Treated as Lepers: The Patient-led Reform Movement at the National Leprosarium, 1931-1946

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What's in a name? We, the patients, may properly conclude much. For leprosy is certainly a fine example of the injustice of giving a dog a bad name. It is the word "leper" above all other factors that fosters the unreasonable dread which in this century of progress still clings to the disease. Even the word, spelled backward, r-e-p-e-l, does not present a pleasant idea.¹

Ancient fears and the centuries-old tradition of isolating and stigmatizing leprosy victims survived until the mid-twentieth century in the United States. From the early 1930s through the mid-1940s, patients at the National Leprosarium, assisted by veterans' groups, mobilized a reform movement that improved living conditions for patients treated at the United States Public Health Service Hospital in Carville, Louisiana. The reformers also worked domestically and internationally through journalism to change public perceptions about the disease. The patients' individual and collective efforts, exposure afforded the movement through the hospital's internationally circulating newspaper, and

the involvement of the Patients' Federation ultimately transformed the Carville leprosarium from a de facto penal colony to a modern treatment and research facility.

In the early twentieth century, many people thought of leprosy victims as "unclean," believing that God had punished them for some awful, most likely sexual, transgression. Catholic priests demonized lepers, noting that they had to dwell "without the camp." Uninfected family members often disowned leprosy victims or concocted lies to explain their absence.

Medical understanding and treatment of leprosy improved markedly over the course of the twentieth century, but popular misconceptions, stigmatization, and jokes based on erroneous, outdated beliefs regarding the disease continued to circulate. Much of the stigma stems from biblical references to lepers; however, medical scholars believe that, as a result of translation errors, the disease currently categorized as leprosy was not the malady identified as such in the Old Testament, for the modern and ancient afflictions had different symptoms. These errors were repeated in the New Testament.2

Confusion surrounding leprosy stemmed partially from uncertainty regarding the cause of the disease, which was not determined until Dr. Gerhard Henrik Amauer Hansen of Norway isolated the Mycobacterium leprae bacterium in 1873. A few leaders

in the international medical community and leprosy patients themselves subsequently renamed the illness in honor of the Norwegian scientist. The American public, however, generally remained ignorant of the disease and its characteristics.3

The ancient belief that leprosy was visited upon sinners survived in the United States well into the twentieth century.4 A perceived connection between leprosy and sexual immorality ex-

3Leprosy or Hansen's disease is an infectious disease spread through a bacterium that primarily affects the peripheral nerves and secondarily affects the skin and "sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, muscles, bones and testes." Before the discovery of sulfone drug therapy at Carville in 1941, no effective treatment existed. Multiple versions of sulfone-based drugs are used to kill nearly all of the Hansen's bacilli, rendering the patient noninfectious. When untreated, advanced cases of Hansen's disease cause nerve damage in the hands and feet of victims. This damage often leads to a "loss of muscle control and crippling of hands and feet." Desensitized hands and feet often are damaged by small cuts or burns that subsequently become infected. Bone absorption and related deformities caused many uninfected observers to think that Hansen's disease victims experienced the "dropping off" of hands and other body parts.

Exactly how Hansen's is transmitted is still unclear, but the most commonly accepted theory is that the bacterium enters the body through the upper respiratory system or skin abrasions. Specialists generally agree that ninety percent or more of the world's population is naturally immune to leprosy. In 1994, the World Health Organization estimated that there were 2.4 million cases of Hansen's disease worldwide, of which 1.7 million were undergoing treatment. The cases are concentrated in Southeast Asia and Central Africa, but it is also found in South and Central America and the Caribbean Islands. In the United States, there are 6,500 registered cases, primarily in California, Texas, Hawaii, Louisiana, Florida, New York, and Puerto Rico, but only 600 of these are active cases requiring drug treatment. Most patients are treated at eleven outpatient centers located throughout the nation. See "Facts About Hansen's Disease," The Star, 54 (November/December 1994): 18. One hundred and twenty-five patients resided at Carville until the late 1990s, when the pace of the long-planned closure began to quicken. For more recent information on the closure process and the federal government's efforts to use monetary incentives to hasten the process of patients leaving Carville, see two articles by John Pope, "Echoes of a Lifetime," New Orleans Times-Picayune, November 19, 1997; and "Film Reveals Lives at Leprosy Center," New Orleans Times-Picayune, August 27, 1998. A political scientist's perspective on the closure of the former Hansen's Disease Center is found in Janet Frantz's "Political Resources for Policy Terminators," Policy Studies Journal, 30 (November 28, 2002). Information about the National Hansen's Disease Museum, which opened at Carville in 2000, can be found via the following website: http://bphc.hrsa.gov/nhdp/NHD-MUSEUM_HISTORY.htm.

4The most comprehensive examination of social conditions for lepers in medieval European culture remains Saul Nathaniel Brody's The Disease of the Soul: Leprosy in Medieval Literature (Ithaca, N.Y., 1974), Chapters I-II.
isted long before the Old Testament in the Middle East, and similar views existed in Asian cultures. In medieval Europe, the Roman Catholic Church ritualistically eradicated lepers from society through ceremonies only slightly different from funerals. Clergymen sometimes held a "Leper Mass" in a cemetery, next to an open grave in which stood a leper. During the ceremony, the priest threw dirt upon the head of the leper before declaring: "Be dead to the world, be reborn to God." Later, the priest read prohibitions explicitly barring lepers from the church and other public buildings and places. A procession then led the leper to a hut outside of the village, where the priest fixed a cross upon the hut's door, attached an alms box to it, and then inserted an offering before instructing the uninfected faithful not to abuse lepers. The priest explained that the lepers' plight resulted directly from the "formidable judgment of God," and victims consequently deserved charity. Although acknowledging the inherent cruelty of their actions, ecclesiastical authorities nevertheless enforced quarantines.5

The Catholic Church's quarantine policy was cruel, but efficacious, and by the sixteenth century, leprosy in Europe was confined to the continent's most isolated regions. The disease, however, remained a potent literary symbol of damnation for sinfulness and lust.6 In the early twentieth century, authors and journalists continued to refer to outcasts and other undesirables as "moral lepers," while clergymen cited lepers as living examples of the damned.

Such references were usually figurative, rather than literal. In the United States, leprosy had existed for centuries in the South, but it surfaced only rarely in other areas. Only Louisiana had institutions devoted exclusively to leprosy victims. In the 1760s, Louisiana's Spanish Gov. Antonio de Ulloa exiled lepers to a colony near the mouth of the Mississippi River. Another leper colony existed at New Orleans from 1785 until 1804, but there was no other American leper colony until the founding of the state home for lepers at Carville in 1894. There was nevertheless a need for specialized care. In Louisiana, state authorities registered 120 leprosy cases between 1808 and 1880.7

5Brody, Leprosy, 65-69, 107-08.
6Ibid., 190-91.
7Philip A. Kalisch, "Lepers, Anachronisms, and the Progressives: A Study in
Despite the large numbers of lepers in Louisiana, the national medical community's attention was focused elsewhere. In the 1850s and 1860s, American medical authorities focused their attention on two groups: Chinese immigrants in the nation's western region and Scandinavian—particularly Norwegian—immigrants in the upper Midwest. Many Norwegian leprosy victims had emigrated to escape mandatory segregation in leprosariums in their native land.\(^8\) Despite the increased presence of leprosy, the great majority of Americans were exposed only indirectly to the disease through newspaper and magazine accounts of lepers in Norway, the Hawaiian Islands, and other foreign locales. In 1886, sensationalized secular and religious press accounts of "Father Damien" stoked public fears about the disease. In 1873, the Belgian priest had dedicated his life to ministering to the Hawaiian lepers exiled to the leper colony on Molokai Island. In 1886, he contracted leprosy, and an international readership followed news accounts of the priest's painful death over the next three years.\(^9\)

Father Damien's death in 1889 contributed to popular interest in the threat to public health posed by leprosy. State and county medical societies began to lobby for a federal investigation to gauge leprosy's presence nationally.\(^10\) In 1889, a United States senator introduced into the Congressional record the results of a Florida physician's investigation into the mysterious disease. Because numerous leprosy cases existed in New York, Michigan, Illinois, and Florida, the doctor argued that the United States Public Health and Marine Hospital Service should be empowered to create and administer an isolated "leper settlement, like other governments, according to science and humanity."\(^11\) In late December 1889, the surgeon general of the Public Health Service successfully lobbied for the power to ban all lepers attempting to enter the country and to deport all aliens who developed the disease within three years of entering the United States.

\(^8\)Ibid., 497-99.
\(^9\)Ibid., 501.
\(^10\)Ibid., 502-03.
\(^11\)Ibid., 502.
The Pelican State was not immune to the growing national hysteria over leprosy. In the early 1890s, a Crescent City dermatologist noted that Louisiana's lepers, who were "usually among the poorer classes," eventually found their way to New Orleans' Charity Hospital. Citing the danger of contagion, he advocated the "complete and permanent isolation of the lepers" as then practiced in Norway and other nations.12 After a series of news articles on ten impoverished lepers living in a filthy New Orleans "pest house" stirred state governmental and medical authorities to action, Louisiana opened the nation's first state leprosarium in 1894.

The Louisiana legislature approved funding for a leper colony, but parish governments consistently opposed establishment of such a facility in their respective communities. While the Louisiana leper home's board of directors prepared the former slave cabins on the abandoned Indian Camp Plantation at Carville—about seventy-five miles above New Orleans—for incoming patients, they told neighboring Iberville Parish residents that an ostrich farm was planned for the site. In November 1894, the board transported at night eight of the ten lepers assigned to the site aboard a coal barge to avoid the glare of public attention. When they discovered the true nature of the board's plans for Indian Camp Plantation, Iberville Parish residents complained, but eventually acquiesced. The leper home board originally intended the Iberville Parish plantation to serve as a temporary facility, but attempts to establish a permanent institution on a former plantation near Kenner, Louisiana, led to sometimes violent protests by local landholders, doctors, and outraged citizens. Some protesters eventually burned one of the Kenner plantation's buildings to the ground, compelling the state leprosy home board to transform the Indian Camp site into a permanent facility.13

The leprosy board initially made no attempt to upgrade the Carville leprosarium's facilities despite its new status. Living


13Isadore Dyer, "The History of the Louisiana Leper Home," (pamphlet), (1902), 3-4, 20-21; and "A Brief History of the Louisiana Leper Home," early 1940s, 1-2; both from the vertical file (United States Public Health Service Hospital, Carville), Tulane University, Howard-Tilton Memorial Library, Louisiana Collection.
conditions at the home remained poor enough to prompt Isadore Dyer, the board president, to advocate fundamental changes in 1902. The Sisters of Charity nursing staff, which arrived at Carville in 1896, lived in the plantation home, but the patients still lived in decrepit cabins. In an address to the Orleans Parish Medical Society, Dyer argued that the horrible conditions deterred lepers of any financial means from submitting to "self-isolation" at the home. He believed that the project could be redeemed only by transforming the institution from an "alms house" into "a well regulated hospital" with decent housing for existing and potential patients. Once these changes were implemented, Dyer argued, Louisiana laws could be rewritten to authorize state and local boards of health to seek out leprosy victims and institutionalize them at the home.  

Louisiana's internal debate over the role of the Carville institution coincided with the American debate over the need for a national leprosarium. The national debate was driven by popular apprehension over the acquisition of the Hawaiian Islands and the territory's notorious leper colony. Congressional legislation sponsored by the Public Health Service in 1898 established a national commission to locate every leprosy victim in the United States. The commission's 1902 report listed 278 leprosy cases, most of which were in Louisiana. The commission called for a national facility, but the proposal foundered on the question of geographic location. Congressmen and state officials quickly suggested use of federal lands in areas—particularly Yellowstone National Park and the New Mexico and Arizona territories—that seemed unlikely to arouse negative public opinion.  

But the suggested venues generated a firestorm of opposition. The following question by New Mexico's territorial delegate is representative of the opposition rhetoric: "How would you gentlemen in the States like to have the tinkling bell sounding and the white shroud of the leper stalking through your backyard in the morning as described in *Ben Hur*?" Other national leprosarium opponents suggested that no continental site would be acceptable; only Guam or Hawaii would suffice. Meanwhile, in the second dec-

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15 Kalisch, "Lepers," 504-05.  
16 Quoted in ibid., 506.  
17 Ibid., 505-07.
ade of the twentieth century, Massachusetts quarantined lepers on Penikese Island in Buzzard's Bay, and Texas and California formulated similar plans for isolated colonies.

As the debate over the eventual location of a national facility continued, sensational newspaper articles occasionally reported the deplorable treatment of lepers, who remained universal outcasts. In 1914, John Early, a military veteran afflicted with leprosy, used the news media to trigger Congressional hearings on the need for a national leprosarium. Early checked into the posh Willard Hotel in Washington, D.C., and mingled with politicians and wealthy guests before alerting the newspapers and the city health department of his condition. He told reporters that he had saved his money for months in order to travel and mingle among the wealthy. Early said that he had no interest in harming anyone, but he reasoned that exposing this select group to leprosy would cause them "to arise out of self-protection and further my plan of a national home." Early was imprisoned in an isolated brick building and charged with entering the District of Columbia as a diagnosed leper without authorization from public health officials.  

Testimony recorded in subsequent hearings on a leprosarium bill made frequent mention of Early, but no action resulted. Louisiana Sen. Joseph E. Randsell, chair of the Committee on Public Health and National Quarantine, championed a leprosarium bill in 1916, and Pres. Woodrow Wilson signed the legislation in early 1917. World War I, however, delayed the site selection. Government health officials suggested islands and federal territories throughout the continent, but in each instance local objections blocked establishment of a national leprosarium. In 1919, a national committee selected Cedar Key, Florida, but intensive lobbying by a delegation of Florida businessmen, Congressmen, and United States Senators led the surgeon general to overturn the committee decision and initiate negotiations for the purchase of the Louisiana Leper Home. Following prolonged discussions over cost, Louisiana transferred the leprosarium to the federal government in 1921.

The national leprosarium at Carville is perhaps best known for its role in educating the world about the age-old scourge through

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18Ibid., 508, 512-14.
19Ibid., 515-19.
its internationally circulating newsletter. This public outreach program distinguishes the national leprosarium from other contemporary isolation sanatoriums treating victims of other diseases. Recent studies of tuberculosis hospitals, for example, portray vividly the misery of individual institutionalized victims, but they make it clear that the weekly or monthly newsletters published by tuberculosis sanatoriums to improve patients' morale served only the needs of the institutionalized inmates.

Tuberculosis was the leading cause of death in the United States during the late nineteenth and early twentieth centuries. Leprosy, on the other hand, was rare, but the disease was more greatly feared by the public. It is thus hardly surprising that the nation's only leprosarium was the nation's most gloomy and rigidly regulated sanatorium. In the 1920s and '30s, the federal leprosarium maintained many regulations and practices similar to those of the Middle Ages. In a ritual intended to reduce the public's fears about the disease, the Carville staff used an oven to sterilize mail leaving the facility. In addition, segregation of the patients was strictly enforced, and a bureaucratic registration process symbolically replaced the Leper Mass. Patients received case numbers and then assumed false names upon entering the institution, in order to protect their families' reputations. Barbed wire ringed the 375-acre grounds, and whenever a patient escaped through a hole in the fence, he or she was treated as a "menace to the public health" and returned to the leprosarium in leg irons by the sheriff's deputies. At this time, the laws of Louisiana and many other states classed leprosy as a quarantinable communicable disease, like bubonic plague and yellow fever. Patients could neither vote nor make phone calls. Regulations forbade marriages between patients, and patients married at the time of their incarceration enjoyed only brief visits with their spouses. Carville authorities could jail without trial patients who had absconded or committed crimes. The medical officer in


21Rothman, Living, 235.

22Kalisch, "Lepers," 520-21, fn103.
charge (MOC) could imprison patients charged with serious offenses "with hard labor," unless the "performance of labor is likely to accentuate the physical suffering caused by the disease of leprosy." Patients with grievances had to report them to the MOC with the possibility of appeal to the surgeon general. Only patients with families in Texas, Louisiana, or Mississippi were allowed to leave the facility for short visits home—provided, of course, that their relatives still acknowledged them.

The federal takeover of Carville in 1921 did produce some significant improvements. The high wooden fence that had separated patients by gender was taken down, and in 1923, Congress appropriated $645,000 to modernize and expand the facility. New wooden cottages replaced the slave cabins, and laboratory and therapeutic equipment was installed. Aside from these improvements to the physical plant, however, not much else changed. Some of the Sisters of Charity remained as nurses employed by the federal government, but physicians continued to avoid physical contact with patients. Indeed, doctors required lepers to stand in the doorway rather than enter their offices. Patients thus fared better materially than in the past, but many problems endured.23

The movement to eradicate the lingering problems began soon after Texas native Sidney Levenson arrived at Carville in 1931 as patient 746. Levenson assumed the name Stanley Stein to protect his family, who had announced to friends and relatives that Levenson had been institutionalized following a mental breakdown. Despite Stein's youthful interests in both theater and journalism, his father had ordered him to study at the University of Texas School of Pharmacy to prepare him to take over the family's pharmaceutical business. Stein completed his training and worked several years as a pharmacist before learning that he had contracted the disease. Within his first few months at Carville, Stein started both a theatrical group to counteract what he termed the "zombie-like" condition of many patients and a newspaper.

The Sixty-Six Star, Stein's weekly "newspaper" initially consisted of mimeographed sheets filled with jokes, dining room menus, and patient gossip, but the publication quickly evolved

23Stanley Stein, Alone No Longer: The Story of a Man Who Refused to Be One of the Living Dead (New York, 1963), 100-01, 230-31.
into a far more important news and education forum.\textsuperscript{24} (The newsletter's name reflected the "colony's" official status as the nation's sixty-sixth United States Marine Hospital.) Although cynical patients had mocked Stein's suggestion that Carville's administration would help patients establish a newsletter, MOC Oswald E. Denney approved of the idea. Denney provided Stein with an old typewriter and promised access to his office's mimeograph machine. Denney also contributed brief, occasional columns and served as the unacknowledged censor. Carville's highest ranking official typically censored material that might prove problematic for his administration; yet, Denney allowed publication of material that challenged much of the status quo.

*The Sixty-Six Star* resembled many of the publications produced by patients in tuberculosis sanatoriums in that gossip and recreational activities filled much of the mimeographed sheets. However, editors of the other sanatorium papers who exchanged papers with their counterparts on *The Sixty-Six Star* staff commented with surprise at the level of honest exchange and spirited debate in the Carville paper. The *Star*'s editors, however, waited two years before aggressively lobbying for reforms.\textsuperscript{25}

Some of the earliest and most creative protests appeared in "The Adventures of Egbert," the humorous, serialized accounts of a new patient learning the facts of life at Carville. Introduced in the fourth issue, the Egbert series focused upon the clash between a naive newcomer and members of a well-established patient sub-culture. The institution and its medical staff provided the main targets for ridicule. For example, in one episode, a veteran patient considers Egbert's patent medicine to be more efficacious than scientific medical treatment. In another installment, Egbert visits Dr. Jo—the patients' nickname for Dr. Johansen, a member of the Carville medical staff—whose best advice is to follow orders and "be a good boy." After Egbert agrees heartily, Dr.

\textsuperscript{24}The *Star*, which began publication in 1941, continues to operate. Internationally distributed, the later series is available in many research libraries. *The Sixty-Six Star* began in 1931 and ended publication in 1934, following a couple of lengthy lapses owing to patient illnesses. Despite the attention that *The Sixty-Six Star* garnered beyond the colony, the most complete collection of these rare issues in Louisiana is located at Carville. Bound copies of the issues are housed in the Stanley Stein Memorial Reading Room, which is maintained by the editorial offices of *The Star*.

Jo responds: "Atta Boy! Spoken like a hero! If you do all these things I can promise you, you won't be here long. (to himself) You'll be in the graveyard. (aloud) Well, come see me any old time."

Gallows humor permeates Egbert's adventures. In his first days, he learns that unlike what he had been told, most patients do not leave Carville after a few months or even many years. The veteran patients tell Egbert that the church bells tolling for a deceased patient are actually tolling for the newcomer: "Well, you see, every patient who comes in here, they count good as dead to all intents and purposes, so they hold a funeral service for him." Egbert then learns that if he does not like the situation, there are many ways through which he might commit suicide. Drinking Lysol is no longer an option because "they don't give you no more Lysol, 'count of a couple of 'em using it just this way." Such dark humor can sometimes be found in contemporary sanatorium newspapers, but never accompanied by direct attacks on a facility's administration.26

The Carville inmates' protests subsequently targeted patients' legal and medical problems. Most complaints initially dealt with their enforced isolation and the lack of recreational opportunities. In the newspaper's fifth issue, a patient pleaded for the chance to watch baseball games at least once a month, concluding: "Give us SOME kind of entertainment to relieve the monotony of things."27

The Sixty-Six Star issue included a patient's complaint about the frequent breakdowns of the facility's movie projector, which had been purchased by the patients. A sidebar contained reports that the Hawaiian legislature had appropriated funds for a modern "talkie" machine at the Kalaupapa leprosy hospital. "We have not been so fortunate," the editor lamented.

Almost all patients attended the weekly movie night, which constituted the colonists' most regular entertainment, so it is understandable that patients first rallied around the idea of a new movie projector. Soon after the first mention of the problematic movie projector, The Sixty-Six Star introduced a formal column entitled "The Voice of the Colony" and invited constructive criti-

26Egbert appeared about one dozen times in the first year of the newspaper's existence. The installments cited are from the following issues: 1 (June 6, 1931): 3; 1 (August 1, 1931): 3-4; 1 (August 15, 1931): 3-4. See also Rothman, Living, 240-43.

icism from patients, provided that they signed their contributions.28 The first contributor, Sidney Atterbury, complained that the administration was aware of the faulty projector, but insisted that not enough money could be rededicated from the operations budget. Atterbury argued that the Carville administration should dedicate money to the purchase of a new projector, which administrators should view as an integral part of the patient's treatment, rather than a superfluous expense.

The same issue called attention to an Associated Press report that a "high public health official" had monitored the Carville patients' many activities. "Yes," the editor noted, "life still holds a persistent lure for us," and he called upon the "big-hearted official" to "give us something more in the way of worthwhile entertainment."29 Oswald Denney had regularly sent copies of the Carville newspaper to Washington officials, and Assistant Surgeon General Fred Smith responded to the editorial. Smith shipped extra beef to Carville, thereby permitting leprosarium administrators to divert hospital funds to the purchase of two new projectors; this action, Stein later recalled, demonstrated that "for the first time in Carville history, patient needs and patient opinion had been made known beyond the barbed wire."30 When it was discovered that additional money was needed to purchase projectors, Smith sent yet another shipment of meat to cover the difference. The leprosarium newspaper sponsored a celebratory unveiling of the two new machines and published an open letter thanking Smith for making the event possible. It also published more than a dozen appreciative comments from "representative citizens" who made witty references to the gloomy days of benign neglect. Stein later described this seemingly trivial event as a turning point in the patients' lives and in his own career. He had now decided that great possibilities for change existed, and he began to think that he might become a crusading editor.31


30Stein, Alone No Longer, 80-81.

During the first month of the newspaper's existence, an American Legion contingent from the Baton Rouge post visited Carville to meet with veterans who had complained of conditions at the national leprosarium. Carville's residents included almost two dozen Spanish American War and World War I veterans, who probably contracted leprosy while serving overseas. The patients listed the outdated infirmary, the need for improved recreational facilities, and increased contact with the outside world as their major grievances. Sam Jones, Louisiana's American Legion commander and a future reform governor, offered to act as the patients' ambassador. Jones subsequently organized a Fourth of July baseball game, party, and dance for all Carville patients, and he reported the conditions faced by veterans at the leprosarium through an article in American Legion magazine, marking the first time that an outsider had advocated changes in the living conditions at Carville.\textsuperscript{32} By the end of 1931, the American Legion's national commander had visited Carville, and preparations for a Carville post were initiated. The Legion connection also brought other veterans' organizations into contact with Carville's veterans. In April 1932, representatives of the veterans groups met with Public Heath Service officials in Washington, D.C., and successfully lobbied for a modern infirmary, which was completed in 1935.

Dr. Smith, the newspaper's benefactor within the Public Health Service, visited Carville late in 1931 and asked to meet with The Sixty-Six Star staff. High-ranking officials rarely visited the leprosarium at the time, but rarer still were direct contacts between patients and visitors. Even staff physicians interacted with patients only during treatment sessions. During the meeting, Dr. Smith praised the efforts of the paper's staff and offered his help. The newspaper staff requested their own mimeograph machine, and Smith requisitioned one immediately. Though still subject to Denney's censorship, the paper was rapidly approaching self-sufficiency, thanks to the equipment donation and increasing subscription revenue. Before the twelfth issue was printed, staff members had signed up more than 100 paid subscribers both inside the colony and throughout the country.

Emboldened by such public support, the Carville journalists began to broaden the focus of their publication. In November 1931, the editors began to publish articles on laboratory research-

\textsuperscript{32}Stein, \textit{Alone No Longer}, 117-22.
ers, another innovation distinguishing Carville's paper from those published by tuberculosis patients. Dr. Denney wrote the first article, which both enlightened and incensed Stein. Denney used the Public Health Service terminology to describe the medical review board that determined whether patients were cleared for "parole," noting that the patients' official release papers stated: "No longer a menace to public health." Stein bristled at these words and wondered in an editorial: "Would they never let us forget that barbed wire?" Overcoming his anger, Stein noted that Denney never used the terms "leper" or "leprosy." Instead, he used "Hansenitis," an eponymous term that the medical field had not yet adopted widely. Denney and other researchers who contributed to The Sixty-Six Star were among an influential group of researchers who recognized the negative connotations of the terms "leper" and "leprosy." The researchers' use of the term Hansen's disease led Stein to realize the "frightful power" of the archaic medical terms. He consequently launched a campaign to ban the use of "the odious word leper."33

Stein's colleagues on the editorial staff joined his effort to re-educate the public. In August 1932, David Palmer, the newspaper's founding co-editor who was wracked with pain from rapidly advancing leprosy, precipitated a dispute with the hospital administration when he responded sarcastically to a New Orleans newspaper article in an editorial entitled "Looking In from Without." The target of Palmer's sarcasm had depicted the institution as a "veritable paradise," where patients were so "happy and content" that a dozen patients paroled from the facility returned begging to be readmitted. In "Looking Out from Within," Palmer articulated the sense of outrage shared by many patients over the reporter's breezy portrayal of their lives. Palmer condemned society for locking away leprosy patients because of unfounded fear: "Robbed of a means of livelihood (by society, not disability); separated by violence from mothers, fathers, wives, and children... why add insult to injury by pointing out to us the beautiful environment?" Palmer concluded his essay by announcing a forthcoming series of articles intended to examine the patients' true condition, but a new patient job materialized, and his journalistic career came to an end. Patient gossip maintained that the ad-

ministration had bought his silence, a charge that Stein later confirmed. The silencing of Palmer demonstrated that the administrators placed boundaries on the patients' journalistic efforts.34

The journalistic campaign to improve conditions at Carville nevertheless continued. In early 1933, The Sixty-Six Star published a few accounts of innovations at Hawaii's leper colony. A patient contributed a letter explaining how the newly created Hawaii Board of Hospitals had modified many of the rules at the territory's leprosy facility. Patients owned cars and rode in a new motorbus on short trips, while some patients had beach houses. This information undoubtedly infuriated Carville's residents, who still had to sneak out at night through a hole in the fence simply to make a phone call. The result was continued pressure for reform at the national leprosarium.

Continued journalistic agitation for change, however, proved increasingly difficult because of the journalists' severe infirmities. Physical ailments in this period before the advent of an effective "Hansenitis" treatment created chronic personnel problems, for it was difficult to replace incapacitated staff members. Few of the Carville residents possessed college educations, and many had limited high school educations. Also, about one-third of the leprosarium's 420 patients were not native English speakers; hence, a limited pool of potential writers and editors existed. As a consequence, the editorial staff's "physical difficulties" soon forced The Sixty-Six Star to shift from a weekly to a fortnightly publication schedule.35

The patient-led reform movement nevertheless continued apace. In April 1933, the paper published a series of complaints ranging from insufficient second helpings of cafeteria food to outsiders who regarded leprosarium patients as "caged-in curiosities." In addition, an editorial called for Carville's administration to provide patients with a new and expensive experimental procedure recently reported in medical research journals. The administration declined the request, but positive letters from readers beyond the "colony" led the editor to acknowledge the newspaper's new role—educating the general public about leprosy.

34Stein, Alone No Longer, 134-36.
New reports that leprosy was not very contagious seemed to spur The Sixty-Six Star to publish additional excerpts from the publications of medical researchers during the summer of 1933. Stein excerpted an editorial from the Leper Quarterly, the official organ of the Chinese Mission to Lepers organization, calling for less emphasis on spiritual and religious work and more effort toward treatment and research. Titled "Is a Leprosarium a Place to Die?," the article's author observed that Jesus cleansed the leper first and later saved his soul. In October 1933, Stein reprinted a Philippine leprosy authority's editorial condemning the compulsory segregation of leprosy patients on "scientific, humanitarian, and public health grounds."

Just as The Sixty-Six Star had begun to mature in its role as a crusading newspaper, health problems began to limit Stein's activities. Stein's disease, now in its advanced stages, affected his eyesight and sapped his energy. The newspaper consequently suspended publication from the fall of 1933 until June 1934.\(^3\) when it was reincarnated as The Star, a monthly publication. Beneath the paper's new title, Stein added a new motto: "Radiating the Light of Truth on Leprosy." Each issue's masthead featured a quotation by two medical authorities, who maintained that an isolation hospital must be judged by "the benefits which it confers on the sick within its walls." On the opening page of the inaugural issue, Stein apologized for The Sixty-Six Star's disappearance, which he credited to that "villain bacillus." After citing letters from throughout the nation asking why the paper had discontinued publication, Stein announced that The Star's new mission was to "creat[e] a broadminded and intelligent public conception of leprosy." Stein argued that tuberculosis, though far more contagious, did not create panic among most citizens because of widespread publicity that had created an informed public. The Star would attempt to eradicate public fear by displacing misbeliefs with facts. In keeping with The Star's new mission, breezy patient news was relegated to the back pages, while lengthy editorials and articles on medical research were featured items.\(^3\)


The next issue contained Stein's lengthy denunciation of "[t]hat word—Leper" and its use by print journalists, the movie and radio broadcasting industries, and members of the scientific community investigating the disease. Stein noted a recent conference in which leading investigators had agreed to substitute "cases of leprosy" for "lepers." One of the researchers had commented that "tubercular" had replaced the outdated term "consumptive." Medical journals nevertheless continued to use the word "leper" freely. Stein also criticized "some missionaries and sob-sister writers who love to describe us" as "the poor lepers." Stein argued that eradication of the term "leper" might dismantle the associated social stigma and help to encourage reluctant patients to emerge from hiding and seek treatment.38

Stein's crusade against the use of the term "leper" lasted until his death in 1967. He researched scholarly treatises on the history of the term leprosy, and then wrote the editors of encyclopedias, newspapers, and magazines to protest misinformation on the topic. His activism began in reaction to an Absorbine Junior advertising campaign of the early 1930s—"Don't be a locker-room leper!" Stein's editorials and public letters belittled the advertiser's ignorance in equating athlete's foot with leprosy. "We do not spread obnoxious infections as those afflicted with athlete's feet may do," he wrote. Stein soon targeted many radio advertisers and broadcasters for misuse of the term. The journalist subsequently recalled that "my war on the odious words leper and leprosy was just because their use kept alive the erroneous relationship of the disease and sin and perpetuated the unjust Biblical stigma."

Responses to his missives along with the comments of like-minded readers were often printed in the The Star's letters to the editor section. Time magazine thanked Stein for one of his editorials and told him that their librarians had added his material to their file on the disease.39 Stein's editorials also garnered praise from readers around the globe, including one of the world's leading "leprologists," whose distaste for the term "leper" Stein had

38 "That Word—Leper," The Star, 4 (August 1934): 6-8. Stein noted that packages delivered to the Carville facility never used the official name, the United States Marine Hospital at Carville; instead, the public used "Leper Home," or worse. In one instance, a shipment arrived addressed to the "United States Insane Hospital, National Home for Lepers."

39 Stein, Alone No Longer, 145-52.
commended. In addition, an expanded letters-to-the-editor section of the newly revived *Star* contained a letter of apology from a Columbia Broadcasting System executive regarding Stein's complaint about misuse of the term. *The Star* also published a copy of Stein's letter of complaint to a Queens, New York, newspaper that had published as truth an urban rumor about a woman who contracted leprosy from a handkerchief laundered at a Chinese laundry.

The issue marked another point of departure in format, for editors no longer merely reprinted medical reports culled from journals. A *Star* reporter cornered Dr. Robert Cochrane, a visiting leprologist, and questioned him about a promising new treatment then under development. The British physician, considered the world's leading authority on leprosy, had sought out the offices of *The Star* during his visit to Carville. In an interview, Cochrane denounced the term "leper," but advised institutionalization in order to protect patients from the mental anguish of hiding the disease.40

This journalistic coup was overshadowed by an article revisiting a smoldering Carville controversy over the Leper Mass. In the summer of 1934 Charles Brown, editor of a newsletter at an Indiana tuberculosis sanatorium, submitted an article on "lepraphobia" and the Leper Mass. Brown's unequivocally negative depiction of the Leper Mass greatly offended Carville's Catholic chaplain, whose response Stein printed in the same issue. What Brown interpreted as a humiliating and dehumanizing ritual, the chaplain described as a beneficial spiritual ceremony practiced in accordance with the Law of Moses.41

In the midst of the resulting controversy, Stein and the other editorial board members discussed the need for leprosy victims to produce their own statement regarding the Leper Mass. The most highly educated member of the editorial board was dentist Eugene Williams, a Dartmouth College graduate and the only black member of the newspaper staff. Advanced leprosy had blinded Williams and forced him to breathe through a tracheotomy tube. Despite his disabilities, Williams contributed his knowledge of ancient and medieval history as the staff wrote a


composite editorial condemning the Leper Mass as "about the cruelest practice that could ever be perpetrated in the name of religion." The staff writers disputed the priest's positive portrayal of leper houses by citing historical accounts of the hospitals' prison-like conditions, functioning primarily to protect the well. Their editorial contended that both the ancient and the modern Church had done more than any other agency to sustain the stigma of leprosy. "If the Church would be as energetic in trying to remove the stigma, which modern science has shown to be wholly unjustified, as it was active during the Dark Ages in instituting fear and horror, leprosy would be rid of the odium that now surrounds it," concluded the editorialists.

Typists, reporters, circulation, and other supporting staff members quickly abandoned their posts after the editorial appeared in the September-October 1934 issue. The staff members disappeared not because of any organized patient or administration-induced boycott; instead, most of the staff members, torn between their allegiance to fellow patients and their allegiance to the priest, feared for the fate of their souls, Stein later surmised. Once again, the paper's staff disbanded, but the reform movement survived.42

While establishing the colony's newspaper, Stein had struggled to transform the Carville patients' activity group from the glibly titled "What Cheer Club" into the Patients' Federation, an organization advocating change. The patient organization originated primarily to manage a canteen and administer a community fund for the indigent and the blind. Articles in The Sixty-Six Star frequently mention patient apathy and the inability to raise a quorum at general membership meetings, but the organization nevertheless sponsored some of the costs associated with the newspaper's short-lived rebirth in 1934. Following The Star's demise, Stein and others began to rely on the organization to advocate change.

The American Legion had continued to wage a campaign to have the government replace the remaining wooden buildings with fireproof structures. When the patients objected to the government's plan for concentrating their housing in two dormitories, the Patients' Federation held a meeting to support the traditional cottage arrangement, though in a modernized form. The American Legion forwarded the patients' requests to the surgeon

42Stein, Alone No Longer, 155-56, 157-61.
general. Despite the planned five million dollar renovation, the federation initiated a losing effort to have the leprosarium moved to a drier location. Recent studies had taught them that researchers considered the Louisiana climate most detrimental for patients. Carville's modernized buildings opened in 1941, and its centerpiece was a large recreation center. The government had answered the pleas of the patients and their American Legion supporters with a massive hall containing a ballroom, a large theater, a library and reading rooms, lounges, and a new cafeteria.43

Stein's condition worsened during this period, and by 1938 he had completely lost his vision. Ongoing discussions about rectifying The Star faltered because of health problems for all concerned. Nevertheless, the opening of the recreation center spurred the erstwhile journalists to try again. In September 1941, one month following the center's opening, The Star reappeared. The paper formalized the publication's previously evolving mission through publication of three objectives. First, it would "promote an educated public opinion on Hansen's disease." Second, the paper would provide training for interested patients, and, finally, it would provide community service. Initially issued in mimeographed form, The Star benefited from the American Legion's donation of a used linotype and printing press in 1943.

During 1941 and 1942, trials of the experimental sulfa drug "promin" began. Within six months, patients in the early stages of the disease began to see their nodules and blemishes disappear. Advanced cases showed great improvement within two or three years. During the mid-1940s, increasing numbers of patients abandoned ineffective treatments, and patient morale improved dramatically.44

The now reinvigorated Star staff both celebrated the medical advance and continued to attack the patients' unique social problems. Another World War I veterans group, the Forty and Eight, initiated a subscription campaign that greatly expanded the number of readers beyond the colony. The popular song "Don't Fence Me In" served as an unofficial theme as writers continued to attack the patients' isolation. Carville patients participated in

43Ibid., 61-62, 202-03.

44The story of the introduction of sulfone drugs is told by Betty Martin, Miracle at Carville (New York, 1950). See also Stein, Alone No Longer, 215-29.
the World War II effort through bond drives, and they noted the irony of their position.45

Betty Martin wrote one of the most powerful protests published during this period in an essay titled "Why am I Not Free?" Martin asked why had she lost her rights of citizenship "when my only crime is being sick?" She directed some of her questions toward the readers: "Why do some of you who call yourselves CHRISTIANS continue to break me in pieces with ONE LITTLE WORD, and torture my spirit, when CHRIST TAUGHT YOU BETTER?" Her comments placed the force of eloquence behind demands that the Patients' Federation address the Public Health Service administration in Washington.46

The resulting changes at Carville were incremental, occurring over many years. Though difficult to identify one year as pivotal, 1946 stands as the point when fifteen years of patient reform efforts began to produce results. The momentum of change increased with the establishment of the National Advisory Committee. After its 1945 convention, the American Legion urged the surgeon general to appoint a committee, which met for the first time in May 1946. Two legionnaires and six physicians, including the surgeon general, met to discuss fifteen patient proposals for bettering conditions at Carville and improving treatment of leprosy patients nationwide. Following a dozen years of work to regain their voting rights, the patients learned that Louisianans chose overwhelmingly to extend the franchise to Carville residents in the fall of 1946. The Star and the federation pushed successfully to open the facility to general visitors, with patients serving as paid tour guides.47

Later in 1946, members of the advisory committee visited the patients and listened to their problems and proposals. Meanwhile, support personnel began to spread rumors about a female patient visiting a local beauty shop and supposedly exposing the customers to great risk. The staff received extra "hazard" pay that they feared losing as reforms mounted and word spread that leprosy was not hazardous. The patients worked quickly to disprove the rumors.

47Stein, Alone No Longer, 278-79.
Late in December, the patients learned that the advisory committee had approved many of their proposals. Among these, the government agreed to hire a professional writer to assist The Star's editor. Significant improvements in the granting of leaves were also forthcoming. In the past, Carville's administration had granted only ten Christmas holiday leaves per year, but henceforth an unlimited number of patients could visit their homes.

The ultimate achievement of the 1946 reforms happened after the patients seized upon one of the most sensationalized accounts of leprosy in many years and used the resulting international interest to counter false information. Newsreels and newspapers exploited the information that the wife of war hero Maj. Hans Hornbostel had contracted leprosy in the Philippines. Reports that her physicians would send her to Carville led to heightened press coverage of the facility and innumerable opportunities to correct false information. The journalists and newsreel crews found an eager reception. The patients' earlier efforts to contact the national media had prepared them well for the onslaught of press attention. Newly available phone access allowed the patients to contact dozens of news agencies immediately, and The Star's printing press provided professional reprints of articles on leprosy and the newly discovered sulfa-drug treatment. Other reforms were implemented over the next few years, but the reformers had already achieved their most important goals.

The establishment of a leprosarium in Louisiana, however, initially did little to improve the lepers' lot. Once ensconced in the national leprosarium, new patients with scarcely any sign of the disease encountered horribly disfigured, long-institutionalized victims. This was the situation at the national leprosarium, when Stanley Stein was institutionalized there. Only months after Stein entered Carville as a patient, however, positive changes began to happen. The efforts of Stein and The Sixty-Six Star newspaper that he founded in 1931 quickly laid the groundwork for reforms fully realized only after World War II. Patient newspapers commonly existed in tuberculosis sanatoriums and other isolation hospitals, but none of these publications developed far beyond the limited goals of reporting hospital news and patient gossip for internal distribution. Hospital administrations typically started newsletters as a therapeutic pastime for the patients. Carville's patients created their newsletter on their own

48 Martin, Miracle at Carville, 250-57.
accord and transformed it into an internationally circulating newspaper that challenged not only the local hospital administration and Public Health Service officials, but also an international audience's ossified misconceptions of the disease.

Stein and his staff fostered connections with individuals and organizations outside of the hospital, and these contacts proved essential in helping the once-isolated patients achieve impressive goals. The sulfone breakthrough of the 1940s afforded patients the physical energy required to manage their reform movement, but their initial efforts in the 1930s had already formulated the strategies that they later employed successfully. The assistance of military veterans groups, the rhetoric of democracy associated with World War II, and sympathetic medical researchers and members of the Public Health Service helped to propel the reform effort. However, frustrated journalist Stanley Stein and other college-educated patients provided the critical energies needed to develop and maintain the movement.