ve seen people let off jail sentences based on DNA…I’m not question[ing] about DNA…given my experiences, there is no reason to doubt the technology.
reconciliation projects

sites and practices in which genetic analysis is put to the task of resolving controversies or answering questions about the past (e.g. racial slavery, *La Asociación Civil Abuelas de Plaza de Mayo*)
We think breast cancer runs in our family. Now that I understand my African Ancestry test—the difference between the mother’s line and the father’s line and all that—I have a better sense of what the genetic counselor at my doctor’s office was telling me.
You know, I was never really interested in genetic science or the genome or whatever until I heard about these [genetic genealogy] tests… After I took my test, I wanted to know learn everything about genetics; I started reading genetics articles in the newspaper, science magazines, scientific journals, those sorts of things.
Considerations

• While changing over time, a troubled history of genetics and race exists and continues into the present

• Deliberations about the uses of new human gene-editing technologies have to necessarily include the communities historically and detrimentally impacted and not only the lay people currently at the table
Considerations

• Interest in and capacity for nuanced thinking about new genetic technologies have been and can be developed among the citizenry who should have a say in this decision, but this will take patience and creativity.

• Marginalized communities’ distrust of medical and scientific research has played a protective function and also a detrimental one. The “halo” effect of contemporary genetics suggests both an opportunity and a risk for the public understanding of the implications of human gene editing.