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# Rising from the Ashes: Hansen's Disease, Carville, and Patient Identity in 20th Century America

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The College of Wooster

Rising from the Ashes:

Hansen's Disease, Carville, and Patient Identity in 20<sup>th</sup> Century America

by

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Presented in Partial Fulfillment of the  
Requirements of Senior Independent Study

Supervised by

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## ABSTRACT

This paper investigates the reactions of patients in the national leprosarium at Carville, Louisiana to the loss of their old identities and the gain of a new one as a patient during the middle of the 20<sup>th</sup> century. The patient identity was formed by isolation, stigma, community, and domesticity within the hospital. Over the course of their time in the hospital, residents rejected, embraced and worked to change the patient identity. They typically reacted in a combination of these ways. This paper uses memoirs, oral histories, and patient published newspapers to investigate questions of patient identity at Carville. The goal of this research is to identify major components of patient identity, how these shape the reactions of Carville residents to their patient status, and why patients reacted to their new identity in certain ways.

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## INTRODUCTION

On March 1, 1931, Sidney Levysen, a pharmacist from Texas, became Stanley Stein. On this day, Sidney entered United States Marine Hospital No. 66 in Carville, Louisiana, the only treatment center for leprosy in the continental United States, and assumed a new identity. Sidney, like most other patients until the mid-1940s, took a new name when he entered the hospital, commonly referred to as Carville, for treatment in order to keep the stigma of his disease from hurting his own reputation or that of his family. This routine part of the entrance process into Carville became symbolic of a larger transition from a life on the outside into a new one isolated in the hospital. New names in this hospital represented a break with old identities and the development of a new one as a Carville patient.

Four major facets of this new patient identity received upon entrance to Carville were isolation, stigmatization, community, and domesticity. Outside social pressures and attitudes towards the disease at the time forced patients into isolation at Carville and stigmatized them as “threats” to the health and well-being of other Americans. These two factors had a strong influence on the ways in which the patients interacted with people outside of the hospital. As a response to these negative aspects of their new identity as patients, Carville residents formed a tight-knit community and transformed the facility from a hospital to a home. Community and domesticity became defining influences on patient life within the hospital and were important facets of the Carville identity. This research explores the ways in which Carville residents reacted to this new patient identity as defined by these four factors. Patients reacted to the change in their



identity upon entering Carville by a combination of rejecting it, embracing it, and working to change it.

Leprosy, which from this point forward will be referred to by the preferred term, Hansen's disease, is caused by a bacillus called *Mycobacterium leprae*.<sup>1</sup> The disease is barely contagious, as only 5% of people are genetically able to contract Hansen's disease. The bacterium that causes it is only transferred through droplets from the nose and mouth of untreated cases over prolonged periods of time, a situation to which those susceptible to the disease are rarely exposed. Hansen's disease is rare in the United States and most of its current sufferers live in Asia and Africa. Before 1941, there was no effective treatment for the disease; however, in that year, doctors studying tuberculosis developed a drug called promin that effectively halted the disease's progress. Today, the disease is easily treatable through the use of a combination of three antibiotics, though it is not completely curable. In the United States, new cases are treated as outpatients and isolation at Carville is no longer required.

The disease has been around for thousands of years, being mentioned as early as 600 B.C.<sup>2</sup> Historically, Hansen's disease has been stigmatized and feared. Mentions of the disease in the Bible<sup>3</sup> portray sufferers as "unclean" subjects to Jesus' miraculous healing. During the Middle Ages, people with Hansen's disease were segregated from the majority of the population and may have endured the infamous "Leper Mass," in which they were given the same rites as a dying person to signify their separation from

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<sup>1</sup> Hansen's disease is named after Doctor Gerhard Armauer Hansen, a Norwegian doctor who identified the bacterium that causes the disease in 1873. This is the preferred term for this disease, as it does not suffer from the same stigma that is attached to leprosy.

<sup>2</sup> WHO fact sheet

<sup>3</sup> Many Biblical scholars argue that the use of the word "leprosy" in the Bible is due to an error in translation. Most likely, the term was used to refer to all skin disease, not Hansen's disease specifically, or simply as a metaphor for "unclean."

the rest of society.<sup>4</sup> Though the disease became rare in the west after the medieval period, rare cases did and continue to occasionally appear.

In the United States in 1924, the federal government appointed Carville as the official hospital for the treatment and mandatory segregation of Hansen's disease patients.<sup>5</sup> Carville's population was diverse, as patients came from a wide variety of economic, racial, and cultural backgrounds, and included both men and women. Because isolation at the hospital was mandatory for patients until the development of effective treatments in the 1960s and 1970s and because the hospital was the only official treatment facility for Hansen's disease, many of these patients spent decades at Carville. Within the hospital, the patient body created their own vibrant and unique society, one that has piqued the interest of scholars.

The experiences of patients at Carville and historical social attitudes toward Hansen's disease have been written about by several scholars. Not much was written about Carville after its heyday of public attention in the middle of the 20<sup>th</sup> century, with some notable exceptions such as Zachary Gussow's *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control*.<sup>6</sup> Once Hansen's disease became easily treatable and less frightening, the public began to lose interest in the disease and the hospital. However, the last decade has seen a renewed interest in the subject, possibly because of the looming threat of Carville's closure as the original patients aged and their population shrank; several historians and scholars have written about Carville. Important

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<sup>4</sup> Whether or not the Leper Mass was an actual medieval practice is debated by scholars. Tony Gould argues that evidence suggests the mass of separation as applied to those with Hansen's disease is a fiction of the 16<sup>th</sup> century.

<sup>5</sup> For more on history of Hansen's disease see Tony Gould's *A Disease Apart*. For more on the science of Hansen's disease and its status in the modern world, the CDC and the World Health Organization both have excellent online resources.

<sup>6</sup> Zachary Gussow, *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control* (Boulder, Colorado: Westview Press, 1989).

works about Hansen's disease in the modern era and Carville include Tony Gould's *A Disease Apart*,<sup>7</sup> Michelle T. Moran's *Colonizing Leprosy*,<sup>8</sup> Marcia Gaudet's *Carville: Remembering Leprosy in America*.<sup>9</sup> Several articles concerning Carville have also been published in the past decade, including Amy L. Fairchild's "Leprosy, Domesticity, and Patient Protest: The Social Context of a Patients' Rights Movement in Mid-Century America"<sup>10</sup> and Michael Mizell-Nelson's "Treated as Lepers: The Patient-Led Reform Movement at the National Leprosarium, 1931-1946."<sup>11</sup> It is important to note that the historiography of Carville, and even of the history of Hansen's disease in the United States, is not extensive, so there is no single established historical view of the actions and lives of patients at Carville; though there are some overlaps between scholarly works, each historian makes a fairly unique argument.

The majority of scholars have significantly used both *The Star*, the patient-published newspaper, and the two classic Carville memoirs, Betty Martin's *Miracle at Carville*<sup>12</sup> and Stanley Stein's *Alone No Longer*.<sup>13</sup> Most historians, particularly Mizell-Nelson and Fairchild, agree that *The Star* was a significant tool for patients at Carville to make themselves heard, demystify their disease, and protest public health policies

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<sup>7</sup> Tony Gould, *A Disease Apart: Leprosy in the Modern World* (New York: St. Martin's Press, 2005).

<sup>8</sup> Michelle T. Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*, (Chapel Hill, North Carolina: The University of North Carolina Press, 2007).

<sup>9</sup> Marcia Gaudet, *Carville: Remembering Leprosy in America* (Jackson, Mississippi: University Press of Mississippi, 2004).

<sup>10</sup> Amy L. Fairchild, "Leprosy, Domesticity, and Patient Protest: The Social Context of a Patients' Rights Movement in Mid-Century America," *Journal of Social History* 39 (2006): 1011-1043, accessed September 13, 2013. <http://www.jstor.org/stable/3790239>

<sup>11</sup> Michael Mizell-Nelson, "Treated as Lepers: The Patient-Led Reform Movement at the National Leprosarium, 1931-1946," *Louisiana History: The Journal of the Louisiana Historical Association* 44 (2003): 301-324, accessed September 13, 2013. <http://www.jstor.org/stable/4233938>

<sup>12</sup> Betty Martin, *Miracle at Carville* (Garden City, New York: Image Books, 1963).

<sup>13</sup> Stanley Stein, *Alone No Longer: The Story of a Man Who Refused to Be One of the Living Dead!* (New York: Funk & Wagnalls, 1963).

concerning Hansen's disease. The researchers that have studied Carville have used the same primary sources, but have not necessarily come to the same conclusions.

One major subject of interest is patient protest. Historians disagree over what the motivations behind these protests were. Mizell-Nelson argues that the main motivation behind patient protests was a desire to shed the stigma attached to their disease. He, as does Christopher Lee Manes in his article "Regarding Carville,"<sup>14</sup> argues that community building was also an important motivation and source of strength for acts of protest. Contrary to this, Fairchild argues that patients were motivated by a desire to create domesticity within the hospital, transforming it from an institution into a home.

Other historians focus on the political and social factors that kept patients isolated at Carville. In her book, Moran argues that imperialism, public health policies, and the patients themselves all contributed to the establishment of leprosariums and policies of isolation in the United States. In *Leprosy, Racism, and Public Health*, Gussow argues that the symbolism, social stigma, and mystery surrounding the disease were all significant factors in the development of isolated leprosariums.

A third area of focus is the experiences of individual patients; interestingly, several of the scholars working in this area are not historians, but study English, particularly folklore and storytelling. Marcia Gaudet argues that telling stories of their experiences at Carville helped patients to build a new identity and community. Gaudet differs from other sources in that a major source for her research was personal interviews with Carville's remaining patients, in addition to the more typically used primary sources.

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<sup>14</sup> Christopher Lee Manes, "Regarding Carville: The Letters of Norbert and Edmond Landry," *Louisiana History: The Journal of the Louisiana Historical Association* 44 (2003): 325-338, accessed September 13, 2013. <http://www.jstor.org/stable/4233939>

Several descendants of the Landry family, such as Claire Manes and Christopher Lee Manes, have used the extensive collection of letters written by their ancestors Edmond and Norbert, two of the five Landry siblings who entered the hospital, to write about the patient experience at Carville. Though the scope of research done on Carville and leprosy in the United States is small, the subject has attracted scholars from different disciplines and a variety of approaches to understanding it. This research falls into this category, but uses a historian's lens to investigate the ways in which patients reacted to new identities as well as the activities they engaged in to form them.

For my research, I have relied heavily on three different primary sources: the patient newspapers, the *Sixty-Six Star* and *The Star*; Betty Martin's memoir, *Miracle at Carville*; and Stanley Stein's memoir, *Alone No Longer*. The *Sixty-Six Star* was published between 1931 and 1933 and became the first major outlet for patients to express their opinions on hospital and national policies regarding their disease. This paper also includes reports on everyday activities within the hospital. *The Star*, which began printing in 1941 and is still published today, was headed by Stanley Stein from its inception to his death in the 1960s and was the main tool of patient advocacy during the heyday of patient activism in the 1940s and 1950s. It featured everything from letters from supporters to articles from medical journals to editorials crusading for patients' rights. *The Star* also included a variety of accounts of the daily experiences of patients at Carville and paints a vivid picture of life within the hospital. Betty Martin was diagnosed with Hansen's disease as a teenager, entering Carville shortly after her diagnosis. In the following decades, Betty became an active member of the Carville patient community and married a fellow patient, Harry Martin. Her memoir, *Miracle at Carville*, details her

life from her entrance into Carville until her discharge several decades later. Because Betty, at various times in her life, rejected, embraced and worked to change her identity as a patient at Carville, her memoir is an excellent resource for research into patient identity. Stanley Stein, the Carville Crusader, was the editor of *The Star*, active in the patient community, and a leader of patient activism during his decades at Carville. His memoir, *Alone No Longer*, covers his life from his diagnosis until the early 1960s. It is important to note that all of these sources were written by Carville's most vocal residents, patients who were involved in activist efforts to demystify and educate the public about Hansen's disease. This involvement may have had an influence on what information they chose to include in their writings. Regardless, these sources are an excellent view into the minds and lives of Carville's patients.

How did people at Carville react to the loss of their old identities and the gain of a new one as a patient? Patients reacted to the change in their identities in three major ways: by rejecting the new identity in favor of retaining their old one, by embracing their new life as a Carville resident, or by working to change the negative aspects of the patient identity. Most patients reacted to the change with a combination of all three of these actions. Many Carville residents rejected the loss of their identity, finding breaks in the isolation forced upon them by their status as patients and ignoring the stigma attached to the patient identity to maintain family relationships and remain active participants in shared national experiences, such as voting and the home front during World War II. Eventually, most patients chose to embrace a new life within the hospital. Because the stigma and isolation now attached to them made maintaining ties on the outside challenging, many Carville residents turned inward, creating a close knit, supportive

community and turning the hospital into their home. Lastly, Carvillians decided to change the stigma and isolation attached to their identity as patients, engaging in activist efforts to educate the public and end the use of the stigmatic word “leper.”

The first chapter of this paper consists of a summary of the history of the hospital at Carville and Hansen’s disease in the United States. It also analyzes the social factors in the 19<sup>th</sup> and 20<sup>th</sup> centuries which contributed to the stigma attached to Hansen’s disease, the rise of segregation policies for patients, and the formation of a patient identity. The second chapter investigates the ways in which Carville residents rejected the patient identity, using breaks in their isolation to stay connected to the outside world. The third chapter looks at how Carvillians embraced the patient identity through community and domesticity. The fourth chapter analyzes patients’ efforts to change their identity through the use of activist campaigns to reeducate the public and end the use of the word “leper” in order to remove the stigma from their disease and eliminate the reasoning behind isolation policies regarding Hansen’s disease patients.

## CHAPTER ONE

### HANSEN'S DISEASE IN THE UNITED STATES BEFORE CARVILLE

Hansen's disease has been present in the United States since its colonial days. Immigrant groups, such as the Acadians, Scandinavians and West Indian slaves, brought the non-indigenous disease with them when they migrated to the United States.<sup>1</sup> The Spanish, who controlled the territory at the time, had established the first American leprosarium in Louisiana in 1785.<sup>2</sup> By the time plans for a national leprosarium were up for debate in Congress in 1917, the disease had been in the country for well over a century. However, the causes of the sudden push for the establishment of this hospital for Hansen's disease patients were comparatively new. Why was it suddenly so important to segregate patients suffering from Hansen's Disease when the disease had already been present for decades? Why did Congress and the Public Health Service eventually settle on Carville for the site of their new hospital?

The federal government established a national leprosarium because of public misinformation, the Marine Hospital Service's expansion of power and control, and the sensationalist actions of John Ruskin Early. The government chose Carville as the location for this national leprosarium because of Louisiana's history with the disease and public opposition to locating it elsewhere. The sensationalism around the death of Father Damian and Hansen's disease's reputation as a mysterious, foreign, and impure disease led to public misinformation about the disease and a fear of Hansen's disease that drove

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<sup>1</sup>Michelle T. Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States* (Chapel Hill, North Carolina: The University of North Carolina Press, 2007), 19.

<sup>2</sup>Marcia Gaudet, *Carville: Remembering Leprosy in America* (Jackson, Mississippi: University Press of Mississippi, 2004), 7.



Americans and their congressional representatives to seek the segregation of patients suffering from it. The Marine Hospital Service, which would later become the Public Health Service, used the push for a national leprosarium to exert their own power and establish the control they had over the health and lives of Americans. Early's sensational protests and antics, particularly his infamous trip to Washington D.C., kick started the establishment of a national hospital for Hansen's disease. Louisiana's higher rates of Hansen's disease and their existing staffed facility at Carville made it an ideal location for this new hospital. Lawmakers also settled on Carville because all other locations were shot down either by that district's representative or the locals themselves. The same public fears and misunderstandings about Hansen's disease that contributed to the establishment of Carville as the national leprosarium also contributed to the formation of the new identity patients obtained upon entering the hospital. Public opinion and policy shaped the isolation and stigma that were a significant part of this identity, which in turn contributed to the formation of an insular community and domestic atmosphere within Carville, also important aspects of the patient identity.

The media hype surrounding the death of Father Damien in the 1880s brought Hansen's disease to the forefront of the American media and public attention and renewed dormant fears about the disease.<sup>3</sup> Damien was a Belgian Catholic priest from humble origins who came to minister and work at Kalaupapa, Hawaii's leprosarium, in 1873. During his time living with the patients at Kalaupapa, Damien undertook humanitarian projects, such as establishing a healthy water supply, petitioning the government for food and supplies on behalf of the patients, and enlisting the Sisters of St.

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<sup>3</sup> Tony Gould and Michelle T. Moran both write about the life, death, and impact of Father Damian in their books, *A Disease Apart* and *Colonizing Leprosy*, respectively. The following paragraph is derived from these books.

Francis to care for the residents. After working at Kalaupapa for over a decade, Damien discovered that he had contracted Hansen's disease, eventually dying from the disease and its effects in 1889. His death marked a major change in prevailing attitudes toward Hansen's disease. Before his death, the disease was largely ignored by the majority of the population. However, Damien's death brought the disease to the forefront, causing the British public to "hysterically proclaim[ed] leprosy to be an imperial danger and menace."<sup>4</sup> Damien's demise attracted significant media attention in Great Britain and the United States, promulgating the idea that Hansen's disease was highly contagious and increasing public fear of the disease. His death and service at the Hawaiian leprosarium was featured in magazines, newspapers, and books throughout the world. For example, several articles about the deceased Damien appeared in *The New York Times* in 1889, including an article in which the author traveled to the colony but did not actually enter because it was "too dangerous."<sup>5</sup> Damien had been garnering media attention since he first arrived at the colony in the 1870s, and the attention continued upon his death. Because Damien had contracted and died from Hansen's disease, a heavily publicized event, many people began to believe it was easily communicable. Doctors and other medical experts also used the incident to criticize Hawaii's lax attitude toward the segregation of Hansen's disease patients and promoted public health policy of segregating people with the disease. As German doctor Edward Arning wrote, Damien's death should "cause us all to work harmoniously and united for the one good end, to confine the dreaded leprosy to its closest limits."<sup>6</sup> Father Damien's death in Hawaii increased public fear of the disease and its contagion and bolstered the argument that

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<sup>4</sup> Gussow, *Leprosy, Racism, and Public Health*, 105.

<sup>5</sup> "The Lepers of Molokai," *The New York Times*, May 26, 1889

<sup>6</sup> Moran, *Colonizing Leprosy*, 54.

patients suffering from HD needed to be isolated from the outside world in order to protect the healthy from contagion.

Despite advances in medical science, Hansen's disease, particularly its transmission and treatment, remained unknown and mysterious, contributing to public misinformation about the disease. During the 19<sup>th</sup> century, medicine became a more exact science and doctors began to identify bacteria that caused diseases. In 1873, G.H.A. Hansen, a Norwegian doctor, identified the bacillus that caused Hansen's disease. Doctors had been debating for years whether or not the disease was contagious or hereditary and whether or not segregation of Hansen's disease patients was needed. Hansen's discovery of the bacillus confirmed that it was contagious and added support to the segregation argument. However, almost nothing beyond the fact that the disease was caused by a communicable bacillus was known about Hansen's disease at the time. Doctors had no methods of treating or curing the disease and had no idea how it was spread. Many doctors were unable to recognize the disease in their patients; Carville patients often had to visit multiple specialists before their affliction was properly identified. Even doctors who recognized Hansen's disease did not understand how it was transmitted. For example, Dr. Ferae, the doctor who diagnosed both Betty and Harry Martin, told Betty's parents to "get her away before she infects the whole city"<sup>7</sup> with Hansen's disease. Though Dr. Ferae correctly identified Betty's ailment, he had no understanding of its communicability, leading him to jump to the conclusion that one patient could cause a citywide epidemic. Health specialists knew that the disease was communicable, but not how it was transmitted or to what extent it was contagious, which left room for doctors and everyday people to jump to dramatic conclusions about the

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<sup>7</sup> Martin, *Miracle*, 13

disease. For example, many newspapers and magazines published variations on the “Chinese Laundry” scare story, a completely false but often republished tale that described one woman’s contraction of Hansen’s disease.<sup>8</sup> In this story, a young woman would cut her hand, which would then be bound by her beau with his handkerchief. A few weeks later, the young woman has contracted a terrible case of Hansen’s disease because the handkerchief had been cleaned at a Chinese laundry. Because actual facts about the spread of the disease were largely unknown, articles such as these were believable to the reading public, causing them to make incorrect conclusions about it. The unknown nature of Hansen’s disease allowed people to imagine it as a much more devastating, harmful, and contagious disease than it actually was.

Many Americans also considered Hansen’s disease to be “foreign,” contributing to the fear surrounding it and the push to segregate patients suffering from it.<sup>9</sup> The disease was classified as a tropical disease and was associated with foreigners, especially those from non-European countries. As explained by Dr. Walter Wyman, immigration law “forbids the landing of immigrants afflicted with a loathsome or contagious disease, thus furnishing an additional protection against the importation of cases of leprosy.”<sup>10</sup> Fears of the importation of Hansen’s disease increased with the influx of Chinese immigrants in the second half of the 19<sup>th</sup> century. The government used the control of Hansen’s disease and other “foreign” diseases as a justification for severely limiting Chinese immigration, though the ban was more likely motivated by a desire to drive off

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<sup>8</sup> *The Star*, March 1942, 3

<sup>9</sup> For more on the perception of Hansen’s disease as “foreign,” as well as the impact of colonial leprosaria on the formation of Carville, see Michelle T. Moran’s *Colonizing Leprosy*, which delves deeply into the subject.

<sup>10</sup> Wyman, “National Control,” 145.

economic competition and racist attitudes backed by social Darwinist theory.<sup>11</sup> Many Americans began to link Hansen's disease with the Chinese, to the extent that the disease was sometimes referred to as "Chinaman's disease," particularly in Hawaii. As the United States began to colonize and annex foreign territories, like Hawaii and the Philippines, fear of Hansen's disease also increased. The disease was more common in both of these territories than in the contiguous United States, particularly in the Philippines. Adding these places to the country's territory made the containment of the disease a problem of the United States government, though not yet on their own soil. Colonies like Culion in the Philippines and Kalaupapa would also provide models for the future national leprosarium at Carville.<sup>12</sup> Involvement in foreign wars was also an issue because these conflicts put soldiers who otherwise would not have been exposed in a position to contract Hansen's disease. Several veterans who had been stationed in the Philippines during the Spanish-American War, like Ned Langford of *Who Walk Alone*<sup>13</sup> fame and John Early, had contracted the disease. World War I had started by the time Congress began to discuss a national home for Hansen's disease patients. With soldiers stationed in foreign countries, policymakers feared some would contract Hansen's disease, as they had during the Spanish-American War. Fear of a foreign disease and the desire to contain or exclude it from American society contributed to the push for a national leprosarium.

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<sup>11</sup> Mishler, *Social contexts*, 179.

<sup>12</sup> Moran discusses the impact of colonial leprosaria on the development of Carville in *Colonizing Leprosy*.

<sup>13</sup> Perry Burgess, *Who Walk Alone* (New York: Henry Holt and Company, 1945). This book, published and widely read in the 1940s, described the experiences of Ned Langford, a veteran of the Spanish-American War who upon hearing his diagnosis with Hansen's disease faked his death to keep the shame of it from his family and eventually moved to Culion in the Philippines.

Hansen's disease was also viewed as impure in the Christian tradition, considered by many Americans to be a moral and social disease with strong religious ties rather than a physical one. The association between Hansen's disease and uncleanness goes all the way back to the Bible, in which "leprosy"<sup>14</sup> is described as a terrible sinner's disease. In modern times, one common belief was that Hansen's disease was a venereal disease, adding to the stigma that it was the disease of the morally wrong. The disease had always had strong ties to religious institutions. Throughout the world, including the U.S., the majority of care for these patients came from missionaries, nuns, or other religious figures, excellent examples of which are the Sisters of Charity at Carville and Father Damien in Hawaii. Caring for Hansen's disease patients was a self-sacrificial activity that brought the caretaker an aura of holiness; Father Damien was even sainted by the Catholic Church after his death.<sup>15</sup> Though religious organizations did provide needed care to Hansen's disease patients, the promotion of their charitable activities to raise funding, particularly for missionaries, perpetuated the idea that the disease was highly contagious and was a morally based disease that could be cured through faith. Many Hansen's disease patients, including Norbert Landry,<sup>16</sup> relied on their strong religious beliefs as a method of curing and treating their disease. The Sisters of Charity themselves imposed strict moral rules on Carville patients before 1921 because they believed that clean, moral living would improve their health.<sup>17</sup> Because Hansen's disease was intertwined with Christianity, the disease was viewed as a moral issue rather than a

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<sup>14</sup> Some historians, Biblical scholars, and epidemiologists argue that the "leprosy" described in the Bible is not actually a specific reference to HD, but is a mistranslated generic term for visible skin conditions, used as a metaphor for uncleanness.

<sup>15</sup> Moran in *Colonizing Leprosy* and Stanley Stein in *The Star* both discuss the impact of missionary activity on the perception of HD. Father Damien was sainted in 2009 and, interestingly, is the unofficial patron saint of HIV/AIDS patients ([http://www.catholic.org/saints/saint.php?saint\\_id=2817](http://www.catholic.org/saints/saint.php?saint_id=2817)).

<sup>16</sup> Manes, "Regarding Carville," 329.

<sup>17</sup> Moran, *Colonizing Leprosy*, 80.

medical condition. In the eyes of the public, the moral implications of the disease trumped medical facts about it. The disease was also often associated with the poor, a false belief that added to the social stigma of the disease. This belief was even held by doctors, like Surgeon General Walter Wyman, who stated in a report on Hansen's disease in the United States that the disease was primarily found amongst the lower class.<sup>18</sup> All of these moral, religious, and social ideas about Hansen's disease contributed to the formation of a false image of it that created "highly objectionable patients"<sup>19</sup> and a stigma that forced those struggling with the disease into isolation and secrecy.

The Marine Hospital Service began to rise in power as an independently functioning government agency at the turn of the century, and the establishment of a national leprosarium was partially an exercise in the strength of their control over the American patient population.<sup>20</sup> During the late 19<sup>th</sup> century, the Marine Hospital Service had gained control of quarantine and regulation of immigrants and interstate commerce. They also began developing laboratories to investigate threatening contagious diseases, such as cholera. Under the leadership of Surgeon General Wyman, the Marine Hospital Service sought to investigate Hansen's disease. By launching this investigation, the Marine Hospital Service tested its limits in regard to the control of public health issues amongst American citizens. The investigation into Hansen's disease was one of the first times that the government agency had the authority to create national health policy and exert control over a large, centralized network of public health officials. The Marine Hospital Service pushed for the establishment of a national leprosarium at the turn of the

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<sup>18</sup> Wyman, "National Control," 146

<sup>19</sup> Wyman, "National Control," 146.

<sup>20</sup> Moran discusses the rise of the Marine Hospital Service and its involvement with Hansen's disease in her book, *Colonizing Leprosy*.

century, another way to expand their authority in public health matters.<sup>21</sup> Though the 1905 bill to establish a national leprosarium failed in Congress, this initial investigation brought the attention of the federal government to Hansen's disease. This disease, with its social stigma, served the Marine Hospital Service as an ideal test subject for their national authority. As an illness subject to quarantine, it fell under the umbrella of the Marine Hospital Service role of quarantining immigrants with contagious diseases. However, because the investigation was focused on the disease within the country and amongst American citizens, it offered the Marine Hospital Service a way to test the limits of its involvement in public health beyond the scope of its existing roles. The Marine Hospital Service made Hansen's disease, a disease which the commission admitted affected few Americans, a relevant public health issue, and though it was initially unsuccessful in establishing a national leprosarium, would do so in the 1920s, after the involvement of John Ruskin Early and his opposition to existing government policy regarding the disease.

John Ruskin Early created a sensation with his opposition to government treatment of Hansen's disease patients in the early 20<sup>th</sup> century, a sensation which pushed Congress into seriously considering the establishment of a national leprosarium.<sup>22</sup> Referred to as the original "Carville Crusader"<sup>23</sup> by Stanley Stein, Early was a corporal in the United States Army stationed in the Philippines from 1900-1902 during the Spanish-American War. After the war, Early married and began working at a pulp mill, where he developed a condition that left him unable to work. He decided to go to Washington,

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<sup>21</sup> Moran, *Colonizing Leprosy*.

<sup>22</sup> This section is based primarily on Kalisch's article "The Strange Case of John Early: A Study of the Stigma of Leprosy" and Gould's *A Disease Apart*.

<sup>23</sup> Gould, *A Disease Apart*, 186.



D.C. and claim the pension he was entitled to as a disabled veteran. However, during his medical examination, Early was diagnosed with Hansen's disease. Health officials quickly isolated him in a dilapidated house on the bank of the Potomac river. He was joined by his wife after the government built a brick wall through the middle of the house to prevent them from coming into physical contact. The case quickly gained media attention, with many reporters questioning the decision of the government to forcibly quarantine a citizen and veteran. Under media pressure, the government folded and sent Early to a New York dermatologist. A team of doctors in New York declared the Hansen's disease diagnosis incorrect, and Early was freed. Early's Hansen's disease positive status was repeatedly contested throughout his life, with doctors as prominent as Hansen himself weighing in on the issue. Until 1914, Early was repeatedly diagnosed, quarantined, cleared, and ostracized upon discovery of his identity, a cycle which eventually ended his marriage and left him quarantined in a remote outpost in Washington State.

In 1914, Early changed his own situation and triggered governmental hearings on the treatment of Hansen's disease patients with his infamous trip to Washington. He escaped from quarantine only to turn up a few weeks later as a guest in the pricey and popular Hotel Willard in Washington, D.C. Senators, representatives, and even the vice president frequented the hotel. Early created a media sensation by dramatically announcing his Hansen's disease positive status at a press conference in the hotel before being arrested by the city's chief medical inspector, stating that:

I 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 of a national home. That is why I chose the Pullman car, why I slept at the best hotels, ate in the best restaurants. No one cares what happens to the poor<sup>24</sup>

John Early wanted to call national attention to his struggle as a Hansen's disease patient with nowhere to go, and knew that the easiest way to change his situation was to take his disease straight to the lawmakers. After being motivated by Early's adventure, talks soon began in Congress about the foundation of a national leprosarium and funding was officially allocated for the hospital in 1917. Early was eventually transferred to Carville after it became a national hospital, where he wrote letters of protest to various presidents, absconded from the hospital on multiple occasions, and generally caused trouble until his death.<sup>25</sup> John Early was the catalyst that created the national leprosarium at Carville. While earlier attempts to create a national leprosarium had failed, Early's succeeded because he put American decision makers at risk of contracting his disease, causing them to panic and forcing them into pushing legislation to establish the hospital. Despite being, according to Stanley Stein, a "religious fanatic, a bigot, an exhibitionist," and a man who "I think, at times bordered on the psychotic,"<sup>26</sup> Early played a significant role in the formation of a national segregationist policy for Hansen's disease patients.

After receiving the swift kick in the pants that was John Early's trip to Washington, Congress approved funding for the construction of a national hospital for HD patients. However, a new home was never constructed because of strong local opposition at all possible sites. For example, a possible site in South Dakota was quickly

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<sup>24</sup> Philip A. Kalisch, "The Strange Case of John Early: A Study of the Stigma of Leprosy," *International Journal of Leprosy* 40 (1972): 298, accessed October 29, 2013, <http://ila.ilsil.br/pdfs/v40n3a09.pdf>

<sup>25</sup> Both Tony Gould in *A Disease Apart* and Philip A. Kalisch in "The Strange Case of John Early" describe the life and actions of John Early upon which I have based my own discussion of his life.

<sup>26</sup> Stein, *Alone No Longer*, 180.

shot down by local residents and their congressional representative. Instead, Congress eventually decided to convert the state leprosarium in Louisiana into a nationally run hospital.<sup>27</sup>

Due to Louisiana's historic struggle with Hansen's disease, the Indian Camp Plantation had been a leprosarium since 1894 and in 1921 became United States Marine Hospital No. 66. Hansen's disease was endemic in Louisiana and had at least twice as many patients suffering from the disease than any other state. According to Gould, there are three different possible causes for the prevalence of the disease in Louisiana. First, Louisiana had attracted a variety of immigrants from different countries in its early years, including France, Spain, and Italy, who may have brought the disease with them. Second, New Orleans was a center of the slave trade, which may have brought the disease into the city and the southern part of the state. Lastly, southern Louisiana has a significant Acadian population, which created a sizeable population genetically susceptible to Hansen's disease. Many of these French-Canadian immigrants came from New Brunswick, where Hansen's disease was also endemic.<sup>28</sup>

Before the establishment of the colony at Indian Camp Plantation, most Hansen's disease patients were cared for in the pest houses, hospitals or buildings that housed patients with highly contagious diseases, of New Orleans. Conditions in these pest houses were poor, and many patients were simply left to die with little or no care. At the end of the 19<sup>th</sup> century, Doctor Isadore Duncan campaigned for the establishment of a charitable hospital specifically for Hansen's disease patients, eventually gaining funding

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<sup>27</sup> Moran gives a detailed history of the search for a national leprosarium location in *Colonizing Leprosy*. Various issues of *The Star*, as well as Stein and Martin's memoirs, also describe the origins of the national hospital at Carville.

<sup>28</sup> Gould, *A Disease Apart*, 196.

from the state. Indian Camp Plantation, about 80 miles outside of New Orleans, was chosen as a temporary site until a better one could be found. The main house and cabins were repaired so they could house staff, administration, and patients. Townspeople in Iberville Parish, where the plantation was located, were told the plantation was to be used as an ostrich farm. The Sisters of Charity, who would continue to nurse Carville patients into the present day, arrived at the hospital in 1896. Until the federal takeover in 1921, the hospital was severely underfunded and run primarily by the Sisters. Patients were segregated by gender and race; the only time men and women were permitted to interact was at funerals. Discipline under the Sisters was strict and poor conditions due to lack of funds contributed to a rather dismal existence at the hospital.<sup>29</sup>

After fruitless searching for a better location, the federal government began renting Carville in 1921, turning it into a National Marine Hospital. Though the Sisters were still employed as nurses at the hospital, they lost their administrative power. The Marine Hospital Service instead installed a Medical Officer in Charge at the hospital to make executive decisions. Nationalization brought an end to gender segregation, brought permanent doctors to the hospital, and improved living conditions for the patients. The nationalization of Carville brought hope to many patients and was, according to Betty Martin, “a happy and exciting day, I was to hear old-timers say often, when this tiny world on the Mississippi was brightened by the national government taking over.”<sup>30</sup> The nationalization of the hospital improved the situation of patients, but, as would be shown by later protests, was not enough to alleviate the miseries of segregation.

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<sup>29</sup> Moran writes about the early days of Indian Camp Plantation and the years in which the hospital was managed by the Sisters of Charity in the second chapter of *Colonizing Leprosy*.

<sup>30</sup> Martin, *Miracle*, 31.

All of these factors had a significant impact on the ways in which Carville patients sought to maintain or build new identities after their arrival at the hospital. The misinformed beliefs commonly held about Hansen's disease, such as its mysterious nature, contagiousness, status as foreign, and moral and social implications, created the social milieu that led patients to lose their past identities, abscond and create secret lives on the outside, build their own community within the hospital, and launch a series of protests and education campaigns to correct these beliefs. The Marine Hospital Service's experiments in control and power, which began at the turn of the century, would have a significant influence on the reforms the Public Health Service attempted to implement in Carville during the 1950s. These reforms led to some of Carville's most vocal patient protests. John Early acted as a model of a patient protestor for his successors, like Stein, and showed that patient protest could be successful. The factors that led to the creation of a national leprosarium also had a significant impact on the identity forming and maintaining activities of later Carville patients.

## CHAPTER TWO

### “DON’T FENCE ME IN:”

#### REJECTING THE PATIENT IDENTITY<sup>1</sup>

Upon first entering Carville, most people initially reacted to the shock of the loss of their previous identity and the gain of a new patient identity by rejecting the new and finding ways to stay connected to the old. Patients rebelled against the isolation that came with their new life in the hospital and instead chose to use legal and illegal means to remain in contact with their families and in touch with the goings on of the larger world. Breaks in the isolation at Carville, such as mail, telephones, roads and transportation, official leave, and unofficial trips outside through the “hole in the fence,” gave patients the tools to establish and maintain a connection with their previous lives on the outside. Carville residents, with help from willing relatives outside of the hospital, used these methods of communication to stay in contact with their families. Within the grounds of the hospital, patients found ways to participate in shared American experiences like elections and the home front during World War II, rejecting their isolation and maintaining an identity as an American citizen.

Patients at Carville used mail, telephones, roads and hospital transportation, formal leave, and trips through the “hole in the fence” to maintain their connection to their lives on the outside. These methods of communication provided patients with the resources they needed to escape from their new patient identity and fall back into their old lives, either in the short or long term. These breaks in Carville’s isolation were

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<sup>1</sup> The title of this chapter comes from the popular 1934 song “Don’t Fence Me In, written and composed by Cole Porter and Robert Fletcher. This song became the unofficial anthem of the patient body at Carville.

mostly sanctioned by hospital administration, except for going through the hole in the fence, though that practice was unofficially tolerated. Isolation at Carville was not complete and it was possible for patients to stay connected to their lives from before their admission to the hospital.

Despite the lack of an on-site post office until 1948, the most common way patients communicated with loved ones on the outside was through the mail. According to Ann Page, who often wrote about the lives of patients, particularly women, in *The Star*, “Any day of the 365 in the year, you will see the largest gathering of patients at mail time of any other time of the day (mealtime excepted).”<sup>2</sup> As will be discussed in the next chapter, food is a central part of patient life at Carville, but according to Page, the arrival of mail is a close second. According to Page, the patients typically used letters to keep up on news from home and stay connected to the lives of their family members on the outside. For example, the five members of the Landry family who were sent to Carville, particularly Edmond Landry, frequently corresponded with their family members on the outside.<sup>3</sup> The exchange of letters kept patients separated from their loved ones in the loop of family life, giving them an opportunity to preserve their roles within their families and stay connected to their lives on the outside.

Even before its official arrival in Carville, the telephone was also an important method of communication between Carville patients and the outside world. Before the arrival of a phone in 1936, patients would make arrangements to go through the hole in

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<sup>2</sup> Ann Page, “Ann Page’s The Ladies,” *The Star*, April 1943, 8.

<sup>3</sup> Several descendants of the Landry family have used the letters written by their relatives to write about Carville. Christopher Manes’ article “Regarding Carville: The Letters of Norbert and Edmond Landry” explains changes in patient attitudes toward their situation through the letters of the two brothers. Claire Manes has recently published a book, *Out of the Shadow of Leprosy: The Carville Letters and Stories of the Landry Family*, also based on the letters of her relatives.

the fence to a payphone. For example, Stanley Stein once arranged for a car to drive him to Baton Rouge so he could make a phone call to his mother.<sup>4</sup> Even when reaching a telephone was difficult and illegal, since it meant going through the hole in the fence, patients were willing to take the risk of punishment in order to communicate with their families. After the introduction of a communal wall phone in the canteen in 1936, which was on a party line with several rural families, calling home became easier. Calling home was further simplified when Carville patients received a private line in 1948.<sup>5</sup> Telephones made contacting family members faster and easier for patients, giving them an opportunity to reconnect with life on the outside.

Newly paved roads and a pair of station wagons made it easier for patients to visit family on the outside and for family and friends to come visit them. Before 1949, only a dirt road led to Carville and there was no available public transportation to and from the hospital.<sup>6</sup> Because Hansen's disease patients were outlawed from using public transportation, trips home were expensive and impossible for many patients who did not have the means to obtain or pay for a private car home. The lack of public transportation to the hospital also limited the ability of family on the outside to visit Carville patients. However, the arrival of two station wagons, donated by the American Legion Auxiliary, in 1945 and the paving of the road to the hospital, ordered by Dr. Johansen, in 1949 made the hospital more accessible to visitors and the outside world more accessible to patients.<sup>7</sup> The station wagons were used to transport patients to their homes for leave and to drive visitors from the nearby town of St. Gabriel, the last stop for public transportation, to

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<sup>4</sup> Stein, *Alone No Longer*, 138.

<sup>5</sup> Stein, *Alone No Longer*, 178.

<sup>6</sup> Stein, *Alone No Longer*, 243.

<sup>7</sup> "Good News," *The Star*, September 1945, 7.



Carville. The improvements to hospital transportation in the 1940s increased accessibility to the outside world for patients, giving them yet another method of staying connected to identities outside of the hospital fences. As the strength of physical isolation at Carville decreased, it became somewhat easier for residents to reject the patient identity and participate in family life, either in their homes or during relatives' visits to the hospital.

Some patients were able to secure formal leave to visit their homes; as these rights expanded, it became easier to break patient isolation and maintain family relationships on the outside.<sup>8</sup> At first, only patients from Louisiana and the nearby states of Mississippi and Texas were allowed to travel home for short holidays. Only ten patients could go out on leave at a time, and each patient had to have permission from their hometown health board before their visit.<sup>9</sup> Betty Martin was one of the first patients to obtain this type of non-emergency leave in the late 1920s.<sup>10</sup> Non-emergency leave was expanded in 1948 under Dr. Johansen, allowing all patients two leaves of one month each annually.<sup>11</sup> Formal leave, especially after its length and availability increased in 1948, allowed many patients to reconnect with their families on the outside. However, formal leave was at times limited and came with the caveat of reporting to local health boards, which sometimes closely monitored patients and occasionally harassed their families. These issues discouraged some patients from using this method to go home; instead, many patients chose to take an illegal form of leave- going through the hole in the fence.

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<sup>8</sup> For more on patient leave and the expansion of these rights for patients during the 1940s, see Amy L. Fairchild's "Leprosy, Domesticity, and Patient Protest."

<sup>9</sup> Fairchild, "Leprosy, Domesticity, and Patient Protest," 1013.

<sup>10</sup> Martin, *Miracle at Carville*, 40.

<sup>11</sup> Fairchild, "Leprosy, Domesticity, and Patient Protest," 1022.

Patients used the hole in the fence, a constantly available and generally tolerated outlet to the outside world, to leave Carville illegally without the restrictions of formal leave.<sup>12</sup> There was a literal hole in the fence through which Carville patients passed to reach the outside. This small hole is located along the hospital boundary with the river road, near the protestant chapel and can still be seen today. Though technically a violation of the rules and known to hospital administrators, the hole was not closed up and patients who left for short periods of time were rarely punished. Nancy Battista, a Carville patient, was once caught going through the hole in the fence by one of the doctors but was never punished for it: “my blouse got caught on the fence, and the car, the government car was passing by. I don’t know who the doctor was. I just waved, and they waved back, but they didn’t punish- I was never punished for it.”<sup>13</sup> Even though Nancy was caught red handed going through the hole, the doctor that spotted her chose to ignore and implicitly allow her rule breaking. Nancy, who waved at the doctor rather than try to hide from him, was not afraid of being caught and continued to use this access point to the outside world. Administrators knew patients used this hole to abscond, but generally looked the other way, allowing patients access to the outside world without a significant fear of punitive repercussions. Going through the hole in the fence was a common practice among patients. As was once reported in an issue of *The Star*, “If our MOC isn’t sleeping well these nights and is counting sheep maybe it is because seven of his flock took it on the ‘lam(b).”<sup>14</sup> Absconding through the hole in the fence was a common shared patient experience at Carville, one that could be joked about. Seven

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<sup>12</sup> For more on the hole in the fence, see Chapter three of Marcia Gaudet’s *Carville: Remembering Leprosy in America*, which includes the stories of many patients who used the hole in the fence to access the world outside of Carville.

<sup>13</sup> Interview of Nancy Batista. Oral Histories. National Hansen’s Disease Museum, Carville, Louisiana.

<sup>14</sup> “Anything Goes,” *The Star*, January 1943, 12.

patients absconding at the same time was not front page newsworthy and only warranted a humorous blurb alongside other tidbits of gossip on the last few pages of the paper. For patients at Carville, going through the hole in the fence was a simple, lightly (if at all) punished, and common way to reconnect with the outside world.

Patients used these modes of connection to maintain their relationships with their families on the outside and reject the loss of their identity as a spouse, child, sibling, or parent. When patients entered Carville, they often left family behind. Isolation at the hospital created several barriers between residents and their families. Children younger than twelve were not allowed to visit Carville and could not be present when a patient visited home, transportation costs were prohibitive to some families, and the stigma of Hansen's disease all complicated the involvement of patients in family life on the outside. Despite these difficulties, patients, along with their family members, found ways to preserve their identities as parents, children, and spouses and reject their new identity as an isolated patient at Carville. The primary ways in which patients stayed connected to their families on the outside included visits from home, legal and illegal visits to home, and the relocation of family on the outside to Carville. Through these activities, residents in Carville rejected their identity as Hansen's disease patients in favor of the family identity they had left behind upon their entrance into the hospital.

Patients' relatives often visited them at Carville, enabling them to maintain family relationships despite the restrictive conditions of their isolation. Before eligibility for leave expanded in 1948, it was easier for the relatives of patients to come visit them than it was for the patients to go home. When patients were unable to go home for visits, their families instead came to them. For example, because only ten patients could go home for

the holidays in 1943, the families of many patients came to Carville to visit them, as reported in *The Star*.<sup>15</sup> Though patients were unable to go home for holiday celebrations, they were still able to break their isolation and participate in this event through visits from their families. Though still hospitalized in Carville, residents had the opportunity to abandon that part of their life temporarily during a holiday visit from their families. Visits from family were common throughout the year. The *Sixty-Six Star* contained a report on visiting friends and family members in every issue, visits that many patients wanted everyone else to know about. For example, the May 16, 1931 issue describes some of these family visits. One man's family joined him to see the minstrel show being put on by other patients, while another man's mother arrived for a month-long visit.<sup>16</sup> Because his family came to watch the show with him, the first patient had an opportunity to share an entertainment experience with them, as he might have on the outside. By visiting for a month, the second patient's mother gave him stable and continuous access to her company. This gave the second patient an opportunity to interact with his mother on a daily basis, like he might have at home. For both of these men, family visits allowed them to temporarily ignore their isolation and separation from their lives on the outside and reconnect to that part of themselves. Visiting family members gave patients a chance to break through their isolation at Carville, return to their roles within their families, and reject their identity as a patient in favor of one as a family member.

Patients invited their families to come to see them in Carville, taking an active role in reconnecting to their lives outside through visits with relatives. The staff members of *The Star* frequently requested that friends and family come to Carville. For example,

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<sup>15</sup> Ann Page, "Ann Page's The Ladies," *The Star*, December 1943, 11.

<sup>16</sup> *The Sixty-Six Star*, May 16, 1931, 2

after pointing out that several patients had recent been visited by family members, one patient wrote that the patients “can’t go to Texas, Mississippi, and Florida, so how about some more of you from home taking the hint and coming out to see us. The trains and buses are still running for you and we’ll send a car to meet you at St. Gabriel.”<sup>17</sup> This acknowledges that leaving the hospital is difficult for patients, but also suggests that patients will do whatever they can to get their visitors to the hospital. By inviting relatives and friends to visit Carville, patients took an active role in this connection to the outside world. Visits from family allowed patients to temporarily resume their roles within that unit, an opportunity that they sought and embraced.

In some cases, the spouses and families of some patients went beyond simple visits, leaving their homes in other states to move to towns near Carville in order to help patients on the inside to preserve their pre-isolation family relationships. For some Carville residents and their spouses, isolation at the hospital was an easily overcome barrier to their relationships, one to which they were able to adapt. One example of this adaptation of home life to the obstacle of physical separation between patient and non-patient partners is the story of Joseph and his wife. After his entrance into Carville, Joseph’s wife moved to a house nearby and visited him daily in his small cottage on the hospital grounds to cook, clean, and fulfill her role as his wife.<sup>18</sup> Instead of living a new, husband-free life back home while her husband started over in Carville, Mrs. Joseph refused to accept the barrier Joseph’s new patient identity put between them. She moved and spent her days at Carville living out their lives as they had before, providing her husband with continuity in his daily life and breaking his isolation. With the help of his

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<sup>17</sup> “All Around the Town.” *The Star*, July 1943, 11.

<sup>18</sup> Stein, *Alone No Longer*, 104.

wife, Joseph was able to reject the isolation of his new patient life and embrace his old life as a husband in a domestic setting.

The most famous case of a spouse moving to the nearby area to be with a partner being treated in Carville is that of the Hornbostels.<sup>19</sup> In 1946, Gertrude Hornbostel, who had spent part of World War II in a Japanese prison camp in the Philippines, was diagnosed with Hansen's disease. Instead of willingly entering an isolated life at the hospital, Gertrude and her husband, Major Hans Hornbostel, a survivor of the Bataan death march, launched a popular media campaign to gain public sympathy for their cause and permission for the Major to live inside of Carville with his wife. Though this campaign was unsuccessful, Major Hornbostel moved nearby the hospital and visited his wife everyday for the duration of visiting hours until her discharge several years later. They purchased a cottage on the grounds of the hospital, where they would spend their days together, gardening or engaging in other domestic tasks.<sup>20</sup> Gertrude and Major Hornbostel refused to take her isolation as a patient sitting down, actively campaigning to end it by allowing her husband to join her in the hospital and, when that failed, using visiting hours to continue their domestic lives together and refusing to submit to separation from one another. With the help of their spouses, patients like Joseph and Gertrude rejected the isolation that was a part of life as a Carville patient. Instead of allowing physical separation to change their relationships, the spouses of these patients dropped everything and moved nearby Carville to help their partners retain their spousal identities and live their marital lives as normally as possible. When patients had the support of their loved ones on the outside, it was possible to reject the loss of their

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<sup>19</sup> For more on the Hornbostels and the impact of their media campaign, see Moran's *Colonizing Leprosy*.

<sup>20</sup> Stein, *Alone No Longer*, 252.

identity as a family member and continue on with family life in a style adapted to their status as a Carville patient.

Some patients were able to legally or illegally break through their isolation at Carville and visit home to their families. Returning home gave patients a chance to resume family life as they had lived it before entering Carville. Though visits home could be difficult at times,<sup>21</sup> patients used these trips to try to forget their identities as Carville patients and focus on their identities as members of families on the outside. Patients used legal means to return home temporarily, while they would use the hole in the fence when the return was more permanent or when travel restrictions kept them from receiving official leave. Carville residents used both methods of leaving the hospital to reject their identity as patients and re-embrace their roles as family members.

Patients were able to obtain official leave to visit their families at home; however, for many years, the restrictions of official leave made it difficult or impossible for patients to leave their isolation and reunite with their families. Some patients visited their families regularly, allowing them to maintain their status as a family member. For example, Betty Martin spent a week at home during her first Christmases at the hospital, giving her a chance to spend time with family members who were unable to visit her at Carville, like her younger sisters and baby brother.<sup>22</sup> Going home on leave gave Betty the chance to resume her role as a sister, and because her siblings did not know that she had Hansen's disease, it also offered her an escape from her patient identity. Though Betty was always

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<sup>21</sup> See Chapter Three, pages 38-41.

<sup>22</sup> Martin, *Miracle at Carville*, 60.

conscious of her condition while visiting home,<sup>23</sup> her time there gave her a chance to return to playing an active role in family life, if only for a short time.

For some patients, going home on leave was a time to show how little their disease had changed them and remove the stigma of the patient identity from their family members' views of them. For example, Esther Casas recalled her first visit home in an interview: "I remember the first time I went home. My father looked at me, and he hugged me and, like he said, "Well, nothing's wrong with you, thank God." And he cried a lot. "Thank God, everything is normal now."<sup>24</sup> By visiting home on leave, Esther showed her father that she had not changed and was still his daughter, not a sick patient. Her trip home helped her to restore her image as a daughter in her family's eyes and gave her a chance to return to her pre-Carville identity as a child within the family. For Esther, a trip home meant a return to normalcy with her family. Carville patients used official trips home to bond with family members they could not see while isolated at the hospital and rebuild their place within their family. By visiting home in this way, Carville residents rejected the patient identity in order to return to their original identities within their families.

When patients were unable to obtain official leave, they continued to reject the loss of their family identity by going through the hole in the fence and illegally visiting their homes.<sup>25</sup> Because leave was limited in availability and length and because local health boards could place restrictions on patients with leave, some patients chose to leave the hospital illegally. Some visits through the hole in the fence were short term outings with

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<sup>23</sup> Betty's struggles with her visits home are discussed in Chapter Three on pages 38-39.

<sup>24</sup> Interview of Ester Casas. Oral Histories. National Hansen's Disease Museum, Carville, Louisiana.

<sup>25</sup> Again, Marcia Gaudet's *Carville: Remembering Leprosy in America* is the best secondary source regarding patient experiences going through the hole in the fence.



family, such as Johnny Harmon's trips through the fence with his wife in order to have picnics with their children, who they were unable to see through legal means.<sup>26</sup> The Harmons used the hole in the fence to play an active role in their children's lives. They broke through their isolation at Carville to take up the identity of parents to their children, an identity that contradicted their status as patients at the hospital. The Harmons chose to reject their patient identity for the duration of these picnics so they could fully embrace the role of parents within their family.

In some cases, patients chose to abscond through the hole in the fence on a more permanent basis in order to resume family life, especially patients who had left children on the outside. One patient, Hazel, left Carville through the hole in the fence in order to care for her daughter, staying on the outside with her child for several years before being forced to return to Carville.<sup>27</sup> Hazel's desire to be a mother overruled her fear of the consequences of absconding. She rejected her identity as a Carville patient in favor of returning to her life as a parent on the outside. Because she could not legally leave permanently to raise her daughter, Hazel used the alternative method available to her, going through the hole in the fence, to restart her family life on the outside. Her willingness to risk going without treatment and imprisonment if caught show that patients like her were willing to do whatever it took to leave their lives as Carville patients behind them and return to the families waiting for them on the outside.

For other patients, being a Carville resident meant forgoing the ability to be a breadwinner for their family. Though some patients did have jobs or businesses, some

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<sup>26</sup> Gaudet, *Carville*, 75. Instead of giving their children up for adoption, a common practice for patients who gave birth to children at Carville without family on the outside to care for them, the Harmons chose to foster their two children with a woman in a nearby town so they could remain a part of their lives.

<sup>27</sup> Gaudet, *Carville*, 43.

were not able to earn enough money to support the families they had left behind on the outside. In his memoir, Stanley Stein tells the story of Harry Dover, whose departure coincided with the disappearance of money from the patient canteen, earning him the suspicion of other patients. The only explanation Harry offered for his possible theft was that “they [his family] were starving”<sup>28</sup> Harry left the hospital behind because of a pressing need to return to and support his family. His desire to earn a living for his wife and children caused him to choose to leave through the hole in the fence, as official leave would have limited his time on the outside and prevented him from working while at home. Like Hazel, Harry was willing to use any means necessary to abandon his identity as a Carville patient in favor of resuming his role in his family. Because it was impossible for some patients to return to their lives on the outside without fully rejecting their status as a patient at the hospital, people like Hazel and Harry refused to accept their isolation. By returning to their families, they willingly severed ties with their institutionalized life. For some patients, going through the hole in the fence was a complete rejection of their identity as a Carville patient.

Despite being denied some of the basic rights of citizenship, many patients found ways to maintain their identity as Americans. In much of the advocacy work of patients in the 1940s and 1950s, their identity as normal, everyday American citizens was a crucial part of their educational strategy.<sup>29</sup> It was important to these patients, and to others, to protect and enhance their identities as Americans. By regaining the right to vote and by participating in the American home front during World War II, residents of

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<sup>28</sup> Stein, *Alone No Longer*, 59.

<sup>29</sup> Moran, *Colonizing Leprosy*, 152.

Carville rejected the isolation of life as a patient and reconnected to their identity as Americans.

By exercising their right to vote, patients at Carville regained one of their fundamental rights as citizens and stayed connected to the country as whole through the political sphere.<sup>30</sup> Even before the right to vote within Carville was legalized, some patients such as Fred Smith, who went through the hole in the fence on five occasions to vote, were willing to risk imprisonment at the hospital jail for a chance to participate in elections.<sup>31</sup> Fred rejected his isolation from the political process and was willing to break the rules to do so. To him, his identity as an American citizen active in the election process was more important than being a good and obedient patient. Though not every patient was willing to go as far as Fred to connect with their identities as Americans through voting, they found other hospital-sanctioned ways to participate in elections. Interest in the 1932 elections was high amongst patients and the hospital held its first straw vote in that year: “Political interest was whipped to a white heat in Carville on Tuesday evening, as crowds gather in the reading room to receive returns from the national presidential election, and to hear the tabulation of the straw vote held Monday in this hospital.”<sup>32</sup> Though patients could not officially participate in elections, they still expressed interest in the process and held their own unofficial vote. Even before voting was legalized for patients, they found ways to stay connected to other Americans who

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<sup>30</sup> For more on the patient campaign to regain their voting rights, see Moran’s *Colonizing Leprosy* and Fairchild’s “Leprosy, Domesticity, and Patient Protest.”

<sup>31</sup> Stanley Stein, handwritten notes, June 1 1961. Stanley Stein Archives. Bin 19733- Voting. National Hansen’s Disease Museum, Carville, Louisiana.

<sup>32</sup> Stanley Stein, “As Carville Goes- So Goes the Nation.” 1932. Stanley Stein Archives. Bin 19733- Voting. National Hansen’s Disease Museum, Carville, Louisiana.

were able to vote by continuing to follow the election and by exercising their right to vote, even in an unofficial capacity.

Patients finally received voting rights in 1946, but were required to register under their real names and give their previous place of residence. Though this deterred some patients who were unwilling to risk making their secret identity as a Carville patient public, a majority of patients registered and voted that year.<sup>33</sup> The Carville patient precinct always had a high turnout and was routinely the first to report its results in state elections, regarded by state politicians as an early predictor of the final tally of votes. Thus, once patients could vote, local and state politicians began to include the hospital on their speaking routes through the state before elections. They frequently brought gifts of food and spoke briefly before weekly movie nights began, though they had to finish on time to ensure that they would not lose the votes of patients eager for a film.<sup>34</sup> Because of these visits, Carville voters were able to make informed decisions about their votes. Carville residents used the voting process to reconnect with American political life and strengthen their identities as dutiful American citizens.

During World War II, patients at Carville found ways to participate in the war effort and find a place in the shared American experience of life on the home front. Even though Hansen's disease patients were not eligible for active military duty, Carville residents found ways to break their isolation and engage actively in the war effort like their fellow civilian Americans. For example, Betty Martin and her friends began selling war stamps after Pearl Harbor was bombed and organized a freedom fair to raise money

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<sup>33</sup> Stein, *Alone No Longer*, 138.

<sup>34</sup> Stanley Stein, handwritten notes. Stanley Stein Archives. Bin 19733- Voting. National Hansen's Disease Museum, Carville.

for the Army and Navy relief fund.<sup>35</sup> Just like other Americans, Carville patients grew victory gardens,<sup>36</sup> held rubber drives,<sup>37</sup> and even used their entire reserve fund to purchase defense bonds.<sup>38</sup> Despite being isolated in Carville, patients found ways to stay connected to the nation and participate in war efforts on the home front. Because their physical separation from the outside world kept them from participating in any scrap drives or fundraising activities on the outside, patients simply created their own opportunities to aid in the war effort. Carville residents who participated in these home front activities rejected their alienation from the United States because of their patient status and embraced the patriotic fervor experienced by Americans on the outside. By creating their own ways in which to aid the war effort during World War II, Carville patients rejected the isolation of their lives at the hospital and embraced their identities as Americans.

Upon entering Carville, most people were unwilling to fully accept their new identity as a patient. They rejected the isolation of hospital life and instead used breaks in their physical separation from the outside world, such as the hole in the fence, to maintain their identities from their lives before Carville. When patients had the support of their loved ones on the outside, they were able to overcome the physical separation imposed by their status as a Carville patient and engage in family life adapted to their changed situation. Though patients could instigate this return to family life by going on leave or through the hole in the fence, their families worked with them to strengthen ties by coming to Carville either to visit or to live nearby for the duration of their loved one's treatment.

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<sup>35</sup> Martin, *Miracle at Carville*, 160.

<sup>36</sup> Ann Page, "Ann Page's The Ladies." *The Star*, June 1942, 7.

<sup>37</sup> "Rubber Drive." *The Star*, July 1942, 1.

<sup>38</sup> "So They Say." *The Star*, May 1942, 5.

Carville residents also rejected the disconnect from their identities as Americans by voting and creating their own ways to participate in the home front during World War II. Many Carvillians refused to accept the isolation that came with their new patient identity and found ways to reach out to the world outside the fence and embrace old identities as members of families and of a nation.

## CHAPTER THREE

### “A NATURALIZED CITIZEN OF CARVILLE:”

#### EMBRACING THE PATIENT IDENTITY<sup>1</sup>

Though some Carville residents rejected the patient identity and remained connected to life on the outside, others chose to embrace a new life within the confines of the hospital grounds. Some patients had resigned themselves to institutionalized life and did what they could to make the best of their situation. This feeling is best summed up by a line spoken by a longtime patient in the “Adventures of Egbert,” a series of stories that appeared in the *Sixty-Six Star* and followed a new arrival through his first days at Carville: “Here you are, Buddy, and here you may as well make up your mind to stay.”<sup>2</sup> The long time patient suggests to Egbert that he should just decide that staying in Carville is the best option he has and that he should embrace it. For many patients, it was not worth focusing on the outside world while in Carville; it was better to focus on their new home at the hospital. Many patients took new names when entering the hospital, and began new lives as Carville patients and community members when they did so. Because their situation made family relationships and life on the outside challenging, many Carville residents instead chose to embrace their new patient identity and life at the hospital. Patients strengthened their new identities by joining the patient community, forming new relationships, and creating a domestic environment within Carville. Because relationships with family and friends on the outside were frayed or sometimes destroyed by distance, isolation, and fear, patients engaged in new friendships and family-like relationships, creating a reliable support network of people who shared a

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<sup>1</sup> Stein, *Alone No Longer*, 55.

<sup>2</sup> *The Sixty-Six Star*, August 1 1931, 4.

patient identity. Patients also strove to transform Carville from an institution into a home, working around restrictions in order to date, dine together, marry, and even construct their own homes on their own terms. By creating a domestic atmosphere within the hospital, patients settled down into living out their lives as patients.

One of the most fundamental building blocks of the patient identity was relationships amongst Carville residents. The isolation and stigma attached to a Carville patient made maintaining relationships with loved ones on the outside challenging. Many residents found it easier to build relationships with other patients than to attempt to salvage relationships on the outside. They established a community of support within the hospital, a unity that was a crucial part of the patient identity. To compensate for the loss of family ties on the outside, patients formed surrogate families and friendships, such as patient “fraternities” within the houses. Even Carville children who had been separated from their parents due to their disease found adoptive caretakers within the community. When people entered Carville and embraced their new identity as a patient, they became a part of an isolated community that for many became a sanctuary from the outside world.

For some Carville residents, their own perception of themselves as “diseased,” which stemmed from the stigma attached to Hansen’s disease, made maintaining relationships with their families difficult.<sup>3</sup> Because they were so afraid of spreading their illness to other family members, reentering family life became stressful for them and

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<sup>3</sup> Many scholars have investigated the stigma of Hansen’s disease and its impact on the people diagnosed with it. In their article “Status, Ideology, and Adaptation to Stigmatized Illness: A Study of Leprosy,” Zachary Gussow and George S. Tracy survey Carville patients on their feelings about the stigma attached to their disease and their reactions to it. In her article, “Learning to be a leper: a case study in the social construction of illness,” Nancy E. Waxler also investigates the impact of the stigma of Hansen’s disease on patients’ actions and the ways in which reactions change in different cultures.



prevented them from coming too close to their loved ones. Betty Martin struggled with this during her earliest visits home, terrified that she would infect her younger siblings and was always conscious of her “diseased” state. As she explains, she “longed to run anywhere, even back to Carville, to escape from this dear place and these people I loved too deeply to want to be with them.”<sup>4</sup> Betty loved her family and wanted to be with them, but was also afraid that by reentering her home she was endangering her loved ones. Because she felt “diseased,” she was unable to leave her patient identity behind her and fully rejoin life on the outside. Even when she was on the outside physically, mentally she was as isolated as she had been at Carville. While with her family on the outside, Betty was always conscious of her disease: “No need for actual hood and bell- I had brought both with me from Carville.”<sup>5</sup> Even without the medieval uniform of a Hansen’s disease sufferer, Betty still felt set apart from her family. Though there were no physical signs of her illness, she and her family were unable to fully forget its presence in her life. Betty constantly felt the weight of her disease and the stigma and perceptions attached to it, making it impossible for her to fully reconnect with her family on her early visits home.

Betty was not the only Carville patient to be too afraid of endangering his or her family to remain a part of that unit. In *Miracle at Carville*, Betty describes the experiences of another patient, called Angelina. Angelina, a mother of seven, spent eight years in Carville before being discharged. She later returned to the hospital because she was constantly harassed by health authorities and wanted to spare her family the shame of her disease. She was also afraid that one of her children would be diagnosed with

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<sup>4</sup> Martin, *Miracle at Carville*, 41.

<sup>5</sup> Martin, *Miracle at Carville*, 41.

Hansen's disease because of their exposure to her.<sup>6</sup> Like Betty, Angelina is afraid of endangering or making outcasts of her family due to her presence at home. The stigmatized and "diseased" patient identity she had obtained at Carville had stuck with her, even after her return home due to her medical discharge. More than anything, Angelina returned to Carville because she feared that by staying home, the stigma and disease attached to her patient identity would become contagious, infecting her family. Her patient identity made returning to normal family life impossible, causing her to return to Carville and embrace its isolation and anonymity.

The stigma of Hansen's disease also led many patients to embrace their new identity as Carville residents and at least partially leave their old lives behind. One patient, called Louis Boudreaux, changed his name because of the impact his entry into Carville had on his family on the outside. His siblings were forced to leave their school and his father's business nearly went bankrupt because people in his community feared his illness.<sup>7</sup> Because of the stigma attached to his identity as a Carville patient, Louis's family suffered. In order to put an end to the difficulties the stigma of his disease had caused his family, he chose to embrace a new life at Carville and partially isolate himself from his family. Pressure from social stigma and outside perceptions of what it meant to be a Carville patient forced Louis to decide between embracing life at Carville and making life easier for his family or enduring with his family the torment of stigmatization on the outside. Like many of his fellow Carville patients, Louis chose the former.

Other Carville residents were simply rejected by their family members due to their new identity as Hansen's disease patients. One patient, called Rita, was turned in to

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<sup>6</sup> Martin, *Miracle at Carville*, 87.

<sup>7</sup> Gaudet, *Carville*, 39.

health authorities by her boyfriend at the time. Her family never came to visit her, and her father told people that she had died, rather than explain she was a patient at Carville. Rita only returned home once, for her father's funeral, at which her sisters were afraid of her and refused to talk to her.<sup>8</sup> Even if Rita had wanted to stay connected to her family, her family no longer wanted to have anything to do with her because of her new identity as a Carville patient. The stigma she now bore was too much for her family to handle; they preferred to say she was dead rather than admit she was at Carville because they were so desperate to avoid the fear and distrust attached to Hansen's disease patients. Patients like Rita had nowhere left to go on the outside and had no choice but to accept the patient identity and life in Carville.

Even when patients tried to reconnect with family on the outside, it was not always successful; their isolation caused gaps to appear in relationships that had once been solid and the differences in experience that emerged after years of separation were difficult to overcome. The life of a patient was in many ways very different from that of their family members on the outside, which could make reintegration into family life difficult, especially during the limited visits home that most Carville patients had. For example, Rachel Pendleton, who entered the hospital as a teenager, had difficulty fitting in with her family when she did go home: "I no longer had a home in Corpus [Christi, Texas]. I had a family, but yet I did not have a family. They didn't- as I said, they didn't mistreat me, yet I did not feel that I was part of them because they had one lifestyle and I had another one."<sup>9</sup> When she went to Carville, Rachel became, in addition to a member of her family, a resident of Carville. Eventually, as she spent more time at Carville and

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<sup>8</sup> Gaudet, *Carville*, 47.

<sup>9</sup> Interview of Rachel Pendleton. Oral Histories. National Hansen's Disease Museum, Carville.

less time with her family, their lives diverged and she felt less and less connected to them. Like many other patients, Rachel's isolation in the hospital made her family unfamiliar territory. At the time, it was easier for her and patients like her to embrace a new life and self in Carville and give in to the challenges of maintaining family relationships during long periods of separation, allowing these relationships to deteriorate.

The patient identity that Carville residents acquired upon their entrance into the hospital put significant strain on relationships with family on the outside. Fear, stigma, rejection, isolation, and long-term separation all played a role in opening difficult-to-mend rifts between patients and their families. Because of these difficulties, many Carville residents chose to embrace their new identities as patients at the hospital and focus on a new life on the inside instead of focusing solely on their past lives. Many patients viewed Carville as a sanctuary, a place where they could be a Hansen's disease patient and not be afraid of endangering their loved ones, experiencing the effects of the stigma attached to their disease, or enduring rejection by friends and family. Carville provided them with a support network of fellow sufferers, all of whom understood their struggles and shared a patient identity.<sup>10</sup>

Many patients chose to embrace their new roles as members of a supportive, unified community within the hospital. As Betty explains in *Miracle at Carville*, the patient experience strengthened feelings of community amongst Carville residents: "How heartfelt are greetings from those with whom one has shared tragedy, disaster, and good

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<sup>10</sup> For more on the patient community at Carville, see Marcia Gaudet's *Carville* and Amy L. Fairchild's "Leprosy, Domesticity, and Protest."

will!”<sup>11</sup> To Betty, only another Carville patient could truly understand her experience. Carville residents shared a common patient identity, one that led them to form a close-knit community with strong camaraderie inside of the hospital, the only place they could find others like themselves. For many, including Betty, Carville became the only place they felt comfortable letting their guard down: “Carville had little to offer us as defense against our enemy. But it offered now sanctuary. Outside, with health and vision changing, Harry was less free than he would be in Carville. Only there, among our own, could we let down our barriers.”<sup>12</sup> Though incarcerated there, patients did not always view Carville solely as a prison. Often, it was their home, isolated not just to keep patients away from the outside world but to keep the fear and misunderstanding of the outside world away from the patients. On the outside, Carvillians had to keep their identity as a patient secret, but on the inside, they were free to embrace this identity. For patients like Betty, Carville became a safe haven filled with understanding friends, something more than a hospital or prison.

Because of the unity created by their shared identities with other patients, the Carville community became an extended, surrogate family for many patients.<sup>13</sup> One example of the community standing in for absent family is the support that José Ramirez received as he became the first patient to pursue a college degree while hospitalized at Carville in the 1960s. When José’s medication made him frequently fall asleep for extended periods of time, members of the patient community came together to keep him awake while he studied and to make sure he woke up in time to drive to Louisiana State University for his classes. José stated that other patients would threaten to “beat the shit”

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<sup>11</sup> Martin, *Miracle at Carville*, 61.

<sup>12</sup> Martin, *Miracle at Carville*, 114.

<sup>13</sup> For more on the formation of a patient community, see Marcia Gaudet’s *Carville*.

out of him if he failed his classes, giving him strong, if somewhat gruff, motivation to study hard. The nuns and patients came together to throw him a party when he graduated.<sup>14</sup> While José was enrolled at LSU, the patient body as a whole took up the role of parent, making sure he went to classes, studied hard, and was rewarded for good performance. Though being a patient often resulted in lost or changed relationships with family on the outside, it also made each Carville resident a part of a larger community, one that would offer them the support they would have received from their family on the outside while they were stuck on the inside.

Another significant part of the patient support network was the patient orderlies. The government employees that cleaned dormitories and cared for the residents of each house were typically patients at the hospital themselves. Though outside employees worked in many other job areas in the hospital, the role of house orderly, one of the most significant non-medical care giving roles in Carville, was mostly filled by the patients themselves. *The Star* described Charles Matherne, a patient who worked as an orderly in one of the blind houses, as “a mother hen with a brood of little chicks.”<sup>15</sup> By using this image, the *Star* writer evokes a sense of familial love felt by Charles for his charges. Patient orderlies were responsible for ensuring the well-being of their patients, both physically and emotionally. It was often the house orderly that first came into contact with new arrivals, introducing them to the Carville way of life. In this way, they acted as ambassadors of the patient community as a whole. Orderlies like Charles were an official extension of the communal patient support network, one that cared for the physical needs

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<sup>14</sup> Interview of José Ramirez. Oral Histories. National Hansen’s Disease Museum, Carville.

<sup>15</sup> “All Around the Town,” *The Star*, March 1944, 14.

of many patients and helped ease the transition into institutional life within the dormitories.

Many patients formed their own smaller surrogate families within the community. One way this was done was through Carville's housing system.<sup>16</sup> Patients were able to request to be moved into dormitories with their friends, causing a system reminiscent of the Greek system at American universities. New patients were recruited into different houses, each one of which had its own reputation and personality, such as the Filipino house or the Lily-whites, female patients with reputations for being proper and ladylike. Stanley Stein described the situation in the men's houses as "fraternities," brotherhoods that offer friendship and support for their members.<sup>17</sup> Stanley himself joined one of the Carville fraternities; his housemates later helped him through the early days of his blindness, lending him brotherly support in his time of need.<sup>18</sup> These subsets within the larger framework of Carville's community helped patients to strengthen their bonds with other patients and fully embrace the communal element of being a Carvillian.

Surrogate patient parents often stepped in to care for the children of the hospital, creating foster families that were a smaller part of the larger Carville community. Children in Carville were, in a sense, orphans. Even though many of them had parents on the outside, some children rarely saw them. Some patients took it upon themselves to unofficially parent these "orphaned" children. Betty and her friend Dorothy took over the roles of parents for Lolita, a 12-year-old-girl who lived in their house.<sup>19</sup> Buddy, hospitalized in Carville as a five-year-old in the 1920s and frequently written about in the

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<sup>16</sup> For more on patient life in Carville's dormitories, see Amy L. Fairchild's "Leprosy, Domesticity, and Protest."

<sup>17</sup> Stein, *Alone No Longer*, 57.

<sup>18</sup> Stein, *Alone No Longer*, 196.

<sup>19</sup> Martin, *Miracle at Carville*, 67.

*Sixty-Six Star*,<sup>20</sup> was similarly taken under the parental wing of another patient: “Buddy’s fortunes took a turn for the better when Mrs. Williams, also a patient, became his Carville ‘mama.’ She ‘Mothered him’ and saw to it that he had good food and clean clothes.”<sup>21</sup> Ann Page and her husband, Hank Simon, took in Sylvia, who lived with them in their house in Cottage Grove; she referred to them as “Momme” and “Poppe” “to distinguish us from her real parents who are not patients.”<sup>22</sup> Because these children were isolated from their families on the outside due to their new identity as Hansen’s disease patients, they relied on another facet of their identity, that as members of a supportive community, to provide them with the family structure they needed. It was the patients, unprompted by hospital officials, who took care of Carville’s children. The Carville support network provided children with the love and care that they needed to make up for the lack of biological parents in their isolated lives at the hospital.

One of the most important facets of the patient identity was membership in a tight-knit community of people who had all undergone the same experiences of stigmatization, isolation, and separation from previous lives on the outside. Though the patient identity put a significant strain on family relationships on the outside, sometimes to the point of breaking them, Carville residents were able to turn to a support network and surrogate families within the hospital to compensate for these losses. When patients joined the hospital community, forming relationships with the other residents, they embraced, in part, their identity as patients.

For some patients, Carville was a clean slate, a chance for them to create a new home and a new life. Many patients sought to create a domestic environment within the

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<sup>20</sup> *The Sixty-Six Star*, May 23 1931, 2.

<sup>21</sup> Stanley Stein, “Carville’s Buddy.” *The Star*, January 1949, 5.

<sup>22</sup> Ann Page, “Our Cottages.” *The Star*, February 1947, 15.



hospital. However, the domestic sphere, like all aspects of life within Carville, was shaped by the patient identity. Carvillians adapted domestic activities like cooking and marriage to the reality of their lives as Hansen's disease patients. Dating, food, marriage, and the cottages in Cottage Grove, the patient-constructed "suburb" of the hospital, were all adapted to fit the patient lifestyle and used to create an atmosphere of domesticity within the hospital's patient community. Through these domestic activities, Carville residents began to build a new life within the hospital and identify it as their home, embracing their identity as patients.

For many patients, dating was the first step in creating a homelike atmosphere in the hospital.<sup>23</sup> Like all other aspects of life, dating at Carville had to be adjusted to fit the constraints of hospital life. There were roughly twice as many men as women at Carville, which made dating highly competitive. According to the *Sixty-Six Star*, romance was constantly in the air at Carville: "Felix is having his swing repaired and says that he will rent it out in the evenings or on moonlit nights to local Sheiks as a trysting place. Judging by the business which Cupid has been doing lately this ought to prove a paying venture."<sup>24</sup> Dating, along with the subsequent gossip, became an integral part of life and the patient experience at Carville. Romantic relationships were always common knowledge within the patient community and never remained secret for long.<sup>25</sup> The defining point in Carville relationships was the couple's debut at movie night; appearing at this event together was essentially the same as announcing an engagement.<sup>26</sup>

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<sup>23</sup> For more on dating at Carville, see Amy L. Fairchild's "Leprosy, Domesticity, and Protest," which specifically investigates the importance of food and cooking in dating and Carville relationships.

<sup>24</sup> *The Sixty-Six Star*, June 20 1931, 2.

<sup>25</sup> "Everybody knew everybody's business- I don't care what time of the day or night you went anywhere. Everybody knew about it."- Interview of Rachel Pendleton. Oral Histories. National Hansen's Disease Museum, Carville

<sup>26</sup> Ann Page, "Courting- - Carville Version." *The Star*, February 1946, 7.

For most patients, the most important part of a relationship and one of the most important aspects of hospital life was food. As Betty Martin explained, “The election of a president or world troubles were as nothing compared to the rumor that there might be fricassee for dinner.”<sup>27</sup> For Carville patients, the most important news was not about the outside world, it was the week’s cafeteria menu. Food was an obsession for Carvillians, even though many of them disliked the cafeteria. The hospital cafeteria served breakfast at seven, dinner at eleven, and supper at four, hours that patients frequently complained about for their earliness and dissimilarity from normal eating schedules on the outside.<sup>28</sup> Patients were often dissatisfied with the food itself. The patient community’s opinion of the cafeteria food is best summed up by this short poem from *The Star*: “Build up your resistance, that’s what you must do/ And soon you’ll be feeling as good as new/ Eat Chef Clayton’s concoctions of hash and stew/ Very rich in Vitamins PU.”<sup>29</sup> Though the hospital food was nutritious, it did not taste as good as home-cooked food, a fact which Carville residents were unwilling to let slide. Thus, patients tried to avoid the institutional meals served in the cafeteria when they could and instead tried to find ways to make mealtimes a more domestic affair.

Because patients disliked the times meals were served and the food itself, many chose to cook their own meals or obtain food elsewhere. Patients could obtain raw food rations from the Public Health Service and could grow produce in their own gardens, giving them some of the materials needed to engage in “Carville cookery”<sup>30</sup> with a

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<sup>27</sup> Martin, *Miracle at Carville*, 37.

<sup>28</sup> Stein, *Alone No Longer*, 82.

<sup>29</sup> “All in Fun.” *The Star*, April 1944, 15.

<sup>30</sup> Martin, *Miracle at Carville*, 39.

hotplate in their dormitory rooms.<sup>31</sup> Patients would even occasionally go through the hole in the fence to hunt for game, such as rabbits, to cook in secret.<sup>32</sup> Even if patients did not cook for themselves, they found other ways to shape traditional cooking and eating to fit the needs of the patient lifestyle. Some Carville residents, including Stanley Stein, joined group supper clubs, where each member contributed money to purchase raw materials to be made into a meal.<sup>33</sup> Patients who did not cook often chose to eat their meals at one of the two Chinese cook shops in Cottage Grove. These small restaurants were run by enterprising Chinese patients who prepared reasonably priced meals at later, normal dinner hours when the cafeteria was closed.<sup>34</sup> Patients at Carville developed a culture of cooking, one that contributed to transforming the hospital into a home.

Cooking and eating supper together was the centerpiece of most Carville couples' relationships. Like they had with the rest of the dating experience, couples at the hospital customized the standard dinner date to fit patient culture and created an atmosphere of domesticity. One of the first gifts a Carville beaux would give to his girlfriend was a hot plate so that she could cook dinner for the two of them in her room: "A gay young blade anywhere else says it with flowers and candy while the Carville Swain's first gift to the girl friend is more often than not cooking equipment and sometimes he does the cooking."<sup>35</sup> Once a couple began dating, it rapidly progressed into a domestic partnership in which the man provided supplies which the woman used to cook dinner. Women would prepare meals in their rooms with the cooking equipment often given to

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<sup>31</sup> In "Leprosy, Domesticity, and Patient Protest," Amy L. Fairchild investigates the tradition of hotplate cooking amongst Carville patients.

<sup>32</sup> Martin, *Miracle at Carville*, 56.

<sup>33</sup> Stein, *Alone No Longer*, 60.

<sup>34</sup> Stein, *Alone No Longer*, 7.

<sup>35</sup> "Cockeyed Carville- - Again." *The Star*, November 1943, 13.

them by their boyfriends. Originally, couples ate together in the woman's room once the food was ready, but restrictions put into place in the 1930s that banned male patients from women's rooms forced patients to adapt their domestic style of dating to fit the parameters of the hospital's rules. Instead of giving up home-cooked meals, patients instead set up card tables on the thresholds of the women's rooms. The women would serve the food and sit on the inside, while the men would sit in the hallway.<sup>36</sup> After dinner, the couple would stay together to talk, play cards, or listen to the radio.<sup>37</sup> For patients, dating was not just about getting to know someone new, it was about creating a home within the hospital. Cookware was a common gift early in Carville relationships, one that typically would be exchanged between married partners on the outside because it served a domestic purpose, instead of more traditional courting gifts. Dating gave Carville residents the opportunity to create a home-like domestic atmosphere within the confines of the hospital. For many patients, food and meals were a central part of a normal home life, as was a partner with whom to share that daily experience. In order to fulfill the requirements of what they viewed as a home environment, Carville residents created their own form of dating centered on sharing food and creating a domestic partnership, even in a relationship's early stages. Through this unique dating process, patients were able to create a home for themselves within the limits of hospital life.

Several patients took the domestic partnership of dating a step further and married the significant other they had met at Carville, creating a new home and new life together at the hospital. Marriage was not uncommon amongst Carville residents; in 1948, 19

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<sup>36</sup> Amy L. Fairchild investigates these small protests against hospital rules that threatened patient domesticity in her article "Leprosy, Domesticity, and Patient Protest."

<sup>37</sup> Martin, *Miracle at Carville*, 126.

married couples, the majority of them living in separate quarters, resided in the hospital.<sup>38</sup> Until the 1950s, patients were not allowed to get married at the hospital. In order to get married, patients either arranged leave at the same time or went through the hole in the fence, secretly preparing for their wedding beforehand. Their simultaneous absences caused a sensation amongst the other patients, who realized what must be going on. Patients would then return and simply tell the Medical Officer in Charge that they were married, and unless they owned a cottage, continued life as they had while simply dating. Ann Page explained the patients' desire to marry despite the lack of change in their living situation in an article in *The Star*: "Married couples will continue to lead a semi-marital life, feeling certain that half a loaf is better than none, planning and dreaming of their homes of tomorrow in lieu of the homes they so yearn for today."<sup>39</sup> Though most patients were unable to create a home exactly like couples on the outside, they still occasionally made the decision to marry because doing so was still a step toward creating a home within a hospital. Though these married couples may not have had a physical home to share, they still had the emotional and social feeling of home that came with marriage. Marriages between Carville residents were also free of the strains of separation that caused issues for patients with spouses on the outside because both partners shared the patient identity, experience, and sense of Carville as a home. Marriages between patients helped these couples to establish a domestic lifestyle adapted to fit the institutional setting of Carville.

The final step in creating a home in Carville was, for some patients, to build a physical home for themselves in Cottage Grove. Cottage Grove was the hospital's

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<sup>38</sup>Stanley Stein, "Staff Snapshots: Ann, Efficiency Plus." *The Star*, September 1948, 13.

<sup>39</sup> Ann Page, "Marriage - Carville Version." *The Star*, June 1946, 17.

suburb, full of homes constructed by patients.<sup>40</sup> By the time the cottages were bought by the federal government in 1957 and torn down to make way for new homes, patients had constructed 18 houses, all of which served as seasonal or year-round homes for patients, except for the building that housed the Chinese cook shop. Each of these cottages had its own unique past and had been passed from patient to patient through wills, purchases, and rental agreements for decades.<sup>41</sup> The patients maintained, painted, and decorated their cottages with their own money, often using their homes as gathering places for dinners and parties with friends.<sup>42</sup> For several patients, living in these small, self-built homes seasonally or year-round was preferable to continuing to live in the more modern dormitories; as Ann Page explained in an article in *The Star*, “Those large two story quarters may have steam heat, plenty of hot water and other comforts but those of us who love a home and a yard prefer our cottages even if we can’t have as many comforts there.”<sup>43</sup> For patients like Ann, the residences in Cottage Grove were the ultimate in domestic life. Though they could obtain the relationships and rituals of a home-oriented lifestyle through dating, marriage, and Carville cookery, living in a house rather than a dormitory gave some patient couples a physical, shared place in which to continue their domestic partnership. Even though the cottages did not have the utilities that the dormitories had, some Carville couples still chose to live in them because they increased their sense that the hospital was their home, not just an institution. By building and living in these cottages, Carville patients embraced the hospital as their home. They molded

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<sup>40</sup> For more on Cottage Grove and the patient protests in the 1950s against its destruction, see Amy L. Fairchild’s “Leprosy, Domesticity, and Patient Protest.”

<sup>41</sup> Stanley Stein. Handwritten notes, 1956. Stanley Stein Archives. Bin 19857- Cottages. National Hansen’s Disease Museum, Carville.

<sup>42</sup> Ann Page, “Our Cottages.” *The Star*, February 1947, 14.

<sup>43</sup> Page, “Our Cottages,” 15.

institutional living situations to fit their own desires for a house and thus created homes that fit within their identities as hospital patients.

Through the creation of a tight-knit patient community and a domestic atmosphere within the parameters of institutional life, Carville residents embraced the patient identity they received upon entrance into the hospital. When patients no longer felt comfortable or accepted on the outside, they turned to their fellows on the inside. Each of these individuals shared the patient experiences of isolation, separation, and discrimination, which strengthened the bond between them and made them feel, at times, more at home within the confines of Carville than outside of them. This supportive community acted as a surrogate family for many patients and became a key part of their identity as a Carville patient. Carvillians also worked to create a domestic atmosphere within the limits of the hospital, which deepened their sense of Carville as their new home and gave them a fresh start at a new life under their patient identity. Carville residents established their own culture of dating and cooking which, in some cases, led to married life and a home in the suburbs, an interpretation of the standard American Dream that fit the patient identity. By engaging in these domestic partnerships, patients embraced their new life within the hospital and transformed Carville from a hated institution into a beloved home. For many patients, their entrance into Carville represented not a loss of their old identity, but the gain of a new one as “a naturalized citizen of Carville.”

## CHAPTER FOUR

“RADIATING THE LIGHT OF TRUTH.”

CHANGING THE PATIENT IDENTITY<sup>1</sup>

Though parts of the patient identity, such as a strong sense of community, were beneficial to Carville residents and willingly embraced by them, others, such as the isolation and stigma, contributed to the trauma of being a Hansen’s disease patient and were disliked. Carvillians often initially rejected these negative elements of the patient identity, but after embracing the positives of their new life in the hospital, some chose to work to change them rather than accept them. Some Carville residents became activists, using the means available to them to work to better their lives within the hospital and the status of Hansen’s disease patients in American society. Patients used methods of activism such as *The Star* and letter writing campaigns to improve life within Carville, change government policy regarding Hansen’s disease, and change public perception of their illness. Through protest, Carvillians were able to alter the negative aspects of the patient identity, reducing the impact of isolation and stigma on their lives at the hospital. Patient protests focused on two main areas: reducing isolation through public policy changes and breaking down the social stigma attached to Hansen’s disease through an educational campaign. The call for a new movie projector in 1931 was the first significant successful patient protest and started an era of activism amongst Carville patients. The United Patients Committee for Social Improvement and Rehabilitation campaigned for policy changes on a national level as well as a local hospital level that

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<sup>1</sup> The title of this chapter refers to the tagline of *The Star*: “radiating the light of truth on Hansen’s Disease.”



would decrease isolation and eliminate the stigma of Hansen's disease. The educational campaign launched by Stanley Stein and *The Star* sought to correct the existing assumptions the public held about the disease and thus reduce the stigma attached to it. One of the most important facets of this campaign was to remove the word "leper" from the popular vernacular and separate the negative connotations of that word from the patient identity.

The campaign for a new movie projector, led by the *Sixty-Six Star* in 1931, was a watershed moment for Carville activism, paving the way for more large scale protests in the future and giving patients the tool they needed to change their identity.<sup>2</sup> At this time, the hospital's movie projector, which had been purchased by the patients, was in terrible condition, which nearly ruined weekly movie nights. Patients began to complain about the equipment to Dr. Oswald Denney, the Medical Officer in Charge at the time, and were told that such an expense was outside of the hospital's operating budget and that nothing could be done. Patients used the *Sixty-Six Star* to express their desire for a new projector; eventually, a copy of the newsletter made its way into the hands of the Surgeon General's office. After reading about the issue of the movie projector, an official in the office of the Surgeon General had several shipments of beef and some hogs sent to Carville to alleviate the strains on the budget and free up funds for a new projector. Though the acquisition of the projector was a small achievement, according to Stanley Stein it "was a turning point in the lives of Carville's people."<sup>3</sup> This occasion marked the first time that patient voices had been used to create change within the hospital. The acquisition of the projector showed Carville residents that protest, particularly through

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<sup>2</sup> Michael Mizell-Nelson discusses the patient movement to obtain a new movie projector in his article "Treated as Lepers."

<sup>3</sup> Stein, *Alone No Longer*, 81.

direct outreach and the use of media, could be successful and could be used to improve their lives at Carville. They could use this newly acquired tool to make improvements on Carville life, change public policy, and influence public opinion. This incident created a new culture of advocacy within the hospital community, particularly amongst staff members for *The Star*. It also marked the emergence of Stanley Stein, who played a significant role in the movie projector project, as a leader in patient activism. The success of the movie projector campaign showed patients that they did not have to accept patient life as it was presented to them upon entering the hospital. Instead of accepting the patient identity, Carville residents now had the option of changing it.

Patient activism took full swing in the 1940s, during which two significant tools of change, *The Star* and the United Patients Committee, were born. *The Star*, founded in 1941 by Stanley Stein, was the main vehicle for patient activism at the hospital.<sup>4</sup> The paper was independently funded, which freed it from the censorship the original *Sixty-Six Star* had endured and gave the patients complete control over what they published. The main goal of the paper was to educate the public about Hansen's disease and dispel the false information that had caused the disease's stigmatization in American society:

We plan to publish many of these facts and to contradict the mass of misinformation that is constantly published in even the best newspapers and magazines. We realize that we will reach only a small portion of the reading public but, like a pebble thrown into a pond causes ripples in an ever widening circle, our message will be carried.<sup>5</sup>

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<sup>4</sup> Most scholars studying Carville use *The Star* as a major source and at least briefly discuss the paper itself. For a more detailed analysis of the role of *The Star* in patient protests and efforts toward change, see Mizell-Nelson's "Treated as Lepers."

<sup>5</sup> "The Star is Born." *The Star*, September 1941, 5.

Because no one else bothered to correct the false information published about Hansen's disease, the patients took it upon themselves to publish the facts about the disease and criticize and correct other media outlets that showed their ignorance of the reality of Hansen's disease by publishing incorrect statements about the disease. The paper had a small circulation, but was sent to university libraries, the offices of government officials, and to leaders in veterans' groups like the American Legion, the patients' strongest allies on the outside. *The Star* gave patients a chance to share their criticisms of everything from the spread of misinformation about Hansen's disease to the quality of the cafeteria food at the hospital with a larger public. The Star quickly became the main vehicle for patient protest within the hospital, particularly regarding the patients' educational campaign.

The United Patients Committee was founded in 1946 by several groups in order to further their goals of reducing isolation and stigma and increasing the quality of life within the hospital. One of the first steps taken by the group was to compose a list of fifteen suggestions for the National Advisory Committee on Leprosy, which included the establishment of a national public education program about Hansen's disease, official nomenclature changes, medical improvements inside and outside of the hospital, and several measures to end the role of isolation in patient life. These suggestions influenced the policy changes enacted by the advisory committee in the next year.<sup>6</sup> This group acted as an unofficial liaison between the patient body and the federal government. It also coordinated help in Carville campaigns for change from outside groups like the American Legion. While the purpose of *The Star* was to spread information to the wider public and bring awareness to Carville's issues, the United Patients Committee took those issues

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<sup>6</sup> Martin, *Miracle at Carville*, 210.

straight to hospital administrators and government officials; it acted as the arms to *The Star*'s mouth. The United Patients Committee widened protest efforts beyond the staff of *The Star* and provided a united front from which patients could advocate for changes in policies regarding Hansen's disease.

One of the most important goals of patient activism was an educational campaign with the dual purpose of correcting misinformation published about Hansen's disease and eliminating the use of the word "leper," often referred to by Stein and other activists as the "odious word."<sup>7</sup> The goal of the patients' educational campaign was to inform the public of the truth about Hansen's disease, dispelling any false assumptions that contributed to the disease's stigma and the continuation of isolation policies. Patients wanted to put an end to "the sort of frightful, fallacious, abandon-all-hope-ye-who-enter-here type of publicity"<sup>8</sup> printed in most mainstream media sources and replace it with their own, more accurate portrayal of Hansen's disease. Patients also searched for and corrected any false information spread through other media outlets, either through articles in *The Star* or through letters to the offending company or publication. In order to show the truth about Hansen's disease in addition to telling the public about it, patients also invited curious visitors to Carville and organized tours of the hospital. Through this campaign, patient activists worked to eliminate both the stigma attached to their disease and compulsory segregation at Carville. By correcting common misperceptions about Hansen's disease, such as its level of contagiousness, patients were able to lessen the impact of social stigma and reduce the perceived need for the isolation of Hansen's disease patients in the eyes of the public and the government. Eliminating "leper" from

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<sup>7</sup> Stein, *Alone No Longer*, 145.

<sup>8</sup> Stein, *Alone No Longer*, 248.

medical terminology and from the popular vernacular also lessened the stigma attached to the disease. With the patient-led educational campaign, conducted primarily through *The Star* and direct contact with companies or organizations using offensive terms or publishing false information, Carville residents sought to change the patient identity by removing the stigma and isolation attached to it.

In order to prevent the further spread of misinformation, activist patients called out any publications or broadcasts that printed or shared incorrect information about Hansen's disease. By correcting these mistakes, patients sought to prevent false published information about the disease from reinforcing the general public's negative attitude toward Hansen's disease and thus the stigma attached to the patient identity. For example, when a radio show sponsored by Procter and Gamble dramatized and provided false information about Hansen's disease, *The Star* published an open letter to the president of the company, chastising him for allowing this dissemination of false information and inviting the writer of the offending radio play to visit the hospital and learn the about the truth of the disease.<sup>9</sup> The patients on the staff of *The Star* refused to allow the fallacious information from the radio broadcast to go unchecked. By publishing their criticism, Carville patients made Procter and Gamble accountable for perpetuating dated and stigmatic ideas of Hansen's disease and responsible for correcting their mistake and ensuring it did not happen again in the future. Procter and Gamble was not the only organization to be criticized by patients for reinforcing the stereotypes and stigmas attached to Hansen's disease. *The Star* frequently featured editorials or similar open letters addressed to other publications and organizations about their participation in spreading false information about Hansen's disease. The paper even occasionally

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<sup>9</sup> "An Open Letter To." *The Star*, May 1944, 3.

included a “Ghost of the Month” column, which criticized periodicals that published old, incorrect tropes about Hansen’s disease, such as a story in *Esquire* that portrayed the disease as rapidly and strongly communicable.<sup>10</sup> The first step of the patient-led education campaign was to stop the spread of false information from other media sources. Holding media outlets accountable for publishing false information often prevented them from repeating that mistake. Stopping the publication of more misinformation for the general public to hear or read prevented that public from using these sources in forming an opinion of Hansen’s disease. The stigma attached to Hansen’s disease was based on such false information; when this information was taken out of the equation, the strength of the disease’s stigma could begin to decrease. By openly criticizing the publishers of false facts about Hansen’s disease, Carville activists were able to begin changing the stigma attached to their identity as a Carville patient.

The second step of the educational program was to publish and draw attention to the truth about Hansen’s disease through a positive, patient-led media campaign. By taking charge of their public image, patients could work to change public perception of their illness and remove the cause of the stigma and isolation attached to the patient identity. The goal of this campaign was to show to the general public that Carville patients were no different than any other Americans and did not fit the stigmatic stereotype of a “leper” held in the popular imagination. One of the biggest successes of this campaign was a broadcast of CBS’s popular radio show “We the People” from Carville’s theater. The program, which was known for sharing the stories of everyday Americans, gave patients the opportunity to talk about their disease to a national audience

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<sup>10</sup> “Ghost of the Month.” *The Star*, August 1948, 11.

for several minutes during the program.<sup>11</sup> The inclusion of Carville residents in a radio broadcast specifically about the lives and experiences of normal Americans implied to listeners that these people were as normal as themselves, aiding Carvillians in their campaign to dispel the reputation of Hansen's disease patients as unfamiliar and different. Patient activists were also able to share their own opinions with a national audience, dramatically increasing the range of their educational efforts. By using media opportunities such as the "We the People" broadcast, Carville residents were able to promote a positive image of Hansen's disease patients to the public, breaking down outdated ideas about the disease that contributed to the perpetuation of the disease's stigma and forced isolation.

In order to further the goals of their educational campaign and promote a positive image of themselves, Carville patients developed a tour program for curious visitors to come to the hospital and learn about the reality of Hansen's disease. In 1946, *The Star* called for a relaxation of visitation regulations so that casual visitors who wanted to learn more about Hansen's disease could be admitted into the hospital in order to "lift the veil of secrecy and mystery" surrounding their disease.<sup>12</sup> Patients then organized a tour committee to walk with visitors through the hospital grounds and educate them about their disease and patient experiences.<sup>13</sup> By freely sharing their lives at Carville and giving visitors the chance to learn about the disease in person, patient activists provided the public with physical proof that Carvillians were simply average Americans in an unfortunate situation. Because the hospital's residents took charge of tours guide duties, they were able to portray Hansen's disease patients in a positive light and showcase their

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<sup>11</sup> "Progress in War Against Darkness." *The Star*, June 1947, 9.

<sup>12</sup> Stanley Stein, "Changing Times." *The Star*, April 1946, 9.

<sup>13</sup> Ann Page, "Timely Topics." *The Star*, May 1946, 6.

normalness.<sup>14</sup> Patient tour guides humanized their disease for visitors, putting a face with the illness and forcing visitors to reconsider any preconceived notions they had about the effects of the disease. By inviting visitors to come to Carville and taking charge of these visits, patients were able to show that they did not fit the stereotypes of their disease and, on a small scale, change their image with the public, reducing the effects of the stigma of Hansen's disease and weakening arguments for continued isolation.

Patients who had been discharged also carried on the educational campaign even after leaving Carville, acting as living proof to the public outside of the hospital that Hansen's disease was treatable and not a condition to be feared. After her time at Carville, Gertrude Hornbostel still remained active in promoting a positive public image of the hospital's patients, making frequent public appearances in her home state of New York to speak about her disease and experiences at Carville.<sup>15</sup> Nick Farrel, another discharged patient and Star staffer, went on a Chicago radio show to talk frankly about the disease and Carville.<sup>16</sup> By showing the public that Hansen's disease patients were able to fully recover with the new treatments that became available during the 1940s, such as promin, discharged patients such as Hornbostel and Farrel dispelled public perceptions that their illness was an untreatable lifelong sentence. These individuals were not afraid of the stigma attached to Hansen's disease and were willing to publicly out themselves as ex-patients to demystify their illness and break the image of Carvillians as the living dead. Public appearances of Carville's past patients helped to change

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<sup>14</sup> In her book, *Colonizing Leprosy*, Michelle T. Moran discusses the efforts of patients to portray themselves as "normal" in the public eye.

<sup>15</sup> "Around the Corner." *The Star*, September 1949, 14.

<sup>16</sup> "Farrel Fights Phobia." *The Star*, February 1949, 8.



commonly held stereotypes of the disease and crack the foundations of the stigma that kept them isolated in Carville.

By blocking the flow of false information and replacing it with a new, positive image, Carville patients were able to alter public opinion about Hansen's disease. This change in public perception weakened the false ideas on which the stigma attached to the disease was built and dispelled the misinformation that reinforced a need for the segregation of patients from the general public. Through public critique of sources of false information, a widespread media campaign to spread the truth about Hansen's disease, patient-led tours within the hospital, and the public appearances of discharged patients on the outside, Carville activists worked to change the negative aspects of the patient identity.

Another significant patient-led activist campaign was the movement to end the use of the word "leper." By removing this word from the medical and public vocabulary, Carvillians could disassociate themselves from the stigma attached to the terms, lessening this negative aspect of the patient identity. For many Carville residents, this word had a demoralizing effect and made them feel ashamed of their identities as patients. The word was everywhere- in newspapers, hospital documents, even in the pamphlets of religious organizations with the goal of helping Hansen's disease patients. In order to combat the use of this word, patient activists engaged in a successful letter writing campaign to criticize offensive uses of the odious words and advocate for widespread changes in terminology and vocabulary.

For many Carville residents, hearing others use the odious word "leper" was a verbal slap in the face, reminding them of the stigma, isolation, and fear attached to their

disease.<sup>17</sup> Even entrenched in community and home life at the hospital, wayward words in periodicals or radio broadcasts could remind Carvillians of the negative aspects of their identity as patients. Betty Martin eloquently explained the effects of hearing these words used in offensive ways: “for sooner or later, without warning, I would be slapped back into reality and Carville by some stock phrase concerning lepers or leprosy, for it is amazing how these words abound in literature, unnoticed, probably, except by those to whom they come as blows over the heart.”<sup>18</sup> The “odious word” was often used to describe not an actual patient suffering from Hansen’s disease, but a morally corrupt person or social pariah. The continued use of the word in this manner reinforced the negative connotations of it, connotations which then strengthened the stigma attached to patients suffering from the disease. Incorrect and offensive uses of the word “leper” served as a reminder to patients that despite facts to the contrary, society continued to view their illness as something frightening and repugnant.

Some Carville residents refused to accept the negative light the continued use of the “odious word” shed on their identity as patients, engaging in a campaign to end the use of the word and eliminate the stigma attached to it and its sufferers. Along with its campaign to educate the public about Hansen’s disease, *The Star* worked to eliminate the use of the odious word: “To this end we set our hearts and our strength. Let physician, missionary and layman banish the word “leper”, not only from their writings and conversations, but also from their thoughts.”<sup>19</sup> By keeping the “odious word” out of speech and even out of the minds of the public, patients wanted to eliminate the

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<sup>17</sup> For more on the impact of the word “leper” on Hansen’s disease patients, see Zachary Gussow and George S. Tracey’s article, “Status, Ideology, and Adaptation to Stigmatized Illness.”

<sup>18</sup> Martin, *Miracle at Carville*, 42.

<sup>19</sup> Stanley Stein, “That Odious Word.” *The Star*, November 1942, 5.

association of the word with their disease. Replacing “leper” with “Hansen’s disease patient” replaced the fear and stigma attached to the former with the milder, medical connotations of the latter. Carville residents wanted to remove the negative impact of the stigma attached to the “odious word” on their identities and replace it with an accurate public image of what they truly were- patients with a treatable illness.

Led by Stanley Stein, Carville activists wrote letters to organizations that continued to use the word “leper,” pointing out incorrect or offensive uses of the word and providing accurate facts and alternative terminology. Activists used these instances as teaching moments, explaining why the word was so offensive and introducing less stigmatic terms. For example, after tiring of repeatedly hearing the odious word used offensively on the radio, staff members of *The Star* wrote to the National Association of Broadcasters, asking them to stop the use of the word when it “is merely dragged in because it is colorful and connotative.”<sup>20</sup> This incident was one of many corrected by patients. Carville activists constantly sent requests to organizations to stop the use of the word in non-medical contexts and replace them with less offensive ones without the stigmatic impact on Hansen’s disease sufferers. By replacing and ending the use of the word “leper” in popular media, patients were able to change the public’s perception of them and their illness. Carville activists directly contacted offenders like the National Association of Broadcasters, encouraging them to participate in changing the public image of Hansen’s disease patients by changing the vocabulary used in their radio broadcasts.

One of the most successful advances in the patients’ quest to end the use of the odious word was an incident with the popular, still-running comic strip *Rex Morgan M.D.*

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<sup>20</sup> “National Association of Broadcasters Cooperate.” *The Star*, May 1943, 2.

After the titular doctor accused another character of treating someone else like a “leper,” Carville activists wrote to its creator, criticizing the offensive use of the word. The strip’s writer, researcher, and artist took this criticism to heart and apologized by creating a storyline in which the doctor becomes interested in the struggles of a rehabilitating Carville patient. All future mentions of the disease were based in fact and used less offensive words than “leper” to describe the disease and its sufferers.<sup>21</sup> Small victories like this one helped patients to gradually change public opinion of Hansen’s disease sufferers. Contacting the comic’s creators about their offensive use of the word “leper” ended the use of the word in the comic and encouraged the creators to take it a step further by representing Hansen’s disease factually and positively in future strips. Small changes, like using the word “pariah” instead of the word “leper,” could eventually lead to bigger changes in the way Hansen’s disease was portrayed by the media. Changes in media representation altered the way that the general public viewed the disease. A new public image caused the misinformed base of the stigma attached to the patient identity to crumble. By vocalizing their opinions on the use of the word “leper” and disassociating the word’s odious connotations from themselves, some patients were able to change the hated stigma attached to their Carville identity.

Through activism, Carville patients were able to take the aspects of their identity they disliked, primarily the stigma and poor public image attached to the disease, and change them. Carvillians used instruments of change, such as *The Star* and the United Patients Committee, to advocate for patients and spread the truth about Hansen’s disease. One of the main goals of patient activism was to build a new, factually based, positive public image of themselves. This was accomplished in two major ways: through an

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<sup>21</sup> Stein, *Alone No Longer*, 278.

educational campaign to dispel misinformation about the disease and the replacement of the odious word, “leper,” with less offensive words to weaken the link between the negative connotations of this word and the public’s perception of Hansen’s disease patients. This new public image contradicted the false basis on which the stigma attached to the patient identity had been built. The removal of the disease’s stigma and a more informed public also weakened the arguments for keeping Hansen’s disease patients isolated. Instead of unquestioningly accepting the beneficial, but flawed identity of a Carville patient, the hospital’s activists worked to change it, eliminating the stigma and isolation attached to it that they had initially rejected.

## CONCLUSION

When people entered Carville, they obtained new names, and with these new names, a new identity as a patient. At first, patients chose to reject this change in identity and the isolation that came with it and found ways to stay in touch with the lives they had left behind in the outside world. Carville residents used breaks in their isolation, such as the hole in the fence, to maintain contact with the identities they had lost when they arrived at the hospital. Many patients, with the aid of their loved ones, were able to overcome and adapt to the obstacles of isolation and physical separation and resume their roles as members of their families by visiting home, legally or illegally, and receiving their loved ones as visitors at the hospital. Carville patients also maintained a connection with their identity as Americans, despite losing citizenship rights such as the ability to vote upon entering the hospital, by campaigning for a return of their voting rights and participating in the war effort on the home front during World War II. When the stigma and isolation of the patient identity began to fray patients' ties to the outside world and their past lives, many Carvillians chose to embrace their new identity as patients. Hospital residents created a tight knit, supportive community within the hospital, participation in which became a key component of the patient identity. Many Carvillians also created an atmosphere of domesticity within the confines of the hospital, adapting activities such as dating, dining, and marriage to fit the patient identity. Both community and domesticity allowed patients to transform the hospital into their home, becoming "naturalized citizens of Carville," another facet of the patient identity. Over time, Carvillians were able to see the flaws in the patient identity and sought to change them

through activism. Patient activists used *The Star* to engage in an educational campaign to demystify Hansen's disease and remove the stigma attached to their disease. These Carville residents also engaged in a campaign to remove the odious word "leper" from everyday and medical language, furthering their mission to lessen the stigma of the patient identity and weaken the reasoning behind isolation policies.

As patients spent longer periods of time in Carville, their reactions to the loss of their old identities and acquisition of the patient identity changed. After initially rejecting the patient identity, they eventually came to embrace it, and later, chose to change the aspects of this identity that had caused them to reject it in the first place. Betty Martin exemplified this evolution in reactions to the patient identity.<sup>1</sup> At first, Betty refused to accept her identity as a patient, remaining aloof and staying in close and constant contact with her family. However, as time wore on, it became more difficult to relate to her family and her relationship with her fiancé, Robert, ended due to her isolation in Carville. She then embraced her new life as a patient, becoming involved in the community and even marrying a fellow patient, Harry Martin. Eventually, Betty began to write for *The Star* and later wrote her own book about her experiences as a Carville patient, working to remove the stigma and change the isolation of the patient identity. None of these reactions to the acquisition of the patient identity were mutually exclusive; like Betty, patients typically reacted in a combination of these ways.

By investigating the ways in which Carville residents reacted to their new identity as patients, historians can gain a new perspective on how people react when their identity causes them to be marginalized. One example of another group marginalized by misplaced fear is people of Japanese descent during World War II. While Hansen's

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<sup>1</sup> See Betty Martin, *Miracle at Carville*.

disease patients faced isolation at Carville because the stigma attached to their disease made the public perceive them as dangerous, Americans in the West were being sent to internment camps simply because their identity as Japanese-Americans was falsely perceived as a threat to the well-being of the United States. Like patients at Carville faced a change in identity, the Japanese-Americans incarcerated in these camps were faced with the loss of their lives on the outside and faced with a new identity as a prisoner. The crisis of identity faced by Carville patients upon entering the hospital is not exclusive to them. By analyzing their reactions, historians may be able to think about other similar situations in the United States in the mid-20<sup>th</sup> century in a new light.

Today, Carville is no longer exclusively a hospital for Hansen's disease patients. As Hansen's disease treatments became more successful, the patient population has dwindled and the federal government struggled with finding a purpose for the facility beyond the treatment of the disease. At one point in the early 1990s, the federal government even used part of Carville as a low security prison.<sup>2</sup> The site was returned to the state of Louisiana in 1999. It is now known as the Gillis W. Long Center and has become a base for the Louisiana National Guard, though a handful of elderly Hansen's disease patients still live on site. Since threats of the government's shutdown of the expensive facility began in the early 1990s, Carville's remaining patients and their allies have successfully protested any attempts to remove them from their home at the hospital. However, as patient numbers continue to dwindle, their place in Carville becomes more unsecure. The history of Carville presents an interesting microcosm of American society in the mid-20<sup>th</sup> century, one that should be researched more extensively by historians.

Carville's patients have left behind a rich variety of primary sources of which most

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<sup>2</sup> For more on Carville's stint as a federal prison, see Neil White's memoir, *In the Sanctuary of Outcasts*.



current research has only scratched the surface. As the lives of those who were forced into segregation at Carville begin to fade into history, it is more important than ever to explore this unique and heartbreaking piece of American history.

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### Primary Sources

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Walter Wyman was the U.S. surgeon general who instituted a nationwide inquiry into HD. This short essay outlined what he believed were the issues of the disease and ways in which the health department planned to control its spread. The essay is strongly biased, as the author supports segregation of HD patients on the basis of HD's contagious nature. This short essay provides valuable insight into public opinion of HD and medical misconceptions of the disease at the time.

Martin, Betty. *Miracle at Carville*. Garden City, New York: Image Books, 1963.

Betty Martin was an on and off again patient at Carville beginning in the 1920s. This book was the first memoir to come out of the hospital. This memoir tells the story of Betty's life from her diagnosis with HD to her release in the 1950s. Betty was active in the community at Carville, wrote for *The Star*, and once absconded with her husband Harry for five years. As a known advocate for patient rights and HD education, Betty uses her memoir to present HD patients as harmless and normal.

Oral Histories. National Hansen's Disease Museum, Carville, Louisiana.

This collection of oral histories, taken by museum staff since the 1980s, consist of interviews with Carville patients, ex-patients, and staff about their experiences at Carville. In these interviews, patients describe everything from the hardship of leaving their families to popular make out spots for Carville couples, encompassing the bad and the good of the Carville experience. The interviews also show the complexity of the reactions of these people to their situation; the same patient may be grateful for some of the opportunities they received while at the hospital, but bitter about the lasting impact of segregation on their lives.

Ramirez, José P. *Squint: My Journey with Leprosy*. Jackson, Mississippi: University Press of Mississippi, 2009.

Ramirez was a young patient at Carville during the late 1960s. This memoir describes his experiences in Carville and with the disease in the outside world, with an emphasis on the impact it had on his personal relationships and the tragedy of the disease. Ramirez wrote this book for a large audience without the strong fear of HD present earlier in the 20<sup>th</sup> century, so he is less concerned with advocating for patient rights and education than others, like Stein and Martin.

*The Sixty-Six Star*. National Hansen's Disease Museum, Carville, Louisiana.

This publication started out as a two page patient published hospital newsletter in 1931, but eventually began to focus more on activism. It was published until 1933, when a controversial article about the Catholic Church was published, which caused the paper to lose the support of hospital administrators and patients. *The Sixty-Six Star* was the precursor to *The Star*, which would begin publication ten years later.

*The Star*, [http://cdm16313.contentdm.oclc.org/cdm/landingpage/collection/p15140\\_coll52](http://cdm16313.contentdm.oclc.org/cdm/landingpage/collection/p15140_coll52)

This publication was edited by Stanley Stein and staffed by other notable patient activists like Betty Martin and Gertrude Hornbostel. It was published by patients beginning in 1941 into today. The main goal of the paper is to “radiate the light of truth on Hansen’s Disease,” and while it does provide information about the daily happenings of Carville, it’s main focus is on education and advocacy intended for the general public’s viewing. The Star was one of the main mediums of protest for Carville activists and drew national attention to their cause. It is also a valuable insight into the minds and lives of the patients who contributed to it.

Stein, Stanley. *Alone No Longer: The Story of a Man Who Refused to Be One of the Living Dead!* New York: Funk & Wagnalls, 1963.

Stein, also known as the Carville Crusader, was the leading Carville activist, editor of *The Star*, and the most well-known patient at Carville. This memoir provides a history of Carville, observations about life there, and Stein’s own story. As always, Stein’s emphasis is on education and advocacy. This memoir provides a valuable viewpoint into patient advocacy and the motivations behind it.

Stein, Stanley Archives. National Hansen’s Disease Museum, Carville, Louisiana.

This collection of manuscripts includes the personal papers and correspondence of Stanley Stein, as well as documents pertaining to *The Star* and other patient organizations, such as the United Patients Committee. The Stanley Stein Archives provide a unique look into life in Carville. Because some of these documents were written without the intent to publish them for a wider audience, they provide a somewhat different perspective than patient memoirs and *The Star*.

White, Neil. *In the Sanctuary of Outcasts: A Memoir*. New York: Harper Perennial, 2009.

Neil White is a reporter who was a prisoner at Carville for a year in the early 1990s. For a few years, Carville patients shared their home with a few white collar criminals, as part of the grounds were rented out to the federal prison system. This memoir provides an interesting outsider’s insight into the hospital and showcases the patient experience in later life, after segregation was no longer

mandatory. The memoir is written as a popular piece and deals primarily with White's own experiences as a prisoner in this unconventional prison.

### Secondary Sources

Fairchild, Amy L. "Leprosy, Domesticity, and Patient Protest: The Social Context of a Patients' Rights Movement in Mid-Century America," *Journal of Social History* 39 (2006): 1011-1043. Accessed September 13, 2013.  
<http://www.jstor.org/stable/3790239>

Amy L. Fairchild, a professor of sociomedical sciences at Columbia University, focuses on the patient protests of the 1950s during the short tenure of MOC Gordon. Fairchild argues that patients fought hard to protect the patient built housing in Cottage Grove and the right to cook for themselves because it added normalcy to their lives, making Carville more of a home than an institution. Unlike most other historians studying these patient's rights protests at Carville, Fairchild stresses the importance of creating an individual home in patient life instead of an entire community. Fairchild relies on *The Star* as well as the papers and letters of various Carville MOCs.

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

Marcia Gaudet is a professor of English at the University of Louisiana at Lafayette. Gaudet's book is based on *The Star*, patient autobiographies, and interviews with patients still living at Carville in the 1980s and 1990s. Gaudet asserts that patients use storytelling as a way to establish a new identity, a new community, and a normal life at Carville. Gaudet's analysis focuses on ideas about storytelling and narrative within the patient community from her perspective as a scholar of folklore. The stories told by patients in their old age to Gaudet during interviews are invaluable, as they cannot be found anywhere else. Gaudet also uses patient memoirs and *The Star* in her analysis.

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

Tony Gould is a British journalist who has worked as for BBC radio and has written several books on disease in the modern world. His book serves primarily as an overview of the history of leprosy in the last two hundred years, featuring chapters on everything from India to Father Damian to Carville. The book is intended for a wider audience, and is thus written in a fairly accessible way. Gould is journalist, but has also written several other books on disease and medicine in history.

Gussow, Zachary. *Leprosy, Racism, and Public Health: Social Policy in Chronic Disease Control*. Boulder, Colorado: Westview Press, 1989.

Dr. Zachary Gussow is a professor of psychiatry at Louisiana State University School of Medicine and has been doing fieldwork at Carville since the 1960s and was one of the first scholars to study Carville from an academic perspective. Gussow argues that the stigma of leprosy in the 19<sup>th</sup> and 20<sup>th</sup> centuries was a result of a “retainting” brought on by modern occurrences, such as imperialism and missionary activity. Gussow’s book is written for scholars and is mainly a work of history, although it incorporates psychiatric and anthropological ideas from the authors non-historical background.

Gussow, Zachary and Tracy, George S. “Status, Ideology, and Adaptation to Stigmatized Illness: A Study of Leprosy,” *Human Organization* 27, 4 (1968): 316-325. Accessed October 30, 2013. <http://sfaa.metapress.com/content/c0077788r2v3p2r7/fulltext.pdf>

Zachary Gussow is a professor of psychiatry at Louisiana State University School of Medicine. George S. Tracy is a member of the sociology department at the same university. This article argues that patients must adapt to the stigma of HD imposed on them by society. Some do this by hiding themselves and their disease, while others become “career patients” and focus on changing the stigma through advocacy and education. The article uses psychiatric and sociological terminology and was written primarily with those who could understand it in mind. Their research was based on 100 patient interviews done at Carville.

Kalisch, Philip A. “The Strange Case of John Early: A Study of the Stigma of Leprosy,” *International Journal of Leprosy* 40, 3 (1972): 291-305. Accessed October 30, 2013. <http://ila.ilsl.br/pdfs/v40n3a09.pdf>

Kalisch is a professor of history at the University of Southern Mississippi. This article is a case study of the effects of the stigma of HD based on the life of James Ruskin Early. It summarizes his life, explains it in the context of stigma, and uses it to draw conclusions about HD stigma and the effects of segregation of HD patients. This article was published by a journal specifically written for those interested in HD. The author uses the case to argue against the institutionalization of HD patients, a minor bias.

Manes, Christopher Lee. “Regarding Carville: The Letters of Norbert and Edmond Landry,” *Louisiana History: The Journal of the Louisiana Historical Association* 44 (2003): 325-338. Accessed September 13, 2013. <http://www.jstor.org/stable/4233939>

Christopher Manes is a writer and descendant of Edmond Landry. Manes’s family owns one of the most extensive collections of letters from Carville, those of brothers Norbert and Edmond. Manes argues that through their letters, these two brothers show that in the 1920s, patient attitudes began to transition from hopeful and complacent to disillusionment and anger at their isolation. This

transition set the stage for the emergence of patient protest in the 1920s and more strongly so in the 1930s and onward.

Mishler, Elliot G. *Social contexts of health, illness, and patient care*. Cambridge: Cambridge University Press, 1981.

Mishler is a member of the department of psychiatry at Harvard Medical School. This book is a collection of essays written by scholars for other scholars about the impact of social factors on patient life and healthcare. Many of the principles discussed in the articles, though not written specifically about HD, can be applied to the study of the disease's stigma and role as a social disease.

Mizell-Nelson, Michael. "Treated as Lepers: The Patient-Led Reform Movement at the National Leprosarium, 1931-1946," *Louisiana History: The Journal of the Louisiana Historical Association* 44 (2003): 301-324. Accessed September 13, 2013. <http://www.jstor.org/stable/4233938>

Michael Mizell-Nelson is a professor of history at the University of New Orleans. In this article, Mizell-Nelson argues that patients led by Stanley Stein used *The Star* to advocate for better living conditions within Carville and to enlist the help of outside groups like the American Legion. This article features plenty of context and background that make it accessible to anyone regardless of how much they know about leprosy in the U.S. Like Fairchild, Mizell-Nelson emphasizes that *The Star* was the most important and effective mode of patient protest and uses it significantly in his analysis.

Moran, Michelle T. *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*. Chapel Hill, North Carolina: The University of North Carolina Press, 2007.

Moran is a professor of history at Montgomery College. This book argues that public health policy, imperialism, and patient advocacy all had a role in the establishment and continuation of leprosariums and segregation policies in the United States, both at Carville and in Hawaii. Moran uses government documents, personal papers of doctors, patient memoirs, and *The Star*, among other sources, in her analysis. Unlike some other works, Moran does not ignore the limited representation of minority patients in the activism at Carville.

Waxler, Nancy E. "Learning to be a leper: a case study in the social construction of illness." In *Social contexts of health, illness, and patient care*, edited by Elliot G. Mishler, 169-194. Cambridge: Cambridge University Press, 1991.

Waxler was a member of the psychiatry department at Harvard Medical School who frequently worked with Elliot Mishler. Her article argues that HD's stigma differs from society to society, that this socially constructed stigma guides patients in their actions after diagnosis, and that the stigma typically has little to

do with the actual disease it is attached to. This article is written from her perspective as a psychiatrist and uses terminology and analytical techniques associated with that discipline. The article is based on case studies from around the world.

World Health Organization. "Leprosy: Fact Sheet." Last Modified September 2012.  
<http://www.who.int/mediacentre/factsheets/fs101/en/>

This fact sheet was produced by the WHO, a leading humanitarian institution that seeks to eradicate disease like HD, particularly in the developing world. It gives basic information on the symptoms, causes, treatments, history, and current status of HD. The fact sheet focuses on the disease in the developing world with a heavy focus on their campaign to eliminate HD.