

THE SECRET PEOPLE: PATRIOTISM, THE PRESS, AND CIVIL RIGHTS IN THE
NATIONAL LEPROSARIUM

by

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UNDER THE DIRECTION OF ROBERT PRATT

ABSTRACT

This project studies patient-activism at United States Public Health Service Hospital 66, the National Leprosarium. The goal is to show how a diverse group of patients adopted mainstream American rhetoric and partnered with veterans' groups in order to establish their own civil liberties and to diminish the stigma of their shared disease. The paper will show first how leprosy became a disease of national concern and regulation, and then how patients worked to dismantle the laws and rules that oppressed them and denied them their civil rights, while maintaining leprosy as an area for national interest.

INDEX WORDS: Leprosy, Carville, Stanley Stein, John Early, Betty Martin, American Legion, Public Health Service, Hansen's Disease, Disfranchisement, the *Star*

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BA, UNIVERSITY OF NORTH CAROLINA, 2011

A Thesis Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment
of the Requirements for the Degree

MASTER OF ARTS

ATHENS, GEORGIA

2013

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ACKNOWLEDGEMENTS

I would like to thank several people who helped me conduct research and gather information to write this paper. First and foremost, I would like to thank Elizabeth Schexnyder, the curator at the National Hansen's Disease Museum, located in the old staff cafeteria from Carville's days as the national leprosarium. I would also like to thank Mr. Pete, who has spoken to me at length about life in the leprosaria in Louisiana and the Virgin Islands. Jose Ramirez has answered numerous questions of mine, and his book provides many interesting insights about life as a patient. Finally, I would like to mention Neal White, who first brought my attention to the existence of Carville with his fantastic memoir, *In the Sanctuary of Outcasts*. If not for this book, I might have gone my whole life never knowing about this fantastic community that existed only twenty miles away from my childhood home.

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1. INTRODUCTION: LA MALADIE QUE TU NE NOMMES PAS

*We cannot expect the authorities of the parish or of nearby municipalities to be continually turning back escaped lepers. We must hold them in the institution by such means as will accomplish the result.*¹

In 1893, a young muckraker for the New Orleans *Daily Picayune* anonymously wrote a series of exposés about the prevalence of leprosy in the city. The reporter, John Smith Kendall, informed the public of the surprising number of New Orleans residents afflicted with leprosy, many of whom went without public notice, handling food in the marketplace or engaging undetected in other potentially threatening behavior. The age of germ theory, of the mycobacterium, had begun only recently, alerting people to the concept of disease-carriers and new methods of contagion, and this series of articles considerably alarmed the public.

Kendall later remembered a Sunday afternoon he spent in the *Picayune* office, alone but for one other reporter named Ball, when “a shabbily dressed individual came quietly in...helped himself to a drink from a tin cup which we all used in common when thirsty, and then drew a chair up beside Ball and said, in a low voice, ‘I’m a leper!’” In the course of the ensuing conversation, Kendall learned of a local pesthouse for people with leprosy, run by New Orleans physician Dr. J.C. Beard, and he made an appointment to visit.² The results of the following articles, exposing the deplorable conditions of the pesthouse, inflamed public opinion, and the New Orleans grand jury affirmed Kendall’s account of “abandon, neglect, and possible

¹ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Board of Control to Sister Benedicta, July 13, 1914

² John Smith Kendall, ‘Little Known Chapter in the History of Carville,’ *The Star*, Nov 1952, pp. 1-2

starvation.”³ The next year, prompted by a combination of public pressure created by Kendall’s articles and extensive lobbying by New Orleans dermatologist Isadore Dyer, the Louisiana state legislature passed Act 88, creating a State Board of Control for what would soon become the Louisiana Leper Home.

The idea for an asylum (or a home or a penal institution) for those afflicted with leprosy did not originate with Dr. Dyer, nor was the stigma associated with the disease new or recent. The patients at the home, locked away by lawmakers motivated by fear and altruism alike, represented a Progressive era incarnation of a class that had been marginalized for centuries. Yet why should this disease, with its low risk of contagion and relative scarcity in most corners of the world be subject to such stigma?

The easiest answer for why the disease has been stigmatized for centuries, at least in Western cultures, is that the Bible demands it, and the Church has certainly had a hand in perpetuating the stigma. The Book of Leviticus demands that lepers wander “without the camp” and decrees them to be unclean. Religious leaders of the Judeo-Christian tradition have long used leprosy as a metaphor for sin.⁴ The practice of shutting the diseased into isolated

³ Zachary Gussow, *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control*. (Boulder: Westview Press, 1989) p. 60

⁴ Many scholars have contested the assumption that the stigmatization of leprosy originated with the Old Testament. In *Disease of the Soul*, Nathaniel Brody states that “the Bible merely contains evidence of the stigma, not of its origin” and that “the connection between leprosy and immorality was established before the Bible was written, and it has appeared nearly everywhere the disease has” (107). Furthermore, African and Asian cultures have developed similar attitudes and prejudices unattributable to Judeo-Christian influence. Mary Douglas suggests that the wholeness and physical perfection demanded in Leviticus account for the exclusion of the diseased, and that even the Biblical stigma should be viewed as based on uncleanness, not immorality. The deforming nature of the disease inspires fear of pollution, but Leviticus demonstrates no relationship between leprosy and sin; the victim

settlements or exiling them to deserted islands “is a modern sub-conscious modification of ritual death,” a medieval practice in which priests delivered last rites to the diseased before performing their funerals, marking them as members of “the living dead.”⁵ In addition to receiving last rites, victims often lay down in a grave “to symbolize irreversible social death,” after which they subsequently lost their property and civil rights.⁶ Future patients would base their strategies for fighting the stigma around removing the religious connotation from the disease and differentiating modern leprosy, caused by the *mycobacterium leprae*, from Biblical leprosy, which actually comprised many afflictions of the skin, including elephantiasis, psoriasis and eczema. Most of the symptoms associated with modern leprosy, often called Hansen’s Disease

returns to the camp for cleansing rituals no more strenuous than those associated with childbirth or menstruation. Rod Edmond suggests that leprosy meets a specific societal need for a basis for exclusion during time of large-scale social movement, as fear of leprosy flourished during the Crusades and during the Age of Imperialism. Alison Bashford supports Edmond’s connection between disease and social movements in her article “Foreign bodies: Vaccination, Contagion and Colonialism in the Nineteenth Century”, claiming that in the twentieth-century in particular, public health was “centrally concerned with global and local movement and displacement” (46). Edmond discusses further legends traversing continents that claim the disease is caused by incest, necrophilia, mental illness, or sodomy, in places as diverse as China and Cameroon. Edmond describes leprosy as a “boundary disease par excellence,” as its capricious nature makes it difficult to sensibly categorize. Douglas, Carlo Ginzburg and Michel Foucault have associated the historical “leper” with the witch, the Jew, and the madman in terms of historical stigmatization and marginalization. The sometimes grotesque symptoms of the disease, its resistance to classification and its historical incurability all contribute to the stigma and fear inspired by the disease.

⁵ G.A. Ryrie, “The Psychology of Leprosy,” in *Leprosy Review*, 1951, p. 15.

⁶ Guenter Risse, *Mending Bodies, Saving Souls: A History of Hospitals*. (New York: Oxford University Press, 1999.) p. 172

in honor of the scientist who isolated and identified the bacillus, do not match up with those described in the thirteenth chapter of Leviticus.

Regardless of origin or reason, since before the dawn of the Common Era, leprosy has inspired a unique dread and societal reaction in diverse cultures, resulting in the need for the afflicted to employ deception and secrecy to avoid being shunned or worse.⁷ When Isadore Dyer and the Board of Control began searching for a location for the hospital, they wanted to build a facility close to the Medical School at Tulane so that they could better conduct research. However, with every location they considered, they met opposition from either the city or the local community. Eventually, they had to settle on a five-year lease for the remote and inaccessible Indian Camp Plantation, eighty miles from New Orleans and twenty-five miles from Baton Rouge, in the town of Carville in Iberville Parish. To avoid local outcry, the community was told that the buyer of the plantation planned to build an ostrich farm on the premises. Health officials transported the patients on a coal barge via the Mississippi River under the cover of night, and moved them into dilapidated fixtures on the plantation that had formerly served as slave cabins. When the truth became evident to the town of Carville, they protested vociferously, often refusing to trade with the hospital, which had to transport supplies from New Orleans.⁸

⁷ A Senate report on leprosy described the story of Mock Sen, a Chinese student in America. Upon being diagnosed with leprosy, he was shoved onto a railroad car by a mob. Wherever the car sought to travel, it was met with mobs of people forewarned by the dangerous person aboard and Mock Sen could not disembark. This went on for thirteen days before a physician intervened, only to find Mock Sen had died. 64th Congress, 1st Session, Senate Report no. 206, *Care and Treatment of Persons Afflicted with Leprosy*, “Report of the Committee on Public Health and National Quarantine of the United States Senate on S. 4086).

⁸ National Hansen’s Disease Museum. “Louisiana’s Lepers” in *The Carville Standard*, February 1895.

Staffing a hospital built for a stigmatized and feared disease in a malarial and inaccessible swamp proved a challenge; the Board desperately needed caretakers and administrators. Dyer, as a New Orleans physician, would have had many encounters with the Daughters of Charity, who administered the New Orleans Charity Hospital, a hospital that accepted the sick and dying without regard for “race, nationality, age, nor sex.”⁹ The Daughters of Charity, a Catholic order of nuns with a nursing charism, had taken vows of poverty and proved willing to assume responsibilities others would not, including caring “for patients with contagious diseases, isolating themselves from their coworkers and risking contagion themselves.”¹⁰ Their calling them made them ideal recruits for the Board of Control. Dyer wrote the head of the Daughters of Charity, Mother Superior Marianna in Emmitsburg, Maryland, who assured the Board “of our willingness to assume the charge of the Leper Home” as long as “a chaplain be regularly appointed for the spiritual needs of the work.”¹¹ The contract stipulated that “The Sister Superior in charge shall be accountable to the Board for their acts and doings, and the Sisters shall have full and exclusive charge of the domestic management, such as servants, kitchen, household and details of nursing.”¹²

⁹ John Duffy, *Sword of Pestilence: The New Orleans Yellow Fever Epidemic of 1853*. (Baton Rouge: Louisiana State University Press, 1966.) p. 52

¹⁰ Judith Metz, “In Times of War” in *Pioneer Healers: The History of Women Religious in American Health Care* ed. Stepsis and Liptak. (New York: Crossroad 1989.) p. 43

¹¹ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana, Letter from Supr. Mariana of St. Joseph’s Academy, November 19, 1895.

¹² Carville: Correspondence, Box 1, Folder 1. Daughters of Charity Province of St. Louise Archives, Emmitsburg, MD. March 1, 1896, Contract between Isadore Dyer, representing the Board of Health of the Louisiana Leper Home, and Mother Marianna, representing the Daughters of Charity of St. Vincent de Paul

However, even the Daughters of Charity, known for their willingness to take on any task, no matter how undesirable, could not live at Indian Camp Plantation as it was then. The Daughters of Charity, who were to move into the original plantation house on the property, demanded at least some improvement in the water supply and the sanitary conditions of the property before moving in. The sisters not only served as nurses and counselors to patients, but they also made physical improvements to the hospital, such as insulating the walls of the patient quarters and planting gardens that provided both vegetables and a diversion to keep patients busy.¹³ Yet physical improvements could not overshadow the general unsuitability of the location. The head administrator, Sister Beatrice, wrote that “I feel as if I will expiate all my sins here, just by putting up with the mosquitoes, frogs, lizards, and all sorts of things of that kind, jumping at me.”¹⁴ Furthermore, “several among the patients in addition to their other sufferings have malaria.”¹⁵ Malaria would haunt Carville for several decades to come.

Sister Beatrice “begged them to look about and find another place more conveniently located on a railroad line” than the remote Indian Camp Plantation, declaring that “twenty years from now no one will commend them for wisdom if they locate permanently here.”¹⁶ Between difficulty of approach, the proximity to the Mississippi River and the lack of access to clean

¹³ Michelle T. Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*. (Chapel Hill: University of North Carolina Press, 2007.) pp. 80-85

¹⁴ Carville: Correspondence, Box 1, Folder 1. Daughters of Charity Province of St. Louise Archives, Emmitsburg, MD. Letter from Sister Beatrice to Sister Juliana.

¹⁵ Carville: Correspondence, Box 1, Folder 1. Daughters of Charity Province of St. Louise Archives, Emmitsburg, MD. Letter from Sister Beatrice.

¹⁶ Carville: Correspondence. Box 1, Folder 1. Daughters of Charity Province of St. Louise Archives, Emmitsburg, MD

water, the property, which one historian has called “a swampy hell-hole in the back of beyond” had little to recommend it.¹⁷ Sister Beatrice would complain of malaria for the five years that she ran the home, and the disease would ultimately take her life in 1901. Unfortunately, because the Indian Camp was meant to be a temporary location, the Board had no motivation to make any remotely costly physical improvements in the first several years of the home, regardless of whether they might ameliorate the problem.

The Board did continue to search for a better property for its permanent location as Dyer had not given up on a hospital close enough to Tulane for easy research. He also envisioned an institution that would serve as home as much as hospital, not a penal institution. Eventually they settled on a property known as Elkhorn, across the Mississippi River from the town of Kennar, which the state purchased in 1901, imploring the Daughters of Charity to keep knowledge of the purchase secret, while setting the rumor that the property “was to be used as a truck farm and fruit orchard.” Yet when angry locals discovered the truth of the purchase, they set ablaze all the buildings on the property in protest to having the hospital in their parish, “with a hope that the act would serve as a warning to the leper board.”¹⁸ Newspaper articles favored paranoia over scientific evidence. Perhaps the Board had hoped that after several years in Iberville Parish wherein no one outside the hospital developed the disease, other communities would be more willing to accept a hospital in their midst, but they miscalculated. The protests succeeded: Indian Camp Plantation became the permanent site of the Louisiana Leper Home. Upon federalization

¹⁷ Tony Gould. *A Disease Apart: Leprosy in the Modern World*. (New York: St. Martin's Press, 2005) p. 375

¹⁸ Carville: Newspaper Clippings. Box 1 Folder 2. Daughters of Charity Province of St. Louise Archives, Emmitsburg, MD. “Jefferson Uses the Torch of Defiance” May 24, 1901

in 1921, this unpopular and rundown sugar plantation would become the repository for the entire nation's leprosy patients. However, quarantine and isolation often proved difficult to achieve.

Quarantine had long been employed as a very controversial response to or as a preventative method against diseases. In New Orleans specifically, a city prone to highly destructive and widespread yellow fever outbreaks, quarantine could greatly hurt local businesses and merchants, making the practice highly contested.¹⁹ However, because leprosy infected and affected very few people, enforced quarantine did not garner the ire of businessmen the way it did in cases of yellow fever. Very few people were impacted economically or otherwise by the expulsion of the afflicted to a far-away place, and the disease inspired such terror that the majority of citizens rejoiced to see them leave.

Isolation at Carville in its infancy as a hospital proved unattractive, and very few people willingly quarantined themselves. Those that did often later "absconded" from the home through a hole in the fence, to the continual consternation of the Board of Control, the Daughters of Charity, and the locals. When an effort was made to round up all of the state's sufferers, many of "the unfortunates" refused to go. *The Carville Standard* lamented that the recalcitrant patients "will have to be taken to the camp by force, which is not pleasant, as no one cares to handle them."²⁰ Transporting the patients often posed many problems as well, as corporations such as the Texas and Pacific Railway Company refused to convey them, claiming that if they were indeed to furnish a car "for the movement of lepers...and use it for any other purpose afterwards,

¹⁹ Deanne Stephens Nuwer. *Plague Among the Magnolias: The 1878 Yellow Fever Epidemic in Mississippi*. (Tuscaloosa: University of Alabama Press, 2009.) p. 39

²⁰ National Hansen's Disease Museum. "Louisiana's Lepers" in *The Carville Standard*, February 1895.

it might be the means of spreading the disease.”²¹ Those willing to transport the afflicted also had to be willing to transport African-Americans, which posed additional problems in Jim Crow Louisiana.²²

Few people offered concern to the patients, forcibly separated from their families and homes. Instead they worried for the health officials or police officers who subjected themselves to possible contamination by coming into contact with the diseased. The designation “leper” tended to subsume the patient’s identity entirely. The neighbors of Indian Camp Plantation, even after they adjusted to hosting the Louisiana Leper Home, continued to complain to the Board whenever patients broke quarantine. For example, a group of citizens of Iberville Parish wrote to the Board, lodging “full owing complaints regarding the manner the inmates of the Leper Home are daily roaming, hunting & trespassing our fields. They have been seen by our citizens roaming thru our cotton fields; placing their hands upon cotton balls, which our laborers necessarily must pick, consequently causing them to come in direct contact with disease.”²³ They believed (at least in the first decade of the Home) that confinement had to be absolute to be effective.

²¹ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letter from Gaston Wesley of the Texas and Pacific Railway Company to the Board of Control, 1894

²² Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letter from G.R. Burgess to Isadore Dyer, August 23, 1895

²³ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Petition from citizens of Iberville Parish to the Board of Control, November 16, 1907.

Other diseases, most notably tuberculosis, led to policies of confinement, especially in the embryonic age of germ theory. The health resort movement had already begun, as victims of tuberculosis (often referred to as consumption) moved to healthier climates to ameliorate their symptoms. As the somewhat romantic and unstigmatized consumption gave way to the medically diagnosable and contagious tuberculosis, the health resort became more associated with quarantine and the disease provoked greater distaste, including attempts to ban the ill from traveling in common carriers.²⁴ In fact, beginning largely in the 1890s, patients diagnosed with tuberculosis often lied or refused to inform their family or friends about their disease to avoid eliciting fear or stigma. Yet in degrees of stigma, tuberculosis could not compete with the stigma of leprosy, and patients in the tuberculosis sanitoriums objected to “the attitude of the public that we were lepers.”²⁵ Similarly, when public health officials imprisoned Mary Mallon, more commonly known as the infamous Typhoid Mary, to prevent the spread of typhoid, she demanded “Why should I be banished like a leper and compelled to live in solitary confinement?”²⁶ Mary Mallon lost her identity to Typhoid Mary as surely as patients at Carville lost their identities to the symbolic leper.²⁷

Many people, stigmatized because of illness, who might have sympathized with the plight of patients exiled to Carville, instead felt a sense of superiority to those with leprosy, despite the fact that tuberculosis and typhoid both had far higher levels of communicability. Tuberculosis had a higher degree of contagion, but a much lower degree of stigmatization, perhaps

²⁴ Sheila M. Rothman, *Living in the Shadow of Death: Tuberculosis and the Social Experience of Illness in American History*. (New York: BasicBooks, 1994.) p. 190

²⁵ *Ibid.*, pp. 212, 234

²⁶ Judith Walzer Leavitt. *Typhoid Mary: Captive to the Public's Health*. (Boston: Beacon Press, 1996.) p. 11

²⁷ *Ibid.*, 125

demonstrated most effectually by the many patients at Carville who, to explain their absences to their friends and family, claimed to have tuberculosis instead. Because both leprosy and tuberculosis were chronic diseases that could force a patient to leave home and affected the victim for years or decades, tuberculosis proved a convenient lie that protected the families of those suffering from leprosy from the extension of the leprosy stigma.²⁸

Victims of the leprosy also often found themselves lumped in with the mentally insane. The Civil District Court for the Parish of Orleans, when sentencing a patient to the Louisiana Leper Home, used the exact form typically used to confine patients to the Louisiana Hospital for the Insane. The scribe simply replaced the words “lunatic” and “insane person” on the warrant with “leper.”²⁹ As often and easily as the outside world used the word “leper” to encapsulate everything that could possibly be important about the victim, the residents of the hospital did the reverse. Many patients internalized the stigma, but could not quite adjust to the idea of being a “leper.” Several patients have acknowledged a refusal to use the word; on the grounds of the hospital, patients referred to their affliction as “the disease,” “the package,” or “the gazeek.”³⁰

The Louisiana Leper Home, as envisioned by Isadore Dyer, would have been an asylum for people that had fallen victim to a terrible disease, where they could be safe from public judgment, as well as a hospital where researchers could work on curing the illness. For other

²⁸ Carville patients Betty Martin and Nick Farrell, among others, claimed to have tuberculosis to explain away their long absence from home, a tactic often recommended by their doctors. Because many tuberculosis patients often sought fresh air, moving to Arizona or New Mexico in search of a healthier climate, tuberculosis provided an adequate excuse.

²⁹ People found to have leprosy often ended up subject to the judgments of courts as if their disease rendered them criminals or mentally incompetent.

³⁰ Betty Martin, *Miracle at Carville*. (New York: Doubleday & Company, Inc, 1950) p. 45

supporters of its establishment, it would serve as a quarantine facility to remove dangerous people from society, sending with them the risk of contamination. Not until the 1940s would Carville become a center for cutting-edge research. Until then, patients entered the hospital with little to no hope of a cure. Because they had no expectation of recovery or even semi-adequate medical treatment, sanatoriums and quarantine stations often “were more like prisons than hospitals.”³¹ According to Tony Gould, an historian of disease in the modern world, the patients’ lack of expectations or hope influenced how they viewed their caretakers as well, considering them both “angels of death as well as angels of mercy.” The state legislature similarly “saw no point in spending money on an incurable disease; it is enough that its victims were isolated and had a refuge.”³² Sister Beatrice, and her successor, Sister Benedicta Roach, would often fight tooth and nail with the Board and Louisiana’s General Assembly in order to secure funds for the hospital to make the patients’ lives more comfortable, but the nuns could only accomplish so much, and by the time of the federalization of the hospital, the Louisiana Leper Home was deeply in debt.

Gould’s assertion that the inadequacy of funding to the Louisiana Leper Home was borne out of the state legislature’s ambivalence toward helping those specific residents unfairly misrepresents the members of the Louisiana General Assembly. As a whole, in 1915 and afterward, the years when the Home began to accrue a significant debt, Louisiana had been cutting spending across the board. Their failure to appropriate enough funds to support Carville

³¹ Rothman, p. 252

³² Gould, p. 203

was not “directed at lepers alone,” because the state of Louisiana had been similarly cutting funding to the seven other state-supported institutions.³³

The Louisiana Leper Home also continued to suffer from staffing problems, despite the employment of the Daughters of Charity. Only a few nuns could not meet the challenge of serving as administrators, nurses, counselors, groundskeepers, and moral authorities to several dozen patients, and so they expected the physically able among the patients to help care for the more seriously ill. The Board of Control scolded noncompliant patients via letter. Patient Madeline Phillips received a letter admonishing her that “It should always be the duty of those patients who are physically strong to assist those who [sic] condition is such that they are not able to do much for themselves.” Concerning the same patient, the president of the Board wrote to Sister Benedicta that “it does seem as if some of the poor unfortunates do not appreciate the many sacrifices made by the sisters in giving up their lives to their cares.”³⁴ Exchanges like this support G.A. Ryrie’s claim that when people motivated by religion or guilt/punishment complexes minister to victims of the disease, “sufferers from leprosy are frequently blamed for ingratitude.”³⁵ However, patients felt that having been locked away against their will, they should not be obligated to work for their keep.

For all of the problems that the Daughters of Charity faced, from patients keeping guns on the premises to patients violating the sexual segregation of the institution, the constant issue

³³ Zachary Gussow, *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control*. (Boulder: Westview Press, 1989.) p. 65

³⁴ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letters from Board of Control to Sister Benedicta and Madeline Phillips, September 17, 1913

³⁵ Ryrie, p. 23

of patients absconding from the Home provided the biggest bone of contention. To address the issue, the Board resolved on November 1, 1913 that “in order to prevent the escape of patients confined to the Leper Home that the same should be enclosed with an iron fence of sufficient height to make it impossible for patients to withdraw there” and that “four watchmen should be appointed to guard the premises.”³⁶ The Board further authorized Sister Benedicta, after several letters of complaint concerning the lack of penalty to returning runaways, “to use such means as may be necessary to enforce the rules of the Home and keep patients on the premises.”³⁷

The Board of Control eventually constructed both a fence to keep patients in and a jail to punish those that returned. Some patients returned in leg-irons, tracked down by law enforcement or officers of health, but even knowing that a jail sentence awaited them as punishment for absconding, some patients returned voluntarily, unable to face the stigmatization of the world outside. The stigma they faced and the isolation of the hospital made them self-sufficient. During its tenure as the Louisiana Leper Home, the hospital at Indian Camp Plantation developed a power plant, a dairy farm, vegetable fields, and poultry farms. As the beginning of the twentieth century wore on, so did a movement to isolate the country’s leprosy sufferers on a national level. Fencing in the afflicted in Louisiana and banishing those in Massachusetts to an island in the middle of a bay was not enough for increasingly paranoid national lawmakers at a time when immigrants and veterans alike imported leprosy with them from foreign parts. The

³⁶ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Enclosed resolution to Harold Newman, New Orleans Commissioner of Public Safety, November 5, 1913.

³⁷ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letters from Board of Control to Sister Benedicta, July 13, 1914.

next chapter will detail the arguments that led to the federal takeover of the Louisiana Leper Home.

As much as an increasingly suspicious nation wished it, the building of fences would not keep the patients from participating in the world for very long. Individuals continued to abscond through a hole in the fence, despite facing penalties upon their return, and as the 1930s rolled around, the patients would band together and reach out to organizations with the political power to help them. They learned to use the power of the press to fight to regain their rights, because for all of the stigma, segregation, and isolation they faced, they did not live in “a world apart.” They became adept manipulators of public sentiment in an effort to turn the forces of public opinion toward their goals.

2. FOR LACK OF BETTER OPTIONS

*Uncle Sam is as slow in taking over the Home as he was in getting into the world war.*³⁸

Leprosy inspired an inordinate amount of fear relative to the actual risk of contagion. Stories of afflicted persons walking the streets undetected, not easily identifiable and potentially contaminating others terrified many. Unsurprisingly, Louisiana, the state with the longest history of both endemic leprosy and charitable hospitals, created a space for its afflicted.³⁹ More surprisingly, in a total departure from previous public health policy, a quarter of a century later the federal government nationalized the Louisiana Leper Home at Carville, Louisiana, creating Marine Hospital 66, run by the Public Health Service. The nationalization of leprosy represented an unprecedented expansion of federal power over public health, yet tuberculosis, syphilis, polio, cholera, yellow fever, and typhoid all posed greater risks of contagion and death. That leprosy, today commonly referred to as Hansen's Disease, would generate such national interest is less indicative of its actual menace and more a measure of growing nativism and the increasing stigmatization and moralization of the disease. As the United States began to build an empire, annexing Hawaii and the Philippines and extending its involvement internationally, leprosy became an issue not only for local governments, but for the federal government as well.

The first time that leprosy appeared before Congress, the Surgeon General Walter Wyman sought approval for an investigatory commission to “inquire further into the origin and

³⁸ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Sister Edith to Secretary of Board of Control, Gary Knobloch, October 15, 1920.

³⁹ Explanations for why Louisiana has a higher number of leprosy patients than any other state vary.

prevalence of the disease, and to determine just how far it is a menace to our people.”⁴⁰ While the Marine Hospital Service (as the Public Health Service was then called) had been steadily expanding in scope over the course of the 1890s, and investigating diseases was well within its purview, the Surgeon General still required congressional approval to spend money on such an undertaking.⁴¹

The bill was passed, and then signed into law by President William McKinley in March of 1899.⁴² The appointed commissioners, Joseph White, George Vaughan, and Milton Rosenau, were all doctors with “extensive experience in colonial quarantine and contagious disease research,” which influenced their views “regarding the kind of intervention the federal government could make.”⁴³ The United States interfered in the health of their colonial subjects far more than they did in their own continental citizens. In 1901, for example, the federal government constructed the world’s largest “leper colony” on the island of Culion in the Philippines.⁴⁴ The Philippines had a much higher incidence of leprosy than the United States,

⁴⁰55th Congress, 2nd session, Senate Report no. 463, from the Committee on Public Health and National Quarantine and House of Representatives Report no. 1215 from the Committee on Interstate and Foreign Commerce, “Investigation of Leprosy.”

⁴¹ Bess Furman, *A Profile of the United States Public Health Service: 1798-1984*. (Washington: U.S. Government Printing Office, 1973.) p. 22

⁴² *Congressional Record*, 55th Congress, 3rd session, 2899, volume XXII, part III: 2492

⁴³ Michelle Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*. (Chapel Hill: University of North Carolina Press, 2007.) p 25

⁴⁴ Philip Kalisch, “Lepers, Anachronisms, and the Progressives: A Study in Stigma, 1889-1920.” *Louisiana Studies: An Interdisciplinary Journal of the South*, Vol. 12, 1973 pp. 510. For more examples of federal intervention in public health abroad, consider imperial politics on syphilis in Puerto Rico (Laura Briggs’s *Reproducing Empire: Race, Sex, Science, and U.S. Imperialism in Puerto Rico* and Eileen Findlay’s *Imposing Decency: The Politics of*

and colonial officials imposed strict laws concerning the spread of disease in addition to improving sanitation and imposing American values. Options available for dealing with diseases of colonial subjects increased dramatically as the government did not feel particularly bound to protect the rights of the ill.⁴⁵ Involvement in the Philippines by colonial governors, missionaries, and the military led to increased reports of leprosy in the United States as Americans abroad carried diseases home with them.

In the commission's report, presented in March of 1902, the doctors confirmed 278 cases of leprosy in the United States, but cautioned that "on account of the loathsome nature of the disease, which has clung to it from antiquity, there is an inclination on the part of the patient himself, as well as upon the part of his family and friends, to conceal the affliction from the public."⁴⁶ The nature of healthcare in hospitals and pesthouses further dissuaded patients from revealing their disease. Pesthouses typically had an eye primarily toward protecting the community by isolating the sick, not toward caring for the sick. Care tended to be custodial only in nature.⁴⁷ The report further concluded that while the number of the afflicted was low, even accounting for the unreported patients, at least one leprosarium, possibly two should be

Sexuality and Race in Puerto Rico, 1870-1920) as well as sanitation measures concerning yellow fever in Cuba (Mariola Espinosa's *Epidemic Invasions: Yellow Fever and the Limits of Cuban Independence, 1878-1930*).

⁴⁵ For a thorough discussion on American health officials in the Philippines, see *Colonial Pathologies: American Tropical Medicine, Race, and Hygiene in the Philippines* by Warwick Anderson.

⁴⁶ Serial Set Vol. No. 4239, Session Vol. No.20, 57th Congress, 1st Session, S.Doc. 269. "Letter from the Secretary of the Treasury, transmitting letter from the Surgeon-General of the Marine-Hospital Service presenting a report relating to the origin and prevalence of leprosy in the United States. March 24, 1902. -- Referred to the Committee on Public Health and National Quarantine and ordered to be printed."

⁴⁷ John Duffy, *The Sanitarians: A History of American Public Health*. (Urbana: University of Illinois Press, 1990.)

established in a “salubrious climate...made as attractive as it is possible to make them...where the inmates can have unlimited and unrestrained outdoor exercise and occupation, roaming over well-kept grounds.”⁴⁸ The commissioners hoped that if given an attractive and comfortable option of quarantine, victims of leprosy would freely enter the institution instead of hiding their disease.

The report presented many arguments for the establishment of this institution, citing a leprosarium as in the best interest of both the public and the victims of the disease. Included in the document was the “Report of the Secretaries of the International Leprosy Conference, Berlin, 1897,” wherein it was concluded that “every leper is a danger to his surroundings.” An article by H.M. Bracken of Minneapolis, reprinted from the *Philadelphia Medical Journal* (Dec. 17, 1898), asserted that not only would leprosaria protect the public, but they would also protect those afflicted from ostracism by the public as well.⁴⁹ And in case the congressmen did not find these findings compelling enough, gruesome pictures of foreigners with debilitating deformities were included to emphasize the foreign and unclean nature of the disease.

Particularly enthusiastic in pushing for the leprosarium was Walter Wyman, the Surgeon General. Walter Wyman took office as Supervising Surgeon General in 1891, and two years later the Quarantine Law of 1893 had authorized the MHS to federalize state quarantine stations—with permission from the state government. The act “places upon the Supervising Surgeon General of the Marine Hospital Service the performance of all duties relating to quarantine and

⁴⁸ Serial Set Vol. No. 4239, Session Vol. No.20, 57th Congress, 1st Session, S.Doc. 269. “Letter from the Secretary of the Treasury, transmitting letter from the Surgeon-General of the Marine-Hospital Service presenting a report relating to the origin and prevalence of leprosy in the United States. March 24, 1902. -- Referred to the Committee on Public Health and National Quarantine and ordered to be printed.”

⁴⁹ Ibid.

quarantine regulations,” granting the MHS enormous power over ports and immigration.⁵⁰

Wyman greatly expanded the MHS under his tenure, enlarging its functions and growing the budget by over a million dollars during his twenty years in the position.⁵¹ Wyman used the opportunity that leprosy provided as a pretext to expand the power of his organization, “translating fears into increased regulatory control over immigration.”⁵²

Pressure for a leprosarium came not only from the MHS, but also from several state governments. Support for the use of sanitarium in convalescence rose in the last decades of the nineteenth century, but most sanitarium, which “applied earlier therapies of beneficial climate, fresh air, and supervised, nutritious diets to groups of patients in an institutional setting,” were both voluntary and very expensive.⁵³ Immigrants without families often consigned themselves to local pesthouses while the wealthier stayed at their homes. Communities began to request the intervention of the federal government in what had before been a matter for individual states. Doctors in Florida and Pennsylvania, states with very few cases of leprosy, petitioned for federal aid because the limited number of individuals in need of care posed too great a strain on the community. A national leprosarium would relieve local communities “of both the financial costs and the social affliction of harboring people with leprosy.”⁵⁴ In the years before the publication

⁵⁰ Laurence F. Schmeckebier, *The Public Health Service: Its History, Activities and Organization*. (Baltimore: Johns Hopkins Press, 1923.)

⁵¹ Fitzhaugh Mullan, *Plagues and Politics: The Story of the United States Public Health Service*, (New York: Basic Books, Inc., 1989.)

⁵² Moran, p. 22

⁵³ Alan Kraut, *Silent Travelers: Germs, Genes, and the “Immigrant Menace.”* (New York: BasicBooks, 1994.) p.

⁵⁴ Moran, p. 20

of the MHS report, North Dakota petitioned Congress to establish a leprosarium, and California legislators called for a policy that would transport any victims out of the state, if not off the continent altogether.⁵⁵ Many county boards of health across the nation had been petitioning the Louisiana Leper Home to accept their afflicted, a responsibility the Board of Health of the Louisiana Leper Home eventually accepted, charging a price of \$5,000 a patient and requiring that the petitioning county provided transportation.

California in particular contained a virulently leprophobic population; its fear of leprosy was closely tied to the yellow peril and sinophobia. Discourse on public health tended to be racist rather than scientific, and leprosy became a political tool used by politicians and nativists to stir up prejudice against the Chinese in the 1870s.⁵⁶ Public health became one of the most effective tools in the effort to limit Chinese immigration, and in 1882, Congress passed the Chinese Exclusion Act.⁵⁷ Leprosy was an important tool in discourse against the Chinese, despite its lack of risk of contagion. Alarm over leprosy and Chinese immigration mutually reinforced each other, as “the fear of leprosy itself rode through Western nations on the tidal wave of the forces of racism and the yellow peril.”⁵⁸ Yet increased imperial involvement also meant that not only was the government probably accepting disease in with immigrants, but that American soldiers serving abroad might acquire diseases and bring it back with them. Veterans

⁵⁵ Moran, pp. 24-25

⁵⁶ Natalia Molina, *Fit to be Citizens? Public Health and Race in Los Angeles, 1879-1939*. (Berkeley: University of California Press, 2006.)

⁵⁷ Kraut, pp. 82-83

⁵⁸ Zachary Gussow, *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control*. (Boulder: Westview Press, 1989.) p. 115

with tropical diseases confused attempts to define certain illnesses as specific to the immoral, the unclean, or the racially inferior.

An American determination to define leprosy as a foreign disease further hardened in the 1904 and 1905 congressional discussions on leprosia. With the annexation of Hawaii, the United States inherited a large number of leprosy patients, sequestered on the island of Moloka'i. When debating the newly renamed Public Health and Marine Hospital Service's adoption of the settlement on Kalua'papa (the peninsula on Moloka'i to which the patients were banished), Representative Hepburn of Iowa presented a bill, that sought to establish *not* "a hospital for the care of lepers on the Hawaiian Islands," as Representative Robinson of Indiana assumed, but instead "a laboratory there for the purpose of studying the disease."⁵⁹ Upon federalization, Hawaiian patients were to become subjects of laboratory experiments in service of treating leprosy on the continent. The bill sailed through Congress.

While Congress easily supported a leprosarium full of foreign patients on a colonial acquisition, the concurrent bill on leprosy that called for a continental leprosarium provoked much more controversy. Again presented by Representative Hepburn (and vehemently supported by Walter Wyman), this bill inspired dissent not only because no congressman wanted the leprosarium located within his own state but also because representatives feared that establishing a national leprosarium extended beyond the boundaries of the federal government and infringed upon states' rights.

Representative Williams of Mississippi was the first to object to H.R. 16913 out of concern that the leprosarium would be foisted on either Arizona or New Mexico. Rep. Stephens of Texas suggested instead that any continental patients simply be shipped to the colony at

⁵⁹ *Congressional Record*, 58th Congress, 3rd Session, Vol. 39, pt. 4, p. 3667

Kaluapapa, to which Rep. Hepburn protested that “if the gentleman had a relative so afflicted he would hesitate long before expatriating and driving him thousands of miles across the sea.” He continued to steer the discussion toward the possibility of a hospital in Indian Territory until the Delegate to Congress from New Mexico, Bernard Rodey demanded of the House “How would you gentlemen like to have the tinkling bell sounding and the white shroud of the leper stalking through your back yard in the morning, as described in Ben Hur?...Instead of being the health resort of the nation, it will become the most abhorred and shunned locality we have.”

Rodey continued on to declare that the nationalization of leprosy was “wrong in principle” as the care of patients was the business of the individual state. The precedent set by the nationalization of leprosy would lead to “care of consumptives nationally, and of fever and smallpox patients nationally, and of every sort of disease.”⁶⁰ However, his argument for New Mexico and Arizona’s status as the “health resort of the nation” held considerable sway with the representatives. Representative Sibley of Pennsylvania suggested that introducing leprosy into the Territory of New Mexico would kill all those with pulmonary and bronchial disease who traveled to the territory for the clean air.⁶¹ Rep. Sims of Tennessee agreed with Sibley and Rodey, and prioritized the relief of those suffering from tuberculosis and lung troubles over those suffering from leprosy. The discussion turned again toward utilizing one of the island acquisitions as a location.

The representatives continued to quarrel over the location of the potential leprosarium until Rep. Hitchcock of Nebraska chastised the gentlemen from the Territories for being “unduly excited by their fears.” Hitchcock held radically different opinions from many of his peers, and

⁶⁰ *Congressional Record*, 58th Congress, 3rd Session, Vol. 39, pt. 4, pp. 3908-3909.

⁶¹ *Ibid*, p. 3909

far from assuming that patients should simply be sent off to one of the island territories, exploiting the islands for the benefits that imperialism could grant the United States, he instead declared that “in entering upon a world-power policy, the evil of leprosy is one of the numerous evils which we have brought upon ourselves. It has not been brought upon us by a single State, but it has been brought upon us by a national policy of imperialism, and it is the duty of the nation having entered upon this policy to deal with this evil in the best way possible.” A staunch anti-imperialist, Hitchcock argued that not only should the United States care for the individuals with leprosy, but that they should not be shipped off to the colony at Moloka’i because “these hundreds of unfortunate beings have some rights which we should consider.” Because their misfortune was a direct result of American imperialism, the American government should not in turn “sentence them to expatriation for life.”⁶²

Hitchcock discredited the argument that the states should hold the responsibility for their care because not only was imperialism a nationally perpetuated sin, but also because with so few victims in each state, the governments of the individual states could not possibly deal with the disease as they should. However, since the representatives generally agreed that the increased incidence of leprosy in the United States was indeed due to imperial politics, and therefore the island nations (especially Hawaii and the Philippines) were to blame, the island territories of the United States became the probable locations once again. Rep. Williams suggested Guam as a possibility if not Moloka’i, as “I do not know what else Guam is good for. It has no population and it would be a good place to send nurses and lepers.”⁶³

⁶² Ibid, p. 3910

⁶³ Ibid, p. 3910

The Representatives, unable to select a location and unconvinced that nationalizing leprosy did not constitute a violation of states' rights, voted 36 ayes and 180 noes. The 1905 bill to establish a national leprosarium was defeated.⁶⁴ Despite the good intentions that many representatives appeared to have had, from caring for the diseased to protecting the healthy, Rep. Hitchcock was the only representative who claimed to be willing to accept a leprosarium. The fate of the colonial territories' role in American public health was determined at the behest of Congress alone. Arizona and New Mexico had delegates in Congress confident in eventually gaining the status of statehood and able to fight against their territories becoming a dumping ground for the diseased; Guam and Hawaii had no such privilege. Congress retained Moloka'i as a "leper colony," and by 1901, the United States had established another in the Philippines, on the island of Culion. The congressional treatment of continental Americans differed vastly from the treatment of their new territorial island acquisitions.

While the idea of a leprosarium still floated through Congress occasionally over the course of the next decade, legislators did not earnestly reconsider leprosy problem until 1914—the year of the famous journey of John Ruskin Early.⁶⁵

John Ruskin Early was born in 1874 in western North Carolina and enlisted in the United States Army in 1896. He served for nine years, traveled both to Cuba and the Philippines in the course of his service, and rose to the rank of corporal. In August of 1908, three years after his discharge, Early left his wife, Lottie, and his two children to travel to Washington D.C. "to see

⁶⁴ Ibid, p. 3911

⁶⁵ *Congressional Record*, 17 June 1910, 8448, James Wickersham, delegate from Alaska attempted to establish a leprosarium for Creoles, Indians and Eskimos. *Congressional Record*, April 7, 1913, p. 87, the House Committee on Interstate and Foreign Commerce killed Rep. Abraham Lafferty of Oregon's attempt for a leprosarium.

about a pension claim for his recently aggravated malaria.”⁶⁶ Suffering additionally from a horrible rash and inflammation on his face, Early contacted a doctor. Upon discovering that Early had served in the Philippines, his doctor called in Dr. William C. Fowler, an inspector for contagious diseases in Washington, and later Dr. Joseph Kinyoun, a pathologist and the founder of the U.S. Public Health Service Hygienic Laboratory. The doctors confirmed that Early had leprosy, and immediately quarantined him in a tent near the Potomac River.⁶⁷ Lottie traveled to share his quarantine, but was told that she could either live with her husband or keep her children. To compromise, Lottie and John were permitted to share a house that had been bifurcated by a brick wall. They communicated by rapping on the wall separating them, with a guard stationed full time to make sure they did not make physical contact.

Over the next several years, Early was shunted from quarantine station to pest house to quarantine station until he allegedly became violent and manic in his segregation.⁶⁸ Lottie divorced him in 1912, and Early began to plot. In May of 1914, he deserted his quarantine station in Port Townsend, Washington and lost his pursuers in British Columbia. Two weeks after eluding his pursuers, John Early was found—on the front page of several newspapers.

Early was well aware of the class component of health regulations. MHS inspections of immigrants, for example, authorized in 1891, were often extremely thorough for the poor, yet merely perfunctory for the wealthy.⁶⁹ The wealthy sick could afford doctors, whereas the poor sick often lived in pest houses. To grab the attention of the wealthy and powerful, Early planned

⁶⁶ Philip Kalisch, “The Strange Case of John Early: A Study of the Stigma of Leprosy.” *International Journal of Leprosy*, Vol. 40, No. 3, Summer 1972, pp. 292-293

⁶⁷ *Ibid.*, p. 292

⁶⁸ “Early, the leper, goes crazy.” *New York Times*, July 11, 1913, p. 7

⁶⁹ Kraut, p. 53

his journey from Port Townsend to Washington D.C. very carefully. He saved his wages and his pension so that he could cross the nation in a Pullman car, stay at the best hotels and eat in the best restaurants. When he finally exposed his identity, he did so in Washington DC's Willard Hotel, where he called a press conference to announce that not only was he a leper, but that he was a leper staying at the same hotel as the Vice-President, several Congressmen, and foreign diplomats.

Early could arouse sympathy because he was not a foreigner who had brought a disease into the country, but an American soldier who had acquired the disease in the service of his country which subsequently shunned him. He told Dr. Fowler, the disease inspector and the crowd of journalists that he had called in that he knew “that if I mingled among the well-to-do and the rich and exposed them to contagion that they would arise out of self-protection and further my plan for a national home...If I had kept to the slums in my travels, the agitation would have been little.”⁷⁰ ⁷¹ The idea for a national leprosarium did not originate with Early, but he certainly served as an important catalyst to getting it put into action.⁷² He displayed “a far better understanding of mass psychology than most medical men” as well as a gift for political theater.⁷³ Disillusioned by the poor treatment he had received at the hands of local governments, Early wanted a national home not for the protection of the community, but for the comfort of the victims.

The very afternoon that Early's surprise visit to the capital appeared in papers, leprosy once again became a topic of discussion on the House floor. Rep. Raker of California declared

⁷⁰ *Congressional Record*, 63rd Congress, 2nd Session, Vol 51, pt. 10, p. 9823

⁷¹ Kalisch, “The Strange Case...” p. 298

⁷² Tony Gould, *A Disease Apart: Leprosy in the Modern World*. (New York: St. Martin's Press, 2005.) p. 192

⁷³ Kalisch, “The Strange Case....” p. 298

the situation to be “worse than turning loose a band of murderers.” Several representatives dithered and panicked over the lack of security at the quarantine station in Washington, and Mr. Johnson of Washington promptly suggested that the United States pay the Moloka’i territory to accept citizens of the United States with leprosy. He declared it absolutely necessary that something be done with the afflicted on the continent, as “a leper nowadays is pursued as he was long before Christ. He has no chance. He must go away.”⁷⁴ The problems of finding a location had not disappeared, but Early’s actions had impressed upon the representatives that a leprosarium must be established for the protection of everyone. The fear that someone with leprosy could contaminate the beds at a fashionable hotel electrified Congress.

After quite a bit of squabbling, the House passed H. R. 20040, which appropriated \$250,000 for the establishment of a national leprosarium, location to be determined.⁷⁵ In the Senate, Senator Ransdell of Louisiana and Chair of the Committee on Public Health and National Quarantine introduced and championed S. 4086 to establish the national leprosarium. Ransdell, as the Louisiana Senator, was familiar with the Louisiana Leper Home and better acquainted with the concept of a leprosarium in action. He also found John Early’s experience to be very important to the discussion. The leprophobic Congress did not permit Early himself to testify before them, but Ransdell went to visit him in his newly re-established quarantine and included Early’s letter in the Senate Report. Early wrote: “To segregate a leprous person is a wise and humane thing to do, but to let matters drift off in the present road is another thing. As soon as a leper is found, under present conditions, he finds himself out of a home and absolutely

⁷⁴ *Congressional Record*, 63rd Congress, 2nd Session, Vol 51, pt. 10, p. 9823

⁷⁵ *Congressional Record*, 64th Congress, 1st Session, Vol 53, pt. 8, p. 7431

unwelcome in the jurisdiction where he is found...Remember we are outcasts of society: yes, with human tastes and feelings.”⁷⁶

The bill passed with relatively little debate. The sole opposition came from Senator Charles Thomas of Colorado, on the grounds that the government should not set the precedent of institutionalizing disease. On February 7, 1917, it was announced in the House that President Woodrow Wilson signed into law An Act to Provide for the Care and Treatment of Persons afflicted with Leprosy and to Prevent the Spread of Leprosy in the United States.⁷⁷ John Early was sent to the Louisiana Leper Home, pending the formation of the federal institution, where he proceeded to make life exceedingly difficult for the administration. After federalization of the institute, in spite of living in the leprosarium he professed to want, he absconded several times to his brother’s farm in North Carolina.⁷⁸

American entry into World War I both delayed the establishment of a national leprosarium and increased American concern with the spread of disease. Also delaying the project was the “comedy of errors” that ensued from attempts to find a location for the leprosarium.⁷⁹ Assistant Surgeon General William Rucker wrote to each of the forty-eight state governments to ask for assistance to no avail. A commission led by a man named Dr. George McCoy was sent to scour the country in search of an ideal location, but the commissioners were run out of several communities when the locals discovered what the federal agents were trying to accomplish. The community of Gulfport, Mississippi almost tarred and feathered a federal

⁷⁶ 64th Congress, 1st Session, Senate Report no. 206, *Care and Treatment of Persons Afflicted with Leprosy*, “Report of the Committee on Public Health and National Quarantine of the United States Senate on S. 4086).

⁷⁷ *Congressional Record*, 64th Congress, 2nd Session, Vol. 54, pt. 3, p 2776. Public Law No. 299

⁷⁸ Gould, pp. 209-211

⁷⁹ Kalisch, “Lepers, Anachronisms, and the Progressives.” p. 517

health agent because they mistook him for a member of the commission.⁸⁰ Eventually the commission settled on a location, and in September of 1919, two islands near Cedar Key, Florida transferred to the Public Health Service.⁸¹

Those living near the islands in question, and most of the rest of Florida, reacted badly. Locals feared that exposure to the disease would contaminate the water, the fish, the fruit, and the cigars. They worried for the health both of their bodies and of their businesses. Sidney Catt, the governor of Florida, as well as both of Florida's Senators, four representatives, and several business officials met with the current Surgeon General, Robert Blue in a meeting that lasted fourteen hours, and the committee decision was overturned.⁸²

There already existed other locations where victims of leprosy were quarantined, and those locations were tossed around as possibilities. Massachusetts had a state leprosarium, established in 1905 on Penikese Island in Buzzard Bay.⁸³ California possessed a couple of small pesthouses managed by county governments. However, the largest and most populous leprosarium was the Louisiana Leper Home in Carville, still under the direction of the State Board of Control and managed by the Daughters of Charity of St. Vincent de Paul. Surgeon General Blue had already eliminated Carville as even an option for a potential location because the facility had "but little to commend it beyond the fact that it would have offered a prompt

⁸⁰ Victor Heiser, *An American Doctor's Odyssey: Adventures in Forty-five Countries*. (New York: Norton & Company Inc, 1936.) p. 256

⁸¹ Kalisch, p. 518

⁸² *Ibid.*, p. 519. No transcript exists for this meeting.

⁸³ Marcia Gaudet, *Carville: Remembering Leprosy in America*. (Jackson: University Press of Mississippi, 2004.) p.

solution to the question of providing a location.”⁸⁴ Carville certainly did not provide the “salubrious climate” recommended by the original commission to study leprosy, nor would a home there entice any of the ill to voluntarily submit themselves.

In fact, most patients already at the home wanted to move, as the leprosarium, located in a curve of the Mississippi River, was hot, swampy, prone to flooding in the summer, and under constant threat of malaria. Carville itself would not have served as a permanent location even for the state institution had the State Board of Control of the Louisiana Leper Home not suffered from many of the same problems in purchasing a property that the federal government now faced. It did not serve as the best possible location even within the state of Louisiana, and Louisiana certainly did not provide the best climate within the entire nation.

However, with an utter lack of better options and under the urging of the Daughters of Charity, Robert Blue decided to federalize the Louisiana Leper Home. Its availability trumped other concerns and considerations. The nuns at the Home hoped that if the federal government took over, the home would receive better funding, and the Major Officer in Charge, Oswald Denney, agreed to retain them as nurses and administrators.⁸⁵ Leadership changed hands from Louisiana to the Public Health Service in February of 1921 after some haggling over the price. The home had been consistently underfunded, and had little equipment, no hospital facility, and poorly built structures. Furthermore, the property had to be drained and the swarms of mosquitos eliminated.⁸⁶ However, despite the amount of work to be done, the federal government only spent a fraction of the \$250,000 originally allocated to the new Marine Hospital

⁸⁴ *Annual Report of the Surgeon General of the Public Health Service of the United States*, 1919, p. 81

⁸⁵ Moran, p. 100

⁸⁶ *Annual Report of the Surgeon General of the Public Health Service of the United States*, 1932, pp. 317-318.

no. 66. The only other continental leprosarium, the home on Penikese Island in Massachusetts containing 13 inmates, was promptly evacuated, and the boxcar the patients travelled in as well as the buildings on the island were burned.

Despite fears of precedent-setting, the federal government has not taken it upon itself to federalize disease management as a whole for the United States.⁸⁷ Though the Public Health Service cares medically for Indian tribes, veterans, Federal employees, and several other groups, there has been no federal law to incarcerate victims of other specific diseases.⁸⁸ The PHS has expanded in scope in the time since the federalization of leprosy, but not to the extent of removing the control of healthcare from local communities. In the federalization of disease, leprosy has retained its unique position in the history of public health and federal intervention. The hospital at Carville shared more in common with federally sponsored places of confinement than recuperation. Furthermore, Public Act 299, which officially created the leprosarium, did not grant the federal government the power to force individual states to send their ill to Carville, nor did it make leprosy a federal crime. As each state still designed its own health policy, the extent of the quarantine depended on local officials.⁸⁹ The Surgeon General could send for “persons afflicted with leprosy” only “at the request of the state or territorial authorities.”⁹⁰

⁸⁷ This does not apply to disease management in imperial acquisitions.

⁸⁸ Ralph Chester Williams, *The United States Public Health Service, 1798-1950*. (Washington: Commissioned Officers Association of the United States Public Health Service, 1951.) p. 159

⁸⁹ Gussow, p. 152

⁹⁰ Schmeckebeier, p. 42. For the most part, discussion about leprosy on the federal level centered around states’ rights against the powers of the federal government. The question of whether an individual patient might have rights of his or her own against the common good or public health rarely arose in this discussion. However, the Progressive

Unfortunately, with the segregation of leprosy and the subsequent decline in Western anxiety, leprosy lost its claim to a place in the scientific community, as U.S. leaders “effectively reclassified the disease. They removed leprosy from a medical context and made it a social or moral issue.”⁹¹ With the patients exiled, fear of contagion and the need for cure dwindled. Even though the federal government refurbished the facility as a hospital rather than just a home or an asylum, the Public Health Service did not even hire a bacteriologist until over a decade later. The Daughters of Charity stayed on as caregivers, nurses, and moral supervisors. However, despite lackluster attention to patient needs and a smaller budget than promised, the federal takeover of the home did lead to vast improvements in the hospital’s infrastructure and the relationship between patients and administrators.

Era saw many controversial disputes over this issue, including both the case of Mary Mallon and the Supreme Court’s 1905 decision in *Jacobson v. Massachusetts* to allow compulsory vaccination laws.

⁹¹ Gussow, p. 131

3. THE BIRTH OF A MOVEMENT

*I was already inspired with the idea of breathing community life into the zombies there.*⁹²

Under the auspices of the State Board of Control of the Louisiana Leper Home, the Daughters of Charity were “entitled and privileged to inculcate good morals among the inmates, without interfering with their religious belief, to maintain proper decorum, good order and discipline, and to enforce the rules now in force.”⁹³ While the Daughters of Charity pushed for many improvements for the patients, their rules often caused friction between the sisters and the patients. One patient complained that “It’s bad enough we have to be isolated here from the outside world for humanity [sic] sake without wanting to take sutch [sic] means that may make our lives more miserable than what it is already.”⁹⁴ Most offensive to the patients were the very strict regulations concerning interactions between the male and female patients. A fence separated the male side from the female side of the campus, and even close relatives of opposite sexes could not spend time in each other’s company.

The patients could write letters of complaint to the Board of Control as their only recourse, and that method often failed them. Because the Daughters of Charity entered quarantine so willingly and cared for the residents so cheaply, the Board of Control proved more than willing to support their methods. One disgruntled patient wrote a politely worded letter to

⁹² Stanley Stein and Lawrence Blochman, *Alone No Longer: The Story of a Man Who Refused to Be One of the Living Dead*. (New York: Funk & Wagnalls, 1963.) p. 107

⁹³ Carville: Correspondence. Box 1, Folder 1. Daughters of Charity Province of St. Louise Archives, Emmitsburg, MD

⁹⁴ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. M.J. Abrams to Mr. Phelps, Sept 7, 1902.

the Board, asking them “to permit the patients of both sex to assemble under the oaks here on Sunday afternoons, between the hours of 1PM and 4PM, with as many chaperones as you wish to accompany them.”⁹⁵ When he received no reply, he wrote a more strongly-worded letter, reminding Mr. Phelps that “when you were up here last year you told the patients here to get together and form a committee of several patients, so that when we had any reasonable request to make the Board of anything that could benefit us, or give us at least a small amount of pleasure, it would be granted to us.” Drew noted that his request for “a few hours of innocent pleasure and amusement on Sunday afternoon” cost no one any money, nor would invite any inappropriate behavior between the sexes, as “we are only asking to be together in the broad daylight...under the keen eyes of as many chaperone or sisters as the Board may see fit.”⁹⁶

Nonetheless, the Secretary of the Board sent a fairly terse response, stating that “in a meeting of the Board, held this day, I was instructed to inform you that the Board will not tolerate any intermingling of the sexes.”⁹⁷ Forming a patient committee had not helped achieve any goals. The committee had no political leverage, nor lobbying power; it could not even send a representative for face-to-face meeting. Any changes or improvements had to be given to them

⁹⁵ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letter from John Drew to Mr. Phelps, July 1, 1907

⁹⁶ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letter from John Drew to Mr. Phelps, July 24, 1907

⁹⁷ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Letter from John Pollock to John Drew, August 16, 1907.

by the Board or the Daughters of Charity. When writing letters in hopes of a change in the rules did not work, the patients settled instead for petty vengeance against the Sisters.

Life for the patients at Carville considerably improved under the administration of the Public Health Service. Not only did the federal government have much more money to spend on structural improvements for the hospital, but some of the restrictions on patient behavior were, if not lifted, lightened. When Oswald Denney took over the running of Carville as the Medical Officer in Charge, reducing the power of the Daughters of Charity who continued on as paid nurses, the first move he made (and a wildly popular one at that) was to tear down the fence separating the sexes. He also allowed the patients to have a dance, at which male and female parents were not only invited, but encouraged to mingle. Eventually, Denney codified many of the regulations implemented by the Daughters of Charity, including restrictions on male/female interactions, but patients easily found ways around them.⁹⁸ Furthermore, able-bodied patients no longer suffered the obligation to take care of their worse-off brethren or help maintain the grounds to earn their keep. Instead, those responsibilities turned into paying jobs that the PHS employed willing patients to undertake. Structurally, in 1923, Congress appropriated \$645,000 to expand the population Carville could support, as well as to build a lab, a facility for a surgery, and to purchase therapeutic equipment.⁹⁹ The Public Health Service also oversaw a great deal of sanitation work, “redigging ditches, clearing underbrush” and a drainage project to ameliorate the mosquito problem.¹⁰⁰

⁹⁸ Moran, p. 126

⁹⁹ Stein, p. 101

¹⁰⁰ Schmeckebier, pp. 85-86

Yet despite these vast improvements, patients Stanley Stein and Betty Martin both remarked on the level of apathy at the hospital. As long as no cure existed, nor any real hope of a cure, the patients floated along as wards of Uncle Sam, stigmatized by the outside world and unable to envision any realistic hope for the future. Until they tested negative for the bacillus twelve months in a row, they could not leave the home, and most patients quickly realized despite propaganda that the chances for that were slim. Many patients pocketed extra chaulmoogra oil, the latest in ineffective cures, to send home to family members with the disease so that their relatives would not also be trapped inside Carville.¹⁰¹

Though living conditions improved and the Public Health Service updated the hospital, it took ten years to hire a bacteriologist; until then, no one at the hospital undertook any research to fix the condition. Nor did all the objectionable rules change overnight. For example, the Public Health Service did not tolerate the patients to own guns and hunt on the property any more than the Daughters of Charity did, but patients simply continued to break many of the rules they despised. The fence still separated patients from the outside community, and while regulations concerning male and female interaction were relaxed, they were not eliminated.

Federalization also led to a huge growth in the patient-body, a patient-body that would prove very diverse and very unusual, especially for a community in the rural South. The Public Health Service regulations stated that anyone living in the United States could be admitted to Carville for treatment regardless of nationality, and leprosy has always been a democratic disease, with little regard for race or class.¹⁰² A relatively small patient body meant that people

¹⁰¹ Stein, p. 57

¹⁰² Even the very small number of patients who wrote memoirs of their time in Carville prove to be a somewhat diverse group: Stanley Stein, a Texan Jew; Betty Martin, a white New Orleans debutante; Jose Ramirez, a Mexican-American; D.J. Lebeaux, a Cajun sharecropper.

interacted regularly with a variety of dissimilar people, as “horizontally, Carville was a cross-section of the world’s races and nationalities; vertically, it cut through all social and economic strata.”¹⁰³ The patient make-up also complicated the job of the chef, as he had to accommodate various religious dietary restrictions.¹⁰⁴

The Public Health Service upheld segregation in housing, separating black, white, and Asian patients.¹⁰⁵ However in other ways, Carville proved entirely anomalous to the rest of the Jim Crow South. When patient Betty Martin arrived in the 1920s, a woman named Mrs. Blake had been teaching students of various races and nationalities as a class.¹⁰⁶ Blacks and whites earned the same amount for the same jobs, as did men and women; salary discrepancies existed between patients and outside employees. Segregation existed most completely between the staff and the patients, not among the patient body, where patients mixed across class and color lines.

In fact, some of the most lucrative jobs in Carville, if not exactly government regulated or sanctioned, belonged to foreign patients. A particularly well-integrated element of Carville society was the gambling table, which “had an international trend.” The Chinese patients ran the most popular game at Carville, linchee linchee. The best-paying jobs in the hospital included running a gambling a table and bootlegging alcohol.¹⁰⁷ Though Carville may have suffered from a lack of esprit de corps, “there was no lack of rugged individualism.”¹⁰⁸ Patient enterprises

¹⁰³ Stein., p. 61

¹⁰⁴ Ibid., p. 71

¹⁰⁵ Moran, p. 128. However, when a black patient decided to move into a white cottage, his request was approved without controversy and he received no trouble from his new roommates.

¹⁰⁶ Martin, p. 33

¹⁰⁷ Ibid., p. 87

¹⁰⁸ Stein, p. 82

thrived. Chinese patients opened the Chinese Cook Shop (also the home of the gambling tables), where “tasty food could be obtained at civilized hours” as opposed to the institutional dinner time of 4:30 in the evening. A couple of patients, Doc Sid and Big Joe, kept bees, selling the honey to other patients. Other less reputable industries also flourished, such as the winery in House 42, or the marijuana patch and cigarette machines run by Billy Lee, Carville’s closest approximation to a political boss.¹⁰⁹

Despite the free intermingling between races and nationalities, segregation defined many aspects of life at Carville. However, the entire patient body faced the segregation from the outside world together. When patients arrived at Carville, one of the first questions asked upon entry was “What name would you like to take?” This question completely demoralized many patients and forced them to part with their identities, yet patients complied as aliases existed to protect the families left behind. Patients came up with elaborate stories to tell their friends and families back home to explain away their absences, because otherwise local boards of health might harass their families, or superstitious communities might prohibit them from attending school.¹¹⁰ Some patients guarded their identities more closely than others. The father of patient Harry Martin feared that his community would boycott his store and that his house would depreciate in value if it came to be known that someone with leprosy had lived there.¹¹¹ The patient-body did not know that two close friends, Ringling and Moore, were in fact brothers until

¹⁰⁹ Ibid., pp. 82-83, 62

¹¹⁰ Patient aliases served another purpose apart from protecting the families of patients. If patients absconded through the hole in the fence (taking “French leave”), fake names and hometowns made it more difficult to track them down and remand them back to the institution.

¹¹¹ Martin, p. 86

the death of one.¹¹² One patient at Carville, Mary Ruth, believed that her sister had left Texas to go to college in New Orleans. Five weeks before Mary Ruth herself departed for Carville, she learned that her sister had been at the hospital the entire time.¹¹³

This world, a small microcosm in a bend of the Mississippi River, separated from the world by secrecy, fear, and barbed wire, was the world that Stanley Stein entered in March of 1931. Stein had kept his condition a secret for ten years with the help of a sympathetic physician in Texas, but as his condition worsened, he decided to seek treatment in Carville. In Carville he encountered the institutionalized patients, and registered confusion at “the strange moral climate” and the “curious feeling of hopeless apathy.” Perhaps unfairly, Stein described the patients as “zombies,” primarily preoccupied with “superficial, day-to-day concerns, makeshift vehicles of escape from despair” and only mildly interested in staying alive.¹¹⁴ The events that garnered the most interest in Carville were the twice-weekly movies, shown via an antiquated projector system.

If Stein believed that the patient body felt apathetic and did not exert any energy in improving their lives, it may be because compared to Stein himself, they were in fact listless about their prospects. Betty Martin, when describing Stein’s arrival to Carville, wrote, “I feel helpless, trying to write about Stanley. Sometimes I think none of us knew what vitality could mean until he came...Stanley turned Carville inside and out and made it shine with possibilities, bringing out the best in all of us.”¹¹⁵ A few months into his life at Carville, Stein threw himself

¹¹² Stein, p. 37

¹¹³ Gould, p. 377

¹¹⁴ Stein, p. 46

¹¹⁵ Martin, p. 89

into building community spirit and within two months of his arrival, “he had urged into existence Carville’s first newspaper.”¹¹⁶

Stein named the community newspaper the *Sixty-six Star* in honor of a newspaper he once worked for in Texas and the hospital designation of United States Public Health Service Hospital 66. The purpose of the *Sixty-six Star* was to link together the entirety of the diverse patient body and serve as “a single rallying point for all factions and cliques.”¹¹⁷ It began as a weekly that printed local news: community gossip, jokes, the Sunday dinner menu. The Medical Officer in Charge, at that point Dr. Herman E. Hasseltine, censored it, and it could not print anything critical of the administration.¹¹⁸¹¹⁹

Before the arrival of Stanley Stein and his concerted efforts to wake up the community, a general malaise infected the patient-body. On their isolated spit of land, surrounded by walls and barbed wire, some patients felt a sense of being lost in time, as if the world passed them by, since they could not participate in it. The gamblers quickly appropriated the newspapers that arrived at the hospital, using them as collateral in their games, and Carville did not have a plethora of available radios. Because of the isolation “the fact that the American economy was coming apart at the seams that summer of 1931 made little impression upon Carville.”¹²⁰ Carville residents

¹¹⁶ Ibid., p. 93

¹¹⁷ *The Sixty-six Star*, Vol. II, No. 2, May 28, 1932.

¹¹⁸ Martin, p. 94

¹¹⁹ The *Sixty-six Star* represented an accurate incarnation of the “house organ” in a total institution as described by Erving Goffman. The inmates supply the contributions, while a member of the staff loyalty to the institution censors them. Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. (Chicago: Aldine Publishing Company 1961) p. 95

¹²⁰ Stein, p. 110

often fixated heavily on their next meal, and important current events “were as nothing compared to the rumor there might be fricassee for dinner.”¹²¹ And yet, patients still loved to talk politics. One patient at Carville, Fred Smith, was “so politically minded that he went through the hole in the fence five times—each time in November—to exercise his franchise in some mysterious precinct,” willingly facing time in the hospital jail upon his return.¹²² When Stein set up a straw ballot for the 1932 presidential election, dividing the cottages into precincts (which provided patients the only opportunity to exercise any sort of franchise at all), 344 out of 367 patients voted.¹²³ The passivity and indifference to the outside world seemed to be a symptom of institutionalization, a reaction to lack of opportunity, not a dearth of patriotic concern. They did not suffer from lack of interest, but rather lack of access. Between the *Sixty-six Star* and the soon-to-be-established American Legion Post, the patients at Carville would soon have many more opportunities to interact with the world around them.

The patient-body first became aware that they could effect change for themselves using the press because of a print-discussion about movies. Stein informed the patients via the *Sixty-six Star* that the patients at the Kaluapapa leprosarium had purchased modern talkie equipment, prompting many letters to the editor expressing a desire for the same. Dr. Denney agreed that the patients should have nicer equipment, but said that the budget had no room for the purchase. However, Dr. Denney had been sending copies of the *Sixty-six Star* to the Public Health Service headquarters in Washington, where the sympathetic Chief of the Hospital Division of the Service, Dr. Frederick Smith, became aware of the discussion. He could not feasibly change the

¹²¹ Martin, p. 38

¹²² Stein, p. 237

¹²³ National Hansen’s Disease Museum, Stanley Stein Collection, *As Carville Goes-So Goes the Nation*, 1932. Roosevelt won with 269 votes. Hoover only picked up fifty-two.

budget solely to accommodate the purchase, so he arranged for several shipments of meat from other PHS hospitals. The free beef and pork alleviated the Carville budget enough to make the equipment affordable. Dr. Smith would later procure a mimeograph machine so that the *Sixty-six Star* would not have to rely on the administration to print each edition.

While a more pleasant movie-going experience in and of itself seems like no great improvement in quality of life, the true victory “lay in the fact that for the first time in Carville history patient needs and patient opinion had been made known beyond the barbed wire.”¹²⁴ The patients discovered that the PHS did not actively try to prevent the patients from living a reasonably happy life inside the hospital, even if it did prevent the patients from living one outside. When the residents of Carville pulled together to express a common desire, the higher-ups listened.

The year 1931 brought more changes for the citizens of Carville. The last Sunday in June, Sam Jones, the Louisiana State Commander of the American Legion and future governor of Louisiana, came to visit Carville and meet the veterans with B.L. Spann, the Sixth District Commander of the Legion. Jones encouraged the veterans to organize a post of the American Legion at Carville, because “In union there is strength. You poor bastards here, twenty-three of you, are helpless. But with a million Legionnaires behind you...”¹²⁵ He echoed Stein’s assertion that a collective voice rises above intramural bickering.

After his visit to Carville, Sam Jones would later write an article for the *American Legion Monthly*, announcing “Here are men, veterans who had served their country, forced by the age-old fear of leprosy to change their names...Here were World War veterans cut off from the

¹²⁴ Stein, p. 79-80.

¹²⁵ Stein, p. 117

world, living under an assumed name as if they were criminals—or dead. They were truly the forgotten men.” He denounced the government neglect that did not grant the twenty-three veterans any sort of disability pension because the Veterans’ Administration had not ruled on leprosy. Since 1897, at least one patient-veteran had also been unable to collect his pension because he, “being a leper, is not allowed to leave the grounds of the Home, [and] he is unable to draw the money which is due him.”¹²⁶

Using the organ of the Legion, Jones could reach a very broad audience with his description of the reality of leprosy as a “feebly contagious” disease, whose victims “are sent, frequently against their will, torn from job, family, friends and home; and condemned by archaic laws and general ignorance to stay there until they recover or die.” During his visit to Carville, Jones had told the patients to organize a post because they could accomplish more with the power of the Legion standing behind them. Yet the post would also serve a secondary goal; he believed that the patient awareness of the support of the Legion not only gave them recourse to political power, but also “the joy of knowing that they belong; that they have comradeship, have an organization to which they can appeal.”¹²⁷ The value of the American Legion crossed the line between tangible and intangible, psychologically improving the lives of patients who had long internalized stigma.

In December of 1931, the patient-veterans had a distinguished visitor in Harry Stevens Jr. of North Carolina, the new National Commander of the American Legion, who pledged the support of his organization. Less than two weeks later, the patients officially established Marine

¹²⁶ Louisiana Leper Home Records, Mss. 2515, Series I, Subseries 1: General Correspondence. Louisiana and Lower Mississippi Valley Collections, LSU Libraries, Baton Rouge, Louisiana. Albert Phelps to US Pension Agent regarding patient R.C. Fisch, November 16, 1897

¹²⁷ Sam Jones, “The Strangest Post in the World,” in *The American Legion Monthly*, August 1935.

Hospital Post 188. Following the American Legion, the American Legion Auxiliary, the Forty and Eight, Disabled American Veterans, the United Spanish War Veterans, Veterans of Foreign Wars, and the AMVETS all threw their support behind Carville.¹²⁸

The Legionnaires saw in Carville an opportunity to draw attention to government neglect of its veterans in Carville, and thereby gain publicity and sympathy on a broader scale. The American Legion also wanted to develop and maintain influence over federal health policy, as veterans benefited from “the largest federally sponsored and funded hospital system in the country.”¹²⁹ Both the Carville veterans and the American Legion as a whole wrestled with the federal government over benefits and pensions for service-connected disabilities. During the Great Depression, the American Legion constantly battled the government over its treatment of the veterans of the Great War, pushing for early bonuses and greater pensions, and they happily included the patients at Carville, who could serve as a prime example of another government failure to provide for former soldiers. The Legion, as well as the other veterans’ groups that established branches at Carville, “played a decisive role in forging patient links with the outside world.”¹³⁰ The *Sixty-six Star* possessed limited sway, but veterans’ groups could apply pressure in Washington on behalf of patients without the influence to lobby for themselves.

In 1936, the American Legion Marine Hospital Post 188 unanimously adopted a resolution to ask B.A. Spann “who has proven his friend-ship for us, by his untiring interest in our welfare, to approach the Governor on behalf of the members of Post 188, who “are isolated and have not the privilege of personally pleading their case,” in order to ask for the installation of

¹²⁸ Stein pp 121-122

¹²⁹ Moran, p. 153

¹³⁰ Gussow, p. 159

a telephone, to pave or blacktop the road to Carville, and most ambitiously, to grant qualified voters among the patient body the franchise, as to deny them the right “places us in the same category with criminals though we are only sick people in forced isolation under archaic laws.”¹³¹

Spann easily obtained a phone for the Patient Canteen, allowing many patients, who lived outside the area and whom the Public Health Service forbade from travelling, to hear their loved ones’ voices for the first time in years. Stein described the phone as more important to the patients than “Hitler’s occupation of the Rhineland, the Italian invasion of Ethiopia, or Franco’s revolt.”¹³² However, the second two goals that Post 188 announced would require much more energy and political savvy to accomplish.

Many of the patients’ goals, backed by the American Legion, required little effort or expenditure, but some of their plans demanded quite a bit of strategy and clout. Despite the drainage done by the PHS upon its initial takeover, the geography of Carville had not changed, and South Louisiana remained a miserably inappropriate place for a hospital community. The debate over moving the hospital had never been resolved, and the American Legion adopted a resolution at its 1931 National Convention to request that the government build a new hospital in a more favorable climate. In 1935, a malaria outbreak broke out, and 155 people out of the patient body alone became ill. Of those 155, forty-two died in the next three years. The epidemic was particularly traumatizing to patients because while leprosy debilitated in many ways, it typically did not kill. Patients lived with leprosy, but they did not die from it. While

¹³¹ National Hansen’s Disease Museum, Stanley Stein Collection, Resolution, by the American Legion Marine Hospital Post 188, April 2, 1936.

¹³² Stein, pp. 178-179

they did suffer physically in a variety of ways, when patients in the hospital died, the cause was typically a secondary infection such as malaria or pneumonia. In the wake of the epidemic, Dr. Hasseltine insisted on a drainage project, but even the \$40,000 the Works Project Administration spent draining the swamp failed to rid the hospital of mosquitos.¹³³

Though the government refused to move the hospital, Congress did appropriate funds for a multi-million dollar renovation of the hospital, which included rebuilding and fireproofing the infirmary and constructing a recreation building, complete with a theater and a ballroom. The WPA project and the construction did not just help the physical appearance or function of the hospital, but it helped connect the patients to the outside. Many of the workmen, who came from various parts of the country, “mingled freely with the patients.”¹³⁴ Patients seem to have felt universally vindicated when outsiders did not treat them with fear or disgust.

It also became evident that the level of politicization and patient-activism at Carville rose and fell with the physical conditions of the hospital and its patient-body. Physical improvements, both to the hospital and to the patients, led to psychological improvements. Because of the new buildings, Carville turned into a beautiful and well-appointed facility, and the patients “were no longer ashamed of the place where we received the fine people of the outside world who came to us.”¹³⁵ They began to take pride in their home, and they developed more ambitious goals. The *Sixty-six Star* had died in the mid-30s, but Stein resurrected it as the *Star* in September of 1941.

¹³³ The *Sixty-six Star* did not survive the malaria epidemic as Stanley Stein became ill as well. Stein and others patients made brief efforts to revive it or to establish a new newspaper, but none of them survived more than a couple issues.

¹³⁴ Martin, p. 160

¹³⁵ Ibid., p. 192

Despite outreach programs to the world outside, an alliance with the American Legion and vast improvements in patient life, doctors and researchers had not developed a workable cure and the leprosy stigma proved persistent. The secrecy utilized by the patients and their families remained an entrenched tradition, even within families. Stein concluded that the tradition of secrecy and the societal stigma were mutually reinforcing, and so with the rebirth of the newspaper, he dedicated himself to “Radiating the Light of Truth on Hansen’s Disease,” a motto that would appear on every future edition of the born-again *Star*.

Stein took stock of the victories and accomplishments of the last decade. The patients had received a movie projector, a telephone, and new buildings. Life had improved, but Stein had loftier goals. He wanted residents of Carville to have the right to vote, he wanted a better road to Carville, he wanted to end segregation, and he wanted to eliminate a stigma that had existed for millennia through a massive re-educative campaign. The new Medical Officer in Charge, a more sympathetic Dr. Guy Faget, subjected the *Star* to less censorship. Stanley Stein and his fifteen staff members would use the opportunities given to them by a world war, the scientific advances in treatment made during the 1940s, and increased political connections to fight not only for better living conditions, but for the right to participate in the world outside.

4. PROGRESSIVE GOALS, CONSERVATIVE METHODS

*Why remove moral and mental qualifications from any voting group?*¹³⁶

Though the patients at Carville had achieved some victories, their legal status remained unchanged. State law not only prohibited them voting, but listed leprosy among its quarantinable diseases, among such highly infectious diseases as Asiatic cholera, yellow fever, and the bubonic plague.¹³⁷ Federal law outlawed them from riding common carriers, while making no such provision for the much more infectious sufferers of tuberculosis. Only patients living in Louisiana, Mississippi or Texas could visit home, and the administration only granted leave to ten patients at any given time. The hospital did not even have a post office, and all mail that traveled out, including subscriptions of the *Star* were baked in an oven for sterilization. Barbed wire separated patients from the outside, and “a miserable cart track that was an almost impassable river of mud in wet weather and a choking, bone-cracking nightmare of ruts and dust the rest of the year” kept the patients rural and inaccessible.¹³⁸ Huey Long had instigated vast improvements in Louisiana roads, but despite the fact that Louisiana possessed one of the most sophisticated highway systems in the country, “there was, by design, no paved road leading to Carville.”¹³⁹

The residents of Carville, confined and segregated by laws unsupported by science, often articulated feelings of alienation from society. Because rules and regulations made leaving

¹³⁶ Unidentified newspaper clipping, “The Amendments,” National Hansen’s Disease Museum, Stanley Stein Papers

¹³⁷ Article VIII, Section 6 of the Louisiana Constitution of 1921 prohibited any “inmates of any charitable institution, except the Soldiers’ Home” from registering, voting, or holding public office.

¹³⁸ Stein, p. 230

¹³⁹ Amy Fairchild, “Leprosy, Domesticity, and Patient Protest: The Social Context of a Patients’ Rights Movement in Mid-Century America.” In *Journal Of Social History* no. 4: 2006. p. 1013

Carville difficult, most of their interactions with the outside were with visitors to the hospital, whether those visitors were family members, representatives of the American Legion or its Auxiliary, or outside workers in Carville to complete a construction project. What Betty Martin called “a world apart,” Stanley Stein named “exile,” and both of them expressed a disconnect between Carville and the outside world, claiming that patients felt the passage of time differently and the importance of current events less.

Yet despite these feelings of existing apart from the normal world, the strategies the patients at Carville employed to fight for their rights display that not only did they pay attention to the politics of the nation, but that they keenly understood how to manipulate their rhetoric and strategies accordingly. The tenor of patient argument shifted dramatically from World War II to the Cold War, and often reflected similar debates occurring outside of Carville. And during the 1940s, the patient goals became very ambitious, aided by a better-equipped *Star* and later, by optimism borne out of realistic hope for a cure.

The new *Star* adopted “a definite three pronged objective: 1. To promote an educated public opinion on Hansen’s disease. 2. To furnish vocational training for interested patients. 3. To provide community service.”¹⁴⁰ As the United States became embroiled in World War II, a great deal of that community service revolved around supporting the war effort.¹⁴¹ The patient-body as a whole contributed. They hosted what would become a semi-annual Freedom Fair to raise money, and many patients began to grow victory gardens.¹⁴² The *Star* promoted the buying of war bonds, and many patients who could afford the expense participated. Though the

¹⁴⁰ Stein, p. 210

¹⁴¹ According to Stein, several male patients sneaked out of the hospital and enlisted in the Army. Without testing for the precise bacillus, men without deformities would not be recognizable as Hansen’s Disease patients. p. 214

¹⁴² Martin, p. 203

residents dedicated a great deal of time and energy to support the war effort, they did not abandon their goals; rather, they found that the two often benefited each other. The veterans in Carville emphasized their military service and patriotism when denouncing segregation.

The rhetoric that the writers for Carville used often echoed the Double V campaign. Black newspapers emphasized connection between “the struggle for equality at home” with the “world-wide struggle against the Axis,” conflating the objectives to muster support for both.¹⁴³ Carville could not employ the same rhetoric condemning the government for hypocrisy, engaging in a war against white supremacy abroad while tolerating it at home, but just as blacks often fought abroad for a nation that discriminated against them upon their return, the number of veterans who fought in the Pacific confined at Carville increased. Subsequently, “the Carville population began to see itself as not just one that served society by taking extreme measures to prevent the spread of a disease; it increasingly viewed itself as a population that had risked life and limb for the liberty of others and deserved the same rewards.”¹⁴⁴

Both campaigns also sought to achieve their goals through fairly conservative methods—the writers in the black press during the Double V campaign sought not to assault segregation through direct action, but “to make inroads using traditional methods of protest such as lobbying committees, letter writing campaigns, and appeals to the courts and the executive branch.”¹⁴⁵ The residents of Carville could not lobby for themselves, but they made use of their allies outside the fence for that purpose. They, too, wrote letters, even though those letters had to be unnecessarily sterilized before leaving the facility.

¹⁴³ Lee Finkle, “The Conservative Aims of Militant Rhetoric: Black Protest During WWII” in *Journal of American History*, Vol. 60 No. 3 (Dec., 1973), p. 694

¹⁴⁴ Amy Fairchild, “Leprosy, Domesticity, and Patient Protest” p. 1019

¹⁴⁵ Finkle, p. 693

The language, articles, and images in the *Star* not only supported the war effort, but also emphasized the citizenship and values of Carville patients—the values that Carville shared with mainstream America, as they portrayed themselves as “attractive, heterosexually active, and able to fulfill their roles as men and women,” in an effort “to eradicate representation of ‘lepers’ as physically repulsive deviants who violated social concepts of femininity and masculinity.”¹⁴⁶ However, efforts to show the conservative and unthreatening values of the patient-body resulted in a representation that did not necessarily reflect the true values of a very diverse group. Ann Page, a woman on the *Star* staff, often put together a page directed at women entitled “The Ladies.” The page exclusively displayed white women concerned with traditional women’s issues.

Diversity had defined the hospital from the beginning. Even in 1894, two of the first eight patients in the Louisiana Leper Home came from foreign countries. In the 1940, about 40 percent of the patients came from foreign countries or U.S. territories, and within the confines of Carville, patients celebrated that diversity. The Filipino patients threw festivals where they danced native dances and served traditional foods.¹⁴⁷ On Chinese and Mexican holidays, the respective patients threw parties and cooked feasts for their fellow residents. Certainly some patients divided into cliques, but barriers were permeable. While many patients lived in cottages with their fellow countrymen based on comfort, language, or happenstance, many cottages comprised multiple nationalities and races.

¹⁴⁶ Moran, p. 158

¹⁴⁷ National Hansen’s Disease Museum, Oral History Collection, Nancy Batista, interviewed by Cassandra White on May 29, 1996.

However, “patient activists downplayed the diversity within their own ranks to construct a narrow and misleading public image of Carville’s community as composed of middle-class, white, native-born American men and women.”¹⁴⁸ Stein and his staff quickly denounced a best-selling book, *An American Doctor’s Odyssey* by Victor Heiser, which claimed that most of the Carville inmates “are Asiatics or West Indian negroes.”¹⁴⁹ Michelle Moran, the author of *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*, condemns the *Star*’s portrayal of the patient body as counter-productive to “the activists’ own efforts to create a common identity of ‘Hansen’s disease patients’ that could incorporate patient experiences from a variety of diverse backgrounds.” Yet while the creation of this common identity might bind patients together with their foreign counterparts, it would have had relatively little political impact. From a pragmatic perspective, a multiracial community in the rural South in the 1940s could hardly expect to appeal to either the outside world or Louisiana lawmakers by emphasizing their diversity. If the rhetoric of patient activists in Carville strategically implied differences between “the behavior and attitudes of American Hansen’s disease patients and those of ‘foreign lepers,’” as Moran posits, then it was because they were battling to achieve rights that should have been theirs *as Americans*, not because they actively wanted to racially differentiate themselves from the patients at other hospitals.¹⁵⁰ Had they emphasized their racial diversity, they would have then had to fight on multiple fronts, against those who wanted to deny Carville patients the vote, against xenophobes who did not want foreigners to vote, and against racists who did not want African-Americans to vote. As foreigners and African-American would not

¹⁴⁸ Moran, p. 161

¹⁴⁹ “A Tragedy of Misinformation” *The Star*, Vol. 1 No. 8, April 1942, p. 3

¹⁵⁰ Moran, p. 161

have gained the vote in the event of a Carville victory, their decision to portray Carville as largely white and conservative made pragmatic sense, even if it did not serve as a soaring example of ideal multi-culturalism and acceptance. The Carville activities emphasized their status as middle-class Americans with conservative values, just as many other minority groups striving for civil rights chose to do—especially those without the economic might to put pressure on a government or economy.

The edition of the *Star* of July 1945 contained perhaps the most poignant and pointed argument for the expansion of patients' rights. The cover of the edition featured a political cartoon of a man gazing outside his window at an American flag situated between his bedroom and a fence topped with barbed wire. His calendar shows the date as July 4, and the letter on his desk lists his name as “Mr John Doe,” referencing the aliases assumed by Carville patients. Underneath the cartoon reads the phrase “...With Liberty and Justice for All.”¹⁵¹

Betty Martin wrote the headline article, entitled “Why Am I Not Free?” for the same edition. The article comprises a series of questions that highlight the frustration of the Carville patients. She demanded why she, an American, should be denied her rights when she had committed no crime, why, “to protect my family from unjust and unbelievable disgrace and humiliation, am I forced by an unwritten law (prejudice) to lose my identity by changing my name and lying about my whereabouts,” why the state denied her the right to vote, and why the facility deemed her labor, “however efficient, worth so much less than the labor of the non-patients employed in this institution.”¹⁵²

¹⁵¹ *The Star*, Vol 4. No. 11, July 1945, Cover

¹⁵² *Ibid.*, “Why Am I Not Free,” p. 1

Martin's article includes much of the rhetoric that Moran criticizes for hindering "any larger efforts to forge ties with patients at Kaluapapa or any other territorial or international facility." Moran argues that, "by staking a claim to U.S. citizenship as their means of resistance, Carville residents also implicitly supported ideas of racial difference upon which their understanding of citizenship rested."¹⁵³ However, their rhetoric did not differ greatly from movements created *because* of racial differences. During the 1940s, the mainstream black media did not try to convince the public that they should be granted their constitutional rights by delineating all the ways in which they differed racially and culturally from lawmakers or the white majority. The tactics employed by the Carville activists matched concurrent movements happening in America. Their outreach to other leprosaria and their attempts to build a community of Hansen's Disease patients occurred as a part of their re-education campaign and their fight against stigma.

Much of Stein's project was re-educative; he wanted to detach the disease from its Biblical stigma. To accomplish this, he attempted to rid the world (or at the very least, the medical community) of the word "leper" and to replace the word "leprosy" with "Hansen's Disease." He subscribed to the Southwest Press Clipping Bureau and Luce's Press Clipping Bureau so that he could receive copies of any newspapers or magazines that employed the word "leprosy" or "leper." If he disapproved of the context, he wrote letters to the editors. He sent free subscriptions of the *Star* to medical schools and seminaries alike, seeking in particular to dissuade members of the clergy from using the word "leprosy" as a symbol for sin or uncleanness. He kept up-to-date with scientific research on Hansen's Disease around the world

¹⁵³ Moran, p. 152

in order to prove that the disease was as scientific as any other, and not one caused by divine punishment.

Every issue opened with a quote from the World Conference on Leprosy in Cairo, Egypt, in March of 1938 that required “a change in the attitude of the public toward the disease,” if early cases are to be diagnosed and any effective plan for dealing with leprosy to be enacted. Below the quote, Stein lists “Facts that you Should Know about Hansen’s Disease,” among which include that “the medical world classes it as ‘feebly communicable,’” that in fifty years, “not a single member of the medical or nursing staff has contracted the disease” at Carville, and that they do not require any particular precautions for visitors.¹⁵⁴

A great deal of the Carville education campaign concerned itself with rhetoric. Abolishing “leper” and “leprosy” from the medical vocabulary, if not the common vernacular, seemed an impossible task. Even non-medical language used in hospital procedures sounded distinctly like language better suited to a prison. The patients, or “inmates” who ran away, or “absconded” did not wait to be “paroled” in order to leave the institution. When a patient did earn a discharge, the form the administration gave him identified him as a “PHS Leper” and declared the reason for discharge as “no longer a menace to public health.” If patients could not change the language and terms used by administrators who had run their facility for less than thirty years, they certainly struggled to alter the vocabulary of the entire medical community world-wide.

A patient newspaper with a relatively small audience could not erase “a backlog of thousands of years of misconception,” but the staff of the *Star* did their best. Stein sent letters to Bible schools and seminaries as well as encyclopedia publishers. To the latter, he requested that

¹⁵⁴ *The Star*

they fact-check their articles on leprosy and stop listing it as highly infectious. To the former, he requested that the clergy stop using “leper” as a metaphor for sin or justification for exclusion. He wanted both academic and religious texts to stop conflating modern leprosy or Hansen’s Disease with the leprosy of the Bible.¹⁵⁵

In the wake of improved success with sulfone drugs, Stein launched a body called the United Patients’ Committee for Social Improvement and Rehabilitation in 1945. The group proposed fifteen goals, among which were the abolition of compulsory segregation, the revocation of the common-carrier ban, a more liberal vacation policy for patients, and the elimination of terms with criminal connotations from hospital regulations.¹⁵⁶

The following year an Advisory Committee appointed by the Surgeon General met to discuss Stein’s agenda. The next year would prove an exceptionally busy time for the patient-activists at Carville.

The outreach and education campaign unexpectedly received both a boost and a blow in May of 1946 when the wife of Army Major Hans Hornbostel, Gertrude, reacted to a leprosy diagnosis by hosting a press conference. The San Francisco *Call-Bulletin* broke the story with a melodramatic front-page headline reading “S.F. Wife Leper; Army Mate Begs to Share Isolation for Life.”¹⁵⁷ The boost to the patients’ agenda came from the immediate ease in gaining an audience suddenly aware of and interested in leprosy as a modern phenomenon. The blow came from the “frightful, fallacious, abandon-all-hope-ye-who-enter here type of publicity.”¹⁵⁸

¹⁵⁵ Stein, pp. 275-276

¹⁵⁶ *Ibid.*, 232

¹⁵⁷ *Call-Bulletin*, “S.F. Wife Leper; Army Mate Begs to Share Isolation for Life.” May 15, 1946,.

¹⁵⁸ Stein p. 248

Newspapers across the country leapt on the story of the wife of a survivor of the Bataan Death March, whose husband loved her enough to follow her into isolation and risk infection. In reality, there was next to no chance that Gertrude could give the disease to Hans. Furthermore, doctors had been using sulfone treatments for six years at this point. Gertrude, who had a relatively early case of Hansen's disease, could expect to be cured after only a few years of treatment.

The Hornbostels rejected the cult of the alias completely in an effort to fight the stigma of the disease, and upon their arrival to Carville, they proved to be great assets to the education campaign. The publicity associated with her case led to a flood of interested reporters and photographers. While Carville had to contend with the many reporters that rejected facts in favor of histrionic story-telling and misinformation, they also gained a great boost in publicity, which they used to their advantage. Gertrude promptly joined the staff of the *Star*, producing sharp-tongued criticisms in a column entitled "How I See It." She also, during her time at Carville and after her discharge, felt perfectly comfortable chastising prominent political figures via letter and via editorials for misusing the word "leper" or "leprosy." Hans, who rented a house outside of the hospital and joined Gertrude during visiting hours, joined the American Legion and took several speaking engagements to spread awareness.¹⁵⁹ Since he did not have the disease, he was not confined to hospital grounds as the patients were.

As Carville's education campaign picked up leverage, it also picked up opposition and backlash. Members of the surrounding community as well as hospital personnel deliberately hindered the Patients' Federation and the *Star* from connecting to the outside world. In November of 1946, the voters of Louisiana were going to vote on Amendment 23, which would

¹⁵⁹ Ibid., p. 251

have extended the franchise to the patients of Carville. The Louisiana Constitution of 1921 denied them the vote as residents of a charitable institution, and the prohibition on patients leaving the hospital further restricted their political potential.

Inhabitants of the parish did not want the patients to vote because of vested political and financial interests in the region. Many of the locals worked at the hospital, and they did not want the world to know the actual danger of the disease. Hospital personnel at Carville earned hazard pay, and “if people ever found out that Hansen’s disease was not the horrible infectious scourge as leprosy is portrayed by the misinterpreters of the Old Testament, some taxpayer was bound to object to paying these Carville employees from 25 to 50 per cent more than employees in other PHS hospitals treating really highly contagious diseases such as tuberculosis.”¹⁶⁰ None of the patients lodged complaints over their personnel receiving a higher salary; rather, they objected to the word “hazard” as detrimental to their campaign to amend the rhetoric of leprosy, an altogether un Hazardous disease to be exposed to. One resident compared the patients to “the goose that’s laying the golden egg. They get very handsomely paid for doing little or nothing.”¹⁶¹

The hospital personnel first tried to convince the Advisory Committee of the PHS that the United Patients’ Committee did not represent the goals of the majority of the patients, but rather a few malcontents with loud voices. In response, the Committee had 312 patients sign a statement to the reverse, to prove that they did in fact speak for the majority of the patients.¹⁶²

¹⁶⁰ Ibid., p. 233

¹⁶¹ National Hansen’s Disease Museum, Oral History Collection, Rachel Pendleton interviewed by Cassandra White on June 21 1996

¹⁶² National Hansen’s Disease Museum, Stanley Stein Collection, Letter from George Alexis, Chairman of the UPC, to Dr. Faget. October 2, 1946

When their first tactic failed, the personnel-neighborhood alliance resorted to scare tactics and false reports. Since Carville patients could not ride in common-carriers, the American Legion Auxiliary had donated a station wagon to the American Legion Post and another to the hospital. Rumors that these station wagons had been seen at beauty parlors in Gonzales, where “lady outcasts from Carville were endangering the health of the parish by getting curled and manicured” began to fly.¹⁶³ The rumors reached the Public Health Service headquarters in Washington as well as American Legion allies. The conflict “was a bitter and dirty scrap, in which the hospital personnel—not one of whom had ever caught leprosy by working at Carville—stooped to scaremongering and outright opposition to patients getting the vote.”¹⁶⁴ “Guerillas” of the personnel-neighborhood alliance tore down road signs to deter visitors from traveling to the hospital.¹⁶⁵

Claude Brown, an advocate for Carville from the American Legion in Little Rock, Arkansas, accepted the rumors as fact and wrote to Louis McCormick, another Legionnaire, that “our big job now is to make patients play the game, and realize that years of effort in their behalf will be destroyed if they refuse to cooperate.”¹⁶⁶ He asked Stein, whom he assumed would be able to exert more control over the patients, if “it may be possible to sell the patients on the idea

¹⁶³ Stein, p. 236

¹⁶⁴ Gould, p. 255

¹⁶⁵ Stein, p. 235

¹⁶⁶ National Hansen’s Disease Museum, Stanley Stein Collection, Letter from Claude Brown to Louis McCormick, February 18, 1947

that they are not free to go anywhere they desire: that they must realize there is a difference between liberty and license, and the rights of others must be respected?”¹⁶⁷

Stein responded that the hospital personnel and their friends nearby refused to quit fabricating a “continuous crop of the damndest, malicious rumors...to discourage the Legion’s efforts in our behalf.” A man who worked in the laboratory at the hospital, Percy Cambre, at the behest of Dr. Faget, who felt “something should be done to curb such maliciousness, traveled to every single beauty shop operator in Gonzales who all willingly signed a statement stating that no patients from Carville had frequented their shop.¹⁶⁸ Stein enclosed a photocopy of the statement so that Brown could see “that this was just another one of their made-up stories, emanating locally.”¹⁶⁹ Dr. Faget, the Medical Officer in Charge, intervened to quell the rumors in Washington, enclosing a photocopy of the same signed statement in a letter to the Assistant Surgeon General, Dr. R. C. Williams.

Many Louisiana newspapers backed the opposition, urging against extending the franchise to the hospital. One article from the New Orleans *Item* recommended that its readers vote against Amendment 23 because “the policy of not permitting those who are direct beneficiaries of state charity to vote should be maintained.” The editor, Marshal Ballard, subsequently received a swift rebuke from Steve McCormick of the American Legion Auxiliary (and the wife of the Louis McCormick named above), informing him that not only are many of

¹⁶⁷ National Hansen’s Disease Museum, Stanley Stein Collection, Letter from Claude Brown to Stanley Stein, February 18, 1947

¹⁶⁸ National Hansen’s Disease Museum, Stanley Stein Collection, Letter from Dr. Faget to Dr. R.C. Williams, March 3, 1947.

¹⁶⁹ National Hansen’s Disease Museum, Stanley Stein Collection, Letter from Stanley Stein to Claude Brown, February, 1947

the patients at Carville veterans, hiding themselves away for the public good, but that they did certainly *not* benefit from state charity as the Public Health Service maintained the hospital.¹⁷⁰ Not only did the patients benefit from the political support of the Legion and its Auxiliary, but the support also meant the *Star* did not bear the sole responsibility for the letter-writing campaign on behalf of the hospital residents.

The Baton Rouge *State Times* issued a more sensible objection to Amendment 23: “The inmates at the hospital should be permitted to vote, but in the state of their residence. Their vote might well take home rule from Iberville Parish.”¹⁷¹ Considering the vast geography that contributed patients to the hospital and the diversity of their country of origin, outsiders very well might influence local politics.

Despite the best effort of the citizenry of St. Gabriel and the town (not the hospital) of Carville, Amendment 23 passed the November 5 election, 72, 696 to 20, 158.¹⁷² Though the vast majority of the state voted in favor of the amendment, the St. Gabriel and Carville wards voted against the bill, 103-18.¹⁷³ Considering that only 347 people in Iberville Parish turned out to vote at all, the idea that patients from the Carville hospital might be able to swing a parish vote was plausible. And of course, as soon as the patients at Carville did have the vote, politicians visited the hospital near election times in order to solicit it, bearing gifts and smiles for the patients they had previously been denied the franchise.

¹⁷⁰ National Hansen’s Disease Museum, Stanley Stein Collection, Letter from Mrs. L.L. McCormick, American Legion Auxiliary, to Marshal Ballard, Editor of the New Orleans *Item*, October 31, 1946

¹⁷¹ “How We Will Vote on the Amendments,” *State Times*, Baton Rouge, LA, November 4, 1946.

¹⁷² “Six Proposed Amendments Lose” in the *Advocate*, Baton Rouge, Thursday, November 14, p. 7-A

¹⁷³ National Hansen’s Disease Museum, Stanley Stein Collection, Letter from Wade Martin, Jr, Secretary of State of Louisiana to Stanley Stein, September 17, 1947

Unfortunately, stigmatization and fear still worked against the patients of Carville, even when they received the franchise. To register to vote, patients had to give their true name and previous place of residence; they could not give their Carville alias and address. Some patients refused to register because they preferred to preserve their anonymity and protect their families. However, a majority of the eligible patients registered. Registration would increase after 1955, when patients with part-time hospital jobs became eligible to collect Social Security benefits.

Though Dr. Faget and his replacement, the wildly popular Dr. Johansen, supported many of the patients' goals, for the most part the patients achieved their victories despite the Public Health Service, not because of it. In May of 1948, the American Federation of Physically Handicapped introduced a National Leprosy Act in the US Congress.¹⁷⁴ The omnibus bill incorporated many recommendations of the United Patients' Committee. The bill gained support from veterans and labor unions, and was backed by a US Army Colonel, G. H. Rarey. Rarey supported "overhauling leprosy policy on the grounds that, as persons who had acquired a socially stigmatized disease while in the service of their country, veterans were entitled to better treatment than that currently accorded to leprosy patients."¹⁷⁵ The act died in committee in both houses, but the pressure generated by it still led to gains for the patients at Carville on a state level, if not a federal level.

In the time between December of 1946 when the National Advisory Committee had its second meeting and the end of the decade, Carville would gain its own post office, and the PHS would allow patients with active cases to leave the hospital as certain conditions were met. In June of 1950, with the support of lobbyists of the American Legion, the Louisiana legislature

¹⁷⁴ Gould, p. 259

¹⁷⁵ Gussow, p. 167

removed leprosy from the list of quarantinable diseases, where it had kept company with smallpox, Asiatic cholera and the bubonic plague.¹⁷⁶

The patients in the beginning of the 1950s rode high on the successes of the decade before, diverting their attention more fully to education. But in 1953, Dr. Johansen, the most supportive MOC the patients had ever had, reached retirement age, and the new Medical Officer in Charge would require them to work against the administration in order to secure their rights and protect their interests.

The activists at Carville proved particularly adept at the art of protest in the Cold War context during which the new MOC would reign. In 1949, the Public Health Service had launched an investigation against the *Star* when the newspaper accused the PHS of regularly violating patients' right to privacy.¹⁷⁷ To avoid the risk of being shut down or subjected to censorship as anticommunist sentiment flourished, the patients at Carville capitalized more on the support of local papers outside the hospital, specifically the *Morning Advocate* and the *State Times* of Baton Rouge, as well as the *Morning World* of Monroe, as they could protest against the Public Health Service.¹⁷⁸ Just as the patients of Carville used patriotic rhetoric during World War II, they maneuvered within the national sentiment of the Red Scare during Gordon's tenure at Carville. As the *Star* was a newspaper operating within a government institution, it faced greater risks if their protests got too loud, especially since they no longer had a supportive Medical Officer in Charge to back their interests and goals.

¹⁷⁶ Amendment 272 to Act No. 79 of 1921

¹⁷⁷ Amy Fairchild, "Community and Confinement: The Evolving Experience of Isolation for Leprosy in Carville, Louisiana," in *Public Health Reports*. (May/Jun2004, Vol. 119 Issue 3.) p. 366

¹⁷⁸ *Ibid.*, p. 367

When Dr. Edward Gordon arrived as the new Medical Officer in Charge in 1953, he began making many immediate changes in hospital policy, many of which the patients supported. For example, Gordon replaced the patient-orderlies in the infirmary with trained professionals. Considering that one orderly had once given out soap liniment as medicine because of a mistake borne out of illiteracy, and many of the patient-orderlies physically struggled to carry out their jobs on account of various deformities, this proposal was extremely sensible.¹⁷⁹

However, he also discouraged outside visitors from the hospital, began actively working to reduce the size of the patient body by attempting to expel able-bodied arrested cases, cancelled sporting events and social functions that promoted mingling between patients and nonpatients, and perhaps most offensively, tried to tear down the individual patient homes that had sprung up over the decades in the back of the home.

The cottages provided by the PHS at Carville served as homes for groups of up to a dozen male or female patients. Unwritten rules prohibited marriages within the institution. However, as in the case of Betty and Harry Martin, patients often left through the hole in the fence to get married. If they wanted to live together inside the hospital, they often moved to the area in the back of the home that the patients called Cottage Grove or Suburbia.

Since before the federalization of the home, patients had been building small hunting lodges and homes in the back of the facility. The homes possessed dubious status within the regulations, but as a rule, if patients built a house and set up plumbing and electricity on their own dime, the Public Health Service paid for the power and water. Single patients and married couples alike built houses that they could later sell to someone of their choosing upon medical discharge. Many of those living in Cottage Grove also took raw rations from the cafeteria,

¹⁷⁹ Stein, pp 76, 194

instead of eating meals there, so that they could cook and entertain in their homes. When Dr. Gordon attempted to bulldoze Cottage Grove, he robbed the patients of not only housing, “but the hard-earned domestic citizenship it represented: freedom from medical authority, patient privacy, and a degree of patient independence in daily routines.”¹⁸⁰ Carville patients would make the importance of the kitchen the center of contention.

The patients appealed to the American Legion as well as newspapers not under government oversight. In a Cold War context, and “given the profound distrust for dissent and emphasis on conformity that characterized the 1950s...Carville patients carefully and precisely marshaled beliefs about the home as representing the center of freedom.”¹⁸¹ They avoided making “potentially inflammatory claims regarding civil liberties,” and instead framed their argument around property ownership, resembling but predating the famous kitchen debates between Richard Nixon and Nikita Khrushchev. One Louisiana newspaper, the *Morning World* of Monroe, ran an editorial entitled “Soviet-Type Prison Camp at Carville?”¹⁸² Patients centered their protest around “the all-American issue of housing” and capitalized on a growing national movement to end socialized housing projects, though the fact that the government owned the land upon which the patient houses sat complicated the debate.¹⁸³ On the one hand, patients resisted the idea of the Public Health Service taking their private houses or what they perceived as their property. On the other hand, they still expected the government to provide their housing and they resisted Dr. Gordon’s attempts to push them out upon medical discharge.

¹⁸⁰ Amy Fairchild, “Leprosy, Domesticity, and Patient Protest,” p. 1027

¹⁸¹ *Ibid.*, 1026

¹⁸² “Soviet-Type Prison Camp at Carville?” in *Morning World*, Monroe, LA, August 26, 1956

¹⁸³ Fairchild, “Community and Confinement,” p. 367

The requirement that able-bodied patients eligible for medical discharge leave the hospital terrified many of the residents. Patients had many reasons to protest Dr. Gordon's attempts to force them out. Many of them had cut off ties with all family and friends upon entry to Carville and no longer had a support system in the world outside. Ex-patients struggled to find work in the world outside as well: they could either admit to having lived at Carville, risking rejection by neighbors and employers, or they had to find a way to explain where they had been for an indeterminate number of years. Betty and Harry Martin decided to protect their identities and not admit to having lived at Carville, but that left them with unexplainable holes in their lives. Furthermore, their former employment had been at the hospital, so they could not even offer job references if they wished to maintain their secret.¹⁸⁴ Had they exposed their secret instead, they ran the risk of facing the same difficulties that drove many patients discharged patients back to the hospital.

Patients protested through the use of the outside press, but they also made their displeasure known within the hospital grounds. They wrote offensive signs on the wall that typically insulted Dr. Gordon. One patient had protested by drawing a line through USPHS (United States Public Health Service) and writing USSR underneath to dispute the authoritarian decision of the PHS to cancel Carville's patient sports. The Patients Federation wrote a letter to the Surgeon General, Leonard Scheele, alerting him to the patient protests, but also lodging many complaints that implied their disapproval of such protests was incomplete. Because opening the hospital to the public constituted a crucial part of the Carville de-stigmatization effort, the Federation worried that disallowing patient sports teams to compete against teams from the outside would not only diminish the patients' enjoyment of life, but it would also

¹⁸⁴ Betty Martin, *No One Must Ever Know*. (New York: Doubleday & Company, Inc, 1959.) p. 77

impede their education campaign. To give weight to the complaint, not only did the entire Executive Board of the Patients Federation sign the petition, but they had it endorsed by the Lion's Club, B.L. Spann, and Voiture 902 of the Louisiana Forty and Eight.¹⁸⁵

The patients had to work harder to protest these new problems: with increased number of medical discharges, the patient body had shrunk. They could not use the usual mouth of the patient-body, the *Star*, for fear of reprisal or a government shut-down, and instead of having at least tacit encouragement from the MOC, they had to actively work against him. However, their tactics worked, and with the help of Sam Rubin of the Forty and Eight and Congressman Otto Passman of Monroe, as well as several newspapers that lambasted him in the press, they succeeded in getting Dr. Gordon removed from Carville.

The patients' ability to manipulate the politics of the outside world in their favor existed long before they had the vote. From John Early's famous journey across the nation and his exploitation of the media, to the patients' alliance with veterans' organizations during the Great Depression, they displayed a keen understanding of politics and strategy. They were not "the secret people" they claimed to be; instead they only had to reach across the barbed wire as a collective, bound together by stigma and community.

¹⁸⁵ National Hansen's Disease Museum, MOC Daybook # 1, Letter from Patients Federation to Surgeon General Leonard Scheele, July 5, 1956

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