CHAPTER 1

"A Moral Astigmatism"

IN late July of 1972, Jean Heller of the Associated Press broke the story: for forty years the United States Public Health Service (PHS) had been conducting a study of the effects of untreated syphilis on black men in Macon County, Alabama, in and around the county seat of Tuskegee. The Tuskegee Study, as the experiment had come to be called, involved a substantial number of men: 399 who had syphilis and an additional 201 who were free of the disease chosen to serve as controls. All of the syphilitic men were in the late stage of the disease when the study began.[1]

Under examination by the press the PHS was not able to locate a formal protocol for the experiment. Later it was learned that one never existed; procedures, it seemed, had simply evolved. A variety of tests and medical examinations were performed on the men during scores of visits by PHS physicians over the years, but the basic procedures called for periodic blood testing and routine autopsies to supplement the information that was obtained through clinical examinations. The fact that only men who had late, so-called tertiary, syphilis were selected for the study indicated that the investigators were eager to learn more about the serious complications that result during the final phase of the disease.

The PHS officers were not disappointed. Published reports on the experiment consistently showed higher rates of mortality and morbidity among the syphilitics than the controls. In fact, the press reported that as of 1969 at least 28 and perhaps as many as 100 men had died as a direct result of complications caused by syphilis. Others had developed serious syphilis-related heart conditions that may have contributed to their deaths.[2]

The Tuskegee Study had nothing to do with treatment. No new drugs were tested; neither was any effort made to establish the efficacy of old forms of treatment. It was a nontherapeutic experiment, aimed at compiling data on the effects of the spontaneous evolution of syphilis on black males. The magnitude of the risks taken with the lives of the subjects becomes clearer once a few basic facts about the disease are known.

Syphilis is a highly contagious disease caused by the *Treponema pallidum*, a delicate organism that is microscopic in size and resembles a corkscrew in shape. The disease may be acquired or congenital. In acquired syphilis, the spirochete (as the *Treponema pallidum* is also called) enters the body through the skin or mucous membrane, usually during sexual intercourse, though infection may also occur from other forms of bodily contact such as kissing. Congenital syphilis is transmitted to the fetus in the infected mother when the spirochete penetrates the placental barrier.

From the onset of infection syphilis is a generalized disease involving tissues throughout the entire body. Once they wiggle their way through the skin or mucous membrane, the spirochetes begin to multiply at a frightening rate. First they enter the lymph capillaries where they are hurried along to the nearest lymph gland. There they multiply and work their way into the bloodstream. Within days the spirochetes invade every part of the body.

Three stages mark the development of the disease: primary, secondary, and tertiary. The primary stage lasts from ten to sixty days starting from the time of infection. During this "first incubation period," the primary lesion of syphilis, the chancre, appears at the point of contact, usually on the genitals. The chancre, typically a slightly elevated, round ulcer, rarely causes personal discomfort and may be so small as to go unnoticed. If it does not become secondarily infected, the chancre

will heal without treatment within a month or two, leaving a scar that persists for several months.[3]

While the chancre is healing, the second stage begins. Within six weeks to six months, a rash appears signaling the development of secondary syphilis. The rash may resemble measles, chicken pox, or any number of skin eruptions, though occasionally it is so mild as to go unnoticed. Bones and joints often become painful, and circulatory disturbances such as cardiac palpitations may develop. Fever, indigestion, headaches, or other nonspecific symptoms may accompany the rash. In some cases skin lesions develop into moist ulcers teeming with spirochetes, a condition that is especially severe when the rash appears in the mouth and causes open sores that are viciously infectious. Scalp hair may drop out in patches, creating a "moth-eaten" appearance. The greatest proliferation and most widespread distribution of spirochetes throughout the body occurs in secondary syphilis.[4]

Secondary syphilis gives way in most cases, even without treatment, to a period of latency that may last from a few weeks to thirty years. As if by magic, all symptoms of the disease seem to disappear, and the syphilitic patient does not associate with the disease's earlier symptoms the occasional skin infections, periodic chest pains, eye disorders, and vague discomforts that may follow. But the spirochetes do not vanish once the disease becomes latent. They bore into the bone marrow, lymph glands, vital organs, and central nervous systems of their victims. In some cases the disease seems to follow a policy of peaceful coexistence, and its hosts are able to enjoy full and long lives. Even so, autopsies in such cases often reveal syphilitic lesions in vital organs as contributing causes of death. For many syphilitic patients, however, the disease remains latent only two or three years. Then the delusion of a truce is shattered by the appearance of signs and symptoms that denote the tertiary stage.

It is during late syphilis, as the tertiary stage is also called, that the disease inflicts the greatest damage. Gummy or rubbery tumors (so-called gummas), the characteristic lesions of late syphilis, appear, resulting from the concentration of spirochetes in the body's tissues with destruction of vital structures. These tumors often coalesce on the skin forming large ulcers covered with a crust consisting of several layers of dried ex-

uded matter. Their assaults on bone structure produce deterioration that resembles osteomyelitis or bone tuberculosis. The small tumors may be absorbed, leaving slight scarred depressions, or they may cause wholesale destruction of the bone, such as the horrible mutilation that occurs when nasal and palate bones are eaten away. The liver may also be attacked: here the result is scarring and deformity of the organ that impede circulation from the intestines.

The cardiovascular and central nervous systems are frequent and often fatal targets of late syphilis. The tumors may attack the walls of the heart or the blood vessels. When the aorta is involved, the walls become weakened, scar tissue forms over the lesion, the artery dilates, and the valves of the heart no longer open and close properly and begin to leak. The stretching of the vessel walls may produce an aneurysm, a balloonlike bulge in the aorta. If the bulge bursts, and sooner or later most do, the result is sudden death.

The results of neurosyphilis are equally devastating. Syphilis is spread to the brain through the blood vessels, and while the disease can take several forms, the best known is paresis, a general softening of the brain that produces progressive paralysis and insanity. Tabes dorsalis, another form of neurosyphilis, produces a stumbling, foot-slapping gait in its victims due to the destruction of nerve cells in the spinal cord. Syphilis can also attack the optic nerve, causing blindness, or the eighth cranial nerve, inflicting deafness. Since nerve cells lack regenerative power, all such damage is permanent.

The germ that causes syphilis, the stages of the disease's development, and the complications that can result from untreated syphilis were all known to medical science in 1932—the year the Tuskegee Study began.

Since the effects of the disease are so serious, reporters in 1972 wondered why the men agreed to cooperate. The press quickly established that the subjects were mostly poor and illiterate, and that the PHS had offered them incentives to participate. The men received free physical examinations, free rides to and from the clinics, hot meals on examination days, free treatment for minor ailments, and a guarantee that burial stipends would be paid to their survivors. Though the latter sum was very modest (fifty dollars in 1932 with periodic increases to allow for inflation), it represented the only form of burial insurance that many of the men had.

What the health officials had told the men in 1932 was far more difficult to determine. An officer of the venereal disease branch of the Center for Disease Control in Atlanta, the agency that was in charge of the Tuskegee Study in 1972, assured reporters that the participants were told at the beginning that they had syphilis and were told what the disease could do to them, and that they were given the opportunity to withdraw from the program any time and receive treatment. But a physician with firsthand knowledge of the experiment's early years directly contradicted this statement. Dr. J. W. Williams, who was serving his internship at Andrews Hospital at the Tuskegee Institute in 1932 and assisted in the experiment's clinical work, stated that neither the interns nor the subjects knew what the study involved. "The people who came in were not told what was being done," Dr. Williams said. "We told them we wanted to test them. They were not told, so far as I know, what they were being treated for or what they were not being treated for." As far as he could tell, the subjects "thought they were being treated for rheumatism or bad stomachs." He did recall administering to the men what he thought were drugs to combat syphilis, and yet as he thought back on the matter, Dr. Williams conjectured that "some may have been a placebo." He was absolutely certain of one point: "We didn't tell them we were looking for syphilis. I don't think they would have known what that was."[5]

A subject in the experiment said much the same thing. Charles Pollard recalled clearly the day in 1932 when some men came by and told him that he would receive a free physical examination if he appeared the next day at a nearby one-room school. "So I went on over and they told me I had bad blood," Pollard recalled. "And that's what they've been telling me ever since. They come around from time to time and check me over and they say, 'Charlie, you've got bad blood.'"[6]

An official of the Center for Disease Control (CDC) stated that he understood the term "bad blood" was a synonym for syphilis in the black community. Pollard replied, "That could be true. But I never heard no such thing. All I knew was that they just kept saying I had the bad blood—they never men-

tioned syphilis to me, not even once." Moreover, he thought that he had been receiving treatment for "bad blood" from the first meeting on, for Pollard added: "They been doctoring me off and on ever since then, and they gave me a blood tonic."[7]

The PHS's version of the Tuskegee Study came under attack from yet another quarter when Dr. Reginald G. James told his story to reporters. Between 1939 and 1941 he had been involved with public health work in Macon County—specifically the diagnosis and treatment of syphilis. Assigned to work with him was Eunice Rivers, a black nurse employed by the Public Health Service to keep track of the participants in the Tuskegee Study. "When we found one of the men from the Tuskegee Study," Dr. James recalled, "she would say, 'He's under study and not to be treated.'" These encounters left him, by his own description, "distraught and disturbed," but whenever he insisted on treating such a patient, the man never returned. "They were being advised they shouldn't take treatments or they would be dropped from the study," Dr. James stated. The penalty for being dropped, he explained, was the loss of the benefits that they had been promised for participating.[8]

Once her identity became known, Nurse Rivers excited considerable interest, but she steadfastly refused to talk with reporters. Details of her role in the experiment came to light when newsmen discovered an article about the Tuskegee Study that appeared in *Public Health Reports* in 1953. Involved with the study from its beginning, Nurse Rivers served as the liaison between the researchers and the subjects. She lived in Tuskegee and provided the continuity in personnel that was vital. For while the names and faces of the "government doctors" changed many times over the years, Nurse Rivers remained a constant. She served as a facilitator, bridging the many barriers that stemmed from the educational and cultural gap between the physicians and the subjects. Most important, the men trusted her.[9]

As the years passed the men came to understand that they were members of a social club and burial society called "Miss Rivers' Lodge." She kept track of them and made certain that they showed up to be examined whenever the "government doctors" came to town. She often called for them at their homes in a shiny station wagon with the government emblem on the front door and chauffeured them to and from the place

of examination. According to the *Public Health Reports* article, these rides became "a mark of distinction for many of the men who enjoyed waving to their neighbors as they drove by." There was nothing to indicate that the members of "Miss Rivers' Lodge" knew they were participating in a deadly serious experiment.[10]

Spokesmen for the Public Health Service were quick to point out that the experiment was never kept secret, as many newspapers had incorrectly reported when the story first broke. Far from being clandestine, the Tuskegee Study had been the subject of numerous reports in medical journals and had been openly discussed in conferences at professional meetings. An official told reporters that more than a dozen articles had appeared in some of the nation's best medical journals, describing the basic procedures of the study to a combined readership of well over a hundred thousand physicians. He denied that the Public Health Service had acted alone in the experiment, calling it a cooperative project that involved the Alabama State Department of Health, the Tuskegee Institute, the Tuskegee Medical Society, and the Macon County Health Department.[11]

Apologists for the Tuskegee Study contended that it was at best problematic whether the syphilitic subjects could have been helped by the treatment that was available when the study began. In the early 1930s treatment consisted of mercury and two arsenic compounds called arsphenamine and neoarsphenamine, known also by their generic name, salvarsan. The drugs were highly toxic and often produced serious and occasionally fatal reactions in patients. The treatment was painful and usually required more than a year to complete. As one CDC officer put it, the drugs offered "more potential harm for the patient than potential benefit."[12]

PHS officials argued that these facts suggested that the experiment had not been conceived in a moral vacuum. For if the state of the medical art in the early 1930s had nothing better than dangerous and less than totally effective treatment to offer, then it followed that, in the balance, little harm was done by leaving the men untreated.[13]

Discrediting the efficacy of mercury and salvarsan helped blunt the issue of withholding treatment during the early years, but public health officials had a great deal more diffi-

culty explaining why penicillin was denied in the 1940s. One PHS spokesman ventured that it probably was not "a one-man decision" and added philosophically, "These things seldom are." He called the denial of penicillin treatment in the 1940s "the most critical moral issue about this experiment" and admitted that from the present perspective "one cannot see any reason that they could not have been treated at that time." Another spokesman declared: "I don't know why the decision was made in 1946 not to stop the program."[14]

The thrust of these comments was to shift the responsibility for the Tuskegee Study to the physician who directed the experiment during the 1940s. Without naming anyone, an official told reporters: "Whoever was director of the VD section at that time, in 1946 or 1947, would be the most logical candidate if you had to pin it down." That statement pointed an accusing finger at Dr. John R. Heller, a retired PHS officer who had served as the director of the division of venereal disease between 1943 and 1948. When asked to comment, Dr. Heller declined to accept responsibility for the study and shocked reporters by declaring: "There was nothing in the experiment that was unethical or unscientific."[15]

The current local health officer of Macon County shared this view, telling reporters that he probably would not have given the men penicillin in the 1940s either. He explained this curious devotion to what nineteenth-century physicians would have called "therapeutic nihilism" by emphasizing that penicillin was a new and largely untested drug in the 1940s. Thus, in his opinion, the denial of penicillin was a defensible medical decision.[16]

A CDC spokesman said it was "very dubious" that the participants in the Tuskegee Study would have benefited from penicillin after 1955. In fact, treatment might have done more harm than good. The introduction of vigorous therapy after so many years might lead to allergic drug reactions, he warned. Without debating the ethics of the Tuskegee Study, the CDC spokesman pointed to a generation gap as a reason to refrain from criticizing it. "We are trying to apply 1972 medical treatment standards to those of 1932," cautioned one official. Another officer reminded the public that the study began when attitudes toward treatment and experimentation were much different. "At this point in time," the officer stated, "with our

current knowledge of treatment and the disease and the revolutionary change in approach to human experimentation, I don't believe the program would be undertaken."[17]

Journalists tended to accept the argument that the denial of penicillin during the 1940s was the crucial ethical issue. Most did not question the decision to withhold earlier forms of treatment because they apparently accepted the judgment that the cure was as bad as the disease. But a few journalists and editors argued that the Tuskegee Study presented a moral problem long before the men were denied treatment with penicillin. "To say, as did an official of the Center for Disease Control, that the experiment posed 'a serious moral problem' after penicillin became available is only to address part of the situation," declared the *St. Louis Post-Dispatch*. "The fact is that in an effort to determine from autopsies what effects syphilis has on the body, the government from the moment the experiment began withheld the best available treatment for a particularly cruel disease. The immorality of the experiment was inherent in its premise."[18]

Viewed in this light, it was predictable that penicillin would not be given to the men. *Time* magazine might decry the failure to administer the drug as "almost beyond belief or human compassion," but along with many other publications it failed to recognize a crucial point. Having made the decision to withhold treatment at the outset, investigators were not likely to experience a moral crisis when a new and improved form of treatment was developed. Their failure to administer penicillin resulted from the initial decision to withhold all treatment. The only valid distinction that can be made between the two acts is that the denial of penicillin held more dire consequences for the men in the study. The *Chicago Sun Times* placed these separate actions in the proper perspective: "Whoever made the decision to withhold penicillin compounded the original immorality of the project."[19]

In their public comments, the CDC spokesmen tried to present the Tuskegee Study as a medical matter involving clinical decisions that may or may not have been valid. The antiseptic quality of their statements left journalists cold, prompting an exasperated North Carolina editor to declare: "Perhaps there are responsible people with heavy consciences about their own or their organizations' roles in this study, but thus

far there is an appalling amount of 'So what?' in the comments about it." ABC's Harry Reasoner agreed. On National television, he expressed bewilderment that the PHS could be "only mildly uncomfortable" with an experiment that "used human beings as laboratory animals in a long and inefficient study of how long it takes syphilis to kill someone."[20]

The human dimension dominated the public discussions of the Tuskegee Study. The scientific merits of the experiment, real or imagined, were passed over almost without comment. Not being scientists, the journalists, public officials, and concerned citizens who protested the study did not really care how long it takes syphilis to kill people or what percentages of syphilis victims are fortunate enough to live to ripe old age with the disease. From their perspective the PHS was guilty of playing fast and loose with the lives of these men to indulge scientific curiosity.[21]

Many physicians had a different view. Their letters defending the study appeared in editorial pages across the country, but their most heated counterattacks were delivered in professional journals. The most spirited example was an editorial in the *Southern Medical Journal* by Dr. R. Kampmeier of Vanderbilt University's School of Medicine. No admirer of the press, he blasted reporters for their "complete disregard for their abysmal ignorance," and accused them of banging out "anything on their typewriters which will make headlines." As one of the few remaining physicians with experience treating syphilis in the 1930s, Dr. Kampmeier promised to "put this 'tempest in a teapot' into proper historical perspective."[22]

Dr. Kampmeier correctly pointed out that there had been only one experiment dealing with the effects of untreated syphilis prior to the Tuskegee Study. A Norwegian investigator had reviewed the medical records of nearly two thousand untreated syphilitic patients who had been examined at an Oslo clinic between 1891 and 1910. A follow-up had been published in 1929, and that was the state of published medical experimentation on the subject before the Tuskegee Study began. Dr. Kampmeier did not explain why the Oslo Study needed to be repeated.

The Vanderbilt physician repeated the argument that penicillin would not have benefited the men, but he broke new ground by asserting that the men themselves were responsible

for the illnesses and deaths they sustained from syphilis. The PHS was not to blame, Dr. Kampmeier explained, because "in our free society, antisyphilis treatment has never been forced." He further reported that many of the men in the study had received some treatment for syphilis down through the years and insisted that others could have secured treatment had they so desired. He admitted that the untreated syphilitics suffered a higher mortality rate than the controls, observing coolly; "This is not surprising. No one has ever implied that syphilis is a benign infection." His failure to discuss the social mandate of physicians to prevent harm and to heal the sick whenever possible seemed to reduce the Hippocratic oath to a solemn obligation not to deny treatment upon demand.[23]

Journalists looked at the Tuskegee Study and reached different conclusions, raising a host of ethical issues. Not since the Nuremberg trials of Nazi scientists had the American people been confronted with a medical *cause célèbre that captured so many headlines and sparked so much discussion. For many it was a shocking revelation of the potential for scientific abuse in their own country. "That it has happened in this country in our time makes the tragedy more poignant," wrote the editor of the Philadelphia Inquirer.* Others thought the experiment totally "un-American" and agreed with Senator John Sparkman of Alabama, who denounced it as "absolutely appalling" and "a disgrace to the American concept of justice and humanity." Some despaired of ever again being able to hold their heads high. A resident of the nation's capital asked: "If this is true, how in the name of God can we look others in the eye and say: 'This is a decent country.' "[24]

Perhaps self-doubts such as these would have been less intense if a federal agency had not been responsible for the experiment. No one doubted that private citizens abused one another and had to be restrained from doing so. But the revelation that the Public Health Service had conducted the study was especially distressing. The editor of the *Providence Sunday Journal* admitted that he was shocked by "the flagrant immorality of what occurred under the auspices of the United States Government." A curious reversal of roles seemed to have taken place in Alabama: Instead of protecting its citizens against such experiments, the government was conducting them.[25]

Memories of Nazi Germany haunted some people as the broader implications of the PHS's role in the experiment became apparent. A man in Tennessee reminded health officials in Atlanta that "Adolf Hitler allowed similar degradation of human dignity in inhumane medical experiments on humans living under the Third Reich," and confessed that he was "much distressed at the comparison." A New York editor had difficulty believing that "such stomach-turning callousness could happen outside the wretched quackeries spawned by Nazi Germany."[26]

The specter of Nazi Germany prompted some Americans to equate the Tuskegee Study with genocide. A civil rights leader in Atlanta, Georgia, charged that the study amounted to "nothing less than an official, premeditated policy of genocide." A student at the Tuskegee Institute agreed. To him, the experiment was "but another act of genocide by whites," an act that "again exposed the nature of whitey: a savage barbarian and a devil."[27]

Most editors stopped short of calling the Tuskegee Study genocide or charging that PHS officials were little better than Nazis. But they were certain that racism played a part in what happened in Alabama. "How condescending and void of credibility are the claims that racial considerations had nothing to do with the fact that 600 [all] of the subjects were black," declared the *Afro-American* of Baltimore, Maryland. That PHS officials had kept straight faces while denying any racial overtones to the experiment prompted the editors of this influential black paper to charge "that there are still federal officials who feel they can do anything where black people are concerned."[28]

The *Los Angeles Times* echoed this view. In deftly chosen words, the editors qualified their accusation that PHS officials had persuaded hundreds of black men to become "human guinea pigs" by adding: "Well, perhaps not quite that [human guinea pigs] because the doctors obviously did not regard their subjects as completely human." A Pennsylvania editor stated that such an experiment "could only happen to blacks." To support this view, the *New Courier* of Pittsburgh implied that American society was so racist that scientists could abuse blacks with impunity.[29]

Other observers thought that social class was the real issue, that poor people, regardless of their race, were the ones in danger. Somehow people from the lower class always seemed to supply a disproportionate share of subjects for scientific research. Their plight, in the words of a North Carolina editor, offered "a reminder that the basic rights of Americans, particularly the poor, the illiterate and the friendless, are still subject to violation in the name of scientific research." To a journalist in Colorado, the Tuskegee Study demonstrated that "the Public Health Service sees the poor, the black, the illiterate and the defenseless in American society as a vast experimental resource for the government." And the *Washington Post* made much the same point when it observed, "There is always a lofty goal in the research work of medicine but too often in the past it has been the bodies of the poor . . . on whom the unholy testing is done."[30]

The problems of poor people in the rural South during the Great Depression troubled the editor of the *Los Angeles Times*, who charged that the men had been "trapped into the program by poverty and ignorance." After all, the incentives for cooperation were meager—physical examinations, hot lunches, and burial stipends. "For such inducements to be attractive, their lives must have been savagely harsh," the editor observed, adding: "This in itself, aside from the experiment, is an affront to decency." Thus, quite apart from the questions it raised about human experimentation, the Tuskegee Study served as a poignant reminder of the plight of the poor.[31]

Yet poverty alone could not explain why the men would cooperate with a study that gave them so little in return for the frightening risks to which it exposed them. A more complete explanation was that the men did not understand what the experiment was about or the dangers to which it exposed them. Many Americans probably agreed with the *Washington Post's* argument that experiments "on human beings are ethically sound if the guinea pigs are fully informed of the facts and danger." But despite the assurances of PHS spokesmen that informed consent had been obtained, the Tuskegee Study precipitated accusations that somehow the men had either been tricked into cooperating or were incapable of giving informed consent.[32]

An Alabama newspaper, the *Birmingham News*, was not impressed by the claim that the participants were all volunteers, stating that "the majority of them were no better than semi-

literate and probably didn't know what was really going on." The real reason they had been chosen, a Colorado journalist argued, was that they were "poor, illiterate, and completely at the mercy of the 'benevolent' Public Health Service." And a North Carolina editor denounced "the practice of coercing or tricking human beings into taking part in such experiments."[33]

The ultimate lesson that many Americans saw in the Tuskegee Study was the need to protect society from scientific pursuits that ignored human values. The most eloquent expression of this view appeared in the *Atlanta Constitution*. "Sometimes, with the best of intentions, scientists and public officials and others involved in working for the benefit of us all, forget that people are people," began the editor. "They concentrate so totally on plans and programs, experiments, statistics—on abstractions—that people become objects, symbols on paper, figures in a mathematical formula, or impersonal 'subjects' in a scientific study." This was the scientific blindspot to ethical issues that was responsible for the Tuskegee Study—what the *Constitution* called "a moral astigmatism that saw these black sufferers simply as 'subjects' in a study, not as human beings." Scientific investigators had to learn that "moral judgment should always be a part of any human endeavor," including "the dispassionate scientific search for knowledge."[34]

Many editors attributed the moral insensitivity of PHS officers to the fact that they were bureaucrats, as well as scientists. Distrust of the federal government led a Connecticut editor to charge that the experiment stemmed from "a moral breakdown brought about by a mindless bureaucracy going through repeated motions without ever stopping to examine the reason, cause and effects." To a North Carolina editor, the experiment had simply "rolled along of its own inhuman momentum with no one bothering to say, 'Stop, in the name of human decency.'" In a sense, then, the government's scientific community itself became a casualty of the Tuskegee Study. The public's respect and trust were being eroded by doubts and suspicions of the kind expressed by an editor in Utah who wondered "if similar or worse experiments could be occurring somewhere in the bureaucratic mess."[35]

Medical and public discussions of the Tuskegee Study fell off sharply within a few weeks, leaving many important questions unanswered. Why was the Public Health Service interested in studying syphilis in blacks, or were they using blacks to study syphilis? Was the experiment good science? Did the PHS doctors who began the study withhold therapy in the 1930s because they thought that treatment with salvarsan was more harmful than the disease? Would penicillin have benefited the men when it became available in the 1940s? Or, for that matter, was treatment for the men ever discussed in the 1930s or the 1940s? Why was the experiment conducted in Macon County? What health care was available to blacks there? Why did the subjects cooperate with the study? Do inducements and ignorance tell the whole story? How did the participating doctors see themselves? Why did the Tuskegee Institute and the Veterans Hospital in Tuskegee, both all-black facilities in 1932, cooperate with the study? How could the experiment last for forty years? Was there any opposition to the experiment before the story broke?

In order to answer these questions, it is necessary to place the Tuskegee Study within its historical and institutional context, explaining how the experiment fits into the development of the public health movement in the United States. The aura of the kindly and priestly healer that surrounds physicians has tended to blind the public to the fact that physicians are people. As people, they reflect the values and attitudes of their society. In Macon County, Alabama, the syphilitic men studied were black; the Public Health Service directors and most of the doctors who studied them were white. Hence, an overview of the evolution of racial attitudes in American medicine is crucial to an understanding of the Tuskegee Study. The discussion must begin in the nineteenth century, when the interaction between white physicians and black patients produced what might be called "racial medicine."

CHAPTER 14

"AIDS: Is It Genocide?"

No scientific experiment inflicted more damage on the collective psyche of black Americans than the Tuskegee Study. After Jean Heller broke the story in 1972, news of the tragedy spread in the black community. In addition to what they read in newspapers and magazines or heard on the radio and television, many blacks learned about the study by word-of-mouth, replete with the embellishments and distortions that usually attend oral traditions. Many blacks (and whites) were told that the government deliberately inoculated black sharecroppers with syphilis, while others were given to understand that the experiment was conducted on black prisoners.

Despite such errors, most black Americans got the gist of the story right: For forty years their government had withheld treatment from men with syphilis so science could learn more about the disease. Many of the men had died from syphilis, while others had gone blind or insane. Confronted with the experiment's moral bankruptcy, many blacks lost faith in the government and no longer believed health officials who spoke on matters of public concern. Consequently, when a terrifying new plague swept the land in the 1980s and 1990s, the Tuskegee Study predisposed many blacks to distrust

health authorities, a fact many whites had difficulty understanding.

"Bizarre as it may seem to most people," declared the lead editorial in the *New York Times* on May 6, 1992, "many black Americans believe that AIDS [Acquired Immune Deficiency Syndrome] and the health measures used against it are part of a conspiracy to wipe out the black race." To support their assertion, the editors cited a survey of black church members in 1990 that revealed "an astonishing 35 percent believed AIDS was a form of genocide." Moreover, a *New York Times*/WCBS TV News Poll conducted the same year found that 10 percent of all black Americans thought the AIDS virus was "deliberately created in a laboratory in order to infect black people" and 20 percent believed it could be true.[1]

Nor were such beliefs limited to the lay public. Many black health workers, the *Times* continued, refused to dismiss these fears out of hand. One individual, testifying before the National Commission on AIDS, declared that she considered AIDS a man-made disease "until proven otherwise." Similar suspicions cast a shadow over efforts to control the epidemic. "Some blacks believe that AZT, the harsh drug used to combat the disease, is a plot to poison them," the editors declared, ". . . 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 druge abuse." The consequences of mistrust were nothing short of tragic. As the *Times* explained, "At its most destructive, the paranoia causes many blacks to avoid medical treatment." Unless black leaders moved to counter "the fears and mistrust," health officials would find it "ever harder to slow the epidemic."[2]

For all its effort to exude reason and good will, the *Times* showed a singular lack of sensitivity in its use of words like "bizarre," "astonishing," and "paranoia" to describe how many blacks reacted to AIDS. By calling others paranoid, the editors used a medical metaphor to underscore their strong disagreement with those who believed in conspiracy theories, contrasting their own rationality and appreciation for the complexity of historical events with the simplistic views of misguided souls who embraced irrational answers to historical phenomena.

Still, telling people they are paranoid is not the same as disproving their beliefs. Nor do blanket dismissals manifest much sympathy for those who embrace such beliefs, and they show even less understanding for why people might come to hold them. A more thoughtful response would be to ponder why many black Americans were prepared to believe conspiracy theories about AIDS.

The attitudes black Americans brought to AIDS were historically constructed. Scientific and medical theories were not the only elements that shaped how blacks viewed this terrifying disease: Social, political, religious, and moral conceptions influenced their perceptions and understandings as well. Above all, may black Americans saw AIDS through the prism of race, which brought more than three and a half centuries of white–black relations into focus. Slavery, sharecropping, peonage, lynchings, Jim Crow laws, disfranchisement, residential segregation, and job discrimination formed the substance to which many Afro-Americans reduced all American history, forming a saga of hatred, exploitation, and abuse.

Two readers who found the editors of the *New York Times* strangely ahistorical drove home this point. M. William Howard, the president of the New York Theological Seminary, was mystified how anyone could think it "astonishing" that many blacks believed AIDS was a form of genocide. To him, such views were "the inevitable result of black people's living in a society in which we are so alienated from the mainstream that many of us believe America will stop at nothing to eliminate us." Another reader thought that the use of words like "bizarre" to describe black peoples' fears "in and of itself reeks of an insensitivity to the history of blacks in this country and why they would have good reasons to feel conspired against." As proof, the man cited "the Tuskegee experiment of the 1930's."[3]

From the moment information about the Tuskegee Study became public, people called it genocide. Upon learning of the experiment in 1972, Dr. Donald Printz, an official in the Venereal Disease Branch at the Centers for Disease Control (CDC), said it was "almost like genocide," while attorney Fred Gray went further, branding the Tuskegee Study "a program of controlled genocide."[4] Over time Gray's assessment gained currency in the black community. For many blacks, the Tuskegee Study became a symbol of their mistreatment by the medical

establishment, a metaphor for deceit, conspiracy, malpractice, and neglect, if not outright racial genocide.

Memories of the experiment refused to die. The anger and fears evoked by the Tuskegee Study's disclosure in 1972 reappeared a decade later when *Bad Blood* was published, setting off another round of discussions as a new generation learned about the experiment. Thus, by the time the AIDS epidemic struck America, the Tuskegee Study had left many black Americans suspicious of health authorities. Mistrust in the black community deepened as many white Americans expressed attitudes about AIDS victims that were remarkably similar to the beliefs most white Americans shared about syphilitic blacks earlier in the century. During the early years of the AIDS epidemic, however, blacks did not bear the brunt of these attacks, as gays became the first targets of middle-class morality.

Much as venereal infections produced a general hysteria in the United States during the Progressive era, AIDS precipitated widespread fear among Americans as the twentieth century drew to a close. In 1981, physicians in Los Angeles, San Francisco, and new York encountered a strange and puzzling disease that appeared to be limited to a particular group of patients. Young and previously healthy homosexual men began dying of overwhelming infections. Many presented distinctive, purple-red skin blotches on their faces and bodies, the classic stigmata of skin tumors associated with Kaposi's sarcoma, a rare cancer of the blood vessels linked to damage to the immune system. Others suffered from a variety of "opportunistic infections" caused by viruses, bacteria, fungi, yeasts, and parasites. The white blood cells that enable the body to fight infections had obviously been impaired or destroyed in these patients, but the exact nature of their illness remained a mystery.

At first physicians had a hard time deciding what to call this strange new illness. Struck by the disease's affinity for homosexual men, physicians named it Gay Related Immune Disease, or GRID. Owing to the patently stigmatizing tone of this label, however, physicians quickly switched the name to Acquired Immunodeficiency Syndrome, or AIDS. The new acronym had the double advantage of being not only morally neutral but far more accurate. Within months of the first medical notices involving gay men, physicians had diagnosed AIDS in intravenous drug users and in Haitians, and by 1982 there

were confirmed cases in heterosexual women, young children, hemophiliacs, and other recipients of blood transfusions.

Public concern grew in direct proportion to the expanding case load. At the end of 1981, physicians had diagnosed 225 cases; by the spring of 1983 the number had risen to 1,400; by the summer of 1985 it had climbed to 15,000; and two years later it had soared to 40,000. Many Americans seemed dazed by these numbers, largely, one suspects, because they had all but forgotten how to cope with health crises. The victories over infectious diseases made possible by the rise of antibiotics and other "wonder drugs" during World War II had shifted the public's attention to chronic, systemic diseases, nurturing the illusion that infectious, epidemic diseases had been banished from the land. True, recent illnesses, such as Legionnaire's Disease and Toxic Shock Syndrome, had sent ripples of fear through the public, but the reaction to AIDS was infinitely more serious, because the diseases were so different with regard to both numbers and consequences. Legionnaire's Disease and Toxic Shock Syndrome involved small numbers of patients, most of whom recovered. AIDS struck tens of thousands, all of whom died.

Confronted with a growing epidemic, many Americans recoiled in terror. The media increased the public's apprehension by spreading rumors that AIDS was a highly contagious disease. Echoing the fears of their Victorian ancestors, who believed syphilis could be contracted by casual contacts, many Americans shared the same misapprehension about AIDS. According to a *New York Times/CBS* poll conducted in 1985, 47 percent of Americans believed AIDS could be caught by sharing a drinking glass, and 28 percent thought it could be acquired from toilet seats. Another survey disclosed that 34 percent of those polled thought it was dangerous to "associate" with anyone with AIDS, even though no physical contact took place.[5]

Much of the concern over contagion centered on the wives and children of infected men, triggering renewed alarm over "innocent infections" analogous to the cries of "syphilis of the innocent" that swept the country at the turn of the century. The press carried stories of wives who had been infected by their husbands, and children who had been infected by their parents. Alarmed by these reports, health care personnel in some communities refused to treat AIDS patients; firefighters

refused to resuscitate men suspected of being homosexuals; undertakers refused to embalm AIDS victims; and police officers insisted on wearing gloves when arresting suspects apprehended in certain sections of the city. The California Association of Realtors ordered its members to inform clients whether or not homes on the market had been owned by AIDS victims. Given the growing hysteria, it was hardly surprising that many communities reported an increase in unprovoked attacks on homosexuals.[6]

Many Americans who would not dream of "gay bashing" thought homosexuals should be quarantined. In Texas a psychologist advised the legislature to incarcerate homosexuals "until and unless they can be cleansed of their medical problems."[7] Appalled by the specter of gay concentration camps, civil libertarians denounced forced quarantine on moral grounds, while others raised practical objections to the idea. Where were tens of thousands of AIDS sufferers to be kept? Who would pay for their care during their forced isolation? While these arguments prevented any widespread quarantine movement from developing, the public remained edgy. Some parents withdrew their children from schools where AIDS patients attended classes, and adult AIDS sufferers encountered similar fears in the workplace, where many of their co-workers demanded their removal.

In their eagerness to assign blame, members of the "Moral Majority" and the "New Right" used the public's fear of AIDS as an opportunity to attack homosexuality. Conflating attitudes toward disease with social values and confusing the means of transmittal with the root cause, they saw AIDS as a moral problem produced by homosexuality, not a disease caused by a virus. Gay promiscuity, hedonism, life in the fast lane, and flagrant disregard for individual responsibility and personal restraint were all cited as underlying causes of the epidemic. Indeed, the attacks on homosexuals would have sounded familiar to anyone who knew the history of white responses to sexually transmitted diseases in the black community during the Progressive era. As one astute scholar has noted, "Attitudes once expressed toward the black population as sexually promiscuous, sexually threatening, and a reservoir of disease have now been, in revived form, turned against the gay male population."[8]

With a self-righteousness reminiscent of earlier descriptions of blacks as "a notoriously syphilis soaked race," spokesmen for the New Right branded AIDS "The Gay Plague." Framing the epidemic in moral terms, they saw AIDS as the punishment meted out against those who violated the moral order. The evangelist Jerry Falwell piously proclaimed that "a man reaps what he sows. If he sows seed in the field of his lower nature, he will reap from it a harvest of corruption." Echoing the views of Victorians who branded homosexuality "a crime against nature," Patrick Buchanan, Director of Communications in President Ronald Reagan's White House, announced that homosexuals had "declared war on nature, and now nature is extracting an awful retribution."[9]

Pointing to AIDS as their proof, critics denounced homosexuals as deviants who threatened the survival of the heterosexual community. One mainline journalist reported, "Suddenly a lot of people fear that they and their families might suddenly catch some mysterious, fatal illness which until now has been confined to society's social outcasts." A cover of *Life* made the same point more succinctly, proclaiming in bold red letters, "NO ONE IS SAFE FROM AIDS."[10]

Despite the public's growing alarm over AIDS, the federal government moved cautiously. After the CDC identified AIDS in 1981, two years passed before the National Institutes of Health (NIH) started research in earnest. While bureaucratic inertia was implicated in the delay, money was also a problem. The Reagan administration did not request any funds for AIDS research in 1982 and 1983, and over the next several years the White House consistently asked for less money than Congress appropriated (in 1984, for example, the administration requested $39 million, far less than the $61 million appropriated by Congress; while in 1986 Congress appropriated $234 million, which the White House recommending reducing to $213.2 million).[11]

How are we to explain this tepid response to an epidemic whose case load was doubling every year? First and foremost, AIDS research was controversial. Because AIDS was widely regarded as a "gay" disease and because homosexuals were a favorite target of the "Moral Majority" and the "New Right," whose political clout had helped put Ronald Reagan in the White House, federal authorities were reluctant to use public

funds to combat the disease, lest their action somehow be con
strued as approval for homosexuality. Voicing his opposition
to federally supported research, the editor Norman Podhoret
asked, "Are they aware that in the name of compassion they
are giving social sanction to what can only be described a
brutish degradation?" Fiscal policy also shaped the govern
ment's response during the early years of the epidemic. In keep
ing with the pattern of Reaganomics, AIDS research becam
another casualty of the sharp reduction of federal funds to so
cial services.[12]

Despite the government's haphazard and poorly orches
trated response to AIDS, researchers made important discov
eries about the disease. In 1984 Robert Gallo, an NIH scientist
discovered the virus that causes AIDS, which he named HTLV
III, or human T-cell leukemia virus, type III. At nearly th
identical moment, Luc Montagnier, who headed a team of re
searchers at the famed Pasteur Institute in Paris, announce
he had discovered the virus that produces AIDS, which h
named LAV, short for lymphadenopathy-associated virus. I
truth, both researchers had isolated the same human retroviru
that causes AIDS. In 1985 a committee of viral taxonomist
met to decide which family of viruses AIDS truly belonged to
and after a year of debate the committee decided to give th
virus a new name: Henceforth, it would be known as "th
human immunodeficiency virus," or "HIV."

Gallo scored a second triumph when his laboratory devel
oped a test for AIDS called ELISA, for Enzyme Linked Im
munosorbent Assay, but a bitter legal controversy ensued whe
the French contested the U.S. government's patent for th
ELISA test. However regrettable the legal controversy tha
greeted its discovery, ELISA offered a reliable tool for diag
nosing AIDS and enabled health authorities to pursue the ar
duous task of constructing an epidemiological profile of th
disease. By 1986 researchers had discovered that nearly 75 per
cent of all cases in the United States were found in gay men
while intravenous drug users who shared needles accounte
for 20 percent of the cases. The remaining victims include
patients who had received infected blood transfusions or bloo
products, and children who had contracted the virus in uter
from their infected mothers.[13]

Despite advances in understanding the disease's etiolog

and epidemiological pattern, the origin of AIDS remained a mystery. How did HIV come into existence? Was it a totally new virus or an existing one that had suddenly mutated and become more virulent? As researchers labored to learn where, when, and how HIV first developed, their inability to answer those questions created a vacuum of public understanding, allowing interested parties, many of whom had no background in science, to advance their own explanations.

Members of the "New Right" and the "Moral Majority" ventured their own theory on the origin of AIDS, one that rested upon teleological reasoning. Seeing a purpose and design for everything that happens in nature, they thought AIDS was a plague sent by God to punish gays for their wicked behavior. Given mankind's long history of viewing disease as evidence of divine displeasure, such pronouncements are as inevitable as they are ignorant and intolerant.

Another theory, endorsed by most experts during the early years of the epidemic, blamed AIDS on the African green monkey. While no one claimed to know precisely how it happened, the monkey virus somehow "jumped species" and infected the human population of Central Africa, who in turn transmitted the disease to others, launching the worldwide epidemic.

Opponents of the "biologic accident" theory insisted that AIDS was a man-made disease, whether by accident or by design. In 1992 Walter S. Kyle, an attorney with broad experience dealing with scientific research, hypothesized "a link between HIV-related retroviruses from the African green monkey in poliovaccine lots, the use of this vaccine by homosexuals in a manner unanticipated when the vaccine was licensed, and the onset of the AIDS epidemic in the United States." Briefly, Kyle reported that as early as 1976–77 scientists, government officials, and drug manufacturers had discovered that the simian immunodeficiency virus (SIV), found in 30 to 70 of African green monkeys (the species used by most American manufacturers to produce poliovaccine), was present in some monopools of live poliovaccine, including lot 3-444, manufactured by Lederle. Despite its knowledge that this test lot of poliovaccine contained SIV, however, the government agreed to allow production, provided the final vaccine did not contain more than "100 organisms"/ml. Children who received the vaccine containing SIV, explained Kyle, were not thought to be in

any danger "because there would be no transfer from the dige
tive tract to the lymph and blood systems and because the
was no reason to suspect inter-species transfer." He theoriz
that SIV was spread to human beings when doctors in sever
urban centers in the United States used poliovaccine to tre
herpetic lesions in homosexual men, administering multip
doses monthly directly on the lesions, a regimen that vast
exceeded the "100 particle per dose" set by the governmer
Kyle challenged the U.S. government to test his hypothesis
analyzing stored samples of the incriminated lots of poli
vaccine.[14]

While Kyle's theory did not posit any malice, other pr
ponents of the "man-made" school were strongly attracted
conspiracy theories, several involving military designs of o
kind or another. One theory suggested that AIDS was develop
by the U.S. Army at its biological research center in Fort D
trick, Maryland; another that AIDS was somehow related
Agent Orange; and still another that AIDS was created by t
Russians. Not to be outdone, the Soviets declared in a rac
broadcast from Moscow that "the AIDS epidemic has be
caused by experiments carried out in the U.S.A. as part of t
development of new biological weapons," a charge officials
Washington strenously denied, insisting that the Soviets we
waging a disinformation campaign.[15]

One of the leading advocates of the "man-made" theory w
Dr. Robert Strecker, M.D., Ph.D., a pharmacologist and g
troenterologist who practices in Los Angeles. Beginning abo
1972, he argued, scientists infected cows with the bovine vis
virus, which he dubs the "mother and father of AIDS." Vi
lesions of the infected cows, he continued, were used to produ
smallpox vaccine, which was administered to humans in Afri
Injected into humans, the new recombined virus produc
AIDS. According to Dr. Strecker, the disease was created a
weapon for biological warfare, with (he implies) governm
approval. "AIDS," he bluntly asserted, "was a disease that w
requested, manufactured and deployed and does exactly wh
it was intended to do." Demanding a congressional investi
tion into the disease's origins, he declared, "It's not a probl
seeing where the virus came from. It's a question of whetl
we're going to do anything about it."[16]

Dr. Alan Cantwell, an M.D. who practices dermatology

Los Angeles, believes that AIDS was introduced into the United States in 1978 by a program to test the hepatitis B vaccine. Influenced greatly by Dr. Strecker, he wrote a book entitled *AIDS and the Doctors of Death*, in which he theorized that the test group, which consisted of more than a thousand gay males living in Manhattan, received vaccine that had been deliberately contaminated with the HIV virus. While Dr. Cantwell did not say who was responsible, he strongly suggested that the HIV virus was developed as a tool of biological warfare and was tested on gays because of the rampant homophobia in American society.

Drs. Strecker and Cantwell articulated the fears of many homosexuals who honestly believed that AIDS was a man-made plague aimed squarely at gays. As an anguished friend told Dr. Cantwell, "This whole AIDS thing is genocide. You must know they are trying to kill us all. They don't care how many of us die. Just look around. There are plenty of people who want to put us away in camps to die."[17]

The gay press echoed the same charge. Charles Ortleb, the publisher of the *New York Native*, insisted that AIDS was a conspiracy to exterminate gays, and he did not hesitate to say who was behind the conspiracy. "We are in a holocaust," declared Ortleb. "I believe that the government has orchestrated AIDS to achieve its religious and social goals. To my mind, people who think AIDS is an accident of nature are naïve. They also consider me paranoid. I consider them to be fools of the same variety that pulled the wooden horse into the city of Troy."[18]

Yet Ortleb had not always viewed AIDS as a government plot to exterminate gays. At first he trusted the government. Working under the assumption that the federal officials assigned to conquer AIDS were honest and well-intentioned people, he cooperated fully. During the early years of the epidemic, government researchers issued reports, and the *Native* dutifully relayed the information to its readers. After a few years, however, Ortleb began to doubt the government's truthfulness regarding the epidemic, and he began to question both the science and the motives of AIDS researchers.

In a sense, this shift was to be expected. Disillusioned by the kinds of human folly uncovered during the Vietnam War and the Watergate scandal, he experienced the same loss of

faith in government that haunted large segments of the American public after the 1960s. Yet this was only part of the story for the public's faith in science had also been shaken in recent years. The skepticism and doubt that began to infect the gay community must be seen against a broader social development the pervasive and marked decline in the cultural authority of scientific experts. Thalidomide, Three Mile Island, Love Canal the space shuttle *Challenger*, and Chernobyl (to mention only a few of the grosser blunders) all contributed to the public's growing mistrust of science.

The Tuskegee Study heightened the gay community's mistrust of government and science. In 1983, two years after the first reports on AIDS appeared in its pages, the *Native* published a long feature article by Martin P. Levine entitled "BAD BLOOD: The Health Commissioner, the Tuskegee Experiment and AIDS Policy." Most of the article was a straightforward summary of this book, which Levine recommended as "must reading for all who are concerned about AIDS," but Levine showed how easily the Tuskegee Study could sharpen the fears of a group that felt marginalized and victimized by the dominant society.[19]

Levine saw striking similarities between the Tuskegee Study and the current AIDS epidemic. "They say we have bad blood," he began. "Nearly forty [i.e., fifty] years ago, they told some black men they had bad blood." He then proceeded to identify the government agencies responsible for the Tuskegee Study, stressing that the same organizations were spearheading the government's research efforts on AIDS. "Bad blood AIDS, syphilis, gays, blacks, the Division of Venereal Disease Control, the Centers for Disease Control. A remarkably similar cast of characters," he declared.[20]

Levine felt even more troubled by "the social positions of the two sets of players." Tuskegee placed black patients under the control of white doctors; AIDS put "gay" patients at the mercy of "straight" doctors. In both cases, this meant that "the socially franchised studied the socially disenfranchised." Levine worried that "gays" would become the victims of homophobic attitudes, much as blacks had been harmed by racial prejudices. "Racist science prompted the Tuskegee experiment," he declared. "It was thought that the innate characteristics of blacks made them more sexually promiscuous, thus

more prone to syphilis." AIDS exposed "gays" to similar thinking, "the myth that all gay men are highly promiscuous." From the outset researchers at the CDC believed AIDS targeted gay men because they were promiscuous, and this thinking formed the foundation for all their research programs. For Levine, then, the message was clear: "What happened in Macon County means we cannot blindly trust the Centers for Disease Control. . . . Be wary, be critical."[21]

Ortleb could not have agreed more. Under his leadership, the *Native* became the official organ for dissidents who rejected conventional thinking on AIDS. Indeed, Ortleb published authors who insisted, among other things, that AIDS is part of an infinitely larger epidemic called Chronic Immune Dysfunction Syndrome (which in the heterosexual population is known as "Yuppie Flu" or "Chronic Fatigue Syndrome"); that HIV is not the cause of AIDS; that the most likely cause of AIDS is a virus called Human Herpes Virus-6; that Human Herpes Virus-6 is the most likely cause of Chronic Fatigue Syndrome; that Human Herpes Virus-6 is not what scientists have described but African Swine Fever Virus, which produces an AIDS-like disease in pigs; and that AZT, the treatment of choice for AIDS, was too toxic and too ineffective to warrant further use in therapy.

Whatever the scientific merit of these claims, those who advanced them had much in common: They did not believe official explanations about what causes AIDS, and they objected sharply to current scientific and social priorities regarding the disease. Suspicious and mistrustful of the government's reports on AIDS, they felt deeply alienated from the experts who purported to have their best interests at heart. And while others (including many gays who disagreed with AIDS dissidents) dismissed these dissenters as at best irresponsible and at worst paranoid, the truth remained that many gay men believed that the government's efforts to understand, prevent, and treat HIV were misguided.

No less than for gays, the AIDS epidemic for blacks was an unmitigated tragedy, all the more so because blacks already suffered markedly higher death and sickness rates than whites when the disease struck. In 1990 black babies in the United States died at roughly twice the rate of white babies, and the racial gap in mortality extended into adulthood, condemning

blacks in every age group up to sixty-five to substantially higher death rates than whites. The average life expectancy for all Americans in 1990 stood at 75.2 years, but blacks lived only 69.2 years, a full six years below the national average. Blacks also suffered disproportionately high infection rates caused by contagious diseases, such as measles, diphtheria, and tuberculosis, as well as certain chronic diseases, such as hypertension, cancer, and diabetes. Many black Americans (perhaps as high as 40 percent) had no health insurance and no family doctor, and had to use the hospital emergency room as their first line of defense against illness as well as injury. In short, when the second wave of AIDS hit the residents of America's inner cities, it struck a population already ravaged by disease and unable to afford adequate health care.

As had so many diseases before it, AIDS took an awful toll in the black community. By 1987 blacks, who composed 12 percent of the population, accounted for 24 percent of the AIDS cases in the United States. Among women stricken with AIDS, blacks accounted for 52 percent of the cases, and blacks compose 54 percent of the cases in children under thirteen. By 1992 blacks accounted for 28.8 percent of the AIDS cases in the United States, 52 percent of the cases in women, and 53 percent of all pediatric cases. Health experts agreed that AIDS was spreading more rapidly among blacks than other groups. In fact, the public had barely grown accustomed to thinking of AIDS as a "gay disease" when health workers discovered that black Americans were suffering a disproportionate burden of infections.[22]

As studies went forward, health officials learned that the vast majority of blacks infected with AIDS lived in inner cities. While some inner-city blacks acquired the virus through homosexual contacts, the vast majority contracted AIDS from contaminated needles passed back and forth among intravenous (IV) drug users. Infected men spread the disease to female sexual partners, who in turn gave birth to HIV-infected babies. As one health official remarked, "In cities like Newark, AIDS has become a disease of the family. We're talking about women, children, men. It's not skipping over anyone."[23]

The spread of AIDS into the inner cities had a profound influence on the responses of many middle-class white Americans toward those who contracted the disease. In 1988 Charles

Murry, a political commentator, predicted that as AIDS came to be identified with IV drug users and inner-city crime, "Understanding and patience are going to dwindle across the political spectrum, to be replaced by animosity and/or indifference." Harsh though it was, his prediction came true. Applying the doctrine of individual responsibility, many Americans believed that IV drug users who contracted AIDS got what they deserved, and the same judgmental attitude extended to women who remained with these men and chose to bear their children. In sharp contrast to their late Victorian ancestors, who had pitied the so-called innocent victims of syphilis, many modern-day Americans blamed women who gave birth to AIDS-infected infants. "What kind of moral universe do these women live in, anyway?" asked an ethicist at a scholarly meeting. The identical question haunted many health officials, policymakers, and members of the lay public, who, according to one recent study, regarded the birth of HIV-infected babies as, "inexplicable, unjustifiable, and immoral."[24]

Like their ancestors who studied syphilitic blacks during the Progressive era, researchers who tracked AIDS in the black community consistently reported that blacks had different perceptions and understandings of AIDS than whites. Surveys and national opinion polls showed that blacks (and Hispanics) were far more likely than whites to have misconceptions about how AIDS was spread. For example, a poll conducted by the Gallup Organization in New York City disclosed that 54 percent of blacks, compared to 28 percent of whites, thought a person could contract AIDS by donating blood. Given their wide acceptance of such misconceptions, blacks were far more likely than whites to feel, as one researcher put it, "personally vulnerable, fearful, and concerned about AIDS." A nationwide poll conducted by the *Los Angeles Times* found that blacks felt far more anxiety than whites about AIDS. At least part of their anxiety centered on government. One health official thought he detected in blacks "a heightened suspicion of 'government' and its representatives, as well as fear of anything that may provide another excuse for discrimination."[25]

Against this background of suspicion, blacks voiced their own conspiracy theories about AIDS. Early in the epidemic, the Nation of Islam distributed literature insisting that AIDS was a weapon used by whites to exterminate blacks. Soon

mainstream black media were sounding the same alarm. *Tony Brown's Journal*, a popular television show on the Public Broadcasting System, aired a series of programs that debated whether or not AIDS was a form of genocide. In 1989 the *Los Angeles Sentinel*, the largest black newspaper on the West Coast, devoted a series of articles to the same issue. *Essence*, a leading black magazine, followed suit in 1990 with a feature article that asked the question: "AIDS: Is It Genocide?"[26]

In *Essence*, Dr. Barbara J. Justice, a New York physician and AIDS researcher, refused to dismiss the notion that AIDS was a white plot to exterminate blacks. "There is a possibility that the virus was produced to limit the number of African people and people of color in the world who are no longer needed," she declared. Dr. Justice also theorized that the melanin in blacks' skin made them more vulnerable to AIDS. "All of a sudden here comes this raging virus that seems to have a propensity for Black people. If you stand back and look at it and you also look at the history of this country," she opined, "at the very least you have to be suspicious."[27]

"Losing Ground," a hard-hitting article published in April 1992 *Newsweek*, surveyed the fears and suspicions that stalked the inner city as the outlook for many blacks grew bleaker. Dr. Alvin Poussaint, an associate professor of psychiatry at Harvard Medical School and himself a black man, drew attention to the "free floating rage" of young people trapped in the inner city and the widespread fear that whites "want to see us dead." *Newsweek* also interviewed Kenneth Goings, a historian at Florida Atlantic University, who said that many of his students attribute the crime and social problems of inner cities to racist conspiracies designed to exterminate all African-Americans. Pointing to crack cocaine, the ubiquitous availability of deadly weapons, and the sudden appearance of AIDS among inner-city blacks, the Reverend Cecil Williams of San Francisco's Glide United Methodist Church declared: "We can't put our finger on any one person or group, but many of us are convinced . . . there is a conspiracy to anesthetize and ultimately do away with . . . as many blacks in American society as possible."[28]

As blacks surveyed their history, the Tuskegee Study provided substance for their fears and evidence for their accusations. James Small, a Black Studies instructor at City College

of New York, cited the Tuskegee Study as an example of white oppression. "Our whole relationship to [whites involves their] practicing genocidal conspiratorial behavior on us," Small declared, "from the whole slave encounter right up to the Tuskegee study." To him, the Tuskegee Study provided the proof to which there could be no reply, as it showed how effectively the government could use science to exterminate blacks. "People make it sound nice, by saying the Tuskegee study," he remarked, "but do you know how many thousands and thousands of our people died of syphilis because of that?"[29]

Health officials who worked in black communities reported that the Tuskegee Study had spawned a legacy of suspicion and distrust toward public health authorities. Testifying before the National Commission on AIDS in December 1990, Dr. Mark Smith, a physician from the School of Medicine at Johns Hopkins University in Baltimore, declared that many Afro-Americans felt "alienated from the health care system and the government and . . . somewhat cynical about the motives of those who arrive in their communities to help them." The Tuskegee Study, he asserted, "provides validation for common suspicions about the ethical even-handedness in the medical research establishment and in the federal government, in particular, when it comes to Black people."[30]

Alpha Thomas, a health educator with the Urban League in Dallas, Texas, made the identical point in her testimony before the same commission. Whenever health officials attempted to conduct HIV education in black communities, the Tuskegee Study, like a psychic wound that would not heal, impeded their efforts. "So many African American people that I work with do not trust hospitals or any of the other community health care service providers because of that Tuskegee Experiment," she declared. "it is like . . . if they did it then they will do it again."[31]

Not surprisingly, then, many health officials encountered difficulties when they tried to study AIDS in black communities. In 1988 federal health authorities had to abandon a planned study of AIDS infections in the District of Columbia. As designed, the scrapped project proposed to ask the residents of a black neighborhood to submit to household blood tests and complete a questionnaire to determine the feasibility of a national survey to gather data on the incidence of AIDS. Accord-

ing to the *New York Times*, city officials "expressed concern that Washington's black community was being used as a 'guinea pig' in a project that would stigmatize the city and its minority communities."[32]

Despite clear and mounting evidence that the Tuskegee Study's legacy of suspicion and distrust was hampering efforts to control AIDS in the black community, public health officials were remarkably slow to admit a problem existed. For example in an article invited by the editor and published in the *American Journal of Public Health* in 1988, Dr. John C. Cutler and Dr. R C. Arnold reviewed the history of venereal disease control by health departments, searching for lessons that might prove useful in the current struggle against AIDS. Wide-ranging in scope and lavish in its praise for the leadership of the Public Health Service, the article opened with the venereal disease campaigns of World War I and closed with the budget cuts made in the Public Health Service's venereal disease control programs by Congress in the late 1950s following the development of penicillin. Along the way Drs. Cutler and Arnold called attention to the support the Rosenwald Fund and the Milbank Memorial Fund (and other voluntary agencies) had provided for clinical research on syphilis and gonorrhea, and the authors praised the pioneering work of Dr. Thomas Parran as Surgeon General of the USPHS. In addition, they quoted at length and with obvious approval from articles written by Dr. Raymond Vonderlehr and Dr. John R. Heller.[33] In fact, to anyone who knew the players, the Cutler/Arnold article read like a Tuskegee Study reunion, celebrating, as it did, the agencies, foundations, and officials that had played such important roles in the experiment's history.

At least one man who read the article felt discouraged by its failure to mention the Tuskegee Study. While admitting he found it "informative and useful," Dr. George A. Silver, professor emeritus of public health at Yale University, saw the article as "evidence of our continued inability to confront our racist past." After specifying that he was referring to "the infamous 'Tuskegee Study,' " he proceeded to sketch out the broad outline of "this noxious 'experiment,' " all the while emphasizing that he did so "without rancor." "After all," Dr. Silver lectured, "the behavior of the PHS officers was no more than representative of the sentiments and prejudices of the

times. But not to remember is to forget, and to forget is a disservice to those who suffered the indignities."[34]

In his reply, Dr. Cutler took the high road. Omitting any reference to his role in the last years of the study, he was at once conciliatory and philosophical. "I understand and accept Dr. Silver's feelings about the Tuskegee Study," he began. "However, there seemed to be no reason to mention this or any other study in our article; all of the studies contributed to the program developments which led to the successes of the national VD control program." Without specifying whether he was referring to the Tuskegee Study, Dr. Cutler added vaguely, "I hope we can apply the knowledge gained from our past errors as well as our past successes."[35]

Dr. Cutler's response summarized the position of many Public Health Service officers on the Tuskegee Study. Asked to comment on it directly, most health officials declined to defend it and sought to distance themselves from it. Simply put, the Tuskegee Study was an embarrassment, a relic of the past they preferred not to have mentioned and had just as soon see forgotten. Other health professionals adopted essentially the same position. Despite the serious questions the Tuskegee Study raised about the racial policies, ethical standards, and scientific competence of everyone who participated in the experiment, and despite growing evidence that the experiment had angered many blacks and had left them deeply suspicious of organized medicine, the medical establishment in the United States made little effort to come to grips with the Tuskegee Study. No medical association conducted a symposium on the experiment; no medical journal devoted an issue to exploring what might be learned from a wide-ranging examination of the experiment by experts from different fields. Yet the Tuskegee Study would not go away. For many blacks it provided the historical lens through which they viewed AIDS.

Stephen B. Thomas and Sandra Crouse Quinn, co-directors of the Minority Health Research Laboratory at the University of Maryland, saw this truth driven home repeatedly. As experts in health education, Thomas and Quinn worked with a variety of groups to plan educational programs to combat AIDS in the black community. In their travels across the country they detected a pattern in the seminars and workshops they conducted on AIDS. Every time the program was opened for discussion,

someone in the audience invariably brought up the Tuskegee Study. Often the individual who did so was a lay person, but not infrequently a health professional raised the subject. And once broached, the Tuskegee Study unleashed such outbursts of anger, suspicion, fear, and mistrust that it became difficult to move the discussion back to AIDS education.

Struck by the power of the emotions they were hearing, Thomas and Quinn decided to study the Tuskegee Study's legacy in the black community as it related to the AIDS epidemic. Among other things, they found that many health officials who work in black communities "are uncomfortable responding to the issue of genocide and the Tuskegee Study." Typically, health officials ignored these issues, a response that often led to "a loss of believability and further alienation."[36]

According to Thomas and Quinn, health officials needed to try a different approach. "One culturally sensitive response would be for public health professionals to discuss the fear of genocide evoked by the AIDS epidemic," they advised. "They must be willing to listen respectfully to community fears, share the facts of the Tuskegee study when it arises as a justification of those fears, and admit to the limitations of science when they do not have all the answers." Above all, Thomas and Quinn advised health officials not to dismiss black peoples' fears out of hand. In their view, the feeling shared by many blacks that "AIDS is a form of genocide," was "justified by the history of the Tuskegee study." Only when white health officials confronted this truth would it be possible to open a dialogue that could "contribute to a better understanding of how to develop and implement HIV education programs that are scientifically sound, culturally sensitive, and ethically acceptable."[37]

In their effort to understand and to chronicle the Tuskegee Study's legacy, Thomas and Quinn had to maintain a careful balancing act. On the one hand, they had to describe black fears of genocide sympathetically and to explain why many blacks shared these fears; on the other hand, they had to make it clear they did not believe AIDS was a white conspiracy to exterminate blacks. Separating himself from conspiracy thinking, Thomas called the genocide theory a "disaster myth," an explanation developed by people who needed to make sense of a calamity that had befallen them. By providing psychic comfort, "disaster myths" enabled people to function after some-

thing catastrophic occurred, but Thomas felt compelled to dispel the myth of genocide conspiracy because it interfered with efforts to control AIDS. "There are Black professionals with Ph.D.'s and M.D.'s behind their names who say safe sex [with condoms] equals a lower Black birth rate, which equals Black genocide. This is ridiculous," he thundered.[38]

While most black professionals denounced such theories as nonsense, many shared Thomas's concern that conspiracy theories were impeding treatment and educational programs to combat AIDS. "It's dangerous to be preoccupied with these theories when we need to work on containing the disease," declared Dr. Wayne Greaves, chief of infectious diseases at Howard University Hospital. "I'm too busy worrying about caring for sick patients and educating people about AIDS to get caught up in this kind of inane rhetoric." Dr. Alvin F. Poussaint, associate professor of psychiatry at Harvard Medical School, stated the matter more bluntly: "If we say that AIDS is a conpiracy to kill us off, it relieves us of any responsibility for helping to stop the disease's spread."[39]

Most leaders in the black community endorsed this view. When *Newsweek* inquired about the conspiracy theories that were sweeping the black community, none of the black academics, politicians, and civic activists interviewed in 1992 subscribed to the genocide theory, at least not in the literal sense. Yet many educated and thoughtful blacks detected a pattern of neglect aimed at American cities that smacked of racism. "You don't need five people in a room saying we're going to jam black people. But if you decide cities are last on your list, and 60 percent of African-Americans live in cities, you have targeted African-Americans," Julianne Malveaux, an economist and writer based in San Francisco, stated. "There is deliberate disregard," she added. "I'm not willing to call it a conspiracy, [but] this is neglect that is not benign."[40]

Lorene Cary, a *Newsweek* contributing editor, suggested that the problem reached beyond the cities to include blacks everywhere. "We Americans continue to value the lives and humanity of some groups more than the lives and humanity of others. It is not paranoia. It is our historical legacy and a present fact," she insisted, adding that such thinking "influences the way we spend our public money and explains how we can read the staggering statistics on black Americans' infant mortality, youth mortality, and mortality in middle and old ag and not be moved to action."[41]

As a symbol of racism and medical malfeasance, the Tu kegee Study may never move the nation to action, but it ca change the way Americans view illness. Hidden within tl anger and anguish of those who decry the experiment is a pl for government authorities and medical officials to hear tl fears of people whose faith has been damaged, to deal wi their concerns directly, and to acknowledge the link betwe public health and community trust. Government authoriti and medical officials must strive to cleanse medicine of soci infections by eliminating any type of racial or moral stere typing of people or their illnesses. They must seek to build health system that will make adequate health care availab to all Americans. Anything less will leave some groups at ris as it did the subjects of the Tuskegee Study.