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LESSONS TAUGHT BY *MISS EVERS' BOYS*: THE INADEQUACY OF BENEVOLENCE AND THE NEED FOR LEGAL PROTECTION OF HUMAN SUBJECTS IN MEDICAL RESEARCH

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Legal regulation and ethical constraints on medical research are again at the forefront of public policy concerns. The reported deaths of a volunteer in a gene therapy research program at the University of Pennsylvania and of a participant in an asthma experiment at the Johns Hopkins Medical Center have raised issues of the adequacy of government surveillance of medical research and the adequacy of current practices eliciting voluntary informed consent from research participants.²

The recognition of the need for legal constraints on medical research and for protection of human subjects was greatly influenced by the reports of the research conducted by Nazi doctors and scientists.³ While no one denies the atrocities committed under the guise of medical research in the Third Reich, there has also been recognition of the significant abuse of research subjects in the United States, most recently in the reports of the Federal Advisory Committee on Human Radiation experiments.⁴ Perhaps the most publicized research involving failure to protect

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²See Stacey Schultz, *Trials and Errors: A Hospital Takes a Hit: Human Research is Halted at Johns Hopkins*, U.S. NEWS & WORLD REP., July 30, 2001. See also Sheryl Stolberg, *Youth's Death Shaking Up Field of Gene Experiments on Human*, N.Y. TIMES, Jan. 27, 2000, at A1.

³See *United States v. Carl Brandt*, I TRIALS OF WAR CRIMINALS, VOL. II 181 (1949), cited in *In re Cincinnati Radiation Litig.*, 874 F. Supp. 796 (S.D. Ohio 1995). Twenty-three German physicians were tried under "principles of the law of nations as they result from the usage established among civilized peoples, from the laws of humanity, and from the dictates of public conscious." *In re Cincinnati*, 874 F. Supp. at 820. The physicians were charged with engaging in human experimentation involving nonconsenting prisoners. *Id.* The experiments included studies of the limits of human tolerance of high altitudes and freezing temperatures. *Id.* Experiments also included "inoculation of prisoners with infectious disease pathogens and tests of new antibiotics," and mutilation of bone, muscle and nerves. *Id.* The court ruled that voluntary consent of human subjects is absolutely essential in medical research. *Id.* The court reasoned that the duty and responsibility for ascertaining the quality of consent rests upon each individual who initiates, directs or engages in the experiment. *In re Cincinnati*, 874 F. Supp. at 820.

⁴See ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, FINAL REPORT (1995).

human subjects in medical research is the Tuskegee Syphilis Study⁵ which provides the subject matter of the film *Miss Evers' Boys*.⁶

The movie *Miss Evers' Boys* is a fictionalized narrative based on the Tuskegee Study of Untreated Syphilis in the Negro Male, a project sponsored by the United States Public Health Service that was initiated in 1932 to determine whether the effects of syphilis in black men paralleled the reports of the effects of this venereal disease in Caucasian men in a Norwegian study conducted in Oslo between 1891 and 1910.⁷

The Tuskegee Syphilis Study was authorized by the United States Public Health Service to observe a number of black men infected with syphilis who were living in Macon County, Alabama.⁸ The purpose of the project, which was run through a clinic associated with the Tuskegee Institute, was to determine the natural course of untreated syphilis in black males and "the difference in historical and clinical course of the disease in black versus white subjects."⁹ Four hundred men with syphilis were initially enrolled in the project, along with 200 uninfected men who served as controls.¹⁰ The first published report of the study appeared in 1936¹¹ followed by reports provided every four to six years until 1960.¹² Although penicillin became generally available in 1950, the infected subjects were not given penicillin.¹³ As late as 1969, the Centers for Disease Control recommended continuation of the study without any treatment for syphilis being provided to the research subjects.¹⁴ The study was halted in 1972 and those subjects still living were given penicillin

⁵See generally JAMES JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (New & Expanded Ed., 1993).

⁶MISS EVERS' BOYS (HBO in association with Anasazi Productions 1997). The film is adapted from the play of the same title by David Feldshuh. *Id.* The screenwriter Walter Bernstein was blacklisted in Hollywood in the 1950's. *Id.* The film, directed by Joseph Sargent, features Alfre Woodward (Eunice Evers), Laurence Fishburne (Caleb Humphries), Craig Sheffer (Dr. Douglas), Joe Morton (Dr. Brodus), and Obba Babatunde (Willie Johnson). *Id.* Executive producers were Laurence Fishburne and Robert Benedetti, and the producers were Kip Konwiser and Derek Kavanagh. *Id.*

⁷See generally U.S. DEP'T OF HEALTH, EDUC. AND WELFARE, PUBLIC HEALTH SERVICE, FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL (1973) [hereinafter "AD HOC ADVISORY PANEL REPORT"]; see also MISS EVERS' BOYS, *supra* note 6.

⁸AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 12.

⁹*Id.* at 6.

¹⁰Dolores Katx, *Why 430 Blacks with Syphilis Went Untreated for 40 Years*, DET. FREE PRESS, Nov. 3, 1972.

¹¹R.A. Vonderlehr, et. al., *Untreated Syphilis in the Male Negro: A Comparative Study of Treated and Untreated Cases*, 17 *VENEREAL DISEASE INFO.* 260-65 (1936).

¹²D. Rockwell, et. al., *The Tuskegee Study of Untreated Syphilis: The 309th Year of Observation*, 114 *ARCHIVES OF INTERNAL MED.* 792-98 (1961).

¹³AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 10.

¹⁴*Id.* at 10-11.

following publication of newspaper stories critical of the Tuskegee Study in the various newspapers, including the *New York Times*.¹⁵

The film *Miss Evers' Boys* portrays the transformation of a government sponsored syphilis treatment program into a clinical research project in 1932 in which existing treatments were to be withheld and later discovered treatments were not offered to the research subjects.¹⁶ The program continued until 1972 despite the widespread acknowledgment of the effectiveness of penicillin in treating the disease by the late 1940's.¹⁷

A 1973 Senate hearing provides the background setting for the film's principal character, nurse Eunice Evers' testimony about the history of the project and her view of the ultimate justification of the role she played, along with that of the directing physicians.¹⁸ In the film, Miss Evers recalls her initial recruitment into the treatment program in 1932.¹⁹ Dr. Eugene Brodus, an African-American physician working in the clinic at the Tuskegee Institute, was himself invited to join in the research project by Dr. John Douglas, a white physician who was assigned by the Public Health Service to administer a private foundation financed syphilis treatment program.²⁰ The Tuskegee Institute was selected because of its stature in the black community and because of epidemiological evidence of widespread syphilis infection among African American men in the surrounding geographical area.²¹ However, according to the film narrative, within less than a year, the effects of the depression on dissipating the sponsoring foundation's assets necessitated a decision to discontinue treatment with the collateral consequence of nurse Evers termination from the initial treatment project.²²

Meanwhile, in Washington, D.C., officials at the Public Health Service developed a proposal to fund a research project to study the course of untreated syphilis in black males by replacing the existing treatment being provided to the

¹⁵J. Heller, *Syphilis Victims in U.S. Study Went Untreated for 40 Years*. N.Y. TIMES, July 26, 1972, Sec. 1, at 1; J. Brody, *All in the Name of Science*, N.Y. TIMES, July 30, 1972, Sec. 4, at 2; *At Least 28 Died in Syphilis Study*, N.Y. TIMES, Sept. 12, 1972, Sec. 1, at 23.

¹⁶See David Feldshuh, *Miss Evers' Boys* 5 (1995) (play script) ("This play was suggested by the book, *BAD BLOOD* by James H. Jones (The Free Press, 1981) and by a number of primary sources including the Senate testimony, medical articles and field interviews conducted in Alabama in the 1930's.").

¹⁷AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 9 ("Penicillin therapy was recommended for treatment of latent syphilis in the late 1940's.").

¹⁸MISS EVERS' BOYS, *supra* note 6. The setting is a schoolhouse that serves as a site for a hearing of the United States Senate in 1972. *Id.*

¹⁹*Id.* See also Feldshuh, *supra* note 16, at 5 ("Although *Miss Evers' Boys* is based on a true event, and although the character of Miss Evers was inspired by a nurse involved in the Tuskegee Study, the play is fiction.").

²⁰*Id.* Dr. Douglas states: "Washington needs your help Dr. Brodus." *Id.*

²¹FRED D. GRAY, *THE TUSKEGEE SYPHILIS STUDY* 29 (1998).

²²MISS EVERS' BOYS, *supra* note 6. Dr. Douglas reports: "There's no more money. . . . Dr. Brodus, I'm just telling you what I've been told to tell you." Feldshuh, *supra* note 16, at 39.

patients with a placebo.²³ The project involved transforming patients into a research project, without informing them of the change in their status from patient to research subject.²⁴

In the film, Public Service officials, including Dr. Douglas, justify their action on the ground that the research could undermine social prejudice by showing that the course of syphilis is no different in black men than in white.²⁵ Moreover, proponents of the research point out that the alternative for the patients would be not only no treatment for syphilis, but the loss of all medical treatment at the clinic.²⁶ By their unknowing participation as research subjects, it was argued by the researchers and government officials that these men would at least receive care for their other medical needs.²⁷

Dr. Brodus, who is generally portrayed as dismayed by the elimination of the treatment program, initially is outraged by the proposal to replace existing treatment with a placebo since the studies on white men done over a quarter of a century before had not only traced the cause of the disease, but had led to successful treatments.²⁸ Dr. Brodus, however, is a pragmatist who becomes convinced that his participation in this research program will not only result in subsequent reinstatement of funding for treatment, but will also establish that human diseases have the same effect whatever the race of the infected person. As he assumes the mantle of research scientist, Dr. Brodus insists the project be called "The Tuskegee Study of Untreated Syphilis in the Negro Male."²⁹

Eunice Evers begins her testimony at the Senate hearing with the words of her ethical pledge as a nurse:

I solemnly pledge myself before God and in the presence of this assembly;
To pass my life in purity and to practice my profession faithfully;
To hold in confidence all matters revealed to me in the practice of my calling;
To abstain from knowingly administering any harmful medicine;

²³MISS EVERS' BOYS, *supra* note 6.

²⁴*Id.* Miss Evers remarks: "[W]hen they find out it's not treatment, they won't come." Dr. Douglas responds: "Then they can't find out." *Id.*

²⁵*Id.* Dr. Brodus asks: "What if it [the study] proves that Negro and Caucasian are equal? That disease affects both races in exactly the same way?" Feldshuh, *supra* note 16, at 41.

²⁶MISS EVERS' BOYS, *supra* note 6.

²⁷*Id.* Dr. Brodus, assuring Miss Evers, asserts: "You'll be able to keep nursing those patients and their families and take those men to the hospital free of charge if they get sick and know that they're all signed up front, first in line, when the treatment money comes through. . . ." Feldshuh, *supra* note 16, at 44.

²⁸MISS EVERS' BOYS, *supra* note 6.

²⁹*Id.* See also Feldshuh, *supra* note 16, suggesting that the role of reputation and prestige fueled scientific research. Suggesting a title for the project, Dr. Douglas states: "A Study of Untreated Syphilis in the Negro Male. That title's clear, uncluttered and to the point." Dr. Brodus retorts: "The Tuskegee Study & Untreated Syphilis in the Negro Male? I want Tuskegee in there." *Id.* at 42-43.

To do all in my power to maintain the standard of the nursing profession;
 To endeavor with loyalty to aid the physician in his work;
 To devote myself to the welfare of those patients committed to my care.³⁰

This oath, based on Florence Nightingale's Pledge of 1893, embodies the main tenets of the oath of Hippocrates that governs the provision of medical treatment as well as research involving patients, including participation of all human subjects in medical research projects.³¹ This pledge provides the ethical background against which the viewer is asked to judge Miss Evers.

Much of the significance of this film is the interpretation of the words of this oath by nurse Evers as a justification for participation in medical research involving withholding of available treatment and lack of voluntary informed consent by patients. From the outset, in the film, Miss Evers is aware and troubled by the nature of the research project when she is asked to return to work at the clinic as a member of the staff of the research study. She questions the direction that arsenic injections and mercury backrubs be replaced by the placebo of heat liniment.³² She is disturbed that patients are not told of this withholding of treatment, and that a procedure involving obtaining spinal taps, to obtain research specimens, is passed off as "backshot" treatment.³³

Initially, nurse Evers accepts the pragmatic view that her engagement in the research project is a temporary expedient necessary to obtain restored funding for treatment which will be available to all infected patients.³⁴ An apparently significant underlying factor in nurse Evers continued participation in the project is her deference to the judgment of physicians about the appropriateness of the project.

With the passage of months and years, new justifications or rationalizations are sought by Nurse Evers by which she sought to find, within her understanding, what was necessary to care for the men who were participating in the study. Throughout her participation in the research project, Nurse Evers accepts the idea that not telling the men that they are participating in a study and not receiving treatment is justified by their lack of education and likely misplaced fear if they were informed.³⁵ However, it is the experience of Caleb Humphries, a research subject with whom

³⁰MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 13-14.

³¹B. FURROW, ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 29-30 (3d ed. 1997).

³²MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 55. Miss Evers complains: "I just want to tell the men what's going on. The straight truth. There's no mercury in those back rubs. They won't stop bad blood. But you got to stick to it. . . ." *Id.*

³³MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 55. Miss Evers states: "You tell a man a 'backshot' is helping him . . . feels like lying. Dr. Brodus I'm giving these men back rubs with heat liniment and calling it 'mercury.'" *Id.*

³⁴MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 44. Miss Evers receives assurance from Dr. Brodus: "You'll be able to keep nursing those patients and their families and take those men to the hospital free of charges if they get sick and know that they're all signed up, right up front, first in line, when the treatment money comes through. . . ." *Id.*

³⁵MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 33. Early on Dr. Douglas is instructed by Miss Evers to: "Talk personal talk. Respectful. Man to Man. And let the 'facts' go on vacation for a while." *Id.*

Eunice Evers, establishes a romantic attachment that becomes a central issue in the film. Caleb Humphries places himself before Miss Evers as a patient who has been cured of syphilis by penicillin injections.³⁶ This evidence of an available cure of syphilis with penicillin treatment creates a significant question for Nurse Evers' mind about the propriety of continuing the study of the effect of untreated syphilis. Again, Miss Evers, however, defers to the physicians conducting the experiment when they assert that penicillin injections would provide a significant danger of death to the research subjects because of their advanced stage of the disease.³⁷ The film epilogue points out that when the project was halted in 1972, the remaining research subjects were given penicillin treatment without any significant side effect.³⁸

Miss Evers also testifies to her awareness that Dr. Douglas at some time avowed the position that completion of the project would necessarily involve autopsies of the untreated subjects in order for the study to be accepted as a major scientific achievement.³⁹ Nurse Evers also reports on her conversations with Dr. Brodus in which he justified the study on the basis that it would demonstrate that race was not a factor in the cause and treatment of most human medical conditions, and that the Tuskegee Study would also establish that black researchers, and the institution with which they were affiliated, could conduct significant medical and scientific research.

The film *Miss Evers Boys* takes its title from a group of men taking part in the project who regularly perform in a music and dance competition.⁴⁰ One character, Willie Johnson, is the star performing dancer who is known as the "best double fly stepper" in the area.⁴¹ Ben Washington plays the washboard, Hodman Humphries slaps the beat while Caleb Humphries plays base.⁴² The development of symptoms of syphilis in these characters, other than Caleb who gains his own access to penicillin, provide the dramatization not only of the course of the disease but of the history of the project. Willie, the dancer, experiences effects on his skeletal system as his bone cartilage deteriorates.⁴³ Another character, Ben, becomes increasingly mentally disordered as the virus moves to his brain.⁴⁴

Miss Evers herself is emotionally tortured by the development of symptoms in her "Boys." At one point she is driven to steal penicillin to halt the development of

³⁶MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 69. In the theatre script Miss Evers is confronted by Caleb who responds: "We're here to get a hip shot and that penicillin, Nurse Evers." *Id.*

³⁷MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 67. Dr. Brodus warns Nurse Evers of the danger of the Herxheimer reaction: "An allergic reaction that could kill a chronic syphilic with a single injection of penicillin." *Id.*

³⁸MISS EVERS' BOYS, *supra* note 6.

³⁹*Id.* See Feldshuh, *supra* note 16, at 43.

⁴⁰MISS EVERS' BOYS, *supra* note 6. See Feldshuh, *supra* note 16, at 28-29.

⁴¹MISS EVERS' BOYS, *supra* note 6. Feldshuh, *supra* note 16, at 27.

⁴²MISS EVERS' BOYS, *supra* note 6. Feldshuh, *supra* note 16, at 28.

⁴³MISS EVERS' BOYS, *supra* note 6. Feldshuh, *supra* note 16, at 72.

⁴⁴MISS EVERS' BOYS, *supra* note 6. Feldshuh, *supra* note 16, at 84-85.

blindness and mental disorder in one of the research subjects.⁴⁵ When this patient dies following the penicillin injection, Miss Evers becomes reconciled to the completion of the project on the terms demanded by the physicians in charge.⁴⁶

The romance between Miss Evers and Caleb has no basis in the historical record.⁴⁷ The play on which the film is based was suggested by the monograph *Bad Blood* by James H. Jones which provides a historical account of the Tuskegee study.⁴⁸ In the actual study, Miss Evers was Eunice Rivers Laurie who was the only full-time staff member of the study.⁴⁹ Nurse Rivers performed a crucial role in providing a bridge of trust between the research subjects and the medical staff. According to James Jones:

The relationship that evolved between Nurse Rivers and the men played an important role in keeping them in the experiment. More than any other person, she made them believe that they were receiving medical care that was helping them. "She knew them [and] they knew her and trusted her," stated Dr. Heller. "She would keep them satisfied that our intentions were honorable and that we were out for the good of the patient."⁵⁰

⁴⁵MISS EVERS' BOYS, *supra* note 6. Feldshuh, *supra* note 16, at 89.

⁴⁶MISS EVERS' BOYS, *supra* note 6. Feldshuh, *supra* note 16, at 92.

⁴⁷See GRAY, *supra* note 21, at 111. The author reports on the critical reaction of participants in the Tuskegee study on viewing the film:

The film inaccurately represented the character of Nurse Eunice Rivers. Each of the participants after reviewing the film, stated that Nurse Rivers was always professional and courteous to them. She did not accompany them to juke joints. The participants did not dance, play music, and entertain people at juke joints with Nurse Rivers. There is nothing that these men remember observing about Nurse Rivers which would indicate that she had a love affair with one or more of the participants as was set forth in the film. Nurse Rivers did not give penicillin to one participant and withhold it from all others.

Id.

⁴⁸Feldshuh, *supra* note 16. The Author's Note provides the following significant background information about the play, and consequently the screen play based on the play:

This play was suggested by the book, *BAD BLOOD*, by James H. Jones (The Free Press, 1981) and by a number of primary sources including the Senate testimony, medical articles and field interviews conducted in Alabama in the 1930's. The Tuskegee Study was a grim reality and Professor Jones' book is recommended to all who would desire a meticulously researched, insightful and absorbing review of it.

Although *MISS EVERS' BOYS* is based on a true event, and although the character of Miss Evers was inspired by a nurse involved in the Tuskegee Study, the play is fiction. The characters (including that of the nurse), the context, and the incidents of the play are products of the playwrights imagination, and any quotations from primary sources have been rearranged, reassigned or paraphrased. *MISS EVERS' BOYS* is not intended to be taken as a factual record of real events or real people.

Id.

⁴⁹See E. Rivers, et. al., *Twenty Years of Followup Experience in a Long-Range Medical Study*, 68 PUB. HEALTH REP. 3901 (1953).

⁵⁰JONES, *supra* note 5, at 160.

While the supportive relationship between the nurse and the research subjects is effectively portrayed in the film, the film's fictional account of the knowledge of the nature of the research and her complicity in withholding of available treatment raises significant ethical issues not presented by the actual involvement of the nurse who participated in the study.

The film departs from the historical record by portraying Miss Evers, from the start, as conflicted about her participation in the research project because of the withholding of available treatment.⁵¹ According to James Jones, there is no evidence in the record to support this portrayal:

Nurse Evers was not troubled by the duties she performed. Indeed, she never thought much one way or the other about the ethics of the experiment. She saw herself as a good nurse, one who always did what the doctors ordered. Not once did she advocate treating the men. In fact, she never raised the matter for discussion. She did not do so, she explained because "as a nurse, I didn't feel that that was my responsibility. That was the doctors." Any other response would have been unthinkable for a nurse of her generation argued nurse Evers, because "as a nurse being trained when I was being trained we were taught that we never diagnosis, we never prescribed; we *followed* the doctor's instructions!"⁵²

This significant departure in the film's depiction of the historical record, while it does not foreclose an ethical assessment of the fictional character's conduct, means a factually based judgment on moral responsibility for the Tuskegee study must be focused on the physicians as well as the authorizing and monitoring agencies of the federal government. In a sense, the film's character, Miss Evers, makes this point when she responds to the chastising remarks of a Senator by charging not only the government authorities who authorized and continued the study, but also pervasive social racism which treated black men as marginal and expendable research subjects, are the real culprits in any finding of ethical lapse attributed to the Tuskegee Study.⁵³

Nevertheless, it seems appropriate to make a judgment about the ethics of nurse Evers *as portrayed* in the film. From the time of her recruitment to take part in the research study, Miss Evers knew that the program involved withholding available treatment, and she took part in deceiving the men into submitting to non-therapeutic research procedures such as spinal taps.⁵⁴ She certainly is not exonerated by her acceptance of Dr. Brodus' argument that its study will show that black doctors and

⁵¹MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 43. Miss Evers reacts with expressed concern upon initially learning of the intention to study the effects of syphilis on untreated patients. Miss Evers exclaims: "Dr. Brodus, I promised the men treatment. Now we just going to let 'em go? Just leave 'em with nothing?" *Id.*

⁵²JONES, *supra* note 5, at 163.

⁵³MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 97. Miss Evers remarks: "Well, now there's big blame and there's little blame. The big blame – that seems to be going to the government and those doctors." *Id.*

⁵⁴MISS EVERS' BOYS, *supra* note 6. See also Feldshuh, *supra* note 16, at 55. Dr. Brodus is confronted by Evers, who exclaims: "You're doing the research. I'm doing the zigzagging." *Id.*

nurses are as good as their white counterparts. It should have been clear that the men in the study were being victimized for the good of science (Dr. Douglas's assertion) or for the good of the race (Dr. Brodus' claim). Totally ignoring the necessity of obtaining voluntary informed consent from patients, nurse Evers only says, "Listen to the doctors, because they know."⁵⁵ Even if Miss Evers' embracing of paternalism could be understood in the context of the rendering of therapeutic treatment, such an attitude can in no way can be justified in the context of non-therapeutic medical research. The film character, Caleb Humphries, makes the point of the nurse's complicity dramatically when nurse Evers refuses to admit that the research subjects should be considered as candidates for the new penicillin drug that cured him; Caleb confronts Miss Evers with the statement: "Yeah I know, doctors know best. But they sure got a good one when they got you."⁵⁶

Beyond the personal drama portrayed in *Miss Evers Boys*, the film identifies two pervasive corrosive aspects of medical science in America that demand continuing legal intervention: racism and abuse of research subjects.⁵⁷ The Tuskegee Syphilis Study involved approximately 400 individuals who had syphilis and 200 who did not; all participants in the study were black.⁵⁸ The United States Public Health Service did not authorize or fund any study involving the study of untreated syphilis in whites.⁵⁹ It seems doubtful that when penicillin became available as a treatment that it would have been withheld from white research subjects.

The fact that the individuals recruited for the Tuskegee Study were poor rural tenet farmers with little or no education is offered in the film, as it was by apologists for the study, as the reason for not telling the participants about the nature of their disease, or that they were not receiving treatment but were, instead, part of a research study.⁶⁰ The fact of the participants vulnerability should have led to greater counseling about their situation, not less. The perniciousness of the failure to obtain informed voluntary consent from these men is exacerbated by the inducements that were given to the men to obtain and to continue their participation.⁶¹ Free medical

⁵⁵MISS EVERS' BOYS, *supra* note 6.

⁵⁶*Id.*

⁵⁷See generally S. Thomas & S. Quinn, *The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education in the Black Community*, 81 AM. J. PUB. HEALTH 1498-1505 (1991).

⁵⁸*Id.* at 1500.

⁵⁹H. Edgar, *Outside the Community*, 22 HASTINGS CENTER REP. 32-35 (1992).

⁶⁰Thomas, *supra* note 57, at 1501. The authors report:

The PHS physicians, believing that their patients would not understand clinical terms, did not even attempt to educate them about syphilis. Participants were not informed that they suffered from a specific, definable disease that was contagious and transmitted through sexual intercourse. Nor were they told that the disease could be transmitted from mother to fetus.

Id.

⁶¹*Id.* ("The PHS also used incentives including free physical examinations, food and transportation. Bunal stipends provided by the Milbank Memorial Fund, were used to gain permission from family members for autopsies to be performed on study participants who reached 'end point.'").

care (except for syphilis treatment), free meals, transportation to and from the Institute, and money for burial were provided.⁶²

With public disclosure of the study both the Tuskegee Institute and the Public Health Service attempted to limit its responsibility to the 1930 period when the study was authorized and when existing penicillin treatments were ineffective or dangerous.⁶³ Public discussion of the study followed the 1972 publication of a report by an Ad Hoc Advisory Panel to investigate the establishment of the Tuskegee Syphilis Study established by the Department of Health, Education and Welfare in 1969 with directions to:

1. Determine whether the study was justified in 1932 and whether it should have been continued when penicillin became generally available.
2. Recommend whether the study should be continued at this time, and if not, how it should be terminated in a way consistent with the rights and health needs of its remaining participants.
3. Determine whether existing policies to protect the rights of patients participating in health research conducted or supported by the Department of Health, Education and Welfare are adequate and effective and to recommend improvements in these policies, if needed.⁶⁴

The scope of the mandate to the Ad Hoc Advisory Panel has been criticized for failure to direct it to make specific findings about the lack of informed consent, the basis for withholding penicillin, racial discrimination in the selection of research subjects, and possible liability to the research subject.⁶⁵

Despite some criticism and skepticism about the Ad Hoc Advisory Panel, it did find that while a short term demonstration project in 1932 might have been justified, the study as it continued past 1936 was “scientifically unsound and its results are disproportionately meager composed with known risks to the human subjects involved.”⁶⁶ Further, the Panel found that penicillin therapy should have been made available to the participants no later than 1953.⁶⁷ As to its third charge, the Panel

⁶²See A. Brandl, *Racism and Research: The Tuskegee Syphilis Study*, 8 HASTINGS CENTER REP. 21-29 (1978).

[B]ecause it proved difficult to persuade the men to come to the hospital when they became extremely ill, the USPHS promised to cover their burial expenses. The Milbank Memorial Fund provided approximately \$50 per man for this purpose beginning in 1935. This was a particularly strong inducement as funeral rites constituted an important component of the cultural life of rural blacks. One report of the study concluded:

“Without this suasion it would, we believe have been impossible to secure the cooperation of the group and their families.”

Id. at 25.

⁶³JONES, *supra* note 5, at 208. (“The [Tuskegee] Institute acknowledged that its medical facilities and personnel had been used in the study, but emphasized that cooperation have been limited to the 1930’s . . .”).

⁶⁴AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 1.

⁶⁵Brandl, *supra* note 62, at 26-27.

⁶⁶AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 12.

⁶⁷*Id.* at 9.

recommended development of a program of regulation of federally funded and authorized medical research.⁶⁸ Two of the findings of the study specifically addressed the need to protect research subjects, and the need to avoid racism and exploitation of vulnerable subjects.⁶⁹ As to the concern about vulnerable patients and the need to eliminate racism, the Panel observed:

History has shown that certain people under psychological, social or economic duress are particularly acquiescent. These are the young, the mentally impaired, the institutionalized, the poor and persons of racial minority and other disadvantaged groups. These are people who may be selected for human experimentation and who, because of their station in life, may not have an equal chance to withhold consent.⁷⁰

The Panel evidenced appropriate sensitivity to the development of increased concern about the need to protect research subjects. Specifically, the Panel suggested that it was axiomatic of ethical medical research that it involve only subjects who have given informed voluntary consent to the research procedures or to treatment which the subject will receive; the Panel stated:

The judgments in 1973 about the conduct of the Tuskegee Study in 1932 are made with the advantage of hindsight, acutely sharpened over some forty years concerning an activity in a different age with different social standards. Nevertheless, one fundamental ethical rule is that a person should not be subjected to avoidable risk of death or physical harm unless he freely and intelligently consents. There was no evidence that such consent was obtained from the participants in this study.⁷¹

Beyond its judgmental findings about the inappropriateness and inadequacies of the Tuskegee Syphilis Study, the report of the Ad Hoc Advisory Panel included valuable recommendations for establishing a program of review and monitoring of human subjects, medical research receiving federal funding or authorization.⁷² The Panel suggested the establishment of a federal agency to regulate all federally supported research involving human subjects.⁷³ In addition, the Panel suggested the development of a two prong process of review of proposals by groups established by the research institutions.⁷⁴ A group of biomedical professionals should determine the scientific merits of any research programs, and a protocol review group or institutional review board, consisting of professionals and lay persons, should determine the adequacy of protections of human subjects involved, including the quality of informed consent to be obtained from the research subjects.⁷⁵ The panel

⁶⁸*Id.* at 23-24.

⁶⁹*Id.* at 23.

⁷⁰*Id.* at 12.

⁷¹ AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 12.

⁷²*Id.* at 23-24.

⁷³*Id.*

⁷⁴*Id.* at 24.

⁷⁵*Id.*

also made recommendations relating to compensation for research subjects harmed as a result of their participation, on-going review of research projects, and specifications about the structure and compensation of local institutional review boards.⁷⁶

Public response to newspaper reports of the abuses involved in the Tuskegee Study led to two months of hearings in 1973 by a United States Senate Subcommittee on Health chaired by Senator Edward Kennedy.⁷⁷ It is these hearings that provide the basis for the framework in which the narrative of *Miss Evers Boys* is developed. In fact, the Senate hearings resulted in enactment of the National Research Act of 1974 which aimed at protection of subjects in human experimentation by mandating institute review board approval of all federally funded research with human subjects.⁷⁸ The Act required:

[T]hat each entity which applies for a grant, contract, or cooperative agreement under this chapter of any project or program which involves the conduct of biomedical or behavioral research involving human subjects submit . . . assurances satisfactory to the Secretary [of Health Education and Welfare] that it has established a board (to be known as an "Institutional Review Board") to review biomedical and behavioral research involving human subjects conducted at or sponsored by [the institution in order to protect the rights of the human subjects of research].⁷⁹

The Act also established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which was directed to identify the ethical standards that should govern research involving human subjects.⁸⁰

The findings and recommendations of the National Commission were published in what has become to be referred to as the Belmont Report.⁸¹ The principles identified in the Belmont Report continue to provide guidance for medical research. The report distinguished medical therapy from research and set out the principal values guiding research including: respect for persons, beneficence and justice.⁸² Respect for persons requires respect for individual autonomy and protection of

⁷⁶AD HOC ADVISORY PANEL REPORT, *supra* note 7, at 23-24.

⁷⁷*Quality of Health Care: Human Experimentation, Hearings Before the Subcomm. on Health of the Comm. on Labor and Public Works*, 93d Cong. (1973).

⁷⁸The National Research Act, *amended as* the Public Health Service Act of 1974, Pub. L. No. 93-348, 88 Stat. 342 (codified as amended at 42 U.S.C. §§ 201 to 300aaa-13) (2001).

⁷⁹42 U.S.C. § 289(2)(a) (2001).

⁸⁰§ 289(1)(i) (1982). This section expired with the completion of the Commission's report. *Id.*

⁸¹THE NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, U.S. DEP'T OF HEALTH, EDUC. AND WELFARE, PUB. NO. (OS) 78-0012, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1978).

⁸²*Id.* at 4-8.

vulnerable subjects.⁸³ Beneficence requires protection from harm and action to secure the well-being of research subjects.⁸⁴ Justice requires selection of research subjects on a basis that is relative to the question under study.⁸⁵

The report of the Ad Hoc Advisory Panel in the Tuskegee Syphilis Study and the subsequent Senate hearings were not without their critics. For example, one medical research emphasized the limited knowledge of effective therapy for syphilis when the experiment began and the lack of established benefit of penicillin to subjects in the late stages of syphilis by the time of its widespread availability in 1950.⁸⁶ Others have maintained there is no reason to believe that the subjects would have otherwise been treated for syphilis.⁸⁷ One defender of the project argued: "The lack of treatment was not contrived by the United States Public Health Service but was an established fact of which they proposed to take advantage."⁸⁸ Finally, the charge of racism has been denied by defenders and by the medical researchers involved in the project, one of whom stated:

I don't see why they should be shocked or horrified. There was no racial side to this. It just happened to be in a black community. I feel this was a perfectly straightforward study perfectly ethical, with controls. Part of our mission as physicians is to find out what happens to individuals with disease and without disease.⁸⁹

The charge of racism as being a pervasive aspect of the Tuskegee Study was at the center of a lawsuit, filed on July 24, 1973, on behalf of the survivors of the Study, and the heirs and representatives of the participants who had since died, against the various federal government agencies, the State of Alabama, the private foundation that provided original funding, and individual physicians working for the United States Public Health Service.⁹⁰ In addition to several charges that dealt with failure to obtain voluntary informed consent and to provide treatment according to the recognized standard of care, the plaintiffs' lawyers maintained that: "The Study was racially motivated and it discriminated against African Americans in that no whites were selected to participate; and, the Study only recruited those who were poor, uneducated, rural and African American."⁹¹ After several court hearings, the attorneys representing the research subjects and their survivors and the attorneys for

⁸³*Id.* at 4-6.

⁸⁴*Id.* at 6.

⁸⁵*Id.* at 8.

⁸⁶R.H. Kampmeier, *The Tuskegee Study of Untreated Syphilis*, 65 S. MED. J. 1247-51 (1972); *Final Report on the Tuskegee Study*, 67 S. MED. J. 1349-53 (1974).

⁸⁷*Debate Revives on the PHS Study*, MED. WORLD NEWS, April 19, 1974.

⁸⁸*Id.* at 37 (quoting Dr. Charles Barnett of the Stanford University Medical School).

⁸⁹MED. TRIB. Aug. 23, 1972, at 14 (quoting Dr. J.R. Heller who participated in the Tuskegee Study).

⁹⁰*Pollard v. United States*, 69 F.R.D. 646 (M.D. Ala. 1976). *See also* *Pollard v. United States*, 384 F. Supp. 304 (M.D. Ala. 1974).

⁹¹F. GRAY, *BUS RIDE TO JUSTICE* 285 (1995).

the United States reached a monetary settlement of \$10 million out of which each surviving subject was to be paid \$37,500, each heir or representative of a diseased subject received \$15,000, each of the members of the control group received \$16,000, and the heir or a representative of each control subject received \$5,000.⁹²

The attorney who brought the lawsuit, Fred D. Gray, also provided a forum for criticism of the film *Miss Evers' Boys*.⁹³ A group of the surviving subjects of the Study were asked by Mr. Gray to view the film and to discuss their reactions; this discussion provided the basis for a press conference in April of 1997 in which a series of objections to *Miss Evers' Boys* were set out.⁹⁴ Basically, the participants felt the film did not accurately portray them or the circumstances under which they participated in the Study.⁹⁵ For example, the film suggests the men were originally enrolled in a treatment program that was discontinued only when funding became unavailable.⁹⁶ The participants maintained they were never treated for syphilis until the Study was ended.⁹⁷ The film is criticized for its portrayal of Dr. Brodus as an African-American physician who serves as a supervisor of the Study and as the immediate supervisor of Nurse Evers.⁹⁸ According to the participants, all of the Study's supervisors and examining physicians were white.⁹⁹ According to the participants' criticism:

[T]he entire film shifts the responsibility for the Study from the federal government to an African American doctor and an African American nurse. The Study was conceived, financed, executed, and administered by the federal government. The African American medical professionals who participated in it were victims as well as the 623 African American participants.¹⁰⁰

The participants also fault the lack of depiction of the role of health agencies in Alabama for their role in failing to provide penicillin treatment to the research subjects.¹⁰¹

The research subjects criticize the film for what they felt was stereotyped portrayal of the participants as carefree, dancing, singing "shuffling sams" instead as hard-working, reputable persons in the community.¹⁰² The participants also

⁹²L. Palmer, *Paying for Suffering: The Problem of Human Experimentation*, 56 MD. L. REV. 604, 610 (1997).

⁹³GRAY, *supra* note 21, at 109-12.

⁹⁴*Id.* at 109.

⁹⁵*Id.* at 109-12.

⁹⁶*Id.* at 110.

⁹⁷*Id.*

⁹⁸GRAY, *supra* note 21, at 110.

⁹⁹*Id.*

¹⁰⁰*Id.*

¹⁰¹*Id.*

¹⁰²*Id.* at 110-11.

criticized the film for its portrayal of the Nurse, Eunice Rivers (“Miss Evers”) as involved in a romantic relationship with one of the subjects, as accompanying participants to dance competitions or as directly involved in denying penicillin to any subject; instead, the participants maintained the nurse was always “professional and courteous.”¹⁰³ Because much of the discussion by viewers of the film will necessarily involve evaluations of ethical and professional aspects of her conduct, it is important to consider what Fred Gray has to say about the portrayal of the nurse in *Miss Evers' Boys*:

The interesting thing about Miss Eunice Rivers is that if you asked any of its participants in the experiment, including those seven who are still alive, what they thought about her, the response was unanimous. Every one of them believed that she was a fine person, she was a professional, and she treated them fairly. As a matter of fact, Charlie Pollard, Herman Shaw, Fred Simmons, and Carter Howard, after viewing *Miss Evers' Boys*, were astonished, because they felt Miss Evers was improperly projected in that movie. They did not believe that she treated any one of the participants better than another, or that she had a love affair with one of them, or that she took them to night clubs, danced and drank corn liquor with them.¹⁰⁴

The comments of these participants in the Study raise a larger question about films that purportedly portray historical events through dramatization that involves conflation of large numbers of people into a few characters and that fictionalize aspects of various characters in order to develop the narrative or portray a specific viewpoint.¹⁰⁵

Despite any shortcomings of the film, the dramatization of the Tuskegee Study confronts the reviewer with stark evidence of abuse of research subjects occurring in

¹⁰³GRAY, *supra* note 21, at 111.

¹⁰⁴*Id.*

¹⁰⁵See R.B. TOPLIN, HISTORY BY HOLLYWOOD: THE USE AND ABUSE OF THE AMERICAN PAST (1996). The author sets out the basic issues about the relationship between film depictions and historical representation; according to Toplin:

If we hold cinematic historians strictly to the standards of most written history, we are almost certain to be disappointed, for filmmakers must attend to the demands of drama and the challenges of working with incomplete evidence. In crating historical dramas, they almost always need to collapse several historical figures into a few central characters to make the story understandable. Often they are pressed to simplify complex causes so that audiences will comprehend their movies' principal messages and not lose interest, and the dramatic medium often leads them to changes in history to the actions of dynamic individuals rather than to impersonal forces. Cinematic historians often lack detailed evidence about situations in the past, so they invent dialogue and suggest impressions about the emotions and motivations of historic figures. Also, they suggest closure on a story, revealing few doubts, questions, or considerations of alternative possibilities.

Id. at 10.

the name of scientific research and of the racism that has and continues to exist in medical research and delivery of treatment.¹⁰⁶

Without asserting any causal relationship, it is interesting to note that the initial showing on February 22, 1997, of the film *Miss Evers' Boys* was followed by a ceremony at the White House on May 16, 1997, at which President Clinton apologized for the federal government's role in its Tuskegee Syphilis Study.¹⁰⁷ The President acknowledged the wrongs embodied in the Tuskegee Study which he said included racism in medical care, misconduct in human research and the arrogance of researchers.¹⁰⁸ The President addressed the harm done to the public's confidence in the integrity of medical research: "The legacy of the study at Tuskegee...has reached far and deep, in ways that hurt our progress and divide our nation."¹⁰⁹ The President went on to address the living subjects of the Tuskegee project: "What was done cannot be undone. But we can end the silence. We can look 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."¹¹⁰

The Tuskegee study is perhaps the most notorious example of abuse in medical research in the United States. It is significant that the project was not ended until twenty-five years after the adoption of the Nuremberg Code of 1947, the first article of which establishes its principle that human subjects should not be experimented on without their consent.¹¹¹ Continuing concern about the ethics of medical and

¹⁰⁶See L. PALMER, *SUSCEPTIBLE TO KINDERS: MISS EVERS' BOYS AND THE TUSKEGEE SYPHILIS STUDY* (1994) (Study Guide for Discussion Leaders); Videotape: *Susceptible to Kinders: Miss Evers' Boys and the Tuskegee Syphilis Study* (Cornell University 1994) (on file with the Cornell University Library). The video examines the ethical issues raised by the Tuskegee Study through selected scenes from a performance at Cornell University of the play *Miss Evers' Boys* by David Feldshuh. *Id.* These scenes are intercut with interviews and commentary, historical footage and photographs related to the study and the ethical issues it raises. *Id.* These materials raise a number of issues including personal and professional ethics, the relationship between law and medicine, as well as matters involving issue of race, gender and socio-economic status as they pertain to the vulnerability of subjects of medical research.

¹⁰⁷V. Gamble, *Under the Shadow of Tuskegee: African Americans and Health Care*, 87 *AM. J. OF PUB. HEALTH* 1773, 1778 (1997).

¹⁰⁸*Id.* at 1773.

¹⁰⁹*Id.*

¹¹⁰J. Harris & M. Fletcher, *Six Decades Later, an Apology: Saying I'm Sorry, President Calls Tuskegee Experiment 'Shameful'*, *WASH. POST*, May 17, 1997, at A1.

¹¹¹See FURROW, ET AL., *BIOETHICS* 379. The first requirement of the Nuremberg Code provides that:

The voluntary consent of the human subject is absolutely essential.

This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject, there should be made known to him the nature, duration, and purpose of the experiment, the method and means by which it

scientific research have been fueled by finding about other research abuse such as the radiation experiments in the 1940's and 1950's that involved subjects being injected with plutonium without their knowledge and feeding of radioactive oatmeal to retarded children.¹¹² Other projects involving withholding of medicine from schizophrenics suggest the need to give additional attention to the protection of vulnerable subjects.¹¹³ A halt in gene-therapy research following the allegation of inadequate reporting of adverse reactions in research subjects has roused anew issues about the adequacy of the informed consent obtained from patients and the sufficiency of government monitoring of medical research.¹¹⁴ The film *Miss Evers' Boys* confronts the viewer with the need for continued regulation and policing of medical and scientific research by adequate laws affecting administration by effective and vigilant independent government agencies.¹¹⁵ *Miss Evers' Boys* serves as a significant reminder of the inadequacy of benevolence as a restraint on abuse by scientists, and of the need for legal protection of human subjects in medical research.

is to be conducted; all the inconveniences and hazards reasonably to be expected; and the effects upon health or person which may possibly come from his participation in the experiment.

The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.

Id.

The Nuremberg Code was elaborated upon and adopted by the World Medical Association in the Declaration of Helsinki in 1964. *Id.* at 380. The Helsinki Declaration distinguishes between therapy, non-therapeutic research, and clinical research which combines research and therapy. *Id.* The Declaration requires informed written consent in medical and clinical research and provides for special protection of vulnerable subjects. *Id.*

¹¹²ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, TIME REPORT 248, 320 (1995).

¹¹³See NAT'L BIOETHICS ADVISORY COMM'N, RESEARCH INVOLVING PERSONS WITH MENTAL DISORDERS THAT MAY AFFECT DECISIONMAKING CAPACITY, VOL. I (1998).

¹¹⁴See Peter Gorner, *Gene Therapy Furor Ends Hemophilia Experiment*, CHI. TRIB., Feb. 8, 2000, at 1.

¹¹⁵See G. Annas, *Regs Ignored In Research*, NAT'L L. J. Nov. 15, 1999, at A20. The author reports:

The most recent study which appeared in the Oct. 11 [1999] issue of *U.S. News and World Report*, found that in 1,000 spot-checks carried out by the Food and Drug Administration, 213 researchers failed to obtain informed consent; 364 failed to follow their approved research plan; and 140 did not report adverse reactions of their test subjects.

Id.