

Living with Leprosy:
Carville Patients in the Early Twentieth Century

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Introduction

Few diseases have been subjected to as much social stigma over as long a period in as many different societies as leprosy.¹ Particularly in times of great social change, leprosy has the ability to become more than itself, to engender fear in people out of proportion to its actual danger to society.² This was true in the United States in the early twentieth century, when, though the number of leprosy patients was small, significant attention and resources were spent addressing the problem of leprosy. The religious, cultural and medical aspects of leprosy made it a “disease apart.”

In his introduction to *The Medieval Leper*, Peter Richards wrote, “People are the theme of this book – people beneath the notice of history but for their disease: leprosy, or the suspicion of it, is their only claim to fame.”³ The theme of this paper is similar, to examine how leprosy patients in the United States in the early twentieth century experienced the stigma of their disease. I will look at the increased political and social interest in leprosy in the late nineteenth and early twentieth centuries in the United States, and how this increased interest produced a public health response that greatly affected leprosy patients; and I will show that the medical, political and social reactions to leprosy in the early twentieth century caused leprosy patients to continue to be stigmatized.

¹ Margaret A. Wheatley, “Leprosy: A Disease Apart, Historical and Cross-Cultural Analysis of, A Historical and Cross-Cultural Analysis of Stigma” (Ph.D. dissertation, Carleton University, June, 1985): 2.

² Rod Edmond, *Leprosy and Empire*, (New York, Cambridge University Press, 2006), 1.

³ Peter Richards, *The Medieval Leper*, (Barnes and Noble, 1977) vii.

To see how leprosy changed the lives of people who suffered with the disease, I will examine the autobiographies of five leprosy patients, Stanley Stein, Betty Martin, Johnny Harmon, D.J. LeBeaux and José Ramirez, all of whom lived at the only leprosarium on the U.S. mainland in the twentieth century, the U.S. Marine Hospital 66 at Carville, Louisiana, referred to as simply, “Carville.” I will also use the PhD dissertation of Emma Claire Manes, which relates the story of the Landry family (her mother’s family). Manes' grandfather and all of his siblings were diagnosed with leprosy and were sent to Carville. For these authors, the diagnosis of leprosy became the most important fact in their lives; their claim to fame. Their stories describe how the stigma of leprosy affected their lives.

These autobiographies were published between 1950 and 2009. Book length autobiographies, written by people with serious illnesses, called autopathographies by G. Thomas Couser, were uncommon before 1950 and almost unheard of before 1900.⁴ Couser described the factors that compelled writers to write autopathographies; to destigmatize the illness and to extend identity politics (the tendency to identify individuals with certain groups such as race or gender of which they are members) to illness. Couser found diseases that are particularly threatening or “fraught with cultural significance” tend to result in a large number of autobiographies. Illness narratives, Couser stated, reflect mixed motives: self-expression and, “a desire to serve those with the same condition.”⁵ Betty and José both expressed this last motivation in the prefaces to their books.

As historical sources, the quality of the autobiographies vary significantly. Stanley’s book, perhaps because he was potent force at Carville, is as much a history of

⁴ G. Thomas Couser, *Recovering Bodies*, (Madison, University of Wisconsin Press, 1997) 5.

⁵ Couser, *Recovering Bodies*, 5.

Carville and a critique of societal attitudes about leprosy as it is an autobiography. In her books, Betty, while primarily staying with her own story, is able to move beyond her own experience and convey the experiences of her fellow leprosy sufferers with insight and compassion. She is also able to convey in a very direct way the effect that the stigma of leprosy had on her and her husband's lives. José not only discusses his experience with leprosy, but gives insight into his Hispanic heritage. DJ's and Johnny's stories concentrate primarily on how leprosy affected their lives and are less insightful and do not look beyond their own experiences.

Looking at the lives of leprosy patients is important for several reasons. Though leprosy never infected large numbers of people in the United States, it became a real fear for people in the United States in the late nineteenth and early twentieth centuries, a period during which the germ theory emerged, the colonization of Africa, Asia and other tropical areas by Western nations was increasing, and masses of people were migrating around the world.⁶ Decisions made by doctors and U.S. public health professionals during this period had a profound effect on the lives of leprosy patients. In many cases, these decisions exacerbated the stigma leprosy patients faced. It is important for historians of medicine to explore the impact that public health policies had on the people afflicted by the conditions the policies were meant to address. The stigma of leprosy is often used as a starting point to examine other stigmatizing diseases, especially HIV/AIDS. In the early years, AIDS was often referred to as the leprosy of the twentieth century, and AIDS patients felt they were treated as lepers.⁷ Until the cause and

⁶ Zachary Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, (Boulder: Westview Press, 1989): 19.

⁷ Douglas Shenson, "When Fear Conquers: A Doctor Learns About AIDS From Leprosy," *New York Times*, February 28, 1988, <http://query.nytimes.com/gst/fullpage.html?res=940DE1DD1738F93BA15751C0A96E948260&sec=health&spon=&pagewanted=print> (accessed January 24, 2009).

method of transmission of AIDS was understood and a treatment developed, AIDS was just as mysterious as leprosy had been in the late nineteenth and early twentieth centuries, and people were as fearful of contracting AIDS as people had been of contracting leprosy.

Throughout history, people who suffered from leprosy have been referred to as “lepers.” In the late 1940s there was an attempt to change the name of the disease to Hansen’s disease, and to call leprosy sufferers “leprosy patients.”⁸ The name, “Hansen’s disease,” has never been used very widely, so I will use the word “leprosy” in this paper. However, I will use the term “leprosy patient(s)” or “leprosy sufferer(s)” in place of the term “leper(s)” unless the term “leper(s)” occurs in a direct quote. All of the leprosy patients whose works I use in this paper agree that the term “leper” should not be used. Some of the writers also object to being referred to as a “leprosy patient” as they feel, quite rightly, that this too reduces them to their disease. I understand that all of the writers are more than their disease, however in this paper I am looking at how their disease affected their lives and believe that “leprosy patient” is appropriate.

⁸ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 161-162.

Chapter One - Leprosy

History of Leprosy

It is unknown where and when leprosy first appeared on earth. Medical historians have posited that leprosy first appeared variously in Egypt, the Middle East, India, China, and Japan. Some scholars maintain that the Ebers Papyrus, a compilation of Egyptian medicine dating from approximately 1500 BCE, contains a description of leprosy. Lucretius (99-44 BCE), a Roman poet and philosopher, claimed that leprosy originated in Egypt by the Nile.⁹ Other scholars argue that leprosy's origins are in India, believing that leprosy was described in the Aryan hymns, the *Vedas*, written around 1400 BCE. A clear description of the clinical symptoms of leprosy is contained in the *Sushruta Samhita*, a Sanskrit text foundational to ayurvedic medicine that was written around 600 BCE.¹⁰ The case for China being the origin of leprosy comes from descriptions of the disease in the *Nei Ching*, which is dated to around 500 BCE.

A 2005 article reporting the results of DNA analysis of the leprosy bacillus theorized that the leprosy bacillus originated in either Central Asia or East Africa, and moved around the world with the migration of people. The authors identified 4 types of leprosy by detecting single-nucleotide polymorphisms or "SNPs." A SNP is an alternation in the DNA sequence. SNP 1 is found primarily in Asia, the Pacific, and East Africa; SNP 2 is the rarest and is found only in Ethiopia, Malawi, Nepal/North India, and New Caledonia; SNP 3 is predominant in Europe, North Africa, and the Americas; and

⁹ Tony Gould, *A Disease Apart: Leprosy in the Modern World*, (New York, St. Martin's Press, 2005), 3.

¹⁰ John R. Trautman, M.D., "A Brief History of Hansen's Disease", *Bulletin of the New York Academy of Medicine*, 60, 7, (September, 1984): 691.

SNP 4 is found in West Africa and the Caribbean.¹¹ The authors presented two scenarios, they viewed as equally plausible. The first scenario was that leprosy of the SNP 2 type originated in East Africa and preceded SNP 1 (which originated in Central Asia and migrated east) and SNP 3 (which originated in North Africa and Europe and migrated westward) with SNP 4 being the last type to occur. The second scenario was that the first type was SNP 1 (originating in Central Asia), which generated SNP 2 followed by SNPs 3 and 4. The authors speculated that leprosy was introduced to West Africa not by East Africans but by North Africans and Europeans because SNP 4 is more closely related to SNP 3. They speculated that the slave trade brought leprosy from West Africa to the Caribbean and South America. Finally, the authors concluded that the strain of leprosy found in most of the Americas is closest to the European/North African strain, SNP 3. This is also the strain found in wild armadillos in Louisiana, indicating that these animals were infected by humans.¹²

For most people in Western societies, the word “leprosy” brings two things to mind; the Bible and the Middle Ages. Trying to identify diseases retrospectively based on historical documents is a tricky business. Given that much of the stigma of leprosy in Western societies is based on how leprosy has been portrayed in the Bible, I believe it is worth reviewing the current scholarship about the relationship between leprosy as described in the Bible and the disease caused by *Mycobacterium leprae*.

Modern scholars do not believe that what was called leprosy in the Bible is the same disease as leprosy caused by *Mycobacterium leprae*. The most important

¹¹ Marc Monot, et al., “On the Origin of Leprosy,” *Science*, 308 (May 13, 2005): 1041 http://go.galegroup.com.ezp1.lib.umn.edu/ps/retrieve.do?retrieveFormat=PDF_FROM_CALLIST_O&inPS=true&prodId=EAIM&userGroupName=mnaumntwin&workId=PI-1300-2005-MAY13-IDSI-84.JPG|PI-1300-2005-MAY13-IDSI-85.JPG|PI-1300-2005-MAY13-IDSI-86.JPG&docId=GALE|A132801911&callistoContentSet=PER&isAcrobatAvailable=true (accessed August 8, 2011)

¹²Monot, “On the Origin of Leprosy,” 1042.

references to leprosy in the Bible are in Leviticus chapters thirteen and fourteen, but the description of leprosy in Leviticus does not match the disease as we know it today.¹³ Leviticus chapter fourteen, also states that the plague of leprosy could strike houses and garments, in addition to people.¹⁴ The Hebrew word used for leprosy in the Bible was “*tsaraath*,” which was translated to “*lepra*” in Greek translations made about 250 BCE. *Lepra* was used as the medical term for the disease, which became “leprosy” in English. Many scholars believe that this translation led to biblical leprosy being equated with the medical term.¹⁵

Many scholars believe that the disease described in the Bible actually referred to a range of skin diseases such as leukoderma and psoriasis. It is unclear whether *Mycobacterium leprae* existed in the Middle East in Moses’ time, and may not have been present in the Middle East even in Christ’s time. Common speculation is that Persian armies introduced leprosy into Greece during the fourth century BCE, and that Alexander the Great brought leprosy from India to Egypt a hundred years later, however research on the genetics of *Mycobacterium leprae* challenge this speculation.

Although it is not known for sure when leprosy was first introduced into Europe, by 150 CE Aretaeus the Cappadocian and Galen had accurately described the disease. Both described the nodules, ulcers, and absorption of the fingers and toes common to leprosy.¹⁶ By this time, it was thought, leprosy was already present in Germany and was probably present in Ireland and England. It may have first appeared in France in the fourth century CE and was known in Belgium in the sixth century CE. While it is difficult to know how prevalent leprosy actually was in Medieval Europe, leprosy seemed to be at

¹³ Trautman, “A Brief History of Hansen’s Disease,” 692.

¹⁴ Patrick Feeny, *The Fight Against Leprosy*, (London: Elek Books Limited, 1964), 33.

¹⁵ Trautman, “A Brief History of Hansen’s Disease,” 692.

¹⁶ Trautman, “A Brief History of Hansen’s Disease,” 692-693.

its height from about 1000 to 1400 CE. During this time hundreds, perhaps thousands, of lazarettos, or leper houses were built, though it is unclear if they were built because of the need for them or because their founders created them as a way into heaven.¹⁷

Throughout the Middle Ages, there were two contradictory religious views of leprosy; that leprosy was a disease inflicted by God because of the sufferer's sinful life, and that leprosy was a sacred disease whose sufferers were singled out by God. This last view became more prevalent after the Crusaders returned from the Middle East following the conquest of Jerusalem in 1099. Some of the Crusaders developed leprosy after their return, and the "equation of leprosy with sin was emotionally unacceptable,"¹⁸ when the disease appeared in men who had participated in the holy war.

The Third Lateran Council of 1179 decreed that the segregation of a leprosy sufferer was to be noted by a ceremony, referred to as the "leper mass."¹⁹ The decree provided a number of variations of the ritual and while the ritual was not done universally, it was performed widely.²⁰ The purpose of the leper mass was to symbolically remove the leprosy sufferer from the world, and the mass differed little from the ritual for the dead. After the person was determined to have leprosy, either by a bishop or priest, or sometimes by a tribunal, which may have included physicians or other leprosy sufferers, the leprosy sufferer was brought to the local church (or sometimes the local cemetery) where he or she was required to kneel before the altar beneath a black cloth. The priest officiating at the mass would throw dirt on the feet of the leprosy sufferer and would read the prohibitions the leprosy sufferer would face in his or her new life. The leprosy sufferer would then put on the costume required in the local

¹⁷ Feeny, *The Fight Against Leprosy*, 28-33.

¹⁸ Feeny *The Fight Against Leprosy*, 32.

¹⁹ Saul Nathaniel Brody, *The Disease of the Soul: Leprosy in Medieval Literature*, (Ithaca, Cornell University Press, 1974,) 64.

²⁰ Brody, *The Disease of the Soul*, 64.

region and was given the bell, rattle or other instrument he or she was to use when approaching other people. Finally, the leprosy sufferer was led to the hut or other accommodation where he or she would be sequestered. The priest made the sign of the cross at the door and hung an alms box on the hut. The conclusion of the ritual marked the point at which the leprosy sufferer was formally segregated from the world.²¹

The civil response to leprosy was inconsistent throughout Europe. Local rules differed on whether leprosy sufferers could marry and if they could inherit or bequeath property. Also, the requirement of segregation was not universal. Even if a leprosy sufferer was in a leprosy house, the confinement was not total. Brody concluded:

It is another curiosity of history that although lepers were victims of constant persecution, abuse, and vilification, in general their mobility was not hampered and they were not effectively isolated from society. A mass of evidence suggests that in practice the sequestration of lepers was not rigidly enforced. ...Furthermore, the leper houses did not succeed in totally isolating the lepers. Even if lepers were forbidden to beg, they often could obtain permission to leave the house.²²

At the beginning of the fourteenth century leprosy began to decline in Europe. There are several theories that attempt to explain this decline. One theory is that segregation of leprosy patients led to a decline in the disease because it inhibited the transmission of the disease, though many historians believe this is unlikely because segregation was uneven and inconsistent. The second theory is that tuberculosis, which is bacteriologically related to leprosy, supplanted leprosy. A third theory is that improvements in housing and diet led to the decline in the disease. Finally, it has been theorized bubonic plague epidemics that swept through Europe beginning in the mid-fourteenth century took a particularly heavy toll on people who were already suffering

²¹ Brody, *The Disease of the Soul*, 66-69.

²² Brody, *The Disease of the Soul*, 93.

from leprosy.²³ Whatever the reason for the decline, leprosy did not disappear from all of Europe. There was evidence that leprosy still existed in Nuremberg in the sixteenth century and that it was still common in Brittany in 1855.²⁴ In the early 1800s leprosy was actually on the rise in Sweden and Norway. It was in Norway, that the first truly scientific investigations of leprosy were conducted.

In 1847, Daniel Cornelius Danielssen and Carl Wilhelm Boeck wrote, *Om Spedalskhed* (On Leprosy). Danielssen and Boeck were Norwegian physicians who worked in leprosy hospitals in Bergen, Norway. In *Om Spedalskhed*, Danielssen and Boeck stated that leprosy was a hereditary depraved condition of the blood and was not at all contagious.²⁵ While the publication of *Om Spedalskhed* gave new respectability to the commonly held theory that leprosy was transmitted by heredity, it did not end the discussion about the origins of the disease. Other physicians believed that the disease arose spontaneously or was caused by a miasma that existed in areas that were especially leprous.²⁶ In the late 1860s, Gerhard Henrick Armauer Hansen, an assistant to Danielssen at Lungegaard's Hospital in Bergen, began research on leprosy.²⁷ Armauer Hansen was given a grant by the Norwegian government to study leprosy, and he tried to determine what happened if relatives of leprosy patients left their families. He found that if a family stayed together, leprosy tended to pass from generation to generation, but if members left the family, leprosy tended to die out in the subsequent generations tied to the departing branch of the family.²⁸ When Armauer Hansen

²³ Gould, *A Disease Apart*, 7-8.

²⁴ Feeny, *The Fight Against Leprosy*, 37.

²⁵ Shubhada Pandya, "Anti-Contagionism in Leprosy, 1844 – 1897," *International Journal of Leprosy and other Mycobacterial Diseases* 66, no. 3, (September 1998): 377.

²⁶ H.P. Lie, "Armauer Hansen and the Leprosy Bacillus," *International Journal of Leprosy* 2, no. 4, (October-December, 1934): 474.

²⁷ Lie, "Armauer Hansen and the Leprosy Bacillus, 474.

²⁸ Feeny, *The Fight Against Leprosy*, 64.

returned to Bergen, he concentrated on looking at samples of the blood and scrapings from nodules of leprosy patients. Armauer Hansen found nothing in the blood samples, but he found the masses that Danielssen had previously seen in the nodular tissue of leprosy patients. Armauer Hansen also saw rod-like bodies in the tissue that would come to be known as the cause of leprosy, *Mycobacterium leprae*. Armauer Hansen published his findings in 1874 in a report to the Norwegian Medical Society in Christiania; however he was cautious about the implications of his findings.²⁹ In an article published in 1880, which described his 1873 research, he explained the reason for his caution:

From the various notes of my investigations in 1873 every one will be easily able to see that I had good reason for supposing that bacteria appear in leprosy products, but also that I, supported alone by these investigations, could not propound a theory on this subject, and still more decide whether these bacteria really were the virus which introduced into the system, produced the disease. In order, if possible to arrive at a decision in this matter, I tried to inoculate rabbits with leprosy by introducing portions of the leprosy growths, especially of the tubercles, under the skin of the animals. I was not lucky in any of these attempts, which however, as a matter of course is a proof against the supposition that the above named bacteria are the real virus.³⁰

Armauer Hansen's discovery of the leprosy bacillus did not result in immediate acceptance of the idea that this bacillus was the cause of leprosy for several reasons. The field of bacteriology was in its infancy. The leprosy bacillus was the first bacterium to be identified as causing disease in man.³¹ In addition to the problems associated with the bacillus he described in his 1880 article, neither Armauer Hansen nor anyone else could culture the leprosy bacillus in artificial medium. It was not until 1960 that attempts to infect animals with the bacillus were successful. Armauer Hansen faced other

²⁹ Lie, "Armauer Hansen and the Leprosy Bacillus," 478.

³⁰ G. Armauer Hansen, "The Bacillus of Leprosy," *Quarterly Journal of Microscopical Science* XX, (1880), 101.

³¹ R.J.W.Rees, "The microbiology of leprosy," in *Leprosy*, ed. Robert C, Hastings (Edinburgh: Churchill Livingstone, 1985), 32.

obstacles in having his theory that leprosy was caused by a bacillus accepted. Leprosy is a chronic disease, and while many doctors were willing to accept that diseases such as small pox were contagious, they were not as willing to accept bacteria as a cause for a chronic and slowly developing disease such as leprosy. Leprosy seemed to behave differently in different places in the world. In western Norway, Hawaii and India, it was epidemic. However in North America, even though there was incidence of leprosy, the disease was not easily transmitted. Finally, Danielssen, Armauer Hansen's father-in-law and mentor, the man that many viewed as the leading international authority on leprosy, though he encouraged the younger man's research, never accepted the idea that leprosy was a contagious disease and not hereditary.

Even when *Mycobacterium leprae* was generally accepted as the cause of leprosy, there was no effective treatment for the disease. Until 1941, the most common treatment for leprosy was chaulmoogra oil. Chaulmoogra oil was made from the seeds of two species of *Hydnocarpus* trees, as well as the *Taraktogenos* tree which are native to Burma and Northeast India.³² This oil had been used for centuries in India and Asia to treat leprosy and various skin conditions.³³ Chaulmoogra oil could be administered either orally or by injection. There were problems with both methods of administration. Patients often became nauseous when they took the chaulmoogra oil orally, and intramuscular injections could be painful and produce fever and reactions at the injection site.³⁴ Other treatments were tried and abandoned at Carville during the 1920s and 1930s. Intravenous injections of dyes, such as trypan blue, experimental injections of

³² John Parascandola, "Chaulmoogra Oil and the Treatment of Leprosy," *Pharmacy in History*, 45, no. 2, (2003): 4-5, <http://lhncbc.nlm.nih.gov/lhc/servlet/Turbine/action/DoPubSets/template/publications,BrowseBy.v.m?set='Branch'&setValue=APDB&setValueName=Audiovisual%20Program%20Development%20Branch> (Accessed March 8, 2009).

³³ Parascandola, "Chaulmoogra Oil and the Treatment of Leprosy," 2.

³⁴ Parascandola, "Chaulmoogra Oil and the Treatment of Leprosy," 9.

smallpox vaccine and diphtheria toxoid, and experimental fever therapy were tried and abandoned.³⁵ Researchers were hampered in their ability to find treatments for leprosy by the fact that the leprosy bacillus cannot be grown in vitro, and an animal model was not discovered until the 1960s when the mouse footpad was found to be a suitable environment to grow the bacillus. In 1941, Dr. Guy Faget began evaluating the use of sulfone drugs to treat leprosy, and found that promin was effective in treating many patients. Promin was given intravenously, but soon another sulfone derivative, diasone, was developed which could be given orally.³⁶ The sulfone drugs in some cases rendered the patient bacteriologically negative, and also led to the decrease in size or elimination of both skin and mucous membrane lesions.³⁷ In the early 1950s, the sulfone drug, dapson, began to be used. It had several advantages over previous sulfone drugs in that it could be administered orally in an ambulatory setting by non-medical personnel.³⁸ Once the mouse footpad was found to be a suitable environment to grow the leprosy bacillus, two additional drugs were found to be effective against leprosy, clofazimine and rifampicin. Since dapson, clofazimine, and rifampicin all had limitations as a treatment for leprosy when used alone, in the 1980s the World Health Organization began to recommend the use of all three drugs in combination.

Diagnosis and Transmission

Leprosy is often difficult to diagnose because in the early stages symptoms may be few or absent. The signs of leprosy are skin lesions that may be lighter than the

³⁵ Stanley Stein, *Alone No Longer*, (Carville, LA: The Star, 1963), 217-219.

³⁶ Frederick A. Johansen, "Advances in the Treatment of Leprosy," *The American Journal of Nursing*, 51, no. 7 (July, 1951): 445.

³⁷ Johansen, "Advances in the Treatment of Leprosy," 446.

³⁸ World Health Organization, *Weekly Epidemiological Record*, "Twenty-five years of multidrug therapy for leprosy," 27 (July 2, 2004): 248 <http://www.who.int/wer/2004/en/wer7927.pdf> (accessed March 11, 2009).

surrounding skin or reddish or copper colored. The lesions often take the shape of macules (flat), papules (raised) or nodules. Loss of sensation in the lesion is also common, as is thickening of the nerve trunk.³⁹ Today, leprosy is generally diagnosed by clinical examination and is based upon the presence of at least two of the three signs listed above. If possible, skin smears are also obtained from lesions, however, bacteriological examination is only positive in patients with certain types of leprosy.⁴⁰

Skin lesions and nasal mucous are known to be sources of the leprosy bacillus. The exact method of transmission is not known, though increasingly it is believed that the bacillus may be transmitted from person to person via the respiratory route. Often, it is difficult to determine how a leprosy patient was exposed to the disease, in part because the disease often has a long incubation period.⁴¹

Classification of Leprosy

There are several types of leprosy, which range on a spectrum from tuberculoid to lepromatous. Tuberculoid leprosy generally presents with relatively few lesions and marked nerve damage. Patients with the lepromatous form have more skin lesions, may have loss of sensation in the lesions, and nerve damage is slow but progressive.⁴² How the disease presents in a given patient depends upon the immune response of the patient to the leprosy bacillus. The majority of the world's population is not susceptible to leprosy. Patients who have a high immune response to the bacillus exhibit the tuberculoid form and patients with a weak immune response exhibit the lepromatous

³⁹ World Health Organization, "Diagnosis of Leprosy," <http://www.who.int/lep/diagnosis/en/index.html> (accessed November 14, 2010).

⁴⁰ World Health Organization, *A Guide to Leprosy Control, Second Edition*, (Geneva: World Health Information, 1988): 18-19.

⁴¹ World Health Organization, *Guide to Leprosy Control*, 7.

⁴² Andrea K. Boggild, Jay S. Keystone, Kevin C. Kain, "Leprosy: a primer for Canadian Physicians, *Canadian Medical Association Journal*, 170, no. 1 (January 6, 2004), 75.

form. Leprosy can also be classified by how high a bacterial load the patient experiences. Paucibacillary leprosy is defined as fewer than 6 skin lesions with no bacilli present on slit-smear testing. Multibacillary is defined as 6 or more lesions, and slit-smear testing may or may not be positive.⁴³ Both clinical and bacteriologically based classification systems are useful because, especially in developing countries, bacteriological testing is often not feasible.

If left untreated the leprosy bacillus can cause impairment of the function of sensory and motor nerves. The loss of sensation that is associated with some forms of leprosy can cause deformity of limbs because patients are unaware that they have injured themselves. Blindness is a potential side effect of leprosy, caused by damage to the trigeminal nerve.⁴⁴

Patients with leprosy can experience leprosy reactions. These reactions can happen more than once and can be quite debilitating. Leprosy reactions are divided into two types. Type 1 is caused by the increase in activity from the immune system or the remains of dead bacilli. The clinical features of Type 1 reactions include inflammation in skin patches and nerves and the patient may be unable to close their eyelid. Type 2 reactions are allergic reactions brought about by proteins from the decomposition of large numbers of dead leprosy bacilli. Type 2 reactions also cause skin inflammation, can cause inflammation of the iris of the eye, and because the reaction is systemic, can create a fever and a general feeling of malaise in the patient.⁴⁵ Mild leprosy reactions can be treated with aspirin to reduce the pain. Severe leprosy reactions are treated using steroids, most commonly prednisolone.

⁴³ Boggild, Keystone and Kain, "Leprosy: a primer for Canadian Physicians," 72.

⁴⁴ Boggild, Keystone and Kain, "Leprosy: a primer for Canadian Physicians, 74.

⁴⁵ International Foundation of Anti-Leprosy Associations (ILEP), *How to Recognize and Manage Leprosy Reactions*, (London, 2002) 11-15, http://www.ilep.org.uk/fileadmin/uploads/Documents/Learning_Guides/lg2eng.pdf (accessed February 18, 2012), 11-13.

Today, leprosy is generally treated by multi-drug therapy. Multi-drug regimens include a combination of rifampin, which kills 99.99% of the leprosy bacilli in a single dose, dapsone and clofazimine. Multidrug regimens are used to avoid drug resistance.⁴⁶ Patients with paucibacillary leprosy are generally treated for six months, and patients with multibacillary leprosy are generally treated for two years.⁴⁷

Current Incidence of Leprosy in the World

In the twenty-first century, leprosy cases tend to be found primarily in Africa, India, south-east Asia and South America. The World Health Organization (“WHO”) global strategy for 2006 to 2010, concentrated on detecting new cases in a timely manner and providing free multidrug therapy.⁴⁸ The number of new cases declined yearly from 407,791 in 2004 to 228,272 in 2010. The goal of WHO’s enhanced global strategy for 2011 – 2015 is to reduce new cases of patients with visible disabilities as a result of leprosy, to further reduce the delay of diagnosis, and to deliver multi-drug therapy promptly.⁴⁹

According to the WHO, most previously highly endemic countries have now reached elimination (defined as a registered prevalence rate of less than one case in 10,000 population). However some localized areas of high endemicity still remain in

⁴⁶ L, Levy, “Scientific Factors (1972-1982),” in *Multidrug therapy against leprosy: Development and implementation over the past 25 years* (Geneva: World Health Organization, 2004, 21 http://www.who.int/lep/resources/MDT_Full.pdf (accessed online April 15, 2012).

⁴⁷ Boggild, Keystone and Kain, “Leprosy: a primer for Canadian Physicians, 73.

⁴⁸ World Health Organization, *Weekly epidemiological record*, no. 35, August 27, 2010, 337 <http://www.who.int/wer/2010/wer8535.pdf> (accessed online November 9, 2011).

⁴⁹ World Health Organization, *Weekly epidemiological record*, no. 36, 2011, 86, September 2, 2011, 389 <http://www.who.int/wer/2011/wer8636.pdf> (accessed March 3, 2012).

Angola, Brazil, Central African Republic, Democratic Republic of the Congo, India, Madagascar, Mozambique, Nepal, and the United Republic of Tanzania.⁵⁰

⁵⁰ World Health Organization, "Leprosy Today" <http://www.who.int/lep/en/index.html> (accessed December 4, 2011).

Chapter Two - Stigma

Erving Goffman's⁵¹ *Stigma: Notes on the Management of Spoiled Identity*, is the seminal essay on stigma.⁵² While much has been written since Goffman's essay was published in 1963, it is still much quoted, and I found his discussion of stigma to be particularly well suited to the discussion of the stigma associated with leprosy.

Goffman was particularly interested in the "self." For Goffman, the "self" does not mean a stagnant and unchanging entity but rather a self that may change depending on who the self is interacting with.⁵³ Goffman conceived of stigma, in terms of relationships as well. Society, said Goffman, "...establishes a means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories."⁵⁴ When individuals are presented with a new person, and this person possesses an attribute that makes the person less desirable than others in his or her category, that person becomes tainted and discredited. Goffman defined stigma as an "...attribute that is deeply discrediting..."⁵⁵ He made the distinction between stigmatized individuals being discredited and discreditable. A discredited individual assumes that his or her stigmatizing attribute is known by others. The discredited person is mainly concerned with managing his or her interactions with "normals" the term Goffman used

⁵¹ Erving Goffman was a sociologist who received his B.A. from the University of Toronto in 1945 and his M.A. and Ph.D. degrees from the University of Chicago, in 1949 and 1953 respectively. Goffman taught at the University of California, Berkeley from 1958 to 1968 and at the University of Pennsylvania from 1969 to 1982. He was the 73rd President of the American Sociological Association.

⁵² Bruce G. Lind and Jo C. Phelan, "Conceptualizing Stigma," *Annual Review of Sociology* 27 (2001): 363.

⁵³ Frances Chaput Waksler, "Erving Goffman's Sociology: An Introductory Essay," *Human Studies* 12, nos. 1 and 2 (June 1989): 3-4.

⁵⁴ Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, (Englewood Cliffs: Prentice-Hall, Inc., 1963): 2.

⁵⁵ Goffman, *Stigma*, 3.

for people who, “do not depart negatively from the particular expectations at issue.”⁵⁶ In contrast, a discreditable individual assumes that his or her stigmatizing attribute is not known or immediately perceivable by others. The discreditable person is concerned with managing the information about his or her stigmatizing attribute. Goffman pointed out that most stigmatized persons will face some situations in which they are discredited and some situations in which they are discreditable.

This distinction is important in applying the theory of stigma to leprosy patients. Many leprosy patients do not show outward signs of their disease, especially when they are first diagnosed. Even when disability resulting from leprosy is apparent, the general public may not identify the disability as being caused by leprosy. Marcia Gaudet in her article “Telling It Slant: Personal Narrative, Tall Tales, and the Reality of Leprosy,” recounted the story that Billy, a leprosy patient who was at Carville from 1952 to 1957, told to strangers at bars. When asked what happened to his hands, which were injured by leprosy, Billy told his drinking companions he would tell them two stories. The first story, which he told them was a lie, was that his hands were injured by a grenade when he served in the Army in the Korean War. The second story, which he told them was the truth, was that he had leprosy. None of his drinking companions believed he had leprosy.⁵⁷ Many leprosy patients are in the position of being discreditable, rather than being discredited.

Two other concepts introduced by Goffman that are applicable to leprosy patients are the concepts of the “own” and the “wise.” The “own” are other people who share the stigma, people who can provide moral support, can assist the stigmatized person in

⁵⁶ Goffman, *Stigma*, 5.

⁵⁷ Marcia Gaudet, “Telling It Slant: Personal Narrative, Tall Tales, and the Reality of Leprosy,” *Western Folklore* 49, no. 2 (1990): 199-200.

learning how to cope with his or her stigma and can provide the stigmatized person a feeling of ease, of being accepted as a normal person.⁵⁸ Many of the leprosy patients whose stories I read expressed the sentiment that they could only feel completely at ease with other leprosy patients. The “wise” are people who are “intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan.”⁵⁹ These individuals could be physicians or nurses or family members of the stigmatized person. The autobiographies of leprosy patients show that many of the patients were extremely grateful for the courteous treatment afforded them by members of the Carville staff. Other Carville personnel were disliked by the patients because the patients felt further stigmatized by the behavior of those staff members.

The last of Goffman’s concepts I believe is useful in discussing the stigma of leprosy is the concept of “moral career.” Persons who have a particular stigma, Goffman stated, “tend to have similar learning experiences regarding their plight and similar changes in the conception of self.”⁶⁰ The point in life at which the stigmatized individual learns he or she has a stigmatizing attribute is important in how the individual copes with his or her stigma. Goffman described four patterns of moral careers: (1) people with an inborn stigma; (2) people who learn of their stigma early in life, but are protected by their family and community so that he or she sees himself or herself as a normal person, and whose introduction to the world where he or she is considered different is delayed until school age or later; (3) people who are stigmatized later in life, so have learned about the normal and stigmatized before he or she finds himself or herself in the category of

⁵⁸ Goffman, *Stigma*, 20.

⁵⁹ Goffman, *Stigma*, 28.

⁶⁰ Goffman, *Stigma*, 32.

the stigmatized; and (4) those who are initially socialized in a community outside the boundaries of normal society.⁶¹

Most leprosy patients introduced in this paper were diagnosed in adulthood, but one of the patients was diagnosed very early in life. Two of the patients, while they were not diagnosed until adulthood, had family members who had leprosy and had been sent to Carville. For Goffman, that point at which the individual learns that he or she possesses a stigma is when he or she is, “likely to be thrown into a new relationship to others who possess the stigma too.”⁶² This was often the case with newly diagnosed leprosy patients in the early twentieth century, as they were often taken to leprosy hospitals or at least were required to be quarantined. Goffman pointed out that the newly stigmatized individuals may feel ambivalent about the people who are now his or her “own.” The diagnosis of leprosy was a traumatic event for most of the leprosy patients whose lives are examined here; it represented a profound change in their lives and separation from their family, friends and homes.

⁶¹ Goffman, *Stigma*, 32-35.

⁶² Goffman, *Stigma*, 36.

Chapter Three - Leprosy Stigma in the Early Twentieth Century

Why in the early twentieth century in the United States would the stigma of leprosy persist? Why should leprosy still be seen as a disease apart, even after the discovery of the bacillus that causes leprosy diminished some of the mystery of the disease? Scholars of the history of leprosy have developed different theories to explain this phenomenon.

Margaret Wheatley, in a Ph.D. thesis entitled: "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma" argued that a society's response to leprosy is determined by a combination of religious, medical, legal, and social ideas.⁶³ Wheatley argued that, in the West, the medical community over reacted to leprosy because of the knowledge that the disease was caused by a bacillus, combined with the biblical concept of contagion.⁶⁴ Wheatley also cited the spread of European influence during the late nineteenth and early twentieth centuries into areas where leprosy was endemic, such as India and China, as a factor that influenced how the West viewed leprosy. For Wheatley, the fact that Christian missionaries often led the way in spreading Western influence in these areas contributed to the stigma of leprosy, because much of the medical care was provided by these missionaries, who modeled their care on the isolation practices of the Middle Ages.⁶⁵ Laws passed during the first half of the twentieth century, Wheatley believed, were consistent with the view of the public health community that leprosy was a potential threat to the healthy population,

⁶³ Wheatley, "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma", 138.

⁶⁴ Wheatley, "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma," 163.

⁶⁵ Wheatley, "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma," 164.

and therefore leprosy patients had to be quarantined.⁶⁶ From a social perspective Wheatley believed that literature and movies perpetuated outmoded perceptions about leprosy. Books such as James Michener's *Hawaii* and movies such as *Ben Hur*, Wheatley argued, perpetuated negative images of leprosy and the idea that leprosy is highly infectious.⁶⁷ Wheatley also argued that the religious, medical, legal, and social perspectives the West had on leprosy combined to create leprosy as a disease apart, and that the Judaeo-Christian religious teachings about leprosy as a punishment for sin continued to influence Western views of leprosy.⁶⁸

Zachary Gussow, who was member of the faculty of the Department of Psychiatry at Louisiana State University School of Medicine, and has written extensively about leprosy in the U.S., did not believe that leprosy's stigma in the West in the late nineteenth and early twentieth centuries stemmed from medieval theological concepts of leprosy. Gussow believed that leprosy was "retained" in the late nineteenth century due to a combination of factors. Like Wheatley, Gussow pointed out that the parts of the world Western nations were colonizing in the nineteenth and twentieth centuries included areas, such as India and Hawaii, where leprosy was hyperendemic. Western peoples were concerned the disease might contaminate the "civilized" world, and in the U.S. the Congress was asked to address the potential spread of the disease into the country by immigrants. The discovery of the leprosy bacillus did not answer the questions of how contagious leprosy was or how the disease was transmitted.

According to Gussow:

⁶⁶ Wheatley, "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma," 172.

⁶⁷ Wheatley, "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma," 178-179.

⁶⁸ Wheatley, "Leprosy: A Disease Apart, A Historical and Cross-Cultural Analysis of Stigma," 182.

The late nineteenth century Western opinion that leprosy was highly contagious, however, was not formed through extended observation and careful studies of the behavior of the disease. Rather it was formed by the general attitudes held in Western nations about the character and the symbolic attributes supposedly possessed by the colonial populations in which the disease was presumed to be inherent.⁶⁹

I believe the factors that Wheatley and Gussow discussed all contributed to the continuation of the stigma of leprosy into the twentieth century. However, I also believe that the “new public health,” which became the dominant view of public health authorities in the early twentieth century, contributed to the view that leprosy patients should be segregated, which worsened the stigma attached to the disease. The concept of the “new public health” was laid out in a series of three papers published by H. W. Hill, M.D., the Director of the Division of Epidemiology of the Minnesota State Board of Health, beginning in 1912. In the first paper, Hill described the difference between the old public health and the new public health:

The essential change is this: The old public health was concerned with the environment, the new is concerned with the individual. The old sought the sources of infectious disease in the surroundings of man, the new finds them in man himself.⁷⁰

Hill went on to say:

The sanitary inspection of the model sanitarian, so far as it relates to infection, begins and usually ends with the search for (a) the infected individual; (b) the routes of spread of infection from that individual; (c) the routes of spread of the ordinary excreta of ordinary uninfected individuals to the mouths of their ordinary associates in ordinary life.⁷¹

For Hill, and for many public health professionals after him, the focus was on the individual sufferer or carrier of disease; the individual and his or her excreta had to be controlled, not the environment. Since the mode of transmission of the leprosy bacillus

⁶⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 20.

⁷⁰ H.W. Hill, M.D. D.P.H., “The New Public Health – First Paper”, *The Journal – Lancet*, 32 (1912): 39.

⁷¹ Hill, “The New Public Health – First Paper,” 40.

was not clear, and still is not clear to this day, under the philosophy of the new public health, the only option to control the spread of leprosy was to control the leprosy patient.

This emphasis on the individual was to have profound consequences not only for leprosy patients, but for patients with other contagious diseases and even for healthy carriers of disease. In the nineteenth and early twentieth centuries, typhoid fever presented a serious health problem. Typhoid bacteria spread primarily through contaminated drinking water. When cities added filtration to their water systems, the incidence of typhoid decreased, but was not eliminated.⁷² Researchers began to realize that people who were recovering from typhoid, and even people who had never been sick with typhoid, could harbor the bacteria in their bodies and pass it along to others. Mary Mallon, also known as “Typhoid Mary” was the first such “healthy carrier” to be identified in North America.⁷³ Between 1907 and her death in November, 1938, with the exception of five years between 1910 and 1915, Mary Mallon was held at North Brother Island in the East River between the Bronx and Riker’s Island in New York. Her incarceration was not due to any crime she had committed, but because the New York Public Health Department considered her a healthy typhoid carrier, who, they believed, was the source of contamination which led to several deaths from typhoid fever. Though other healthy carriers of typhoid fever were identified in New York City, they were typically not confined but merely told that they could not work in professions that involved preparing or handling food for others. Some of these health carriers were occasionally confined for short periods if they continued to work in a food handling profession, but none were confined for nearly as long as Mary Mallon. Whether this was because she was the first healthy carrier of typhoid fever identified, or because of her

⁷² Judith Walzer Leavitt, *Typhoid Mary*, (Boston: Beacon Press, 1996) 29.

⁷³ Leavitt, *Typhoid Mary*, 14.

unwillingness to believe that she carried the disease and that cooking for others jeopardized their health is debatable. What is certain is that during the early twentieth century many departments of health, some of which were found in state governments others of which were located in city government, were invested with the authority to use extraordinary measures to deal with public health problems. Hermann Biggs, who was appointed chief of the division of bacteriology and disinfection of the New York City Board of Health in 1892 and remained with the Board for twenty-six years⁷⁴ stated:

“The Board of Health of New York City has legislative, judicial, and executive powers. Its regulations on all matters pertaining to the public health are final, and there does not exist in any individual or in any body any power of review or revision of the action of the Board of Health excepting in the courts....I do not think that any sanitary authorities anywhere have had granted to them such extraordinary and even arbitrary powers as rest in the hands of the Board of Health of New York City.”⁷⁵

These “extraordinary and even arbitrary powers” were put to use to try to halt the spread of another deadly disease of the nineteenth and early twentieth centuries -- tuberculosis. During the first half of the nineteenth century, tuberculosis claimed more lives than any other disease in America, accounting for one out of every five deaths.⁷⁶ By the early twentieth century, while the death rate from tuberculosis was declining, it was still a serious health threat to the immigrant poor.⁷⁷ To control tuberculosis, many departments of health required that doctors report cases of tuberculosis to health department officials, including the names and addresses of the patients.⁷⁸ The most powerful weapon in the arsenal of the public health official was the power to segregate the tuberculosis patient. New York City reserved one wing of the Riverside Hospital for the care of tuberculosis

⁷⁴ Leavitt, *Typhoid Mary*, 40.

⁷⁵ Leavitt, *Typhoid Mary*, 42.

⁷⁶ Sheila M. Rothman, *Living in the Shadow of Death: Tuberculosis and the Social Experiment of Illness in American History*, (New York: Basic Books, 1994), 13.

⁷⁷ Rothman, *Living in the Shadow of Death*, 184.

⁷⁸ Rothman, *Living in the Shadow of Death*, 187.

patients. New York public health officials tended to reserve the power to confine to poor tuberculosis patients or those patients who were considered undesirable in other institutions.

While both typhoid fever and tuberculosis presented major public health challenges because they affected tens of thousands of people each year, the number of leprosy cases in the early twentieth century numbered only in the hundreds. A study of leprosy conducted in 1898 documented only 278 cases in the country, which did not yet include Hawaii.⁷⁹ The public health reaction to leprosy was out of proportion to its actual incidence in the country. Gussow wrote:

Leprosy was the first disease to elicit a socialized response at the federal level. The move to establish a national leprosarium was unprecedented. Leprosy was considered to be contagious and disfiguring and was thought to be spreading. But other contagious diseases were also spreading in the United States to a far greater extent.⁸⁰

As late as 1950s, when there was a relatively effective treatment for leprosy, twenty-six states had laws requiring the isolation of leprosy patients at Carville; though these laws differed as to whether they applied to all cases or only to bacteriologically active cases.⁸¹ States also varied on how strictly they enforced their leprosy laws.

There is no clear answer to why a disease like leprosy should result in the only U.S. federal institution to be devoted to the treatment of a single disease in the general population, when the incidence of the disease in the United States has always been low.⁸² Wheatley and Gussow, I believe, provide compelling arguments as to why this was so; the philosophy of the public health community also was a contributing factor.

⁷⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 11.

⁸⁰ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 11.

⁸¹ James A. Doull, "Laws and Regulations Relating to Leprosy in the United States of America," *International Journal of Leprosy*, 18 (1950): 149.

⁸² Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 12.

The mysterious nature of the disease and its cause, the lack of effective treatment and the religious and racial symbolism carried by leprosy, all combined to keep leprosy a “disease apart” in the early twentieth century in the United States.

Chapter Four - History of Carville

The U.S. Marine Hospital Number 66 at Carville, Louisiana, more commonly known as “Carville,” started its life as the Louisiana Home for Lepers in late 1894, when eight leprosy patients from a pest house in New Orleans were brought to the old Indian Camp Plantation in Iberville Parish near Carville.⁸³ A newspaper reporter from the New Orleans *Daily Picayune* wrote a series of articles on the wretched conditions at the pest house, and these articles and a report from Dr. Isadore Dyer, a dermatologist from New Orleans, persuaded the Louisiana Legislature to create the State Board of Control for the Leper Home in September, 1894.⁸⁴ It was not surprising that such a step was taken in Louisiana. Leprosy had been known to exist in Louisiana since the late eighteenth century, and a leprosy hospital, known as “*La Terre des Lepreux*” was established in 1785 when Louisiana was under Spanish rule.⁸⁵ Public attention to leprosy in Louisiana waned during the early nineteenth century, but in the 1870s, the Louisiana medical community began paying attention to the incidence of leprosy in the state. In the late 1870s and early 1880s Dr. Joseph Jones, who became president of the newly formed State Board of Health in 1880, conducted a series of investigations into the prevalence of leprosy in Louisiana, bringing the disease to the attention of the public and the medical community. In the 1890s Dr. Dyer wanted to create a leprosy control program based on science and medicine.⁸⁶ The creation of the Louisiana Home for Lepers was part of Dr. Dyer’s vision. In November, 1894, Dyer leased Indian Camp Plantation, some eighty miles north of New Orleans to house the new leprosy home. He also

⁸³ Gould, *A Disease Apart*, 199.

⁸⁴ Gould, *A Disease Apart*, 199.

⁸⁵ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 44.

⁸⁶ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 59.

procured the services of Dr. L.A. Wailes to act as resident physician. In 1896, Dyer arranged for sisters from the Daughters of Charity of St. Vincent de Paul, commonly known as the Sisters of Charity, to run the Louisiana Home for Lepers. When the Sisters of Charity began their work at the Louisiana Home for Lepers in February, 1896, they were appalled at the conditions.⁸⁷ The patients were quartered in six cabins that had formerly been slave cabins. During the life of the Louisiana Home for Lepers the Sisters of Charity waged an ongoing battle with the State of Louisiana to obtain sufficient funds to run the institution, make repairs, and improve facilities. The State refused to provide the funding for medical research or treatment that Dyer had envisioned.⁸⁸

Beginning in the 1880s, attention was given to the idea of creating a national leprosarium. Gussow has argued that leprosy was not an issue in Louisiana or the nation until the late 1880s when articles and speeches calling for the creation of a place to isolate leprosy patients began to appear.⁸⁹ During the 1880s, leprosy also became an issue in Minnesota, where Swedish and Norwegian immigrants who had contracted leprosy in their home countries settled. Dr. Charles Hewitt, the secretary of the Minnesota Board of Health from 1872 through 1897, was interested in leprosy, attempted to maintain an accurate list of all leprosy patients, and saw that any new cases were investigated. Hewitt did not believe segregation of leprosy patients was warranted. Henry Bracken, who succeeded Hewitt, disagreed. In an article in the St. Paul Medical Journal in 1900, Bracken described the living conditions of over 100 leprosy patients. He concluded that the persecution experienced by some of the

⁸⁷ Gould, *A Disease Apart*, 201.

⁸⁸ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 64-65.

⁸⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 130.

patients called for the creation of not one, but two leprosaria. Two institutions were required, he believed because:

It would not be humane to transport those who by inheritance and birth belong in a tropical climate to a leprosarium in Minnesota, while on the other hand people of Scandinavian or Icelandic origin should not be sent to Louisiana or the Hawaiian Islands.⁹⁰

In 1905, the first law to create a Federal leprosarium was introduced. This law was passed by the Senate, but was defeated in the House. Various other bills were introduced, but, according to Gussow, "Congress, however, did not become sufficiently leprophobic until the 1916-1917 session, when bill S. 4086 passed the U.S. Senate and was signed into law by President Woodrow Wilson on February 3, 1917."⁹¹ According to Gussow, what motivated Congress to pass the bill to create a national leprosarium was fear that Americans who went abroad would bring the disease home, as had some soldiers who fought in the Philippines and Cuba during the Spanish-American War. America's entry into World War I delayed the implementation of the law; finding a location to put the leprosarium was another obstacle.⁹² When the committee formed to select a site settled on two islands in the Florida Keys, Florida business interests mobilized to oppose placing the leprosarium in Florida. After meeting with the Floridians, Surgeon General Rupert Blue overturned the committee's decision to site the leprosarium in the Keys. Instead, though Blue had once characterized the Louisiana Leper Home as having, "but little to commend it beyond the fact that it would have offered a prompt solution to the question of providing a location," the Louisiana Leper

⁹⁰ Henry Bracken, "Are National Leprosaria in the United States Desirable? *The Saint Paul Medical Journal* II (January to December 1900): 839.

⁹¹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 139-140.

⁹² Philip A. Kalish, "Lepers, Anachronisms, and the Progressives: A Study In Stigma, 1889-1920," *Louisiana Studies* 12 (1973): 517.

Home was purchased by the federal government on January 3, 1921 to become the site of the national leprosarium.

The new federal leprosarium was managed by the U.S. Public Health Service (“PHS”), one of the uniformed services of the United States government. Then known as the Marine Hospital Service, the PHS had conducted the first national leprosy survey in the first years of the twentieth century, and its scope and power in national health issues had been expanding since the 1880s. It was tasked with conducting the health inspections of individual immigrants that were required after 1891, and with issuing health certificates to foreign vessels before they left their home ports.⁹³

Dr. Oswald E. Denney was the first Medical Officer in Charge at Carville, and he set the tone for Carville under federal control.⁹⁴ He drafted the “Scheme of Regulations for the Apprehension, Detention, Treatment and Release of Lepers,” which I will refer to as the “Regulations.” The Regulations forbade any leprosy patient to leave Carville or to have physical contact with anyone who did not have leprosy, including hospital staff, and provided for the imprisonment of leprosy patients who broke the rules. In addition, when a leprosy patient entered Carville, they were stripped of their right to vote.⁹⁵ The Sisters of Charity continued their work at Carville as federal employees, but the tone of the institution changed. Emma Claire Manes’ great-uncle Norbert’s stay at Carville spanned the change from state to federal control, and his letters give some clues to the changes that the federal administration brought. The Louisiana Home for Lepers was always underfunded and the food provided to the leprosy patients reflected this lack of resources. Norbert’s letters express his approval of the meals provided under the

⁹³ Michelle T. Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*, (Chapel Hill: The University of North Carolina Press, 2007), 22.

⁹⁴ Kalish, “Lepers, Anachronisms, and the Progressives,” 520.

⁹⁵ Kalish, “Lepers, Anachronisms, and the Progressives,” 521 - 522.

federal regime. “Let me tell you we have been having much better food [...] and more of it too. Milk three times a day where we used to have it once a day. We get eggs nearly every day, once, and Irish potatoes which we hardly ever saw any but very seldom and now we get them nearly every day.” he wrote in February, 1921, only a couple of months after Carville went under federal control.⁹⁶ According to Manes her uncle’s letters before federalization show there was much more emphasis on religious activities, “Religious services prevailed in Norbert’s life at Carville, especially from 1919 to early 1921, for there is additional mention of novenas, benediction, and masses during the week; on the first Friday of each month; and at Thanksgiving, Easter and Christmas.” In writing about Norbert’s letters post-federalization, Manes states, “Norbert’s letters after federalization of the hospital indicate religious services continued, but there seems to be less emphasis on the religious activities at the hospital.”⁹⁷ It would make sense that the religious tenor of the institution would change under federalization. When Carville was a state home, the Sisters of Charity were in control of the institution, and they were as concerned with the spiritual aspects of their patient’s lives as the medical aspects. Under federal control, the Sisters of Charity stayed on, but now only in a nursing capacity. Manes describes the change in this way, “The Sisters, no longer in charge of the Home, were hired as Civil Servants at the hospital, and thus exercised less direct control of the patient’s lives and were not allowed the same freedom to direct religious activities.”⁹⁸ Manes and Gussow described the Louisiana Home for Lepers as a “home” while Carville under federal control was a “hospital” to Manes and a “reservation” to Gussow (this term is also used in the Scheme of Regulations for the Apprehension,

⁹⁶ Emma Claire Manes, “Letters from Carville: Narrating the Unspoken Story of the Landry Family,” (Ph.D. dissertation, University of Louisiana at Lafayette, Fall, 2007): 18-19.

⁹⁷ Manes, “Letters from Carville.” 15.

⁹⁸ Manes, “Letters from Carville.” 15.

Detention, Treatment and Release of Lepers), and both indicated that the relationships between patients and staff became less personal. Under state control, patients and Sisters of Charity had mingled freely together, but after federalization leprosy patients had less contact with staff, and the Regulations forbade contact between staff and patients unless the patient required medical care. Gussow described how this decline in contact between the patients and their caregivers lead to the development of a patient community:

The number of patients in residence at Carville at any one time has never been very high, about 400 at the most. Many patients have been able-bodied and capable. With patients physically separated and formally segregated from their PHS caretakers, and with medical care taking up only a small portion of their time, life in the colony developed its own character. Soon patient organizations began to spring up. In the early 1930s, a former social club evolved into the Patient's Federation and a newspaper was started.⁹⁹

In addition to patients' organizations, patients set up private businesses, such as barbers, hairdressers, photographers, and fix-it shops to provide services to the patients. The autonomy that the patients experienced created a separation between the "colony" what Gussow calls the patient side of Carville, and the administration. This autonomy also led Gussow to believe that Carville was "the antithesis of the type of establishment that Erving Goffman, in his study of asylums, called a 'total institution.'"

⁹⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*,157.

Chapter Five - Diagnosis

All of the leprosy patients whose stories I looked at described their initial reaction to their leprosy diagnosis as horror and terror. The diagnosis of leprosy marked the beginning of their journey in the world of illness. Immediately after their diagnosis the leprosy patients began to get a sense of the impact that the stigma of leprosy would have on their lives. The patients were diagnosed as a result of bacteriological examination, the leprosy bacillus was found in their lesions. Some showed few outward signs of the disease when they were diagnosed. Though the method of determining whether someone had leprosy differed from the method used in the Middle Ages, some of the language regarding the finding was similar. In the Middle Ages, in the absence of the knowledge of bacteriology, whether or not a person had leprosy was determined by a panel of citizens which included the clergy, but often did not include a physician.¹⁰⁰ The person who was "accused" of having leprosy, usually by a neighbor or family member, was brought before the panel, whose members would look at the signs and symptoms the person showed and would either declare the person clean or hand down a sentence of leprosy. If the person was determined to have leprosy, which was referred to as sentencing, the person was required to leave their family and go to a lazaretto or pest house. If the findings were not clear, or if the person had the means to be isolated at home, the sentence may be home isolation. In the twentieth century, the language of leprosy did not change much. Many states had laws requiring people with leprosy to go to Carville, so essentially they were sentenced to Carville. If a patient absconded, they could be punished by imprisonment in the Carville jail. When patients were discharged,

¹⁰⁰ Peter Richards, *The Medieval Leper*, 41.

they were given certificates which stated they were no longer a “menace to public health.”

Below, I have included short descriptions of the leprosy patients’ lives before their diagnosis, and descriptions of their diagnosis and travel to Carville. It is important, I think, to understand the background of the leprosy patients and see how dramatic and life-changing their diagnosis of leprosy was. The leprosy patients had plans for their lives; marriage, careers, avocations, that had to be abandoned or put on hold because of their diagnosis. They also, for the most part, lost their names. During the 1930s, new Carville patients were encouraged by the Daughters of Charity to change their names. When Sister Laura asked Sidney Levysen, “Have you decided on your new name, young man?” Sidney protested that he did not want to change his name. Sister Laura explained to him, “...there are stupid people in the world and you must protect your family from their stupidity.” Sidney chose the name “Stanley Stein.”¹⁰¹ In later years, patients tended not to choose new names. José Ramirez, who went to Carville in the 1960s, kept his given name.

Betty

Betty Parker Martin, whose real name was Edwina Parra, was born in Jeanerette, Louisiana in 1908 to an old Louisiana family of French descent. Her family moved to New Orleans when she was young, where she led a life similar to any daughter of an old French New Orleans family; attending convent school and going to

¹⁰¹ Stanley Stein, *Alone No Longer: The Story of a Man Who Refused to Be One of the Living Dead*, with the assistance of Lawrence G. Blochman, (Carville, Louisiana: The Star, 1963): 36-37.

dances.¹⁰² Betty was nineteen years old and newly engaged to Robert, a medical student, when she was diagnosed with leprosy in December, 1927. She had not felt ill, but had noticed rose colored spots on her thighs. She visited her physician uncle, and when the spots had not gone away as he had predicted, she went to a skin specialist who sent her to a pathologist for skin scrapings. Two days before Christmas, the skin specialist told her uncle that the smears were positive for leprosy. Her uncle could not summon the courage to tell her parents about the diagnosis until Christmas day.¹⁰³ Several days later, Robert told Betty she had leprosy. In her book, *Miracle at Carville*, Betty described the night she was told she had leprosy:

Sleep did not come, and all night I wept and trembled, asking myself the age-old questions: How has this happened, and why, to me?

What in my nineteen happy years had betrayed me to this horror out of the Dark Ages?¹⁰⁴

On January 15, 1928, Betty was taken to Carville by Robert and her mother. There she would become known as Betty Parker.

Stanley

Stanley Stein, whose real name was Sidney Levysen, was born in Gonzalez, Texas on June 10, 1899. During part of Stanley's childhood, his father was a pharmacist in Boerne, Texas and Stanley's family lived in an apartment behind his father's drug store. Stanley was familiar with leprosy because the doctor who had an office in the same building occasionally saw a female patient who arrived in a closed carriage

¹⁰² Betty Martin, *Miracle at Carville* (Garden City, New York: Doubleday & Company, 1950), 178-179. Note: Reprinted in full in a compendium by Catholic Family Book Club, Doubleday & Company, 1962. Page references are to the 1962 edition.

¹⁰³ Martin, *Miracle at Carville*, 176.

¹⁰⁴ Martin, *Miracle at Carville*, 178.

and wore black clothes and heavy veils.¹⁰⁵ This woman, Stanley would later find out, had leprosy.

Stanley followed in his father's footsteps, received a degree from the University of Texas, School of Pharmacy in Galveston and began working in a family drug store in Boerne. Stanley was diagnosed with leprosy in 1920 at the age of 21. Stanley described his initial reaction to his diagnosis:

I scarcely heard what he had said. Leprosy! The word was not a diagnosis, it was a pronouncement of doom. My hopes and ambitions were collapsing about me. My future was in ruins. My present? A great, cold emptiness...¹⁰⁶

This description may have been influenced by Stanley's later life and his belief that the stigma of leprosy resulted from the societal belief that the leprosy described in the Bible was the same disease as the modern bacteriological-identified leprosy.¹⁰⁷ But certainly the diagnosis was deeply troubling to Stanley and his family. The doctor who diagnosed Stanley's leprosy treated him with chaulmoogra oil. Stanley showed few signs of the disease, and for the next ten years he was able to continue with his career as a pharmacist, purchasing his own pharmacy in San Antonio. He also had an active social life, which included participating in amateur theatricals. Still, Stanley was afraid that people would find out about his disease; he said in his memoir, "...the stigma was far more terrifying to me than the progress of my disease."¹⁰⁸ During this time, using Erving

¹⁰⁵ Stein, *Alone No Longer*, 14.

¹⁰⁶ Stein, *Alone no Longer*, 21

¹⁰⁷ Stein believed the confusion between leprosy as described in the Bible and the disease caused by the *Mycobacterium leprae* was one factor in the stigmatization of leprosy in the twentieth century. In his book, *Alone No Longer*, and in the Carville newspaper the *Star*, Stein reviewed the scholarship regarding the difference. In *Alone No Longer*, Stein quoted Dr. Frederick C. Lendrum, who wrote an article in the *American Journal of Tropical Medicine and Hygiene*, which distinguished the two: "The word 'blemish' appears twenty-eight times in Leviticus...it was not a medical term designating Hansen's disease or any other disease. Rather it denoted an inflicted stigma or blemish which marked the victim as 'unclean' under the Hebrew ritualistic law" (Stein, *Alone No Longer*, 148).

¹⁰⁸ Stein, *Alone no Longer*, 24.

Goffman's terms, Stanley was discreditable rather than discredited. Stanley assumed that people, except for people who were among the "wise" (people who knew of Stanley's diagnosis such as his doctor and his parents), were not aware that he had leprosy. Stanley's main preoccupation was with managing the information about his disease. He went to his doctor for chaulmoogra oil injections on Sundays, so he would not encounter other patients. When he visited Detroit to attend a cousin's wedding, he did not inform his uncle, who was a doctor, of his condition.

In 1930, Stanley's leprosy symptoms became more pronounced; spots appeared on his face and his left eye became inflamed. When his friends began to notice that he was ill, and the doctor who had so discretely cared for him died, Stanley decided he needed to leave San Antonio. He went to New York with his mother because he had heard New York laws regarding the treatment of leprosy patients were liberal, and he hoped to receive the best of medical care in New York.¹⁰⁹ Going to New York did not turn out as Stanley had planned. The first doctor he saw, a Dr. Loch, who had been recommended by a rabbi in San Antonio, informed Stanley that New York law forbade the treatment of "lepers" with open lesions and told him that he should go to Carville.¹¹⁰ Stanley went to a second physician, Dr. Wolff, who agreed to treat Stanley in New York. Dr. Wolff, however, felt obligated to notify Dr. Loch that he would be treating Stanley. Dr. Loch immediately notified the New York Department of Health of Stanley's illness. While the Department of Health doctor who visited Stanley was not as concerned about his illness as was Dr. Loch, Stanley was convinced that Dr. Loch would not leave him in peace until he went to Carville. Stanley went to the Department of Health, and the staff there recommended that he go to Kingston Avenue Hospital for observation and

¹⁰⁹ Stein, *Alone No Longer*, 28.

¹¹⁰ Stein, *Alone No Longer*, 28.

treatment. On New Year's Eve, Stanley was taken from the Department of Health offices to the hospital in an ambulance with a police escort. In February, Stanley made the decision to go to Carville. The doctor at the Kingston Avenue Hospital recommended against going to Carville saying that once his lesions were healed, there was no reason Stanley could not be treated in New York. However, William Danner of the American Mission to Lepers, who visited Stanley several times while he was hospitalized, convinced both Stanley and his mother that he would get good care at Carville. Stanley went to Carville in late February, 1931 traveling in a locked railroad car compartment.

Johnny

Johnny Harmon's journey with leprosy started somewhat differently from those of Betty and Stanley. Johnny was born in a small town in south-east Texas in November, 1911.¹¹¹ His brother, Elmo, who was two years older than Johnny, was diagnosed with leprosy when Johnny was fourteen years old. Johnny became familiar with the stigma of leprosy when the Harmon family's doctor made Elmo's diagnosis public. When the signs of Elmo's leprosy became more pronounced, the local barber refused to cut Elmo's hair.¹¹² By 1934, Elmo's leprosy was advancing, and he was sent to Carville. Johnny's first visit to Carville was to visit Elmo, who had been at Carville for a couple of months. Elmo was in good spirits for the visit and his family learned that he was happy at Carville.¹¹³ So unlike Betty and Stanley, Johnny's first impression of Carville was positive.

¹¹¹ Johnny Harmon, *King of the Microbes*, (Baton Rouge, Louisiana, privately published, 1995), 1

¹¹² Harmon, *King of the Microbes*, 15.

¹¹³ Harmon, *King of the Microbes*, 17.

In the autumn of 1934, Johnny was working as a draftsman for the Texas Highway Department when he began to notice a loss of sensation in his left hand. Given his experience with Elmo's leprosy, Johnny knew the significance of this symptom. Even before he went to a doctor to confirm his diagnosis, he was resigned to the fact that the course of his life would be changed because of leprosy. Johnny wanted to travel, so he, his cousin Angus, and his father took a trip to California. After they got home, Johnny went to a dermatologist in Houston, who took a specimen, which Johnny referred to as "a frying size hunk of my skin" to send to the lab for analysis.¹¹⁴ As Johnny had suspected, he had leprosy. His diagnosis, like Elmo's, became public when the Beaumont paper contained a news item which said, "Health Officer discovers case of Leprosy in the Texas Highway Department," and went on to describe Johnny in every way but name.¹¹⁵ Driven by his father and brother, Johnny went to Carville on August 2, 1935. In Carville he took the name, Jimmy Harris.

D.J.

D.J. LeBeaux's journey with leprosy began early in life. D.J. was descended from Arcadians who had fled to Louisiana from Canada in 1775.¹¹⁶ His family lived on a farm, and young D.J. loved to work with wood and animals. One morning when he was in fifth grade, D.J. found a lump on the back of his thigh.¹¹⁷ The next day his mother took D.J. to the closest doctor, in a town seven miles away. The doctor's examination took almost an hour, and D. J. could see that his mother was shaken after she emerged from the doctor's office. During the anxious ride home, D.J. asked his mother what the

¹¹⁴ Harmon, *King of the Microbes*, 21.

¹¹⁵ Harmon, *King of the Microbes*, 21.

¹¹⁶ D.J. LeBeaux, *Love Me, Somebody*, (New York, Vantage Press, 1985), 2-3.

¹¹⁷ LeBeaux, *Love Me, Someone*, 6.

problem was. She answered, "My son, the doctor said you have leprosy."¹¹⁸ D.J.'s mother told him that people would believe that his disease was contagious, and would consider him "unclean" because of the biblical references to leprosy. She also told D.J. that he might have to go to a faraway hospital just for people with leprosy. She told him, "We must keep it a secret, ...Don't ever tell anyone."¹¹⁹

During the months following his diagnosis, D.J.'s disease did not progress, but his worry about it affected his life dramatically. He could not concentrate in school, so he was no longer one of the best students in his class, of which he had been proud, but rather one of the worst. He isolated himself from his friends. His mother continued to provide D.J. information about his disease, telling him about the blemishes that could develop on the hands and feet, and the shortened lifespan of leprosy sufferers. She told him the decision to leave home to go to a leprosy hospital was his decision to make.¹²⁰

One day, D.J. felt for the lump on this leg that had triggered his leprosy diagnosis, and he found it was not there. His mother verified this, and for a few glorious months, D.J.'s seemed to have his pre-leprosy life back. Just a few months later, however, D.J.'s leprosy began to show itself again when his earlobe began to swell and a marble-sized lump developed on his eye. His friends at school began to question him about these symptoms. D.J.'s symptoms were also attracting the attention of school officials. One of these officials, Mr. Doo, approached D.J. and told him the board of education wanted to talk to his parents about the blemishes on his face, which the board was concerned might be contagious. D.J. could not work up the courage to tell his mother that the board of education wanted to talk to her. The following Friday Mr. Doo

¹¹⁸ LeBeaux, *Love Me, Someone*, 8.

¹¹⁹ LeBeaux, *Love Me, Someone*, 9.

¹²⁰ LeBeaux, *Love Me, Somebody*, 20.

met D.J. as he was getting off the school bus, and told him he could no longer come to school. Someone in the community, D.J. later surmised, must have figured out what his symptoms meant. D.J. did not tell his family what had transpired at school, but on the following Monday, he did not go to school, and was surprised when his mother did not question this. He learned later his mother had been told D.J. could not return to school until she had taken him to the doctor.

D.J. did not return to school, and neighbors questioned his family about why this was so. When the community learned D.J. had leprosy the LeBeaux family was shunned. Family and neighbors no longer visited the family and D.J. was even shunned by his beloved Uncle Yas. Three years passed during which time D.J. did not go to school, his family continued to be shunned, and his symptoms worsened. During this time, D.J. did not leave his farm and would hide whenever a non-family member came to the farm. D.J. thought more and more about going to Carville. When D.J. finally summoned the courage to tell his parents of his decision to go to Carville, his mother's wailing was so loud neighbors a quarter mile away could hear her and rushed to the LeBeaux farm to see what was wrong. On August 29, 1938, D. J. Lebeaux set out for Carville. The entire community gathered outside his family's home to watch him leave.¹²¹

José

José's story differs from the stories of the other leprosy patients I have discussed above, because his leprosy was diagnosed only after years of misdiagnoses. José was born into a large Mexican American family in Laredo, Texas in 1948. During his high

¹²¹ LeBeaux, *Love Me, Somebody*, 51.

school years, he began to notice small sores on his legs and hands and noticed loss of sensation in the pinkie and ring fingers of both hands and his forearms.¹²² After his high school graduation in 1966, José's physical problems continued. His father brought him to a dermatologist, who diagnosed José as having "grease balls." This was the first of many misdiagnoses José would face from both conventional and alternative medical providers. During the next year his symptoms worsened, and the loss of sensation and pain increased. His parents brought him to alternative Mexican healers, one of whom diagnosed his condition as resulting from having been rejected by a girl when he was fifteen. While José's condition continued to deteriorate, he was able to continue his studies at Laredo Junior College and maintain his relationship with his girlfriend, Magdalena. One morning in February of his sophomore year, José was too weak to get out of bed. He was bedridden for an entire week, and José's sister convinced him to go to the hospital to try to obtain a conclusive diagnosis of his illness. José was taken to Mercy Hospital in Laredo, Texas. It was there that José learned of his diagnosis, when a doctor from the Texas Department of Health asked him, "You mean that no one has told you that you have leprosy?"¹²³ Immediately after José's diagnosis his family began plans to take José to Carville. Because José was so ill, his parents wanted him to travel to Carville via air or ground ambulance rather than the station wagon offered by the Texas Department of Health.¹²⁴ At the time, Laredo funeral homes often owned ambulances to transport accident victims to the hospital, but no funeral homes wanted

¹²² José P. Ramirez, Jr., *Squint: My Journey with Leprosy*, (Jackson, University of Mississippi Press, 2009), 4.

¹²³ Ramirez, *Squint*, 1.

¹²⁴ Ramirez, *Squint*, 21-22.

their ambulances out of commission for an out-of-state trip. Only years later did José learn he had been transferred to Carville in a hearse.¹²⁵

Edmond

Edmond Gilbert Landry was born in 1891 in Louisiana. He and his four siblings would each be diagnosed with leprosy and end their lives in Carville. In her 2007 Ph.D. dissertation, Emma Claire Manes pieced together her grandfather's biography from his letters to his family. Edmond attended Soulé College in New Orleans in 1909, learning office work. Manes described Edmond as a serious and competitive student who resisted frivolity.¹²⁶ Edmond joined the U.S. Army during World War I, obtained the rank of Sergeant, and was discharged on November 4, 1918. By this time he had married his wife, Claire, and they were expecting their first child. Also around this time, Edmond observed a small anesthetic spot on his left heel.¹²⁷ Edmond got a job as bookkeeper at Estorge Drug Company in New Iberia, Louisiana. He was diagnosed with leprosy in 1922. Edmond would have been familiar with the disease. His brother, Norbert, the first of the Landry siblings to be diagnosed with leprosy, went to Carville in 1919 when it was still the Louisiana Home for Lepers.¹²⁸ Edmond left his job at Estorage Drug Company in May, 1923. He was isolated in a room of his home for a year. Edmond's two small children were only allowed in his room in the company of their mother, Claire, or their grandmother. Edmond was, "sent forward" and "transported by automobile" to Carville and was admitted under the alias "Gabe Michael" on October 10, 1924.¹²⁹ Dr. W.F.

¹²⁵ Ramirez, *Squint*, 30.

¹²⁶ Manes, "Letters from Carville", 128.

¹²⁷ Manes, "Letters from Carville," 134.

¹²⁸ Manes, "Letters from Carville." 14.

¹²⁹ Manes, "Letters from Carville." 120.

Carstens, chief health officer for Iberia Parish described Edmond to Dr. Denney, the head of Carville, as a “mighty good citizen, an exemplary father and husband and valued highly by our entire community.”¹³⁰ Edmond would never again be a member of that community.

There are two common themes in these biographies. First, according to the writers, their initial reaction to hearing they had leprosy was to call up images of leprosy from the Bible or the Middle Ages. Betty wrote that after being told she had the disease:

I thought back to the Bible, to old books and old words-and before my eyes, staring into the dark, appeared afflicted creatures shrouded in rags, walking down endless roads, ringing little bells to warn all within hearing to get out of the way before the cry: “Unclean.”¹³¹

When Stanley was diagnosed, he thought, “Leprosy was not just a disease-it was a stigma, a disgrace, a visitation from on high, a punishment for some dreadful sin. What had I done to bring the wrath of God upon my head?”¹³² After his diagnosis, D.J.’s mother told him, “People believe this thing is contagious. They will be scandalized by the mere mention of the word because of the ugly stigma, ‘unclean’ associated with it, as quoted in the Holy Bible.”¹³³ José, even though he was relieved to finally have a conclusive diagnosis of his illness said:

The one comment that sent chills down my spine was hearing Dr. Dickerson refer to me as a “leper” while he handed me a blue and white “Booklet for Patients with Leprosy.” This term caused me incomprehensible, confusing guilt.

Growing up Catholic and going to mass every Sunday during my childhood, I must have tuned in to what may have been informally referred to as the “leper Mass”.¹³⁴

¹³⁰ Manes, “Letters from Carville.” 119.

¹³¹ Martin, *Miracle at Carville*, 178.

¹³² Stein, *Alone No Longer*, 21.

¹³³ LeBeaux, *Love Me, Someone*, 9.

¹³⁴ Ramirez, *Squint*, 3

The second theme that emerges from these stories is how each leprosy patient and their family tried to manage the information that the patient had leprosy. In Betty's case, it took a few days after her Uncle Pierre was told she had leprosy for her family to summon the courage to tell her, and even then, they had her fiancé, Robert break the news to her. In describing her trip to Carville, Betty wrote, "It had been a furtive departure. Besides Robert, Mamère, and two of Mama's sisters, only one friend, pledged to secrecy, knew about our 'disgrace.'"¹³⁵ Stanley Stein, during the ten years between his diagnosis and going to Carville, was, "...in mortal fear of being found out..."¹³⁶ Similarly, after his diagnosis, D.J. LeBeaux was told by his mother, "We must keep it a secret, don't never ever tell anyone." Johnny Harmon, remembering the public reaction to the news that his brother, Elmo, had leprosy, had hoped to keep the news of his diagnosis quiet by asking his doctor not to publish his name. However, this did not stop the article, "Health Officer discovers case of Leprosy in the Texas Highway Department," from showing up in the local paper. Though the article that did not include Johnny's name, it did include enough detail to allow anyone who knew him to identify him as the leprosy sufferer. José did not try to keep his disease a secret, though, he reported, "My three older siblings and parents devised a plan-'*un plan*'- to keep my diagnosis a secret from everyone except the immediate family." José however, did not agree with the plan, and wrote, "Luckily for me, they abandoned this plan prior to my lengthy trip to Carville, Louisiana."¹³⁷ José's father even paid for a notice in the *Laredo Times* telling the community that José was at Carville and where to write him. This candor might have come because José was so sick by the time he was diagnosed, and

¹³⁵ Martin, *Miracle at Carville*, 181.

¹³⁶ Stein, *Alone No Longer*, 24.

¹³⁷ Ramirez, *Squint*, 21.

had been misdiagnosed so many times, that he was happy he had a diagnosis and a plan of action, however unpleasant, or because José's leprosy was diagnosed in the 1960s not the 1920s or 1930s. Manes wrote that Edmond, unlike his brother Norbert, who preceded him at Carville, did not make any attempt to conceal his identity, though he chose a "Carville name" as did most of the other leprosy patients. He did not use this name with his family, however. Unlike his brother, Norbert, who asked his family not tell anyone where he was or that he had leprosy, Manes described Edmond's stay in Carville this way, "In general his incarceration seems to have been treated with much less circumscription than that counseled by Norbert."¹³⁸ But this openness did not extend to how his wife dealt with his disease. Manes' primary thesis is that Edmond's wife, Claire, kept the truth about his disease from his children, and created an "edict of silence" that Edmond Landry was not to be talked about; an edict that was maintained until after Claire Landry's death. Even the discovery of Edmond's letters in 1977, four years before Claire's death, did not open up discussion. Silence, Manes believed, was an "...understandable reaction to Hansen's disease. At the most profound level it is the visceral response of one unable to articulate the horror that centuries of prejudice have heaped upon those diagnosed with this condition."¹³⁹

¹³⁸ Manes, "Letters from Carville." 37.

¹³⁹ Manes, "Letters from Carville." 33.

Chapter Six - Life at Carville

I will examine what life was like at Carville, using Erving Goffman's concept of a "total institution." In his book, *Asylums*, Goffman defined a total institution as, "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life."¹⁴⁰ Goffman went on to describe the characteristics of total institutions:

First, all aspects of life are conducted in the same place and under a single authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution.

I agree with Gussow that Carville is the antithesis of a total institution.¹⁴¹

Because Carville did not regiment every aspect of a patient's life, the patients had some ability to create a "normal life" for themselves within Carville. There are several ways in which the lives of patients at Carville demonstrate that Carville was not a total institution. First, the lives of the patients were not tightly scheduled with a series of activities arranged by hospital authorities. Gussow described Carville as having two elements, the "station" where the staff lived and the "colony" where the patients lived. In the colony, Gussow wrote:

It was in the colony that a distinct patient subculture evolved. The formation of a patient community within the colony area of the leprosarium was a satisfactory development insofar as the PHS was concerned. A laissez-faire attitude by the

¹⁴⁰ Erving Goffman, *Asylums*, (Chicago, Aldine Publishing Company, 1961) un-paginated Introduction.

¹⁴¹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 155.

PHS to patient organizations, activities and enterprises represented an accommodation to the fact that staff possessed few formal rules or sanctions for the control of patient behavior.¹⁴²

Even if a patient worked, and many did, jobs often took up only a couple of hours in the day, so patients had time to pursue other activities. Edmond Landry, who took the Carville name “Gabe Michael,” started the What Cheer Club and a patient’s canteen. Early in his stay at Carville Stanley Stein thought Gabe Michael was, “the only altruistic character I had met so far at Carville.”¹⁴³ Claire Manes described Edmond as a “man who continued to direct his life with the limited choices available to him.”¹⁴⁴ When she first got to Carville, Betty Parker taught school for the younger patients two hours each morning. Later she worked in Carville’s laboratory taking smears, doing urinalysis tests and blood counts four hours a day. With the rest of her time, she visited friends, took piano lessons from one of the Sisters of Charity, and with her housemates, planned activities for themselves and other Carville residents. Stanley Stein talked about the “strange moral climate” at Carville when he arrived.¹⁴⁵ He described his fellow patients as having a “curious feeling of hopeless apathy” and said that most were “quite content to be lodged, fed, clothed, and treated medically by the United States.”¹⁴⁶ But he also commented on the “rugged individualism” of his fellow patients in starting up private enterprises:

Some of the private enterprise I have mentioned grew out of stark necessity – breadwinners exiled to Carville, leaving their families without support, desperately needed to augment the \$25 or \$30 monthly they received for Government jobs; there was no provision for dependents when father was driven from home and society. There were others who simply liked to have extra

¹⁴² Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 157.

¹⁴³ Stein, *Alone No Longer*, 53.

¹⁴⁴ Claire Manes, “In His Own Hand: The Correspondence of Edmond G. Landry from Carville, Louisiana,” *Louisiana Folklore Miscellany*, http://louisianafolklife.org/LT/Articles_Essays/lfmcarville.html, (accessed September 7, 2011).

¹⁴⁵ Stein, *Alone No Longer*, 46.

¹⁴⁶ Stein, *Alone No Longer*, 46-48.

spending (or gambling) money in their pockets. And there were still others who were born with the acquisitive instinct and could not resist the opportunity of making an honest or fairly honest dollar by catering to an obvious need.¹⁴⁷

Stanley Stein was ambitious with his use of free time. Within three months of arriving at Carville, he and a fellow patient, David Palmer, began the *Sixty-Six Star*, a patient newspaper with the blessings of Carville's Medical Officer in Charge (MOC) Dr. Oswald Denney. The first issue of the *Sixty-Six Star* was published on May 16, 1931. Stein called the initial incarnation of the *Star* a "small town weekly" which contained jokes, announced the weekly movies and had a column for the lovelorn.¹⁴⁸ By 1933, Gussow wrote, it had become a crusading journal. The *Star*, whose masthead included the phrase, "Radiating the Banner of Truth on Hansen's Disease," became a vehicle for Stein, who was its editor until shortly before his death in 1968, to, as Stein put it, "promote an educated public opinion on Hansen's disease."¹⁴⁹ The *Star* stopped publication twice during the 1930s, the second time because of a series of articles that dealt with the medieval "leper mass" described earlier in this paper. The series began with an article by Charles Brown, the editor of the *Hoosier Res-Cuer*, published by patients of the Indiana State Sanatorium at Rockville, which condemned the leper mass and which stated that attitudes about leprosy in the twentieth century had not changed materially since the Dark Ages. Father Abbot Paul Schaeuble, Carville's Catholic chaplain, took issue with Brown's characterization of the leper mass, and said, that the leper mass had, "...real spiritual significance." In the words of the Apostle Paul, said Father Schaeuble, "the leper was reminded that although now dead to the world, he would live in God." Stanley could not let this be the last word on the issue. He wrote a

¹⁴⁷ Stein, *Alone No Longer*, 82.

¹⁴⁸ Stein, *Alone No Longer*, 70.

¹⁴⁹ Stein, *Alone No Longer*, 210.

follow-up article which concluded, “If the Church would be as energetic in trying to remove the stigma, which modern science has shown to be wholly unjustified, as it was active during the Dark Ages in instituting fear and horror, leprosy would be rid of the odium that now surrounds it.”¹⁵⁰ Stein expected approval from the Carville patients but he heard none. Most patients at Carville were Catholic and as Stein wrote, “We knew that most of our fellow patients were Catholics, but we assumed that they were patients first and Catholics second. We were wrong.”¹⁵¹ The *Star* staff and reporters stopped showing up for work, and the *Star* died until it was resurrected in 1941. Once the *Star* was resurrected, Betty Martin wrote articles for the paper, and Johnny Harmon was one of the *Star*’s photographers.

Johnny Harmon turned his love of photography into a business at Carville. He acted as a photographer and cartoonist for the *Star*, but also took photographs of the patient baseball games and other events at Carville and took private pictures for Carville patients.

José’s experience working at Carville was different from the experiences that Edmond, Betty, Stanley and Johnny encountered. José was at Carville during the 1960s and 1970s, when there was effective drug therapy available to treat leprosy. The first drug that was effective against leprosy, promin was discovered in 1941 and began to be used extensively in the mid-1940s. At the beginning of his stay at Carville, José Ramirez taught English to some of the patients and also worked as a tour guide for the visitors that came to Carville. José remembered that many visitors were inspired to visit Carville because they had read Betty Martin’s book, *Miracle at Carville*, as children.¹⁵² In

¹⁵⁰ Stein, *Alone No Longer*, 156-160.

¹⁵¹ Stein, *Alone No Longer*, 161.

¹⁵² Ramirez, *Squint*, 84.

January, 1969, with funding from the Texas Vocational Commission, José became a full time student at Louisiana State University. He did not find out until decades later that Carville staff had been instrumental in his acceptance at the school, because they persuaded LSU to change their rule that Carville patients who were bacteriologically positive could not attend.¹⁵³

Having some control over their time and how they used it was important. All of the patients were relatively young, and some healthy, when they entered Carville. By being able to develop certain aspects of a normal life, such as having a job, seeing friends in an unsupervised manner and starting enterprises, the patients at Carville were able to not only earn money, but make their forced segregation at Carville slightly less painful.

The second way the lives of patients at Carville demonstrate that Carville was not a total institution was their ability to determine whether they would take treatment for their disease, what treatment they would take, and to a certain extent, when and whether they would leave Carville. Before sulfone drugs were introduced in 1942, Carville had little effective treatment to offer patients. Chaulmoogra oil was the accepted treatment, but it was not very effective. Carville physicians tested other types of treatments, including fever therapy and diphtheria toxoid, without success. Stanley Stein described the myriad “unofficial and clandestine” remedies that patients tried to treat their disease. When Carville was still the Louisiana Home for Lepers, red mangrove bark was tried to treat leprosy, but the treatment was not effective. “The bark legend persisted, however”, said Stein, “...at one time a group of patients stripped the bark from scores of willow trees on the reservation and sold willow bark tea to addicts of self-medication. When the

¹⁵³ Ramirez, *Squint*, 98.

old houses were torn down to make way for the new Carville, bags and bags of unsold willow bark were discovered hidden away in attics.”¹⁵⁴ Leprosil, developed by a Mexican physician, was popular in the early 1930’s, and after the Carville administration declined to offer the remedy, Mexican patients had their families purchase it for them. Even after effective drug therapy was established, Gussow argued, “The freedom of colony life gave patients control over decisions about whether to engage in rehabilitation programs or even to take medication.”¹⁵⁵ Gussow’s research assistant who spent two days a week at Carville for almost a year in the 1960s described the Carville patient’s autonomy like this:

“The daily lives of the patients are not scheduled by the staff; participation in treatment and rehabilitation programs is voluntary. Indeed, about one-third of the patients at Carville do not even make appointments with the doctors for treatment of their leprosy. . . .it is quite possible for a patient at Carville to have practically no interaction with the staff.”¹⁵⁶

In addition to deciding whether to take the treatment prescribed by their doctors, Carville patients had the ability to decide whether and when to leave the institution. Leaving Carville without official medical leave was prohibited, and if patients did leave the health department of the State in which the patient lived was notified, but as a practical matter the authorities could do little as most Carville patients did not give their real names or addresses upon admission. In 1933, Harry Martin and Betty Parker decided to leave Carville after Harry tested positive for the leprosy bacillus after nine negative tests.¹⁵⁷ Still in their mid-twenties and feeling relatively well, Betty and Harry were afraid that they would never get a chance at a life outside the institution if they did

¹⁵⁴ Stein, *Alone No Longer*, 217.

¹⁵⁵ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 179.

¹⁵⁶ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 179.

¹⁵⁷ Until 1948, to be discharged from Carville, a patient had to be bacteriologically negative for twelve consecutive monthly examinations. If a patient tested positive for the leprosy bacillus one month, the twelve month clock started over again.

not leave at that time. Betty and Harry realized that their chance of capture was slight because neither of them had given their real name or address when they were admitted. They were also disillusioned with the effectiveness of the treatment then available at Carville – chaulmoogra oil - and reasoned they could obtain the same treatment outside of Carville. Betty and Harry left Carville, married, and began their life together in a small apartment in New Orleans. Harry opened a small hardware store, and after their marriage Betty worked in the store with him. Harry's medical condition began to deteriorate, however, and by their first wedding anniversary Betty and Harry were packing their belongings to return, voluntarily, to Carville. They had lived outside of Carville for over five years. After their admission tests were completed, Harry was sent to the Carville jail and Betty was confined to a cottage with barred windows for thirty days.¹⁵⁸

Doctors at Carville complained that patients did not follow the medical advice of the staff, that patients would leave the institution against medical advice, and that they had no ability to discharge patients. The patients, on the other hand, often felt they knew more about leprosy than most of the doctors at Carville, which may have been true given that it was PHS policy that junior officers were assigned to Carville for two to three year periods.¹⁵⁹ Gussow concluded, "The system of voluntary treatment at Carville collided with the professional expectations of the medical staff."¹⁶⁰

This does not mean that patients had complete control over their treatment. In 1969, José was taking thalidomide to try to control the leprosy reactions to which he was prone. While he was studying for his final exams in May, 1969, José began to

¹⁵⁸ Martin, *Miracle at Carville*, 241-259.

¹⁵⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 182.

¹⁶⁰ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 184.

experience what he thought was a reaction. He was told he had been taken off thalidomide and given a placebo because he had been randomly selected to participate in an experimental protocol. José developed a severe leprosy reaction and was unable to complete all of his exams. Once he was put back on thalidomide, he recovered and was able to complete the remaining exams.¹⁶¹

Stanley Stein's story also shows that doctors at Carville, despite their lack of total authority, could have a profound effect on the lives of patients and that the official regulations that governed Carville, which were often unenforced, could rear their ugly heads at unexpected moments. In December, 1951, Stanley got the news that his twelfth consecutive lab test was negative for leprosy bacillus. Stanley was elated. Though he was blind and had been at Carville for almost twenty years, he was looking forward to going home to his mother in San Antonio. However, Dr. Wolcott, the Clinical Director invoked a provision in the regulations that allowed the Clinical Director to call for a Medical Board Examination before approving a patient's discharge, even if the patient had twelve consecutive negative tests. The Medical Board Examination was conducted in January, 1952 by Dr. Wollcott alone. After taking additional scrapings from six locations on Stanley's body, Dr. Wollcott found a small number of leprosy bacillus. Stanley's discharge was denied. Dr. Johanson, the Medical Officer in Charge, who was beloved by most of the patients, could not help Stanley, and Stanley remained at Carville of the rest of his life. It is not possible to know Dr. Wollcott's motivation for invoking the regulations. Stanley said that he and Dr. Wollcott had an icy relationship, but did not

¹⁶¹ Ramirez, *Squint*, 112.

state positively that he believed that Dr. Wollcott consciously decided not to agree to Stanley's discharge out of spite.¹⁶²

The third way in which the lives of patients at Carville demonstrate that Carville was not a total institution is in the way they managed their domestic relations. In *Asylums*, Goffman wrote,

Total institutions are also incompatible with another crucial element of society, the family. Family life is sometimes contrasted with solitary living, but in fact the more pertinent contrast is with batch living, for those who eat and sleep at work, with a group of fellow workers, can hardly sustain a meaningful domestic existence.

At Carville, some patients were able to create a family life, though it may have looked different from and have been more difficult to sustain than it would have been outside of the institution. In her paper, "Leprosy, Domesticity and Patient Protest," Amy Fairchild wrote of Carville, "But those confined created a community in which they articulated their own version of American political, suburban and domestic culture as they sought to gain control over the private sphere."¹⁶³ There are three ways in which Carville patients showed their autonomy in their domestic relations; the cooking of food, housing, and their relations with the opposite sex.

Fairchild wrote that there was, "a long tradition of patients preparing meals in their dorms or cottages."¹⁶⁴ Betty Martin described how, between five and six p.m., Carville ladies would sit down to meals with their boyfriends that they had struggled to prepare in their rooms on electric hot plates. The male patients also cooked. Stanley Stein was a member of the "supper club" formed by Bill Collins who lived in House forty-

¹⁶² Stein, *Alone No Longer*, 294-297.

¹⁶³ 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 no. 4 (Summer 2006), 1011.

¹⁶⁴ Fairchild, "Leprosy, Domesticity and Patient Protest," 1015.

one with Stanley. The club consisted of an “inner circle of fellow gourmets.”¹⁶⁵ Patients could get food at the canteen or from workmen who sold vegetables and chickens to patients. The Sisters would also pick up items for patients in their weekly trips into Baton Rouge.¹⁶⁶ In addition, the PHS would issue raw rations of flour, sugar, eggs, and meat to patients who wanted them. Cooking in patient rooms was “grudgingly tolerated” by most of the Carville administrations. During the time that Guy Faget was MOC (from 1940 to 1947) he did not deny patients the right to cook in their rooms, but he discouraged it as he felt that the food served in the cafeterias, which was cooked by experts, was a key part of the treatment of leprosy.¹⁶⁷

Housing was another area in which some Carville patients tried to create a more normal life. When first admitted, all patients were assigned to dormitories, consisting of twelve private rooms and one shared bath. The houses were separated according to sex and each house had a different atmosphere. Stanley Stein described the difference between the houses:

...each house had its own special character, for at Carville as elsewhere birds of a feather did flock together. Sometimes the plumage was a question of nationality; there was a Mexican house, a Chinese house, a Filipino house. There were three “blind” houses with extra orderlies to take care of the special needs of the sightless. House 42 had a reputation of being a den of roughnecks, and it was true that its occupants - all Protestants and almost all veterans of the war to make the world safe for democracy – were more obstreperous and outspoken than the average. The women of House 31 were known as “lily-whites,” probably because they had higher moral standards, a higher bathing index and were more fastidious in their dress. The lily-whites dated only men from House 30, with one exception: they invited me to their parties.¹⁶⁸

Betty Martin lived in House thirty-one with her friend Dorothy Kimble, a New Orleanian about ten years older than Betty and several girls in their early teens who Dorothy and

¹⁶⁵ Stein, *Alone No Longer*, 60-61.

¹⁶⁶ Martin, *Miracle at Carville*, 196.

¹⁶⁷ Fairchild, “Leprosy, Domesticity and Patient Protest,” 1016.

¹⁶⁸ Stein, *Alone No Longer*, 57-58.

Betty looked after. Betty described living in house thirty-one this way, "...a congenial group formed and lived there under conditions pleasanter than we had known before."¹⁶⁹ Harry Martin, her future husband lived in house thirty with other men close to his age.

Even before Carville became a federal institution, patients would go the secluded areas of the hospital's grounds to cook meals or meet with friends. These campsites became shacks, some of which were turned into homes using materials that were either purchased by the patient or were obtained by foraging for materials at the Carville dump. This group of cottages was called "Cottage Grove" or "suburbia" by Carville patients. The number of cottages reached a high of eighteen by the early 1950s.¹⁷⁰ For patients who could connect to water, electricity and/or gas, the PHS would supply these utilities for free. The patients who built the cottages owned them and would sell them to other patients when they left Carville or if they became too disabled to live on their own. Stanley Stein purchased his cottage, which he named "Wit's End," for \$500.00 from a friend who was leaving Carville. Wit's End was to be Stanley's home for nearly twenty-five years.¹⁷¹ When Johnny Harmon and his wife Anne were married in May, 1948, they were living in separate dormitories, but wanted a home of their own. Johnny bought a small storage shed for \$100.00 and, using his drafting skills, began to design a small house. He bought some of the materials, and salvaged others from leftovers after some of the buildings at Carville were remodeled. The plumbing and electrical systems were installed by Carville employees. Johnny and Anne lived in their "little mansion" for six and a half years. Johnny left Carville in 1954 and Anne followed him in 1957.¹⁷²

¹⁶⁹ Martin, *Miracle at Carville*, 214.

¹⁷⁰ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 158.

¹⁷¹ Stein, *Alone No Longer*, 170.

¹⁷² Harmon, *King of the Microbes*, 80.

Fairchild saw the impulse of Carville patients to create their own homes as a corollary to the suburban ideal that flourished during the Second World War. “The home,” Fairchild wrote, “particularly the suburban home represented the promise of egalitarianism and democracy within the broader society. It represented domestic living, privacy and independence. This social transformation also gripped the Carville patient population who likewise wished to be treated and regarded as resident citizens, not merely as dependent ‘patients.’”¹⁷³

Patients also tried to make their lives more normal by having normal relationships with the opposite sex. I use the term “opposite sex” consciously, as only Stanley mentioned homosexuality at all, and then to comment that to his knowledge it did not exist at Carville. Stanley wrote:

Considering the 5 to 2 ratio of men to women that has always prevailed at Carville...it is surprising that there were not more internal manifestations of the men-without-women situation. As far as I know, there has never been any homosexuality of record, certainly none that was obvious, and the alert Carville grapevine would hardly have missed the obvious.¹⁷⁴

Some patients were sent to Carville when they were young and in relatively good health. Betty Parker was nineteen and newly engaged when she was sent to Carville. The years of separation, however destroyed her relationship with her fiancé, and she eventually found comfort in her relationship with a fellow patient, Harry Martin. When she was first at Carville, Betty was scandalized by the relationships between men and women who met without chaperones.¹⁷⁵ Later on, however, she would better understand the loneliness that patients felt at Carville could lead even married patients

¹⁷³ Fairchild, “Leprosy, Domesticity and Patient Protest,” 1018.

¹⁷⁴ Stein, *Alone No Longer*, 140-141.

¹⁷⁵ Martin, *Miracle at Carville*, 194.

to seek the companionship of the opposite sex. Speaking of a fictional Mrs. John Doe,

Betty wrote:

Separated from all she has loved, living in a tight little world complete in itself, where she has no need to be furtive since everyone knows why she is there, her homesickness turns to hunger for companionship. It is difficult to blame her if the understanding she craves is furnished by someone who knows exactly what she is experiencing and who comes perhaps from her own state or even city. It is not her fault if this person is a member of the opposite sex. The colony is small, and they meet constantly – at breakfast, dinner, supper, mailtime. She could not avoid him if she tried. He observes how often she is disappointed when no letter comes. He is lonely and disappointed too. One evening he escorts her to the movies, and according to Carville tradition, another romance has begun.¹⁷⁶

At Carville, small actions could signal major changes in a couple's relationship.

According to Stanley, taking his girlfriend Lorene to the movies was, "an act which in Carville was tantamount to announcing an engagement" and instead of an engagement ring, "Carville tradition" required that Stanley buy Lorene an electric percolator.¹⁷⁷

Stanley did not accept Lorene's proposals of marriage. Later, Lorene fell in love with one of Stanley's friends and married him in Little Rock, Arkansas, after they were both discharged.

Marriages between patients were discouraged by the administration, and being at Carville complicated the ability to create a normal married life, sometimes in heartbreaking ways. If a woman became pregnant, she was sent to New Orleans to give birth, and had to give up her baby, either to a family member or other family who was willing to take the baby. Johnny Harmon's wife, Anne, gave birth to two children and the Harmon's were able to find a Cajun family who lived not too far from Carville to care for the children. Their children knew that Johnny and Anne were their parents, and the children were brought to Carville for picnics, where Johnny and Anne would go through

¹⁷⁶ Martin, *Miracle at Carville*, 219.

¹⁷⁷ Stein, *Alone No Longer*, 109.

the “hole in the fence” to see the children. Betty Parker resisted marrying Harry Martin because of her fear of having children. Betty finally agreed to marry Harry, when her mother said if Betty and Harry had a baby she would care for it.

By stating that Carville was not a total institution, and by arguing because it was not, patients had some ability to create something like a normal life with its walls, I am not implying life at Carville was idyllic, nor am I stating it was a conscious decision by the federal government that Carville not be a total institution. The Scheme of Regulations for the Apprehension, Detention, Treatment and Release of Lepers drafted by the first Medical Officer in Charge (MOC), Oswald Denney were still in force during the 1930s, 1940s and 1950s, and while most of the MOCs did not strictly enforce the provisions of the regulations some of the administrations did try to exert more control over the patient population. When Dr. Herman E. Hasseltine took over as MOC on November 1, 1935, his first executive order was to forbid male patients to enter the rooms of female patients. This rule threatened the ability of female patients to dine with their male companions. Carville patients came up with a solution to this problem. Couples set up their card tables in the doorway of the lady’s room, with the lady sitting on the inside, where she had access to the hot plate on which the dinner was cooking, and the man in the hallway outside the room. Stanley reported, “If Dr. Hasseltine had expected that his restrictions would diminish the popularity of sexual congress within the confines of the barbed wire, he must have been disappointed. Before his five year term was up, the patients were calling him ‘Grandpappy.’ Probably more children were born during his regime than during any similar period in the history of Carville.”¹⁷⁸

¹⁷⁸ Stein, *Alone No Longer*, 171.

Dr. Edward M. Gordon, who was MOC from 1953 to 1956, attempted to make more substantive changes. According to Gussow, "What the PHS officials intended was to reshape Carville into a formal communicable disease facility. They had two objectives: (1) to dismantle the community structure that had developed within the colony at the leprosarium, and (2) to invoke a harder line on contagion."¹⁷⁹ The PHS decided to discharge patients for whom, in the opinion of their doctors, continued hospitalization was not justified. This included patients who were bacteriologically negative and were able-bodied or partially disabled. Patients who were permanently disabled because they were blind or severely handicapped could leave if they had family or friends who would care for them, but PHS would not force them to leave. Starting in 1954, able-bodied patients were asked to leave. Johnny Harmon was one of the patients forced to leave Carville. Though he was negative for the bacillus, his wife, Anne, was not and he wanted to stay at Carville until Anne could leave with him. Johnny tried unsuccessfully to convince Dr. Gordon to let him stay at Carville. He moved to Vacherie, Louisiana where his children lived and set up Harmon's Photo Shop. He went to Carville, fifty miles from Vacherie, every weekend to visit Anne.¹⁸⁰

To further disrupt the community life Carville patients had developed, Gordon announced that patients who were dischargeable would not be able to hold either government jobs or jobs with any of the private enterprises that had been formed. To reflect the new administration's harder line on contagion, Gordon banned all activities with non-patients, such as golf outings, baseball games and dances. While these changes were unpopular, the PHS's decision to demolish the cottages in Cottage Grove

¹⁷⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 170.

¹⁸⁰ Harmon, *King of the Microbes*, 92-94.

was the most explosive.¹⁸¹ In 1947, the federal government had promised to provide funds to build new cottages, as many of the existing cottages were in need of repairs. In 1953, PHS began to discuss buying the cottages from their owners. The owners assumed that they would continue to live in the cottages even after the titles passed to PHS. When the chief of the division of hospitals for the PHS, Dr. C.K. Himmelsbach, testified before Congress in July, 1956, he stated the cottages, “‘have helped to preserve family relationships.’”¹⁸² But in August, 1956, he told Carville patients the cottages would be demolished and the patients who had lived in the cottages would be moved to apartments with no kitchens. According to Fairchild, while Carville patients were unhappy with all of the changes, their focus was on the loss of their kitchens, which Fairchild said, “...lay at the heart of a conception of what we might call ‘domestic’ citizenship and the achievement of ‘everyday’ rights that made Carville livable on a day-to-day basis: the freedom to make decisions about when to eat, what to eat, what to wear, which movies to watch, where to live.”¹⁸³

Carville patients hired a lawyer in 1956 and contacted their Congressman, Otto E. Passman. Passman sided with the residents in the dispute, and in September, 1956, Gordon stepped down as MOC at Carville. In 1957, the government purchased the cottages in Cottage Grove from the patients who owned them. Between 1957 and 1960 all of the cottages but one was demolished and ten new brick cottages were constructed along with twelve “plush housekeeping apartments.”¹⁸⁴ Stanley Stein’s beloved Wit’s End was demolished along with the other cottages. However, he was offered and

¹⁸¹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 172.

¹⁸² Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 173.

¹⁸³ Fairchild, “Leprosy, Domesticity and Patient Protest,” 1026.

¹⁸⁴ Fairchild, “Leprosy, Domesticity and Patient Protest,” 1028.

accepted the chance to live in Chateau Simon, the only cottage that was to remain standing.

Living at Carville did not mean that leprosy patients were no longer subject to being stigmatized for their disease. Carville regulations included requirements that the patients found insulting. Patients were prohibited from eating in the staff dining room. All mail going out of Carville was heated to “disinfect” it and often got burnt. Until 1946, Carville patients could not vote in state or federal elections. The Carville staff sometimes added to the stigma. Stanley Stein told a story about when a Carville resident handed a staff doctor a \$100.00 bill to make change, the doctor asked the resident to drop the bill into a beaker of alcohol, telling a visitor, “that’s how we protect ourselves from these people.” When the doctor handed him back some bills, the Carville resident, irked by the actions of the doctor and knowing the doctor had an active case of tuberculosis, asked the doctor to drop the bills in the alcohol, looked the doctor in the eye and said, “That’s how we protect ourselves from these people.”¹⁸⁵ Patients at Carville were also offended by the fact that federal workers at Carville were given hazardous duty pay for performing their work there.

Carville patients viewed their time at Carville differently. Johnny Harmon stated “In 1935, the U.S.P.H.S. hospital was a paradisiacal haven for a HD [Hansen’s Disease] patient for there he or she could find complete rest and escape the embarrassment and ostracizing that increased in direct proportion to the disfiguring and crippling advance of Hansen’s Disease.”¹⁸⁶ Johnny’s opinion of Carville did not change over the years. Johnny later described his reluctance to leave Carville, at least partially because his wife remained behind and said he “was leaving my little paradise in the UPHS Hospital.”

¹⁸⁵ Stein, *Alone No Longer*, 64.

¹⁸⁶ Harmon, *King of the Microbes*, 24.

Betty Martin's view of Carville was more nuanced. In 1941, Betty wrote an article for the *Star* saying, "Only in America could a hospital like this be found, where the sick are treated by our government, not as the least among men, but as the best."¹⁸⁷ In July 1945, however, Betty wrote an article for the *Star* entitled, "Why Am I Not Free?" The article asked why leprosy patients were required to leave their families and homes and go to Carville, where they were encouraged to change their names, could not vote and were employed in jobs that paid much less than the prevailing wage. Betty understood that Carville could be both a refuge and a prison. She wrote of patients who had left Carville, only to return because of the prejudice they faced in the outside world. "No wonder," she wrote, "there were patients living on in Carville who had long been declared bacilli free, who lacked the strength, or the courage, to face the outer world."¹⁸⁸ Betty and Harry were determined, however, to try to live in the outside world once they were declared free of the bacillus.

D.J. was very young when he entered Carville, and his initial reaction was how clean and beautiful it was. He was amazed at the electricity, the modern bathroom fixtures and the vast selection of food served buffet style (D.J. was so overwhelmed at the food choices his first night at Carville he ate only bread and milk). Having loved growing up on a farm, he was also delighted to find that Carville has a working dairy farm with a "herd of healthy well-fed Holsteins," vegetable fields and a poultry farm."¹⁸⁹ However, on hearing from an older resident that his, "prospects of leaving were practically nil," he concluded:

¹⁸⁷ Fairchild, "Leprosy, Domesticity and Patient Protest," 1017.

¹⁸⁸ Martin, *Miracle at Carville*, 314.

¹⁸⁹ LeBeaux, *Love Me, Someone*, 63.

I was in prison for life, I thought, and my only crime was that of being sick. That wasn't fair. The place didn't look like a prison, quite the contrary, but not all prisons look like prisons.¹⁹⁰

Stanley Stein stayed at Carville for 36 years, and made it his life work to educate the world about the realities of leprosy, to overcome the stigma of leprosy, and to improve the conditions for patients at Carville. In the last chapter of his biography he described his feelings about his life with leprosy:

I have missed much in my life. More than half of it has been spent in an institution. I have for years been denied the companionship of family and friends and other blessings that go with good health. But I have gained a great deal.

My sense of values has been completely changed. What I thought was important before Carville now seems very unimportant. I feel wanted and useful. Had I not been sent to Carville, I would have gone on being just a little neighborhood druggist. I did not really want to be a druggist in the first place, and would never have become one had not my father insisted. As a boy in Texas, when I wrote paragraphs for the Boerne *Star*, I aspired to be a journalist. I probably would have settled then for editorship of the Boerne *Star*, which certainly would not have given.

It is hard to know from the limited number of letters that Edmond Landry left how he viewed his time at Carville. His granddaughter Emma Claire Manes described Edmond as a caring man whose "concern for his fellow patients seems to transcend his own inner demons, of which there were many."¹⁹¹ The demons that Manes describes were Edmond's homesickness, his difficulty in finding things to write to his family, and his physical health. With all these issues, Manes concluded that from his letters, "Edmond Landry appears as a man who has constructed a meaningful life in a meaningless environment."¹⁹² Manes does not explain her description of Carville as a "meaningless environment," but it may spring from her mother's evaluation of Edmond's stay at Carville as being unnecessary, and that leprosy was nothing. Manes described

¹⁹⁰ LeBeaux, *Love Me, Someone*, 66.

¹⁹¹ Manes, "In His Own Hand"; 5.

¹⁹² Manes, "In His Own Hand": 6.

her mother as trying to puzzle out the changing reality of leprosy, “They said it was inherited and it’s not; they said it was [highly] contagious and it’s not.”¹⁹³ Manes’ mother seemed to be trying to decipher the disease and the place it played in her life.

José was conflicted in his opinion of Carville. Because of the frequency and severity of his leprosy reactions, he understood the care offered by Carville was necessary. José was taking thalidomide to try to stop the reactions, and because thalidomide was a tightly controlled substance, he had to live at Carville while he was taking the drug. Some of José’s siblings also had leprosy, but because they were not prone to chronic reactions like José they were treated on an outpatient basis. Though he was able to leave Carville more often than patients had in the 1930s and 1940s living at Carville meant that José was away from his girlfriend, Magdalena, and his family, and this separation often led José to despair. José was also distressed about the continued stigma attached to leprosy in both the society at large and at Carville. He was upset by television host Hugh Downs’ use of the term “leper” and his obvious disgust for the disease during an interview with the leprologist Stanley Browne in February, 1970. During the same month, Johnny Cash released a song that contained the phrase, “Christ cured the lepers and the lame,” and the Smother Brothers featured a comic who mimicked a leprosy sufferer’s loss of limbs and facial disfigurement.¹⁹⁴ In addition, the “separate but equal” principle applied to the patients and staff at Carville, angered José. On the last Sunday of February, 1970, he rebelled against the practice of having patients sit on one side of the Catholic church at Carville and the staff and Sisters of Charity on the other, and the use of separate chalices for communion. José sat on the staff side of the church and drank the communion wine from the staff chalice. While nobody stopped

¹⁹³ Manes, “Letters from Carville.” 71.

¹⁹⁴ Ramirez, *Squint*, 129.

him, when he exited the church through the patient's side, he exited to silence rather than the usual after church greetings. A month later José was given a clear message by Darryl Broussard, a fellow patient who José looked upon as a second father, that such behavior was not looked on favorably.¹⁹⁵ José's attitude about Carville appears to have mellowed over the years. In the frequently asked questions section of his book, which was published in 2009, he included the question, "How do ex-residents remember Carville?" His answer to this question? "Fondly."¹⁹⁶

¹⁹⁵ Ramirez, *Squint*, 130-132.

¹⁹⁶ Ramirez, *Squint*, 212.

Chapter Seven - Leaving Carville

At the end of *Miracle at Carville*, Betty wrote of leaving Carville:

Harry, his eyes ahead, turned the car down the river road. And with spring in the air and springtime in our hearts we drove on our unknown way, knowing the road ahead would be rocky and long before we reached at last the place of our own we had talked and planned and dreamed about through the twenty lost years that could never be lost, that would always be a part of us.¹⁹⁷

Though this description is one of guarded optimism, Betty's second book, *No One Must Ever Know*, published in 1959, was much darker in tone. It was Betty Martin's second book, which described her and Harry's life after leaving Carville, that gave me the idea for the theme of this thesis. I was struck by the difficulty Betty and Harry had putting together a reasonably secure life and was especially struck by Betty's fear that someone would find out she or Harry had leprosy. Stanley Stein said that this book described the, "great feeling of fear and insecurity" leprosy patients experienced outside of Carville.¹⁹⁸ Betty's fear also dramatically exemplified Goffman's concept of a person being "discreditable," that the person assumes that his or her stigmatizing attribute is not known or immediately perceivable by others. The discreditable person is concerned with managing the information about his or her stigmatizing attribute. Both Betty and Harry spent much energy ensuring no one but the "wise," their family and few friends who knew they had leprosy, would find out about their past and their disease. Betty and Harry believed Harry could not tell potential employers about his background because it would mean he would not be considered for any positions. This put Harry in the awkward position of having to explain where he had been for the 20 years he was in Carville.

¹⁹⁷ Martin, *Miracle at Carville*, 358.

¹⁹⁸ Stein, *Alone No Longer*, 329.

Even if he was offered a job, many companies required new hires to have physical exams. Harry did succeed in obtaining jobs, but mostly they were low paying jobs that required strenuous physical labor, which was hard on Harry because leprosy had weakened his hands. And there was always the fear his employer might find out about his background and fire him.

Even under this veil of fear, Betty and Harry began to try to build a life outside of Carville. In the decades they were in Carville, Betty wrote, she and Harry had “lived in the comfortable protective custody of Carville.”¹⁹⁹ Outside of Carville, they faced reality. They were able to fulfill their dream of buying a travel trailer, but the trailer was so poorly designed that it endangered their lives each time Betty and Harry took it on the road. The trailer also had inadequate heat and the roof leaked. They settled for a while in a trailer park in North Carolina, where Harry found a job selling household goods door to door, but carrying the heavy suitcase filled with his wares put a strain on Harry’s hands and being out all day in the cold weather further undermined his health. Betty was reluctant to mingle with her neighbors in the park because, what if they knew? It was during their time in North Carolina that Betty began writing *Miracle at Carville*. After a few months in North Carolina, they sold the faulty trailer, bought a smaller but more reliable model, and moved back to New Orleans, where they stayed in a trailer park close to their families. Their plan was that Betty would finish her book there, and they would move on to California. Betty did finish her book and sent the manuscript to friends who said they would help her get it published. They waited over a year in New Orleans with no contract to publish the book, when Betty took matters into her own hands and brought the manuscript to Father Edward Murphy, a Josephite priest and author. Father

¹⁹⁹ Betty Martin, *No One Must Ever Know*, with the assistance of Evelyn Wells, 1959, 18.

Murphy recommended that Betty bring the manuscript to Tess Crager, who represented Doubleday in New Orleans. Tess told Betty to go to California; that she would do the best she could to get Betty's book published.

Betty and Harry had always dreamed of moving to the American west, and owning a home. While in Carville, Betty wrote a poem, "Yearning" one stanza of which described her yearning for a home of her own:

I want a site with trees and stream-
Near some majestic mountain scene-
On which to build a little home;
A place to call my very own.²⁰⁰

The poem was published in a Christmas folder by the American Leprosy Foundation.

Betty and Harry headed to California. One of the reasons they moved to California, thousands of miles away from their families in Louisiana, was because they thought they were less likely to meet people who would recognize them as Carville alumni.

Betty and Harry fell in love with California at first sight. They parked their trailer in a park in Southern California, and were mesmerized by the abundance of fresh fruit and vegetables. Betty got the good news that her book was to be published shortly after they arrived in California. But Harry had trouble finding a job. Jobs were scarce in California at the time, and Harry's lack of local references and the twenty year gap in his resume made job hunting even more difficult. Eventually Harry did get an arduous and low paying job delivering packages. The income from this job and the royalties from the publication of Betty's book created a more stable financial existence for Betty and Harry. But the publication of the book was a mixed blessing. The book was published under the name of Betty Martin, and Harry and Betty were living under their real names, Henry

²⁰⁰ Martin, *Miracle at Carville*, 321.

and Edwina Meyer. Edwina was terrified someone would find out she was the author, Betty Martin. She did not attend an award banquet celebrating the book winning a Christopher award (her editor, Evelyn Wells, attended in her place). She developed an elaborate mailing system to answer letters from readers whereby the letters were sent to a friend who “knew,” who in turn sent them to Betty. When Betty responded the process was reversed. Betty and Harry were even careful not to display a copy of the book in their home.

Their fear other people might “find out” also caused them to isolate themselves and turn down invitations to parties and other social gatherings from neighbors. Being very lonely, twice they made a leap of faith and told two couples to whom they were particularly close about their backgrounds. Neither couple changed their opinion of Harry or Betty. Even when they had decided to settle in California, they continued to live in the trailer, though it was Betty’s dream to own a home. For some time Harry’s fear of being found out kept them from purchasing a home. Betty wrote that Harry would argue:

It would be foolish for people in our position to buy a house even if we had the money. What if we did buy and someone found out about us and we had to move? With a trailer we can hitch up and drive away if there is any trouble. We can always get rid of a trailer on short notice. You can’t get rid of a house overnight.²⁰¹

Finally, they took another leap of faith, and, using the Christopher award money as a down payment, they bought a small house in Lemon Grove, California.

Sometime in the mid to late 1950s, Betty again tested positive for the leprosy bacillus, and spent five months at Carville so she could develop a tolerance for a new drug, diasone. This drug was very toxic, but unlike promin, which had allowed both

²⁰¹ Martin, *No One Must Ever Know*, 154.

Betty and Harry to leave Carville, diasone could be taken by mouth instead of requiring intravenous administration. While at Carville, Betty saw that many of her former Carville friends were living openly as ex-Carville patients and were able to get good jobs and live a normal life without experiencing either “injustice or shame.”²⁰² Even though Betty did fight her fear and report her leprosy to the California Department of Health and find a doctor in California to treat her after her return from Carville, she and Harry were not able to overcome their fear and live openly as leprosy patients. At the end of *No One Must Ever Know*, Betty wrote:

The lifting of the stigma is a slow process, and it has begun too late to help Harry and me. We are nearing the half-century mark, Harry and I. In all we have spent thirty years in hiding.
'Come into the open! Admit who you are! Face this threat to your peace of mind.'

We are still urged in these terms. We cannot. We have suffered too long in loneliness and in fear. The truth is that our fear of stigma has grown instead of lessened, because we now have more to lose if we are exposed.²⁰³

Harry and Betty lived in California until 1990, when they moved back to Carville.

Harry died in 1996, and Betty followed him in 2002. It is hard to know if their fear of being discovered lasted for the remainder of their lives. There is some evidence that Betty's fear may have diminished. A *People* magazine article from 1999, contained quotes from Harry's brother, using his real name, Hirsch Meyer. However Hirsch's quote lends credence to the idea that the fear may have remained. “They were happy in their own way..., But their secret past remained a heavy burden. That's why they traveled so much, so they didn't have to explain.”²⁰⁴ Betty is identified by her real name, Edwina Meyer, in a memorial in the newsletter for the International Association for Integration,

²⁰² Martin, *No One Must Ever Know*, 200.

²⁰³ Martin, *No One Must Ever Know*, 230-231.

²⁰⁴ Rogers, Patrick, “Cast Away,” *People*, 51, no. 19, (May 24, 1999), <http://www.people.com/people/archive/article/0,,20128323,11.html> (accessed October 1, 2011).

Dignity and Economic Advancement (IDEA) published shortly after her death.²⁰⁵

Though this newsletter was likely to have only limited circulation, Tony Gould's mass market book, *A Disease Apart*, published in 2005, included the same picture of Betty that appeared in the IDEA newsletter, and identified her as Edwina Meyer. Since the author had met Betty, it is unlikely that he would have identified her in that way if she had requested that he not do so.

D.J. also was afraid to tell potential employers about his time in Carville, and gave potential employers fictitious references. In May, 1951, he found a job in a supermarket in Lake Charles, Louisiana. However, a few days after he met a former Carville groundskeeper at a filling station, he was fired from his job without explanation. After this, D.J. and his wife decided to move to San Antonio, where they were less likely to meet acquaintances from Carville. The move to San Antonio was successful, and D.J., despite having health problems that required him to return to Carville every six months and have a kidney transplant, was able to work and own a home.

Johnny Harmon, on the other hand, made no effort to conceal his status as a former Carville patient when he left Carville. This may be because he moved to Vacherie, Louisiana, a small town where his wife's, family had lived and where his children then lived. He wrote of his experience trying to rent a house:

In a small town like Vacherie, 'grapevine' news and gossip travels at Mach I. My wife and her family had lived in Vacherie most of their lives and now our children were living there so I feel sure Mr. Becnel must have known some of my story already. Never-the-less, I explained the situation to him and told him about my stay in Carville and that I would like to rent the little house.²⁰⁶

²⁰⁵ International Association for Integration, Dignity and Economic Advancement (*IDEA*): *A Pathway of Hope*, 7, no. 2, 11, <http://www.idealeprosydignity.org/newsletter/vol7-12/NewsLetterV7N2.pdf> (accessed October 1, 2011).

²⁰⁶ Harmon, *King of the Microbes*, 94.

Johnny self-published his memoir under his real name, "Johnny Harmon" and participated in a PBS show about Carville entitled *Triumph at Carville*. Johnny owned Harmon's photo shop and worked as a photographer until his retirement in 1974. Johnny and Anne moved back to Carville on March 15, 1993 because of declining health.

Johnny's memoir and Betty's book, *No One Must Ever Know* had very different tones, with Johnny's book being much more upbeat. This could have been a function of their personalities, but it also could have been a function of when the books were written. Johnny's book was finished in 1995, when he was 84. Therefore he had the prospective of looking back on his life, of knowing that his life had turned out ok. In 1959, when Betty's book was published, she was in her early fifties and she and Harry were still in the process of building their lives together. Betty could not know that she and Harry would live another thirty-seven and forty-three years respectively, years that were relatively secure. Also, in 1959 attitudes about leprosy in the U.S. may have begun to change. In a 1972 article entitled "The Phenomenon of Leprosy Stigma in the Continental United States," Gussow and Tracy reviewed studies on leprosy stigma from 1955 to 1971. One of their conclusions was that there was a "generational lag" in attitudes to leprosy. The traditional view of leprosy, stated Gussow and Tracy, was that, "leprosy is stigmatized and that patients should be protected and second, that leprosy could develop epidemic proportions especially in 'fresh' populations."²⁰⁷ "Many leprosy workers and the older members of the public" they said expressed this traditional sentiment. Young people, they wrote:

²⁰⁷ Z. Gussow and G.S. Tracy, "The Phenomenon of Leprosy Stigma in the Continental United States," *Leprosy Review*, 1972, 43, 92-93.

...who tend to be better educated seem to be more open and neutral about many things, including leprosy. This statement is buttressed by noting that a young patient from the United State Public Health Service Hospital at Carville who was known to be from there, secured a degree in sociology at Louisiana State University and in his senior year was president of the Sociology Club. He was also instrumental in organizing several trips to the hospital.²⁰⁸

The young patient Gussow and Tracy referred to was José Ramirez.

José's experience in leaving Carville was very different from Betty's, D.J.'s or Johnny's. José had not been confined to Carville as the others had. He had attended college, gotten married to Magdalena, and even taken a job in Houston all with the knowledge of the Carville authorities, while listed as a Carville patient. He was formally discharged on August 31, 1977, but could have been discharged much earlier if he had not been prone to leprosy reactions, which were treated with thalidomide, a controlled substance whose use required physician supervision. José and Magdalena both became social workers and had two children, J.R. born in 1979 and Erika born in 1984. José became an advocate for Hansen's disease patients around the world.

²⁰⁸ Gussow and Tracy, "The Phenomenon of Leprosy Stigma in the Continental United States," 93.

Chapter Eight - Closing Carville

The number of patients at Carville was never high, topping out at about 400.²⁰⁹ The success of sulfone drugs to treat leprosy and the opening of outpatient clinics meant the population of Carville decreased. However, some leprosy patients who had been sent to Carville before effective treatment was available, and others who had left but returned for treatment in their old age, did not want to or could not leave Carville. In 1985, the U.S. Marine Hospital 66, was renamed the Gillis W. Long Hansen's Disease Center.²¹⁰ In 1990, the federal government leased part of the institution to the Federal Bureau of Prisons. Less than 2 months after Johnny Harmon and his wife, Anne, moved back to Carville, Neil White, who was convicted for bank fraud, stepped into Carville as a federal prisoner. About 130 leprosy patients still lived at Carville at the time.²¹¹ Though the prisoners were not allowed to fraternize with the leprosy patients, White was able to get to know several patients because he was given a job of working in the cafeteria from 4 a.m. to 1 p.m. One of his duties was to write the daily menu on a white board in the patient's cafeteria, which was separated by a lattice wall from the prisoner's cafeteria.²¹² In the early morning, before anyone was eating breakfast, he could talk to some of the leprosy patients. During his incarceration at Carville, which lasted slightly less than a year, he met Johnny Harmon, who he referred to by his Carville name of Jimmy Harris, and several other patients. In 1994, the federal prison was closed. Given the small number of patients left in Carville, the federal government looked for ways to either close the facility or find other uses for it.

²⁰⁹ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 157.

²¹⁰ Gould, *A Disease Apart*, 375.

²¹¹ Neil White, *In the Sanctuary of Outcasts*, (New York, HarperCollins, 2009), 9.

²¹² White, *In the Sanctuary of Outcasts*, 29.

On March 11, 1999, the Carville Patients Federation and IDEA sponsored an “International Day of Dignity and Respect” to draw attention to federal legislation that would require leprosy patients left at Carville to move to a different facility. José was one of the leaders of the event. Several days after the event, the federal government announced that patients at Carville would have three choices, remain at Carville as long as they wanted, move into an assisted living facility in Baton Rouge, known as “Summit Hospital” or receive an annual tax-free stipend of \$33,000 and free medical care for their disease for life. After his wife Anne’s death in 1999, Johnny Harmon fell and fractured his hip and moved from Carville to Summit Hospital, where he later died.²¹³ Betty Martin died in Summit Hospital in 2002.²¹⁴

In April, 1999, the deed to Carville passed back to the State of Louisiana, which turned it into a quasi-military camp for at risk youth. In 1999, fifty-eight patients elected to remain at Carville, by 2001, this number had been reduced to thirty-eight.²¹⁵ By March, 2007, only sixteen elderly patients remained at Carville.²¹⁶

²¹³ Harmon, *King of the Microbe*, Addendum 3, 2001, 1.

²¹⁴ Gould, *A Disease Apart*, 377.

²¹⁵ Gould, *A Disease Apart*, 377.

²¹⁶ José Ramirez, Jr. “A Day at Carville: My Home-Mi Casa,” *Public Health Reports* 123 (March – April 2008), 224. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2239333/pdf/phr123000222.pdf> (accessed March 24, 2012).

Conclusion

When friends asked me what my thesis topic was, I told them I my topic was leprosy in the twentieth century United States. Almost to a person they responded, “We have leprosy in the United States?” While leprosy may not be on the minds of the majority of Americans, the words “leprosy” and “leper” have not lost their power, even at the beginning of the twenty-first century. A couple of years ago, while driving in my St. Paul neighborhood, I saw a billboard that said, “Ever had Leprosy? Thanks to animal research you won’t.” The billboard listed a website ResearchSaves.org. This website, which promotes the benefits of animal research, identifies its sponsors as the Foundation for Biomedical Research and the National Association for Biomedical Research. Though the banner on the organization’s website references other diseases such as malaria and rabies, I believe that the billboard referenced leprosy because of the evocative power of the disease. In a debate between the democratic contenders for the nomination for president in 2008, Bill Richardson, former governor of New Mexico, decrying the fact that his experience in government was viewed by some as a liability rather than an advantage, asked, “Is experience a leper?”

The most compelling example I found of the power of leprosy in early twenty-first century America was a controversy surrounding Lou Dobbs, the host of the CNN program *Lou Dobbs Tonight*. In a show that aired on April 14, 2005, Dobbs included a segment on public health and illegal aliens. The segment included discussion of tuberculosis and malaria as well as leprosy, but it was a statement by Madeleine Cosman, who was identified as a “medical lawyer” that became controversial. According to the report, Dr. Cosman, who held a Ph.D. and was a lawyer, but not a medical doctor, told reporter Christine Romans, “... there were about 900 cases of leprosy for 40 years.

There have been 7,000 in the past three years. Leprosy in this country.”²¹⁷ This show did not create controversy until Leslie Stahl brought up this statement in a May 6, 2007 interview with Lou Dobbs on the news program *60 Minutes*, saying that there was no evidence to support this statement.²¹⁸ The next night on *Lou Dobbs Tonight*, Dobbs defended his use of this statistic, reiterating that the information came from an article Dr. Cosman had published in the Spring, 2005 edition of the *Journal of American Physicians and Surgeons*. The theme of this article, entitled “Illegal Aliens and American Medicine,” was that “The influx of illegal aliens has serious medical consequences.”²¹⁹ The four page article contained one paragraph on leprosy which stated:

Leprosy, a scourge in Biblical days and in medieval Europe, so horribly destroys flesh and faces it was called the “disease of the soul.” Lepers quarantined in leprosaria sounded noisemakers when they ventured out to warn people to stay far away. Leprosy, Hansen’s disease, was so rare in America that in 40 years only 900 people were afflicted. Suddenly in the past three years America has more than 7,000 cases of leprosy. Leprosy is now endemic to northeastern states because of illegal aliens and other immigrants brought leprosy from India, Brazil, the Caribbean, and Mexico.²²⁰

The 7,000 cases statistic came from a 2003 *New York Times* article written by Sharon Lerner entitled, “Leprosy, a Synonym for a Stigma, Returns.” This article, which said that the “infection has actually been on the rise in the United States,” stated:

While there were some 900 recorded cases in the United States 40 years ago, today more than 7,000 people have leprosy, or Hansen’s disease, as it is now called. “And those are the ones we know about,” said Dr. William Levis,

²¹⁷ Christine Romans, interview by Lou Dobbs, *Lou Dobbs Tonight*, CNN, April 14, 2005. <http://transcripts.cnn.com/TRANSCRIPTS/0504/14/ldt.01.html> (accessed October 15, 2011).

²¹⁸ David Leonhart, “Truth, Fiction and Lou Dobbs,” *New York Times* May 30 200., <http://www.nytimes.com/2007/05/30/business/30leonhardt.html?pagewanted=all> (accessed October 15, 2011).

²¹⁹ Madeleine Peiner Cosman, Ph.D, Esq., “Illegal Aliens and American Medicine,” *Journal of American Physician and Surgeons*, 10, no. 1, 6.

²²⁰ Cosman, “Illegal Aliens and American Medicine,” 8.

attending physician at Bellevue Hospital's Hansen's Disease Clinic. "There are probably many, many more."²²¹

In the May, 2007, show, Dobbs commented on the statistic, saying, "It's remarkable that this – whatever confusion, or confoundment over 7,000 cases, they actually keep a registry of cases of leprosy. And the fact that it rose was because - one assumes – because we don't know for sure – but two basic influences – unscreened illegal immigrants coming into this country primarily from South Asia, and secondly, far better reporting."²²²

Two things struck me about this controversy. First, the tying of fear of leprosy to immigration from non-Caucasian countries echoes the fears about leprosy from the late 1800s and early 1900s – the fear that eventually led the federal government to buy the Louisiana Leper Home from the state of Louisiana and to create Marine Hospital 66. Gussow, in *Leprosy, Racism and Public Health*, said that at the turn of the twentieth century, "The idea of domestic quarantine was a hard notion to dislodge in light of the assertion that the United States was threatened on all sides by lepers gaining entry into the country undetected and in light of unsubstantiated claims as to the number already here, to say nothing of the numbers expected in the future."²²³ Over one hundred years later, the fear of the spread of leprosy is still being tied to immigration from primarily non-Caucasian countries such as Mexico and India. The use of unsupportable statistics regarding the number of known leprosy cases and the assertion that there are probably

²²¹ Sharon Lerner, "Leprosy, a Synonym for a Stigma, Returns," *New York Times*, February 18, 2003. <http://www.nytimes.com/2003/02/18/health/leprosy-a-synonym-for-a-stigma-returns.html> (accessed November 9, 2008).

²²² Lou Dobbs, *Lou Dobbs Tonight*, CNN, May 7, 2007. <http://transcripts.cnn.com/TRANSCRIPTS/0705/07/ldt.01.html> 10/15/11 (accessed October 15, 2011).

²²³ Gussow, *Leprosy, Racism, and Public Health, Social Policy in Chronic Disease Control*, 134.

many more unknown cases of leprosy in the United States, echoes exactly the arguments made for the quarantine of leprosy patients in the early twentieth century.

The second thing that struck me about these reports was that they use old biblical and medieval images of leprosy. Cosman deliberately used these images, of destroyed flesh and faces and lepers sounding noisemakers to warn of their approach, to further her argument that illegal immigrants are a danger to the public health in the U.S. Lerner, in the 2003 *New York Times* article that contained the 7,000 cases statistic, evokes these same images, saying, "...leprosy is usually regarded as a plague of the past, a disease relegated to biblical times or, perhaps, to poor and distant countries." and saying that "The disease, even with its sanitized name [Hansen's disease] can still confer pariah status on the victim."²²⁴ Though Lerner correctly states that leprosy is relatively easy to treat if diagnosed early with a multiple drug regimen and such patients are non-infective, she said the disease can be spread and the route of transmission is still not known. She does not mention that leprosy is not very infectious and generally requires prolonged exposure to be transmitted. The patients she describes were patients who were afraid to tell their friends and family of their diagnosis, or have experienced disability because of the disease. So she carried forward the old stereotypes of leprosy as deforming and a disease that patients should keep hidden.

That the issue of leprosy is used in arguments regarding immigration and old stereotypes are still evoked in newspaper articles about leprosy in the modern day, especially in a well-respected newspaper such as the *New York Times*, shows that despite the progress made in treating leprosy, and the work that Stanley Stein, José

²²⁴ Lerner, "Leprosy, a Synonym for a Stigma, Returns."

Ramirez and others have done to eliminate the stigma associated with the disease, leprosy is still, in twenty-first century America, a disease apart.

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