5-2021

Stories from Both Sides of the Hedge: A History of and Digital Exhibit for the National Hansen's Disease Museum

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Repository Citation

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Stories from Both Sides of the Hedge: A History of and Digital Exhibit for the National Hansen's Disease Museum

STORIES FROM BOTH SIDES OF THE HEDGE: A HISTORY OF AND DIGITAL EXHIBIT FOR THE NATIONAL HANSEN'S DISEASE MUSEUM

By

LAURA J. TURNER, Bachelor of Business Administration
Master of Business Administration

Presented to the Faculty of the Graduate School of

Stephen F. Austin State University

In Partial Fulfillment

Of the Requirements

For the Master of Arts Degree

STEPHEN F. AUSTIN STATE UNIVERSITY

May, 2021

STORIES FROM BOTH SIDES OF THE HEDGE: A HISTORY OF AND DIGITAL EXHIBIT FOR THE NATIONAL HANSEN'S DISEASE MUSEUM

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ABSTRACT

The national leprosarium of the United States, located in Carville, Louisiana, started as the Louisiana Leper Home in 1894. Since Louisiana contained the largest endemic population in the contiguous United States of people suffering from leprosy, or Hansen's disease as it would later be known, and maintained a successful institution dedicated to the care of such patients, the federal government purchased the leprosarium for national use in 1921. Although the national leprosarium was closed as a hospital in 1999, a small analog museum located on site preserves the history of the facility, the lives of the former patients, and tireless work of the medical staff. This thesis summarizes the history of the national leprosarium and describes museum exhibition and interpretation theory utilized during the creation of a digital exhibit for the National Hansen's Disease Museum that focuses on patient and staff life at the facility as well as the milestones in medical history that occurred at Carville.

ACKNOWLEDGEMENTS

The process of completing this thesis project was a long one and there are many people that I would like to thank for helping me see it through to the end. First, I would like to thank my family for constantly supporting me throughout this process. It is only because of their encouragement that this project is complete. I would especially like to thank my mother, Wini Turner, for travelling with me many times to the National Hansen's Disease Museum archives so I would not have to make the long drive alone. With as much as you had to hear about the topic, you could probably have written this thesis yourself.

I would also like to thank my friends and coworkers for their encouragement and guidance. I would like to thank my friends that I met in the history department during graduate school; Shelby DeWitt, Hayley Hasik, Chris Cotton, Kurt Terry, Hannah Colletti, and Jim Stingley. The gratitude that I feel for their reassurance that I was on the right track and the advice from those who had been through this process before cannot be overstated. You guys are the best.

Next, I would like to thank my professors and committee members. Thank you Dr. Perky Beisel for your patience and insight into the thesis writing process. Without

your input and direction, this thesis would never have been completed. Your passion for history and your tireless work in the name of preservation make me proud to be a part of the public history program at SFA. I hope to show the same zeal in all that I do. Thank you also to my thesis committee members, Dr. Scott Sosebee, Dr. Andrew Lannen, Dr. Chay Runnels, and Dr. Mari Nicholson-Preuss for your guidance and for taking this journey with me.

Last, but certainly not least, I would like to thank Elizabeth Schexnyder. Her willingness to work with me over the course of several years, helping me rein in and direct my project, and spend hours with me in the museum archives will never be forgotten. I hope that this project is able to provide a thank you to the National Hansen's Disease Museum, even in some small way, for all of the help it has given me.

Laura Turner
Nacogdoches, Texas
April 7, 2021

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INTRODUCTION

Leprosy is an ancient disease. It was known to Europeans as early as the tenth century and became commonplace in Louisiana decades before the territory became a part of the United States.[1] Despite the centuries of study of this dreaded disease, the care and treatment of leprosy remained largely the same until well into the twentieth century. When the Louisiana Leper Home opened in 1894 and then became the national leprosarium in 1921, the official policy in the United States for treatment included isolation from society. Even for decades after the causative bacillus discovery in 1873, two schools of thought persisted among the global medical community about the communicability of leprosy. Some doctors believed that the condition was highly contagious; therefore, many in the medical community recommended segregation from the public. Others asserted that leprosy was hereditary, rendering isolation of those infected unnecessary. Since no doctor or researcher could say with certainty how transmission of the disease occurred, isolation for patients in the United States continued well into the twentieth century.

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[1] Luke E. Demaitre, *Leprosy in Premodern Medicine: A Malady of the Whole Body* (Baltimore: The Johns Hopkins University Press, 2007), ix; Marcia Gaudet, *Carville: Remembering Leprosy in America* (Jackson: University Press of Mississippi, 2004), 7. Leprosy was reportedly present in New Orleans during both French and Spanish rule.

Initially, segregation stemmed largely from compassion.[2] Since the Middle Ages, the idea of Christian welfare had already been well established. This concept focused on “the performance of good works in the city as a proper model for the fulfillment of Christian obligation.”[3] The power and wealth of the Roman Catholic Church gave it the ability and political authority to organize shelters for the sick and needy. According to medical historian Dr. Guenter Risse “during the Middle Ages, the Church essentially owned leprosy.”[4] There was no consistent medical explanation as to its transmission or cure so society turned to the biblical understanding of the disease and how the afflicted should be managed. In addition to accomplishing their Christian duty, members of the Church were able to use the nursing of the sick as an opportunity for conversion. By medieval times, “women were already assigned to bear the major burdens of physical care” within their marriages and families and became instrumental in “the recovery of countless victims of disease.”[5] The continuation of this practice led to the creation of Christian organizations like the Daughters of Charity, who worked with the patients at the national leprosarium until their mission ended in 2005.

Isolation policies later were discovered to be essentially ineffective. Segregation served mainly to “foster distrust, fear, and panic, and thus encouraged flight,

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[2] Guenter B. Risse, *Driven by Fear: Epidemics and Isolation in San Francisco’s House of Pestilence* (Springfield, IL: University of Illinois Press, 2016), 29.
[3] Risse, *Mending Bodies, Saving Souls: A History of Hospitals* (New York: Oxford University Press, 1999), 79.
[4] Risse, *Mending Bodies, Saving Souls*, 175.
[5] Risse, *Mending Bodies, Saving Souls*, 83, 80.

concealment, and social chaos."[6] Additionally, the moral connotations of the disease heightened the stigma surrounding it even further. The many misconceptions about leprosy fed into the fear surrounding the disease. Leprosy is more than just a disease affecting the skin. The condition attacks the peripheral nervous system, causing extreme nerve pain, loss of muscle control, and, if left untreated, total loss of feeling in the extremities. Many patients' first indication of the disease was the appearance of pale, numb patches on their skin. The most common symptom, desensitized feeling, is responsible for the familiar myth that leprosy causes the loss of body parts. In actuality, individuals with no feeling in their arms and legs are unknowingly injured, which can lead to infection. Patients' pain sensors no longer function properly so infections can become so severe that the only course of action is amputation. Bone and cartilage absorption is another common side effect of the disease, causing fingers, toes, and noses to become shorter as the body reabsorbs the bone, seemingly lending more credence to the fallacy of missing limbs. The disease also impacts the eyes and nasal cavities which can lead to nose deformities and often blindness. The most well known effect of leprosy, thickened skin with protruding nodules, usually occurs once the disease is fairly progressed. Although a devastating diagnosis for much of the history of the disease, the prognosis of leprosy was not a death sentence. Patients could live decades after a diagnosis of leprosy, and rarely was the disease fatal for those infected.[7]

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[6] Risse, *Driven by Fear*, 22.

[7] "What is Hansen's Disease?," Center for Disease Control and Prevention, last modified February 10, 2017, accessed October 30, 2020, https://www.cdc.gov/leprosy/about/about.html. Claire Manes, *Out of the*

The history of the national leprosarium spans from its time as a state-run facility from 1894 to 1920 and then a federal-owned institution from 1921 to 1999. Beginning in the 1930s and 1940s there was a large patient-led movement to combat the stigma and misinformation surrounding leprosy. Patients began to fight for the rights afforded them as American citizens and used their voice to reach out to local politicians, veterans' organizations, and through their patient produced newspaper *The Star.* From this crusade came the now widely accepted name for the illness, Hansen's disease, named after Gerhard Armauer Hansen who discovered the causative bacillus. To respect the wishes of the former patients and those suffering from the disease worldwide, the name of the illness used for the remainder of this project, besides its use in direct quotes, will be Hansen's disease.

The hard work of the patients in "radiating the light of truth on Hansen's disease" and the many accomplishments of the medical staff at the national leprosarium is commemorated at the National Hansen's Disease Museum located on the site of the former institution in Carville, Louisiana. The museum, like the leprosarium it memorializes, is isolated. Many of the people who visit have a familial tie to the institution or are researchers. This thesis project, to satisfy the capstone requirement of the Master of Arts in History with a concentration in Public History degree, will focus on the creation of a digital exhibit for use by the museum that will provide additional

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Shadow of Leprosy: The Carville Letters and Stories of the Landry Family (Jackson: University Press of Mississippi, 2013), 6, 8, 33-34, 38, 97; Gaudet, *Carville,* 11-15.

research opportunities, greater context and interactive experiences for patrons, as well as providing more public access to the museum's archival collection holdings. The museum has expressed interest in providing audio files, oral history transcripts, and photographs that are typically only available to researchers who have scheduled an appointment to visit the museum's archive.

This digital exhibit project benefits the National Hansen's Disease Museum in multiple ways. The museum's existing exhibit space is at capacity and since the entire facility is now owned by the state of Louisiana and operated by the Louisiana National Guard, they are unlikely to receive additional space to expand their exhibits. A digital exhibit will take up little additional space within the museum and can regularly, more easily, and less expensively be modified and enhanced than a physical exhibit. The addition of a digital exhibit will also better utilize the museum's limited resources. The current staff at the museum consists of one full-time curator and a part-time assistant. This interactive, heavily collections driven exhibit will allow for patrons and researchers to find in depth information while staff assist other visitors elsewhere. Additionally, the cost associated with maintaining a digital exhibit, especially with many of the free or low cost options available, make it much cheaper to add and change exhibit information digitally than physically. The National Hansen's Disease Museum is also in a unique situation. The museum falls under the purview of the Department of Health and Human Services and therefore any information on its website or linked to it must be reviewed at the federal level before it can be posted. This digital exhibit will first be made available to visitors within the physical museum location on a touchscreen television in the existing museum space with plans to add it to the website for those interested in the museum to view, pending governmental approval.

This capstone thesis project contains three chapters related to the history of the national leprosarium and the creation of the digital exhibit. Chapter One is an overview of the facility's history from its inception through 1921, when the institution was purchased by the federal government. This chapter also discusses the United States' history on public health and isolation policies for quarantinable diseases. Chapter Two focuses on institutional history while the hospital was known as the national leprosarium. Both of these chapters also discuss the broader national historical narratives that impacted the creation and management of the leprosarium. Chapter Three considers theories on online and digital exhibits and delineates the process utilized in creating the exhibit. Lastly, the Appendix provides drawings, photographs, and documents used to further contextualize the institution's history, many of which are also in the final exhibit.

The importance of this thesis project cannot be understated. The National Hansen's Disease Museum is like so many small, underfunded and understaffed museums with incredible stories and history to tell. The digital era has allowed information to become so much more widely and cost effectively disseminated around the globe in a way never previously possible. Accounts of the patients and staff at the national leprosarium no longer need to be hidden away like they were for the century that the institution was in operation. The messages that the hospital holds carry even more weight today as not only our nation but the world is gripped by the fear of another disease, COVID-19. As historians begin to focus more and more on “history from below,” “it seems worthwhile to lift the anonymity that has hung over people with leprosy as a result not only of stigma but also of history’s ‘blind spot.’”[8]

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[8] Demaitre, *Leprosy in Premodern Medicine*, x.

CHAPTER 1

The Louisiana Leper Home: 1894-1921

“Welcome to a community unlike any other in the world.”[9] This is the opening statement on the plaque at the entrance to the National Hansen’s Disease Museum in Carville, Louisiana. The national leprosarium, called simply Carville by many, was a unique institution. The patients housed within its walls were often held there against their will; victims of a society that did not understand the disease which afflicted them, known then as leprosy. The constant fear of discovery led many “lepers” to admit themselves voluntarily into the leprosarium, however, in doing so these patients gave up many of the freedoms they had enjoyed outside the walls of the institution. Some patients never again experienced the independence they once knew when they were unencumbered with this dreaded ailment. Despite their circumstances, patients at Carville created a community with its own culture and traditions. They strove to maintain a sense of normalcy and fought against policies instituted by those who saw them as inferior. The following chapters focus on the history and evolution of the national leprosarium and the people who lived and worked there, as well as how the facility fits into the larger national historical narrative.

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[9] Marcia Gaudet, *Carville: Remembering Leprosy in America* (Jackson: University Press of Mississippi, 2004), 189.

The history of Hansen's disease (HD) in Louisiana is lengthy. Historians credit European settlers with the disease's first occurrence in North America.[10] Reports of the disease in Louisiana began as early as the 1700s and by the late nineteenth century, southern Louisiana was home to the highest rates of reported cases of what was then known as leprosy.[11] In the 1890s New Orleans *Daily Picayune* journalist John Smith Kendall began to write articles about the local New Orleans "pest-house," a run-down home where people diagnosed with HD were confined by doctor's orders. The patients had little medical attention, as there was no effective treatment for the disease at that time. Kendall's articles prompted a movement to remove the "lepers" from the city. Some citizens, such as local dermatologist Dr. Isadore Dyer, were concerned for the well-being of these patients, as the home was in a great state of disrepair. Others feared the spread of the disease.[12] In September 1894 the Louisiana State Legislature passed "An Act to Provide for the Appointment of a Board of Control for the Leper Home, and to provide for the care and treatment of persons so afflicted with leprosy."[13] The Board of Control for the Louisiana Leper Home oversaw the removal of these patients from New Orleans. The state awarded the Board a budget of $5,000 for building improvements

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[10] J. R. Trautman, "A Brief History of Hansen's Disease," *Bulletin of the New York Academy of Medicine* 60, no 7 (September 1984): 693, accessed June 15, 2019, https://www-ncbi-nlm-nih-gov.steenproxy.sfasu.edu/pmc/articles/PMC1911721/?page=1.

[11] Gaudet, *Carville*, 2, 7. The disease is believed to have been brought to Louisiana from Acadian French immigrants.

[12] Isadore Dyer, "The History of the Louisiana Leper Home," 717-719, Carville Rules and Regulation file, *Legislative History of Leprosy*, The National Hansen's Disease Museum and Archives (hereafter Hansen's Museum), Carville, LA.

[13] "An Act, No 80," Carville Rules and Regulations file, Legislative History of Leprosy Collection, Hansen's Museum.

when a facility was acquired as well as an annual budget of $10,000. The Board also handled arrangements to employ a physician with adequate knowledge of the disease to care for these patients.[14]

Thus, the search for an official residence for HD patients in Louisiana began. Dr. Dyer, then the first president of the Board of Control, found the solution in an over three-hundred acre abandoned sugar plantation formerly known by locals as Indian Camp (Figure 1). The property is remote, even today, and is located on the Mississippi River outside of a small community, later named Carville, in Iberville Parish, about twenty miles south of Baton Rouge.[15] Finding an isolated location was the goal. When the Board leased the property, it claimed the land would be used as an ostrich farm to avoid any resistance from locals. On November 30, 1894, seven patients, five men and two women, travelled from New Orleans by way of coal barge up the Mississippi River to the plantation under cover of night.[16] An article published in *The Daily Picayune* detailed the arrival of the patients to their new home. Despite the home's state of disrepair, the author describes the main house as "a grand sight."[17] Even in its current state, the white Greek

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[14] Dyer, "The History of the Louisiana Leper Home," 716.

[15] U.S. Department of Health and Human Services: Health Resources and Service Administration, "History of the Hansen's Disease (Leprosy) Program," accessed April 7, 2016, http://www.hrsa.gov/hansensdisease/pdfs/faq.pdf. The town was originally named Island, Louisiana however there were constant mail mix-ups due to the fact that there are multiple Louisiana towns with Island in the name. The town was renamed Carville in 1909 after the local postmaster, Louis Carville, grandfather to well-known political analyst James Carville.

[16] John Parascandola, "PHS Chronicles: The Gillis W. Long Hansen's Disease Center at Carville," *Public Health Reports* 109 (1994): 728, accessed October 1, 2016, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1403572/?page=3.

[17] "The Leper Board Begins Its Work," in *Known simply to the rest of the world as Carville…100 Years,* ed. Julia Rivera Elwood (N.p.: Department of Health and Human Services, 1994), 27.

Revival plantation house complete with "decorative cornice moldings, a sweeping cross hall, and Palladian-style hyphenated wings" bespoke its previous grandeur (Figure 2).[18] As was the case of many antebellum homes, the site was abandoned around 1890 and the Board of Control determined the main house to be uninhabitable. The patients were forced to take up residence in the former slave quarters (Figure 3).

The Board of Control assigned local doctor L. A. Wailes to visit the plantation weekly. However, the property was less than ideal as a care facility according to correspondence between Dr. Wailes and the Board of Control. There was no running water so patients were unable to bathe regularly and the proximity to the Mississippi River meant the area was prone to flooding, which could bring further disease to the patients.[19] It became apparent that relying solely on weekly visits from a physician would not be sufficient, so in 1896 Dr. Dyer reached an agreement with the Daughters of Charity of St. Vincent de Paul to assist in caring for the HD patients, whose numbers had grown to more than thirty. Initially, four Daughters of Charity arrived at the leper home from New Orleans in April 1896, joined by many more from their home base in Emmitsburg, Maryland in the following years. The Daughters of Charity were already well-known in the New Orleans medical community, working in the local Charity

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[18] Sally K. and William D. Reeves, "Carville-One Hundred Years of Public Health," in *Known simply to the rest of the world as Carville…100 Years*, ed. Julia Rivera Elwood, 30-31.
[19] Michelle T. Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States* (Chapel Hill: University of North Carolina Press, 2007), 77, accessed February 1, 2016, http://web.b.ebscohost.com/ehost/ebookviewer/ebook?sid=604b933d-2f2e-487b-8848-36e3d962147d%40sessionmgr114&vid=0&hid=118&format=EB.

Hospital and the Poydras Asylum.[20] The Sisters agreed to handle nursing, administrative, and domestic duties for the patients and would receive no salary for doing so.[21]

Upon their arrival, the Sisters found that the plantation home "walls oozed moisture; the roof admitted torrents of rain, broken floors furnished shelter to rats, while long unused attics and rooms were veritable havens for bats and snakes."[22] They converted the only two useable rooms in the old plantation home into a dormitory, refectory, and community room for their use. The patients inhabited four slave cabins, two for men and two for women, and one cabin was used as a kitchen. Although the grounds were expansive, the patients were only allowed a twenty-two acre living area that was enclosed by an eight-foot high fence.[23] Sister Beatrice Hart, one of the original four Sisters to work at the Leper Home, stated "it was touching to see the happiness of these poor people when they caught sight of the Sisters. They almost wept for joy."[24] A year after the Sisters began their work at Carville, the patient census had risen to thirty-five. (Figures 4 & 5)

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[20] Reagan Laiche, "The Daughters of Charity: From New Orleans to Carville," *New Orleans Historical*, accessed September 17, 2019, https://neworleanshistorical.org/items/show/1280. The Order of the Sisters of Charity in the United States was founded after the French order of Vincent DePaul who organized young peasant women to care for the sick and poor during the seventeenth century. The Sisters served as nurses during the U.S. Civil War and the Spanish-American War as well as during times of peace. In 1850 the Sisters of Charity merged with the Daughters of Charity. Joy J. Jackson, *New Orleans in the Gilded Age: Politics and Urban Progress, 1880-1896* (Baton Rouge: Louisiana State University Press, 1969), 187.
[21] Dyer, "The History of the Louisiana Leper Home," 719-720.
[22] "Excerpts of letters written by the first four Sisters to their Superiors in Emmetsburg, Maryland," 35, Sr. Hilary Ross Carville History file, Daughters of Charity of St. Vincent de Paul Collection, Hansen's Museum.
[23] "How They Came to Carville," *With Love in their Hearts: The Daughters of St. Vincent de Paul, 1896-1996,* 20, Daughters of Charity of St. Vincent de Paul Collection, Hansen's Museum.
[24] "Sister Beatrice Hart: The Saintly Pioneer," *With Love in their Hearts,* 37, Daughters of Charity of St. Vincent de Paul Collection, Hansen's Museum.

Although Hansen’s disease had been prevalent in Louisiana for decades at this point, it was just beginning to gain national attention. In 1899, Congress tasked the Surgeon General of the Marine Hospital Service to appoint a commission to survey the extent of the disease in the United States and report on what would be necessary to prevent its spread.[25] The National Quarantine Act of 1878 and the renewal of the act in 1883 gave the Marine Hospital Service authority over quarantine for communicable diseases.[26] The investigation was extensive, lasting from 1899 to 1902, and resulted in over 10,000 letters issued to public health officials in every state to determine the known diagnoses across the nation. The commission submitted its report to the Secretary of the Treasury in 1902, since the Marine Hospital Service fell underneath the direction of the Department of the Treasury at that time.[27] The recommendations included “the establishment of at least one, preferably two, national leprosaria for the care and treatment of these unfortunate people, to be maintained by and under the supervision of the General Government” and that the leprosaria be on “sites covering broad areas in healthful localities…in order to make their retreat a comfortable home rather than a miserable place of confinement.” The committee suggested ideal locations for the

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[25] An Act for the Investigation of Leprosy, Chap. 349, 55th Cong., 3rd sess. (March 2, 1899), http://www.loc.gov/law/help/statutes-at-large/55th-congress/session-3/c55s3ch349.pdf.

[26] W. G. Smillie, “The National Board of Health, 1879-1883,” *American Journal of Public Health and the Nation’s Health* 33, no 8 (August 1943): 925, 930. The creation of marine hospitals follows the medieval tradition of lazarettos. Venice established the first public lazaretto in 1423, where foreign traders and their goods were quarantined to lessen disease spreading through the city. Guenter B. Risse, *Mending Bodies, Saving Souls: A History of Hospitals* (New York: Oxford University Press, 1999), 202.

[27] “Department of the Treasury,” U.S. Department of the Treasury, accessed September 21, 2019, https://www.treasury.gov/about/education/Documents/brochure%20(1).pdf.

leprosaria as being "(1) the arid Southwest; (2) similar regions farther north; (3) an island in the Gulf of Mexico, or an island near the Pacific coast of the United States."[28]

As the federal government discussed how best to handle the problem of HD, the Board of Control was attempting to improve the situation of the patients at the Louisiana Leper Home. M.D. Lagan, President of the Board of Control for the Leper Home in 1900, petitioned the state of Louisiana to purchase property where a permanent state-run facility could be operated. There was no long term plan when the five-year lease of the Indian Camp plantation ended and the Board of Control did not have the money to do what it felt was in the best interest of the patients. No research of the disease was being conducted, there was not enough infrastructure at the facility, and the patients often felt lonely and did not have enough to occupy them, causing some to flee the home and risk spreading the disease to others.[29] In addition, newly diagnosed patients were not always encouraged to move to the Louisiana Leper Home despite the fact that the national report showed that the vast majority of disclosed cases of HD resided in Louisiana. Louisiana passed Act 85 in 1892 which required that any person with a known HD diagnosis in the state be quarantined, however, the Board of Control lacked the resources to police this policy.[30]

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[28] Letter from the Secretary of the Treasury, transmitting Letter from the Surgeon-General of the Marine-Hospital Service presenting a Report relating to the Origin and Prevalence of Leprosy in the United States, 57th Cong., 1st sess., 1902, S. Doc. 269, 10, accessed June 22, 2019, https://babel.hathitrust.org/cgi/pt?id=loc.ark:/13960/t2r50sm6c&view=1up&seq=7.

[29] Dyer, "The History of the Louisiana Leper Home," 728-731.

[30] Sally K. Reeves and William D. Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center* (Carville, LA: Gillis W. Long Hansen's Disease Center, 1991), 28.

There was also difficulty getting the patients to the facility due to its isolation. Once the Board of Control and Sister Superior were notified that a patient was to be admitted to the Leper Home, the patients had three options. They could travel by train to Burns Station, a simple platform with no walls or roof, inconspicuously placed between two sugarcane fields. There the facility's horse-drawn carriage would meet the patient to take them to the Louisiana Leper Home.[31] As one patient described the facility, "the only access to the hospital was by a precarious pair of rutty cart tracks that could be called a dirt road only by courtesy. And even that was impassable in wet weather."[32] Patients could also travel to the facility by boat down the Mississippi River which could take anywhere from thirty-six to forty-eight hours depending on the weather. Patients could also be delivered to the Leper Home by their family, but if public health officials had been notified of their diagnosis patients only had a limited window of time to report to the facility.[33] For many this would be the one of the last times they saw their families. Patients could have visitors, but since the Leper Home was isolated, trips were difficult and only patients from Louisiana, Texas, and Mississippi were permitted to leave the facility for visits.[34]

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[31] Sister Catherine Sullivan, "Sixty-Forty," *The Star* 14, no 3 (November-December 1954): 1, accessed September 5, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A3403#page/3/mode/2up.
[32] Stanley Stein and Lawrence G. Blochman, *Alone No Longer: The Story of a Man who Refused to be One of the Living Dead* (New York: Funk & Wagnalls Company, Inc, 1963), 50.
[33] Sullivan, "Sixty-Forty," 2.
[34] Stein and Blochman, *Alone No Longer,* 52.

Since the disease's mode of transmission had not been determined, ensuring that those diagnosed with HD were admitted to the facility, and stayed there, was paramount. However, the only treatment available at that time was varied and inconsistent in its effectiveness. Although Gerhard Armauer Hansen, for whom the disease's name would ultimately be changed, discovered the causative bacillus in 1873, a successful cure was still almost a century away.[35] Medicine of this time was still largely following a specificity model of treatment rather than universalism. This means that remedies were often based on the individual and their "natural balance" which was impacted by their environment, ethnicity, and behaviors among other things.[36] Dr. Wailes, the first physician to work with the Louisiana Leper Home, found it difficult to treat some of the patients because "each individual has a preconceived idea as to what medicine has come to be the most beneficial in his particular case."[37] Prior to an understanding of germ theory, it was also believed that fresh air and light activity would help patients improve

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[35] Venita Jay, "The Legacy of Armauer Hansen," *Archives of Pathology and Laboratory Medicine* 124, no 4 (April 2000), accessed January 27, 2020, https://www.archivesofpathology.org/doi/full/10.1043/0003-9985%282000%29124%3C0496%3ATLOAH%3E2.0.CO%3B2

[36] John Parascondola, "From Germs to Genes: Trends in Drug Therapy, 1852-2002," sesquicentennial meeting of the American Pharmaceutical Association, Philadelphia, March 17, 2002, 4, accessed January 26, 2020, https://www.lhncbc.nlm.nih.gov/system/files/pub2002042.pdf. Universalism dictates the same treatment for everyone based on their diagnosis.

[37] Moran, *Colonizing Leprosy*, 78, accessed February 1, 2016, http://web.b.ebscohost.com/ehost/ebookviewer/ebook?sid=604b933d-2f2e-487b-8848-36e3d962147d%40sessionmgr114&vid=0&hid=118&format=EB.

their conditions. One newspaper argued that "it is thought that leprosy is a food disease, almost entirely, and that proper diet will go a long way in affecting a cure."[38]

Dr. Isadore Dyer began using chaulmoogra oil as a treatment option in 1901 on patients in the Leper Home, a remedy that had been used for hundreds of years in India.[39] The oil could either be ingested or given in shot form. Taking the medicine orally caused intense nausea and injections regularly abscessed or became infected.[40] In a 1916 report to Congress, Dr. Dyer stated that most of the patients at Carville took the oil orally.[41] The treatment worked well for some, ameliorating some of the symptoms of HD even though it did not cure the disease, however for others the effects were negligible. In addition to chaulmoogra oil, patients were given supplementary treatments such as hot baths, an attempted vaccine made from lepra bacilli, horse serum, and strychnine sulfate, among others. No combination of treatments was deemed consistently effective.[42] Since there was no cure and the treatment available was limited, many physicians continued to work

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[38] Edward W. Coffin, "Bringing Hope into Lepers' Lives: U.S. Public Health Service Tests New Cure," *Washington Herald* (Washington, D.C.), September 11, 1921, accessed January 25, 2020, https://chroniclingamerica.loc.gov/lccn/sn83045433/1921-09-11/ed-1/seq-45/.

[39] John Parascondola, "Chaulmoogra Oil and the Treatment of Leprosy," *Pharmacy in History* 45, no 2 (February 2003), 51, accessed June 23, 2019, 8, https://www.researchgate.net/publication/277597573_Chaulmoogra_Oil_and_the_Treatment_of_Leprosy. The oil is collected from the seeds of several species of trees in genus *Hydnocarpus.*

[40] Parascondola, "Chaulmoogra Oil and the Treatment of Leprosy," 9, https://www.researchgate.net/publication/277597573_Chaulmoogra_Oil_and_the_Treatment_of_Leprosy.

[41] Report of the Committee on Public Health and National Quarantine United States Senate on S. 4086, 64th Cong., 1st sess, 1916, Report No. 306, 34, accessed January 27, 2020, https://curiosity.lib.harvard.edu/contagion/catalog/36-990039103920203941.

[42] Julia Rivera Elwood, ed., *Known simply to the rest of the world as Carville…100 Years* (n.p.:Department of Health and Human Services, 1994), 49.

with their patients and did not report them to local public health authorities.[43] One doctor even discouraged his patients from going to Carville stating "Don't. They'll just shut you up, keep you out of sight, and forget about you."[44]

The Board of Control eventually purchased land closer to New Orleans, another old plantation named Elkhorn Place in Kenner, Louisiana, but when the plan for the property leaked to the newspapers, locals burned the property to protest its use by the patients.[45] The stigma associated with HD created immense difficulty in finding a more suitable location for the leper home. The isolation of the facility, while necessary to calm the fears of the spread of the disease, made it challenging to provide adequate medical care for the patients. Ultimately, the Board was unable to find a suitable location and in 1905, the state of Louisiana purchased the Louisiana Leper Home at Indian Camp plantation. With an influx of money from the state, a new building project commenced. Three female and four male patient cottages were built, adding over seventy new rooms to meet the needs of the facility's growing population.[46] (Figure 6) The building project also included the construction of a clinic, a small cottage to house both the physician and the priest, a laboratory/operating room, a Catholic chapel, and a steam plant that provided heat to the institution. In addition to the new structures, covered walkways were

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[43] Claire Manes, *Out of the Shadow of Leprosy: The Carville Letters and Stories of the Landry Family* (Jackson: University Press of Mississippi, 2013), 32; Stein and Blochman, *Alone No Longer*, 22, 24.
[44] Stein and Blochman, *Along No Longer*, 28.
[45] Dyer, "The History of the Louisiana Leper Home," 732; Sister Catherine Sullivan, "In the Old, Old, Days," *The Star*, Nov.-Dec. 1944, accessed August 22, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A1183#page/3/mode/2up.
[46] U.S. Department of Health and Human Services, "History of the Hansen's Disease (Leprosy) Program." http://www.hrsa.gov/hansensdisease/pdfs/faq.pdf.

constructed between the buildings to help patients, many wheelchair bound, navigate the often marshy terrain.[47]

Patients at the Louisiana Leper Home from 1894 through the early twentieth century lived very monotonous lives. Day-to-day operations changed little after the state purchased the institution in 1905. The Daughters of Charity still maintained the administration of the facility and intake of new patients. The Sisters made the institution as pleasant as they could, but nothing could change the fact that the patients were confined to the facility like prisoners, many for the remainder of their lives. Residents passed their days writing letters, attending religious services delivered by the Sisters, and playing games. The Sisters encouraged "those that are able to share with the domestic duties of the household in order to divert their minds from melancholy brooding over their unhappy condition."[48] Patients would perform sundry maintenance tasks as needed around the facility, partially because maintenance workers were too scared of disease transmission to perform work at the facility. In 1913, the Board of Control provided the patients of the Louisiana Leper Home with a restrictive list of rules and regulations (Figure 7).[49] These guidelines included the strict separation of men and women at all times, which included building a fence between the men's and women's dormitories.

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[47] Reeves and Reeves, *National Register Evaluation*, 64-65.

[48] "Excerpts of letters written by the first four Sisters to their Superiors in Emmetsburg, Maryland," 38, Sr. Hilary Ross Carville History file, Daughters of Charity of St. Vincent de Paul Collection, Hansen's Museum.

[49] "Rules for the Inmates of the Louisiana Leper Home, 1913" Carville Rules and Regulations file, Legislative History of Leprosy Collection, Hansen's Museum.

Relatives could only visit at certain times and then only in specially designated places within the property. The institution also employed around-the-clock guards to keep an eye on the patients.

By 1914, Hansen's disease was in the national spotlight again. John Early, a "diagnosed leper," was discovered to be staying at the "exceedingly fashionable" Willard Hotel in Washington, D.C. Early contacted the Chief Medical Inspector and several newspapers to tell them that he had "mingled among the well-to-do and the rich and exposed them to contagion." He had travelled by Pullman car, "slept at the best hotels, and ate in the best restaurants," and was currently staying at the same hotel as the Vice President, his wife, and several representatives and senators.[50] Early had been diagnosed with HD years before, most likely having contracted the disease in the Philippines during his time serving in the Spanish-American War. He and his family had traveled all over the country trying to escape the stigma of his condition. For years, he had been in and out of quarantine in different states, at one time living in a home with his wife in North Carolina with a makeshift wall constructed down the middle of the home in order to keep them apart. The state also commissioned a twenty-four hour guard to ensure that there was no contact between Early and his wife. Once locals in a town discovered that Early was a "leper," he and his family were forced to move on to another city.[51] The stress of

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[50] Philip A Kalisch, "The Strange Case of John Early: A Study of the Stigma of Leprosy," *International Journal of Leprosy* 40, no 3 (1972): 298, accessed June 22, 2019, https://pdfs.semanticscholar.org/4a1e/8b1eb7dadd94c88bf93299db220cdb0bf71d.pdf.
[51] Kalisch, "The Strange Case of John Early," 293-295.

the situation eventually led to his divorce and “a paranoia not unlike the psychotic reactions of prisoners.”[52] His reason for contacting newspaper reporters was to call attention to the fact that people afflicted with HD had nowhere to go for treatment and were not able to maintain employment or a home once their condition was revealed.

The panic that ensued after the John Early incident sped up the process of establishing a national leprosarium. On February 15 and 16, 1916, the Committee on Public Health and National Quarantine held a hearing to discuss bill S. 4086 to “provide for the care and treatment of people afflicted with leprosy.”[53] The topic of John Early was brought up many times by the committee members since he had recently been arrested in Washington D.C. for “coming into said District while suffering from leprosy and without a permit to do so.”[54] Among those who testified were Dr. Isadore Dyer, the first president of the Board of Control for the Louisiana Leper Home, as well as the Superintendent of the Massachusetts Leper Colony, and numerous other medical professionals familiar with cases of HD in their states. All of the experts spoke of the benefits a national leprosarium would provide to lessen the spread of the disease and hopefully bring about a cure.

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[52] Kalisch, “The Strange Case of John Early,” 300.
[53] Report of the Committee on Public Health and National Quarantine United States Senate on S. 4086, 64th Cong., 1st sess, 1916, Report No. 306, 7, accessed January 27, 2020, https://curiosity.lib.harvard.edu/contagion/catalog/36-990039103920203941.
[54] Report of the Committee on Public Health and National Quarantine United States Senate on S. 4086, 146.

The bill passed in the Senate on January 25, 1917 and was signed into law by President Wilson on February 3, 1917.[55] Despite the momentum gained during the hearing and the public outcry following the John Early incident, it would be four more years before the national leprosarium was established. Part of the reason for the delay was the United States's entrance into World War I.[56] After the war, the federal government found the task of obtaining a suitable location for the national leprosarium as difficult a task as the Board of Control had. After the recommendation for a national leprosarium had been made to the Treasury Department in 1902, the territory of New Mexico issued a joint resolution in 1905 that stated that they believed it "an insult that our fair and healthy commonwealth should be chosen by congress as the abiding place for such unfortunates, with all its attendant evils and miserable repute that such an establishment would entail upon our prosperous and growing territory." New Mexico asked that Congress "keep from us this bitter cup."[57] Locals all over the country rejected the idea of having a leper colony in their communities. When the Texas legislature approved funding to build a colony in Galveston, local community leaders later decided that it would be difficult to attract tourists, whose numbers had fallen drastically following the hurricane of 1900, with a leprosarium on the island. Bostonians arranged

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[55] Kalisch, "The Strange Case of John Early," 300.

[56] "History of the National Leprosarium," U.S Department of Health and Human Services, Health Resources and Services Administration, accessed September 10,2020, https://www.hrsa.gov/sites/default/files/hansensdisease/pdfs/hansenshandout3.pdf.

[57] "Joint Resolution 8," Document number NHDM-17651, New Mexico file, Legislative History of Leprosy Collection, Hansen's Museum.

the “largest public hearing ever held in Massachusetts” to protest the purchase of Cape Cod for a state leprosarium.[58]

During the 1916 committee hearing, committee member John D. Works, a Senator from California, asked Dr. Dyer if he thought it would be satisfactory for the federal government to take over the operation of the Louisiana Leper Home.[59] Despite Dr. Dyer’s answer that “that was not the best solution” and that “it would be very much better to have lepers in the colder climate,” the federal government purchased the Leper Home from the state of Louisiana for $25,000 on January 3, 1921.[60] On February 1, 1921 the United States flag was raised at the leprosarium signaling the official transfer of control from the state to the federal government.[61] Now under the direction of the United States Public Health Service, the facility was renamed U.S. Marine Hospital No. 66.[62] The facility from this point forward took on a more institutional feel with stricter policies and guidelines for its patients. With additional resources and funding from the federal government, the patient numbers in the following decades ballooned into the hundreds.

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[58] Jose P. Ramirez Jr., *Squint: My Journey with Leprosy* (Jackson: University Press of Mississippi, 2009), 50-51. The leprosarium in Massachusetts was ultimately put on Penikese Island. Once Carville was named the national leprosarium and the Massachusetts HD patients were transferred to Carville, local officials burned the old colony buildings in Massachusetts.

[59] Report of the Committee on Public Health and National Quarantine United States Senate on S. 4086, 37.

[60] Report of the Committee on Public Health and National Quarantine United States Senate on S. 4086, 27, 37; “An Act #77,” Document number NHDM-DOC-STL-2914, Louisiana file, Legislative History of Leprosy Collection, Hansen’s Museum.

[61] “History of the National Leprosarium,” U.S Department of Health and Human Services, Health Resources and Services Administration, accessed September 10, 2020, https://www.hrsa.gov/sites/default/files/hansensdisease/pdfs/hansenshandout3.pdf.

[62] Gaudet, *Carville*, 8-9.

CHAPTER 2

The National Leprosarium: 1921-1999

The United States Public Health Service finally provided the support necessary to turn the Louisiana Leper Home into a properly run medical institution. No longer focused on just treatment, the medical staff under the Public Health Service worked aggressively to find a cure for HD, provided a wider range of medical assistance, and created rehabilitative programs so that people suffering with this disease could live a more normal, full life. As a Commissioned Corps, the doctors working for the Public Health Service were militarily uniformed, which gave the hospital a more official and institutional feel.[63] Although no longer the sole source of authority at the institution, the Daughters of Charity remained an integral part of the national leprosarium for the remainder of its operation. There was already a well-established relationship between Marine hospitals and the Catholic Church. Specifically, in the Midwest "Catholic hospitals were a vital part of the American marine hospital system" so it only made sense for the national leprosarium to maintain this relationship.[64] The Daughters of Charity

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[63] Russell O. Wright, *Chronology of Public Health in the United States* (Jefferson, NC: McFarland & Company, Inc., 2005), 45.

[64] John Jensen, "Before the Surgeon General: Marine Hospitals in the Mid-19th-Century America," *Public Health Reports* 112, no. 6 (November-December 1997), 527, accessed September 18, 2020, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1381932/?page=1.

continued to prove invaluable in the research and discoveries that were to come. This chapter will focus on the federal history of the institution as well as the evolution of patient autonomy during this time.

The origin of the U.S. Public Health Service began in 1798 when President John Adams signed the Act for the Relief of Sick and Disabled Seamen, which established the Marine Hospital Service. Initially, this act ensured that any sick or injured merchant seamen could receive treatment in any port hospital in the United States, however, shortly after the law was enacted these benefits were extended to men serving in the United States Navy as well.[65] The name of the division changed a few times, once in 1902 to the Public Health and Marine Hospital Service and then shortened in 1912 to the Public Health Service (PHS). The title shifts coincided with additional divisional responsibilities, such as quarantine, medical inspections of immigrants, and directing public health activities.[66] A Medical Officer in Charge (MOC) oversaw the operations of each of the government-owned facilities. The Treasury Department housed the Public Health Service until 1939, when it as well as other health and welfare-related divisions, such as the Food and Drug Administration and Social Security, moved under the newly created Federal Security Agency. In 1980, the Department of Health and Human Services was created to replace the Federal Security Agency.[67] Although the national leprosarium

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[65] Ralph Chester Williams, *The United States Public Health Service, 1798-1950* (Washington, D.C.: Commissioned Officers Association of the United States Public Health Service, 1951), 29-32.
[66] Wright, *Chronology of Public Health in the United States,* 45.
[67] Wright, *Chronology of Public Health in the United States,* 45.

has been dissolved, the National Hansen's Disease Museum, which is located in the old staff cafeteria on the grounds, reports to the Health Resources and Services Administration (HRSA) which is part of the Department of Health and Human Services.[68]

The creation of a government-run healthcare institution had become a relatively common occurrence at the beginning of the twentieth century. State run hospitals for the equally feared tuberculosis appeared all throughout the United States. Although "leper houses" date back to the middle ages in Europe, the Progressive Era in the United States brought a desire for the government to become more involved in solving healthcare issues.[69] The medical historian John Duffy states that "a major objective of the Progressives in this era was the conservation of national resources, and, among these, health ranked high on the agenda."[70] This included not only communicable diseases such as Hansen's disease and tuberculosis, but other illnesses such as epilepsy and mental health conditions. There was a growing trend to provide treatment and "regulated health facilities" to patients rather than just guardianship.[71] A greater understanding of how diseases spread combined with the increasing professionalism of the medical field led many major cities to establish self-contained communities dedicated to treating patients.[72]

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[68] Elizabeth Schexnyder, "The National Hansen's Disease Museum," Health Resources and Services Administration, last modified September 2020, accessed September 20, 2020, https://www.hrsa.gov/hansens-disease/museum.

[69] Guenter B. Risse, *Mending Bodies, Saving Souls*, 167.

[70] John Duffy, *The Sanitarians: A History of American Public Health* (Urbana, IL: University of Illinois Press, 1990), 241.

[71] National Register of Historic Places Registration Form, "State Epileptic Colony Historic District," Abilene, Taylor County, Texas, National Register #91001539, Section 8, 4.

[72] National Register of Historic Places Registration Form, "Chicago Municipal Tuberculosis Sanitarium," Chicago, Cook County, Illinois, Section 8, 26.

Like in Carville, many people afflicted with these illnesses could not afford the level of care that they needed or wanted to avoid the humiliation of living in a "poor house."[73] In keeping with the regulatory nature of the Progressive Era, many of these institutions even looked similar. They often contained their own water and power plants, laundry facilities, dormitories, and recreation centers.[74] There was a "proliferation of federal programs dealing with the nation's health" during this time period, which were concerned not only with the medical needs of American citizens, but sanitation and food regulation as well.[75]

The national leprosarium's first Medical Officer in Charge (MOC) was Dr. Oswald E. Denney, who already had extensive knowledge of the disease from his previous experience as the director of Culion, the leper colony in the Philippines.[76] By 1921, patient numbers had risen to ninety and were expected to increase as other states closed their facilities and sent their wards to Carville.[77] Dr. Denney was in charge of a larger and more professionally diverse staff than the institution had ever seen which included "three full time medical men, three attending specialists, two chaplains, eleven nurses and numerous clerical help."[78] Patients now had access to physicians in multiple

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[73] "Chicago Municipal Tuberculosis Sanitarium," 29.

[74] National Register of Historic Places Registration Form, "Arkansas Tuberculosis Sanatorium Historic District," Booneville, Logan County, Arkansas, Section 7, 1-2; "Chicago Municipal Tuberculosis Sanitarium," 5-17; "State Epileptic Colony Historic District," Section 7, 2-3.

[75] Ronald Hamowy, *Government and Public Health in America* (Northampton, MA: Edward Elgar Publishing Limited, 2007), 12, 25.

[76] Sally K. and William D. Reeves, "Carville-One Hundred Years of Public Health," in *Known simply to the rest of the world as Carville…100 Years*, ed. Julia Rivera Elwood, 33.

[77] Stein and Blochman, *Alone No Longer*, 101.

[78] Sister Martha and Sister Catherine, "The National Leper Home (U. S. Marine Hospital, No. 66)," *The American Journal of Nursing* 24, no 10 (July 1924), 795, accessed September 26, 2020, https://www.jstor.org/stable/3406541?seq=1#metadata_info_tab_contents.

fields: dentistry, ophthalmology, neurology, pharmacy, and dermatology.[79] As understanding of Hansen's disease increased, medical professionals began to recognize how the disease effected all parts of the human body. For the first time, patients received specialized treatment in all of the fields that are impacted by HD. In 1931, a bacteriologist was added to the staff to research the bacillus itself in the hopes of finding a cure.[80]

Although a long way from the sprawling complex it would become, the 1920s brought many new additions to the institution. The first building constructed by the federal government was a wooden, one-story home for the Medical Officer in Charge in 1921. This was followed by two more wooden homes for other resident medical staff as well as a power plant in 1924.[81] During the early 1920s, the federal government constructed seven more patient cottages and erected over 500 feet of additional covered walkways between the new buildings. The facility could now house up to 425 patients. Also in 1924, Union Chapel, the Gothic Revival Protestant chapel was completed. This project was funded by private donations given to the leprosarium from the American Leprosy Missions organization.[82] In 1923, a water treatment plant was added to the facility. During the days of the Louisiana Leper Home, cisterns were the only available

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[79] Sister Martha and Sister Catherine, "The National Leper Home," 798.

[80] Reeves, "Carville-One Hundred Years of Public Health," 34.

[81] Sally K. Reeves and William D. Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center* (Carville, LA: Gillis W. Long Hansen's Disease Center, 1991), 91, 85.

[82] Elizabeth Schexnyder, *The Evolution of Carville's Building & Grounds* (Carville, LA: National Hansen's Disease Museum), 11.

source of clean water. Now patients and staff had access to filtered water pumped directly from the Mississippi River.[83] As a self-sufficient facility, livestock had been a part of the leprosarium since its state-owned days. An "animal care" building was added in 1925 near the existing dairy barn and silos for storing grain for the animals were built in 1928.[84]

As stated in the original 1902 report to the Secretary of the Treasury, it was the recommendation of the committee that "patients must not be made to feel that they are under any restraint."[85] Their desire was that a national leprosarium would be an appealing place for people suffering from HD to seek treatment so that they would not risk infecting others by remaining in the general population. However, once patients were admitted to the institution, the federal government wanted to ensure they stayed. A gate house to guard the entrance to the institution was built in 1929 and was the only official entrance into and out of the facility.[86] The grounds were surrounded by an eight-foot fence topped with hurricane wire.[87] Patients were not able to leave the facility of their own free will.[88] They had to obtain a medical release to travel away from the institution to visit family or friends. Patients from Louisiana received ten days of leave a year and patients from

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[83] Elizabeth Schexnyder, "Federal Staff Housing, Site Utilities, The National Leprosarium," New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/808?tour=55&index=1.
[84] Reeves and Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center*, 93.
[85] Letter from the Secretary of the Treasury, transmitting Letter from the Surgeon-General of the Marine-Hospital Service presenting a Report relating to the Origin and Prevalence of Leprosy in the United States, 57th Cong., 1st sess., 1902, S. Doc. 269, 16.
[86] Reeves and Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center*, 91.
[87] Gaudet, *Carville*, 74.
[88] Parascandola, "The Gillis W. Long Hansen's Disease Center at Carville," 728.

Texas received fifteen days of leave.[89] The only other way to leave the facility was to be discharged if the disease was found to be "arrested." Patients were subjected to monthly skin scrapings which were then tested for active bacillus. If twelve consecutive tests came back bacteriologically negative for active infection a patient could be discharged.[90] Patients who left the facility without permission, called going "through the hole in the fence," risked up to thirty days in the on-site jail for "absconding" or "leaving against medical advice."[91] Additionally, a hedge was planted to further segregate patients from the healthy, separating the staff and patient sides of the hospital. Patients were not allowed to cross over to the staff side of the grounds, which housed many of the same amenities as the patient side: laundry, residential area, cafeteria, and even a golf course.[92]

Other official rules and regulations dictated patient behavior inside the walls of the leprosarium. Men and women were relegated to separate dorms and were not allowed in the rooms of patients of the opposite sex. A "Carville date" would often consist of sharing a meal on a card table set up across the threshold of a female patient's room while the man sat in the hallway.[93] Patients were prohibited from marrying at either the

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[89] Gaudet, *Carville*, 72.

[90] G. H. Faget, "What the Patient Should Know About Hansen's Disease," *The STAR* 2, no 8 (April 1943), 2-3, accessed October 1, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A958#page/5/mode/2up.

[91] Gaudet, *Carville*, 74. The jail was eventually closed in 1954.

[92] Elizabeth Schexnyder, "Federal Staff Housing, Site Utilities, The National Leprosarium," https://neworleanshistorical.org/items/show/808?tour=55&index=1.

[93] Elizabeth Schexnyder, "Carville, The National Leprosarium: Patient Life," New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/636?tour=55&index=4. According to Stanley Stein, one of the patients living in the facility at this time, the dormitories were largely segregated by race as well, but not necessarily because of any official policy. Patients admitted to the leprosarium were assigned a room but were able to move to another dormitory should they chose to if a

Protestant or Catholic chapels on the grounds and if any patients escaped to marry outside of the facility, their marriage was largely unrecognized upon their return. These married patients were not allowed to live together in the dormitories.[94] There was a small community of homes at the back of the facility, known as "White City" or "Cottage Grove," whose homes were built by patients from their own personal funds. In these homes, married couples could cohabitate as they were not part of the federal housing complex.[95] Additionally, there was no telephone available to the patients, visitors were only allowed between the hours of 7:00 am to 7:00 pm unless attending a weekend social function, any outgoing mail or money had to be sterilized before it was allowed to leave the facility, and patients, like felons, were not allowed to vote in either state or national elections.[96]

One of the most significant changes to the facility was the creation of the federal cemetery. Prior to 1921, patients were buried in what is now a courtyard in one of the facility's quadrangles created by the patient dormitories. Although patients were not required to be buried on site, they were not permitted to be buried in the town of Carville or at a local church cemetery.[97] Patients' bodies could be released to family members for

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room became available. The dormitories were mostly segregated by patient choice. Stein and Blochman, *Alone No Longer,* 57-58.

[94] Stein and Blochman, *Alone No Longer,* 51.

[95] Julia Rivera Elwood, ed., *Known simply to the rest of the world as Carville….100 years,"* 61. This area of the leprosarium was referred as White City because all of the houses were painted with standard government-issued white paint.

[96] Stein and Blochman, *Alone No Longer,* 61. Patients likely were not denied the right to vote because they had leprosy but rather were not permitted to leave the facility in order to vote.

[97] Gaudet, *Carville,* 148.

burials, however the sanitary codes of 1911 required that bodies infected with leprosy "had to be thoroughly disinfected before being accepted for transfer."[98] Some states required that bodies that left Carville be in a metal coffin that was soldered shut. If a patient's body had to travel through multiple states to be buried, every state along the route had to be notified.[99] This tedious process meant that ultimately many patients remained at Carville as their final resting place. A memorial plaque was placed on the site of the old cemetery to commemorate those buried from 1894 to 1920. (Figure 8) The plaque lists patients by their patient number and name, however, many patients chose to be buried with just their initials or under their "Carville name." Picking a "Carville name" was a common practice, one even encouraged by the Daughters of Charity, for the first half of the facility's existence. These aliases were adopted to shield families' identities from any stigma from being related to a "leper." Once the hospital became federal property, any patients buried on the grounds were laid to rest in a new cemetery at the back of the property amongst a grove of pecan trees. This being a national cemetery, the federal government provided standard, identical gravestones for all of the patients buried there. (Figure 9) Some families later added more personalized markers, but the cemetery overall maintained a uniform look.

With the influx of federal funding came not only better facilities and medical care, but also more recreation for the patients. One patient, who saw the facility change from

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[98] Gaudet, *Carville,* 165.
[99] Elizabeth Schexnyder, "Infirmary, National Leprosarium, Carville, Louisiana," New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/770?tour=55&index=3.

state to federal authority, wrote to his family in 1921 that "Dr. Denny [sic] is back from Washington since last night, with lots of good news to our interest…He says that the Red Cross is going to send us fourteen Phonographs, one Player Piano and two Standard size Motion Picture Machines. I tell you that this little Dr. is putting this place up to date, and this is a great thing for us."[100] Sometime in the early to mid-1920s a patient named Gabe Michael, real name Edmond Landry, created the patients' canteen which provided a place for patients to purchase "minor luxuries such as chewing gum, candy bars, silk stockings, and pipe tobacco."[101] Gabe kept none of the profits for his own salary, but instead created the What Cheer Club whose members would decide how to dispense the funds. The proceeds paid for many of the social events at Carville but also provided monies for some of the more needy patients.[102]

During the federal era of the institution, patients began to feel more empowered to exercise their autonomy. There was a proliferation of new social clubs: The Mexican Club, Glee Club, Bridge Club, 41 Supper Club, the Carville Little Theatre group, among others.[103] Patients began to truly build lives here and a community not unlike any other small town developed. The What Cheer Club petitioned the MOC for items that would make the patients' lives more enjoyable: park benches for the facility grounds, sand for a

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[100] Manes, *Out of the Shadow of Leprosy*, 167.
[101] Stein and Blochman, *Alone No Longer*, 61.
[102] Stein and Blochman, *Alone No Longer*, 61-62.
[103] *The STAR* 1, no 1 (September 1941), 1, 4, 11, accessed October 1, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A709#page/12/mode/2up; Stein and Blochman, *Alone No Longer*, 60, 111.

baseball diamond, and to fix the "moving picture machine."[104] One of the patient dormitories was even designated as the "Carville Mall" where patients could operate their own businesses. These enterprises ran the gambit from beauty salons and laundry services to various repair shops for radios and bicycles (Figure 10).[105] Although children were not allowed at the leprosarium unless they had received a diagnosis of HD, there was even a sizeable enough population of young children to warrant a school.[106]

A few patients also got together to produce an institutional newspaper, *The Sixty-Six Star*. The first issue was published May 16, 1931 and provided patients with a voice. The newspaper covered the events and gossip of the leprosarium and "since eating was an obsession with Carville patients," the Sunday and holiday menus were printed as well.[107] The circular was widely read throughout the facility, but an editorial response to the Carville priest's article on Leper's Mass caused the death of the newspaper. The overwhelmingly Catholic patient population sided with Father Abbot Paul and as the newspaper's typist and reporters sited other obligations, the paper folded.[108] Years later, another patient produced newspaper would be more successful in challenging commonly held views about "leprosy."

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[104] Manes, *Out of the Shadow of Leprosy,* 127; Stein and Blochman, *Alone No Longer,* 119.
[105] Elizabeth Schexnyder, "Carville, The National Leprosarium: Patient Life," New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/636?tour=55&index=4.
[106] 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 (Summer 2006): 1024. Patients who had children while living at the leprosarium could not keep their children. They had to be cared for by family members on the outside.
[107] Stein and Blochman, *Alone No Longer,* 69-70. Sixty-six in the newspaper title referred to the hospital number and star was an homage to the *Boerne Star*, the hometown newspaper of the editor-in-chief.
[108] Stein and Blochman, *Alone No Longer*, 161.

Many of the patients living at the leprosarium were veterans and became increasingly frustrated with the situation they found themselves in. They had served their country, were willing to sacrifice their lives for its cause, and returned only to be denied some of their most basic rights. Some patients even contacted the Veteran's Bureau to appeal what they felt was insufficient compensation due to the fact that they could not prove when they had contracted the disease.[109] In June 1931, a group of twenty-three veterans, led by a patient who was a veteran of the Spanish-American war, met with Sam Jones, an American Legion representative and future Governor of Louisiana, to air some of their grievances. The patients relayed their desire to have "a decent infirmary building, a recreation hall to replace the filthy canteen, more contact with the world outside, if only with outside baseball teams to play on the Carville diamond."[110] Jones promised to speak on behalf of the patients but encouraged the group to form their own American Legion post at Carville because "in union there is strength."[111]

The patients did just that. On October 26, 1932 U. S. Marine Hospital Post No. 188 was granted its charter. The American Legion's interest in Carville led other veterans' organizations, such as The Disabled American Veterans, the Veterans of Foreign Wars, the United Spanish War Veterans, and the Forty and Eight, to lend their support to Carville as well.[112] The assistance of the American Legion was instrumental in

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[109] Manes, *Out of the Shadow of Leprosy*, 131.
[110] Stein and Blochman, *Alone No Longer*, 117-118.
[111] Stein and Blochman, *Alone No Longer*, 118.
[112] Stein and Blochman, *Alone No Longer*, 122.

creating the institution as it stands today. With the help of the Legionnaires, baseball teams from nearby Baton Rouge began playing at Carville and outside bands played at some of the social events. The American Legion also made sure that the patients had access to a telephone. It was installed in the Patients' Canteen in 1936.[113] This was the start of patients having regular contact with the outside world. In 1932, the What Cheer Club changed its name to the Patient's Federation. Its mission had grown from simply an organization that planned social events to a platform where patients could make their voices heard by the hospital administration.[114] Patients were beginning to see the leprosarium as a home and, since many would spend the majority of their lives there, expected that the government allow them the liberties they enjoyed before their confinement. There was a still a long road ahead.

In 1934, the patients received one of their requests, a new infirmary. This remains the most prominent building on the grounds. The massive, white, two-story building mirrors the original plantation home in its Greek Revival style and tall front columns (Figure 11).[115] Now all of the hospital departments would be housed in the same building which made things much more convenient for patients, many of whom had issues with mobility. The infirmary included the bandaging clinic, eye clinic, surgery, laboratory,

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[113] Stein and Blochman, *Alone No Longer*, 178.

[114] Sister Hilary Ross, "Various Clubs," Daughters of Charity of St. Vincent de Paul Collection, Sister Hilary Ross Carville History folder, 191.

[115] Reeves and Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center*, 90.

pharmacy, physical therapy, x-ray clinic, dental clinic, and the morgue.[116] The roof of the infirmary provided a covered pavilion where patients could rest and relax and glimpse an aerial view of the entire facility. 1934 was a busy year for construction at the leprosarium. A new red-brick Mission-style Catholic chapel was built, Sacred Heart Chapel, with funds from the Catholic Church Extension Society of America.[117] Additionally, a new home for the MOC was constructed along with six more staff houses.[118]

The 1940s proved to be the most significant decade for not only the patients at Carville, but for any person afflicted with Hansen's disease. The American Legion began campaigning for the replacement of the wooden patient dormitories and campus wide walkways which were fire hazards and put the patients at great risk. The Supervising Architect of the Treasury Department presented preliminary plans which included a change to the existing cottage plan design of the dormitories. The Patients' Federation met to discuss the plans and presented a resolution to the MOC, Dr. Hasseltine. With his support, the Federation sent a letter to the Legionnaires stating their wishes that the current model of the leprosarium remain. The Surgeon General responded that he

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[116] Elizabeth Schexnyder, "Infirmary, National Leprosarium, Carville, Louisiana," New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/770?tour=55&index=3.
[117] Julia Rivera Elwood, ed., *Known simply to the rest of the world as Carville….100 years,"* 39.
[118] Reeves and Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center*, 91.

approved with constructing new fireproof buildings using the existing plan. With that, the Patients' Federation secured their first major victory.[119]

Seventeen white, two-story, stucco dormitories were completed in 1941 (Figure 12). Each dorm had thirty rooms with a shared bathroom and living space on each floor. The covered walkways were also rebuilt, in white stucco as well, and also two stories tall. They connected both levels of the dormitories to almost all of the buildings across the facility. Combined, there are over two miles of corridors winding throughout the institution.[120] The Daughters of Charity also received new living quarters. They had outgrown the plantation house, which was also being utilized as the Administration building. A new staff dining hall was built as well.[121] Patients also received a Recreation Hall in 1941, the look of which was similar to the infirmary.[122] The patients had successfully secured all of the wishes they had expressed to the American Legion just ten years before. The leprosarium was growing in leaps and bounds, not only in structural size but in patient size as well. By 1941, the patient population was at 372.[123] The facility today, with the exception of a few additional staff houses that were built in 1959, looks much as it did in 1941. (Figure 13)

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[119] Stein and Blochman, *Along No Longer*, 202-203. Dr. Hasseltine was the second MOC at Carville. He took over in 1935 and stayed until 1940.
[120] Elizabeth Schexnyder, "Carville, The National Leprosarium: Patient Life," New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/636?tour=55&index=4.
[121] Reeves and Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center*, 86.
[122] Reeves and Reeves, *National Register Evaluation: Gillis W. Long Hansen's Disease Center*, 85.
[123] Elizabeth Schexnyder, "Carville: Annual Patient Census," 2, Hansen's Museum.

Reveling in their recent patient victory, former staff members of *The Sixty-Six Star* began discussing the idea of starting the patient-run periodical again. In September 1941, *The Star*¸ the new and improved iteration of the institutional newspaper, made its debut.[124] While still filled with hospital news and gossip, the facility movie schedule, sports news, and editorials, the mission of the newspaper had shifted. No longer content with simply circulating amongst hospital patients and staff, *The Star* staff wanted to share their news with a larger community. Three hundred copies of the first issue were sent to friends and family outside of the institution. The objective of the paper was now "1. To promote an educated public opinion on Hansen's disease. 2. To furnish vocational training for interested patients. 3. To provide community service."[125] The newspaper's new motto was "Radiating the Light of Truth on Hansen's Disease" and regularly printed articles from experts on HD about updates on the disease around the world.[126] In 1943, days before Christmas, the staff of *The Star* received a gift from their friends in the veterans' organization The Forty and Eight, "a press, type, and all the necessities" for the periodical to become a professionally printed magazine (Figure 14).[127]

1941 also provided hope for sufferers of Hansen's disease worldwide. In 1940, Dr. Guy Faget was appointed as the Medical Officer in Charge at Carville. Though he had no experience with Hansen's disease, his previous work on tuberculosis proved to be

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[124] Stein and Blochman, *Alone No Longer*, 207.
[125] Stein and Blochman, *Alone No Longer*, 210.
[126] Stein and Blochman, *Alone No Longer*, 210.
[127] Stein and Blochman, *Alone No Longer*, 210-211.

invaluable. He recognized that there were several similarities between tuberculosis and Hansen's disease and decided to try an experimental treatment with sulfone drugs which had proven successful in patients with tuberculosis. Although Carville had an extensive animal menagerie, no animal had yet been found that was a suitable host for Hansen's disease. Because of this, the medical staff at Carville had to rely on human volunteers to test out new medical treatments.[128] Dr. Faget and his staff hoped that the sulfanilamide the nine volunteers were prescribed would clear up secondary infections that HD caused in many of the more advanced cases. Progress was slow at first and many of the patients became discouraged, however, after six months they began to see remarkable improvements in their ulcers and pus infections they had been experiencing. In 1941, Dr. Faget started experimenting with Promin, another sulfone drug, which provided even better results.[129]

Patients were thrilled with the results of the sulfone trials. One patient, Betty Martin, wrote a book about her experiences in Carville and titled it *Miracle at Carville* because of the hope that patients felt now that the "miracle" treatment had been discovered. While not a complete cure, some patients were sulfone resistant, a large number of patients not only saw their secondary infections clear up but they also regained much of their pre-HD appearance as the nodes on their faces shrunk. Although Promin

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[128] G. H. Faget, "The Story of the National Leprosarium (U. S. Marine Hospital), Carville, Louisiana," *Public Health Reports* 57, no 18 (May 1942), 649, accessed October 1, 2020, https://www.jstor.org/stable/4584083?read-now=1&seq=11#metadata_info_tab_contents.
[129] Williams, *The United States Public Health Service, 1798-1950*, 385.

could not reverse any of the damage already done to a patients' peripheral nervous system, it kept the damage from further progressing. By 1950, over half of the patients in Carville were regularly running negative bacteriologically tests.[130] One of the Daughters of Charity who worked in the laboratory, Sister Hilary Ross, began taking photographs of patients as they improved through their Promin treatment (Figure 15). Her documentation was presented at the Second Pan-American Leprosy Conference in 1946 to show the great promise of sulfone drugs.[131] By 1947, the much reviled chaulmoogra oil was no longer used as a treatment option at the national leprosarium.[132]

The hope provided by new treatment possibilities drove patients to fight for more freedom. This time period saw the beginning of a tremendous amount of change in the United States. Amy Fairchild states that "beginning in 1942, President Roosevelt began to promote attention to fundamental civil rights as the nation increasingly embraced the notion of a pluralistic society."[133] Additionally the onset of U.S. participation in World War II further strengthened patients' desires to fight for their rights. It seemed unfair to patients, many of whom were American veterans, that they be confined to Carville while the nation fought a war against Nazis imprisoning millions in concentration camps.[134] In

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[130] Williams, *The United States Public Health Service, 1798-1950*, 827.
[131] Cynthia M. Gould, "Sister Hilary Ross and Carville: Her Thirty-Seven Year Struggle Against Hansen's Disease," in *With Love in Their Hearts: The Daughters of Charity of St. Vincent de Paul 1896-1996,* 33, The Daughters of Charity of St. Vincent de Paul Collection, Hansen's Museum.
[132] John Parascandola, "Chaulmoogra Oil and the Treatment of Leprosy," *Pharmacy in History* 45, no 2 (February 2003), 56.
[133] Amy L. Fairchild, "Community and Confinement: The Evolving Experience of Isolation for Leprosy in Carville, Louisiana," *Public Health Reports* 119 (May-June 2004), 364.
[134] Fairchild, "Community and Confinement," 365.

1945, a group of patients formed the United Patients' Committee for Social Improvement and Rehabilitation. In yet another act of solidarity, members of the Louisiana group of the American Legion suggested to the Surgeon General that he create a National Advisory Committee on Leprosy in the United States. The United Patients' Committee submitted a fifteen-point list of recommendations to the Advisory Committee for its review.[135] The list included many issues that patients had complained about for years to both the hospital administration and to their loyal friends in the American Legion. Included were items such as "abolishing compulsory segregation, in the light of modern scientific knowledge, and make institutionalization voluntary, establish outclinics for early diagnosis and treatment in other parts of the country, expand research facilities, grant more liberal vacations, recognize Hansen's disease as an official term for so-called leprosy," among others.[136]

The Advisory Committee first met in May 1946 and was made up of numerous doctors, Legionnaires, and people involved in various HD related pursuits. They reviewed the list of recommendations from the United Patients' Committee and were encouraged by the Surgeon General to visit Carville before they held a second meeting. The attention that the United Patients' Committee received was worrying to some of the staff, particularly the non-medical staff that lived in the communities surrounding the leprosarium. They were worried that a visit to the institution and an assessment of the

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[135] Stein and Blochman, *Alone No Longer*, 231-232.
[136] Stein and Blochman, *Alone No Longer*, 232.

hospital's policies would result in the removal of the hazard pay they received as employees. As one patient explained, "I have no personal objection to workers at Carville getting extra money. My objection to the principle of hazard pay is merely that the differential helps keep alive all the alarmist, mistaken beliefs about the contagiousness of the disease."[137]

On December 17, 1946, the Advisory Committee held its second meeting and provided their own list of recommendations. This proposal was read to the patients at the annual Christmas party. Almost all of the United Patients' Committee's suggestions were addressed. The Advisory Committee recommended that all patients, not just those from Texas and Louisiana, be allowed leave and that the patients be allowed a month of leave twice a year as long as the patient's medical progress would not be negatively impacted. They recommended that the Public Health Service also provide transportation for patients going on leave. They requested that the existing recreational facilities and vocational training program be expanded, that diagnostic and treatment centers be created in all states where HD regularly occurs, that financial assistance be given to families in which the majority wage earner has been sent to Carville, and that housing be given to married couples. Although it took some time for many of these initiatives to come to fruition, the most immediate result from the Committee's ruling was that many more patients were able to travel home for Christmas than ever before.[138]

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[137] Stein and Blochman, *Alone No Longer*, 234.
[138] Stein and Blochman, *Alone No Longer*, 239.

1946 would also see another great victory for the patients. On November 5, 1946, "the electorate of the State of Louisiana went to the polls and voted overwhelmingly" to give patients at Carville the right to vote.[139] This established the national leprosarium as its own precinct. Interestingly, Carville became an important indicator of overall Louisiana election results. Because the polls closed earlier than the rest of the state and voter turnout at Carville was nearly 100 percent, election results from Carville were the first to be reported and often were a good predictor of how the rest of the state would vote.[140] Candidates even began to travel to the leprosarium to campaign.[141] Patients at Carville made sure to not take their renewed voting rights for granted.

In addition to voting, Carville residents continued to make sure their voices were heard through *The Star.* With the support of Carville's network of friends and sympathetic organizations, *The Star* circulation continued to rise. The magazine had developed a large following outside of the leprosarium, including public libraries, churches, colleges, hospitals, and even sororities, and the staff of *The Star* did not waste the opportunity to educate the public about Hansen's disease.[142] Although the magazine continued to provide updates about life at Carville and patient written articles about events happening around the world, it often featured articles from doctors, religious

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[139] Stein and Blochman, *Alone No Longer,* 236.
[140] Gaudet, *Carville,* xi.
[141] Stein and Blochman, *Alone No Longer*, 237.
[142] Heather Varughese John, "Translating Leprosy: The Expert and the Public in Stanley Stein's Anti-stigmatization Campaigns, 1931-60," *Journal of the History of Medicine and Allied Sciences* 68, no 4 (October 2013), 664.

clergy, or organizations that spoke to the low communicability of HD and how people suffering from HD should not be feared. *The Star* also published the latest medical updates on HD treatments from around the world. Writers for *The Star* often used the magazine as a platform to speak out against stigma they found prevalent in society. Beginning in the second volume of *The Star*, there was the same message which graced the back of the front cover of every issue until 1949. It was titled "Facts That You Should Know About Hansen's Disease." At the bottom of the page was another disclaimer, "this paper, and all outgoing mail, is sterilized before leaving the hospital."[143] These messages were included to not only educate the subscriber, but to put them at ease as well. Even though it had long been determined to be unnecessary, the practice of sterilizing mail was discontinued in 1949.[144]

The use of the word leper, "that odious word" as *The Star* labeled it, was something patients were immensely sensitive to.[145] "Leper" was used indiscriminately in all forms of media "to describe any social outcast" with no understanding from society about the negative impact the use of that word may have.[146] One of the Daughters of Charity described one such instance when the patients were excitedly listening to the 1937 World Series on the radio. She says,

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[143] *The Star* Collection, Louisiana Digital Library, accessed October 12, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3Acollection?page=2.
[144] Stein and Blochman, *Alone No Longer*, 241. 1949 also saw the paving of the road to Carville and the removal of the barbed wire fence surrounding the property. 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 (Summer 2006), 1022.
[145] Stanley Stein, "That Odious Word," *The Star*
[146] John, "Translating Leprosy," 666.

> "the day of one of the games every patient was listening to the broadcast, forgetting for the moment their oft-times multiplied pains of body and mind. Now just at the close of the game the genial and jocular voice of the announcer said: 'Well, the umpire, you know, the umpire is the Leper of the game. Everybody despises him but nobody touches him.' Oh, the pity of it! Could you have seen the joy drain from their faces and the hard bitter looks as the radios were switched off."[147]

The stigma that the patients endured from society, even while isolated in their own community, was seemingly unescapable.

Stanley Stein led the charge for combating the stigma of "leprosy." His plan to change the world's mind about this dreaded disease contained three parts; first he focused on finding an alternative name to leprosy, then he worked towards updating the biblical translation for leprosy, and lastly he campaigned to modernize encyclopedias and medical texts on the reality of the disease. The Stanley Stein Collection at the National Hansen's Disease Museum archive houses hundreds of letters of correspondence between Stein and various groups that speak to his tireless work of changing the narrative around HD. The first stage of his plan, finding a new name for the disease, largely took place from 1931-1952.[148] In this area, Stein found that he already had advocates. Dr. Denney, the first MOC of the national leprosarium, never used the term "leprosy" or "leper" but instead referred to the disease as Hansenitis, named after Gerhard Armauer Hansen the scientist who discovered the causative bacillus.[149] This was later modified to Hansen's disease and became the term that many patients preferred and Stanley Stein advocated for. In 1948,

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[147] Elwood, ed., *Known simply to the rest of the world as Carville….100 years,"* 46.
[148] John, "Translating Leprosy," 660.
[149] Stein and Blochman, *Alone No Longer*, 127.

The International Leprosy Congress began using Hansen's disease rather than leprosy, however, medical professionals remained divided on the issue for years to come.[150]

Stanley Stein's next course of action was to combat the biblical definition of leprosy. The patients were not alone in their desire to remove the preconceived notions of this disease from its biblical namesake. Many medical professionals as well felt that the word leprosy "had become so closely associated with notions of contagion, deformity, and fear that it was not relevant to the modern-day disease and that its use contributed to the continuing stigmatization of the disease."[151] During this time, many new biblical translations were being published which made it a favorable time for change.[152] Dr. Robert Cochrane, an internationally recognized expert on HD and advisor to the American Leprosy Missions, wrote an article in *The Star* discussing the biblical use of leprosy. He stated that the Hebrew word tsraath has been incorrectly translated to mean leprosy rather that its true meaning of defilement. While defilement could include a myriad of diseases, it could also be interpreted as any sort of biblical uncleanliness due to sin that would separate one from God.[153]

Besides the mention of leprosy in the bible, there were other strong religious connections with the disease. There were multiple religious organizations devoted to

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[150] John, "Translating Leprosy," 668.
[151] John, "Translating Leprosy," 670.
[152] John, "Translating Leprosy," 675.
[153] R.G. Cochrane, "Biblical Leprosy—A Suggested Interpretation," *The Star* 15, no 10 (June 1956), 1, accessed October 16, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A3743#page/2/mode/2up.

working with people with the disease, such as the American Leprosy Missions. The story of Father Damien (1840-1889), the Catholic priest who contracted the disease and ultimately died from it at the leprosarium in Hawaii, became a worldwide sensation.[154] The connotations of HD, that those afflicted were morally deficient, might have been further substantiated by the very presence of the people sent to the leprosarium to help them. In a largely Catholic state such as Louisiana, the Daughters of Charity would be seen as the perfect nurses to heal not only the physically sick but the spiritually sick as well. Despite the support of many in the medical and religious fields, Stein received little support from the various publishers of religious texts he contacted. Stein eventually came to agree with many of the publishers who responded to requests for change, that leprosy was a biblical word and "the important thing is for the medical people to get rid of it as a medical term."[155]

Stanley Stein's update on his various campaigns in *The Star* stated that people suffering from Hansen's disease were "neatly boxed in on the one side by the persistent use of leprosy by medical men and on the other by the failure of the clergy to distinguish between today's disease and leprosy of the Bible."[156] In 1960, Stein launched his campaign to encourage modernization of the term leprosy in encyclopedias. He published an article in *The Star* illustrating how the disease was being described at the time. One

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[154] Michael Mizell-Nelson, "Treated as Lepers: The Patient-led Reform Movement at the National Leprosarium, 1931-1946," *Louisiana History: The Journal of the Louisiana Historical Association* 44, no 3 (Summer 2003), 305.
[155] John, "Translating Leprosy," 681.
[156] Stein and Blochman, *Alone No Longer*, 276.

encyclopedia stated “because of the ulceration, fingers and toes may drop off,” another encouraged “better control through segregation of lepers.”[157] The article proposed that an advisory committee of HD experts be formed that publishers could confer with on information for future encyclopedias. Stein also sent a copy of the article to thirty-four encyclopedia publishers. A few months later, he wrote another article for *The Star* praising the encyclopedias who had responded and promised to make efforts to publish correct information in the future. The other publisher who chose not to respond were listed and Stein’s disappointment made clear when he wrote “our reasonable request was made as much for their benefit as ours.”[158] Ultimately, all three of Stein’s destigmatization projects did not return the results that he had hoped for at the time, however, *The Star* is still in operation in 2021, although it is no longer printed at the facility by patients, and continues its mission of spreading “the light of truth about Hansen’s disease” to all that will hear.

Patients were not just focused on fighting for equality outside of the leprosarium during the 1950s. Unfortunately, the appointment of a new Medical Officer in Charge in 1953, Dr. Edward Gordon, required patients to again fight for their already hard won rights. Unlike the previous much-loved MOC Dr. Fredrick Johansen, who had

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[157] Stanley Stein, “Modern Encyclopedias Misinform Public about So-Called Leprosy,” *The Star* 19, no 5 (May-June 1960), 16, accessed October 15, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A4296#page/19/mode/2up.

[158] Stanley Stein, “More About *The Star*’s Encyclopedia Project,” *The Star* 20, no 1 (September-October 1960), 19-20, accessed October 15, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A4298#page/1/mode/2up.

encouraged a community atmosphere at the leprosarium, Dr. Gordon reverted back to old Carville policies. He discouraged fraternization between staff and patients, cancelled the popular baseball games between patients and outside teams, and forcibly discharged all Carville residents who had met the required criteria of twelve negative tests. While many patients longed for the day that they would receive their twelfth negative test result, there were just as many patients who had nowhere to go if they left Carville. Either because they had lived at the leprosarium for so long that they did not know how to start a life on the outside or because they had no family who wanted them, their "lives had become institutionalized."[159]

The cultural shift within the institution that created the greatest patient uproar, however, was Dr. Gordon's attack on "Cottage Grove." The economic prosperity of post-World War II America meant that the "dream of homeownership appeared achievable for all Americans."[160] "Cottage Grove" allowed patients at Carville to live out that same dream. When Carville residents passed away, absconded, or were properly discharged, they rented or sold their cottages to other patients.[161] Dr. Gordon's opinion was that, since these homes were built on hospital property, they were government owned, even though patients had spent considerable money building and maintaining these homes. His plan was to move all residents living in the cottages back to the dormitories and tear "Cottage Grove" down. Patients valued the privacy that these cottages afforded them, but

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[159] Fairchild, "Leprosy, Domesticity, and Patient Protest," 1023.
[160] Fairchild, "Leprosy, Domesticity, and Patient Protest," 1018.
[161] Stein and Blochman, *Alone No Longer*, 166.

interestingly the largest source of contention about moving out of their institutional suburbia was the lack of a kitchen. Since patients could control little of their lives while confined to the leprosarium, they cherished the ability to eat on their own schedule. Not confined to the prearranged hospital cafeteria menu, patients of Cottage Grove clung to the normalcy of cooking and providing for their spouses. Dr. Gordon failed to understand that Carville residents were unlike other hospital patients, he was infringing on their home lives. He was genuinely surprised by the patients' strong reaction to this change. He stated that "he thought the women would be delighted to get out of cooking."[162]

Taking a page from the civil rights movement, patients responded to Dr. Gordon's new policy by cancelling all community activities at Carville. The Chairman of the Patients' Federation, Darryl Broussard, stated that "the cancellations will continue until they give us back what they took from us."[163] Once patients obtained a lawyer to help them fight this issue, Dr. Gordon decided that his time at Carville was over. He requested and was granted a transfer in 1956. The MOC that followed, Dr. Edgar Johnwick favored friendlier policies that allowed patients their original freedoms. He also promised that no patients would be forced to leave Carville against their will. Although all but one cottage was eventually torn down from 1957 to 1960, the federal government built "ten new fully apportioned brick cottages and one complex with plush housekeeping apartments."[164]

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[162] "PHS Plan to Raze Cottages Raises Rumpus, " *The Star* 16, no 1(September-October 1956), 7, accessed October 16, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A3745#page/15/mode/2up.
[163] "Patients Cancel Activities," *The Star* 16, no 1 (September-October 1956), 10.
[164] Fairchild, "Leprosy, Domesticity, and Patient Protest," 1028.

Ironically, the patient's triumph over hospital administration came at a notable time in Carville's history. While at one time patient numbers had been almost as high as 400, the resident population at Carville was down to 281 by 1960.[165] Due to the continued success of the sulfone therapy many of the patients receiving treatment at Carville were able to be discharged after only a few years, even in the most advanced cases. Additionally, new prodecures enacted by Dr. Johnwick, specifically a more liberal pass policy, allowed more freedom than patients had ever experienced. Some patients had cars and were permitted to roam relatively freely in the surrounding communities. Some even held jobs outside of the hospital for the first time since 1894.[166] Adopting Carville names slowly became a thing of the past as well, as more and more patients decided to keep their real names while receiving treatment at Carville.[167] Newer patients admitted to Carville had a different relationship with the leprosarium than those who arrived earlier in the institution's history. Patients began to see the facility as a way station before beginning the rest of their lives rather than a home where they would spend the remainder of their days. This change in mentality meant that "the new generation of patients had little reason to be concerned with individual rights and community welfare within Carville."[168]

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[165] Elizabeth Schexnyder, "Carville: Annual Patient Census," 2, Hansen's Museum.
[166] Fairchild, "Community and Confinement," 368.
[167] Joses P. Ramirez, Jr., *Squint: My Journey with Leprosy* (Jackson: University Press of Mississippi, 2009), 46.
[168] Fairchild, "Community and Confinement," 368.

1960 saw the last compulsory isolation enforced at Carville. Louisiana had already removed HD from its list of diseases requiring quarantine in 1957 as long as the person diagnosed could find a doctor that would agree to supervise their case.[169] There had been continued improvement in the medication used to treat HD, but another breakthrough came in 1971. Using the old dairy barns on the grounds, in 1968 researchers at Carville led by Dr. Kirchheimer had begun an attempt to infect armadillos with the M. leprae bacillus. The reason that HD had been so difficult to study is because it cannot be grown in a lab and no suitable host had been discovered. What was known about the disease is that it thrives in cooler parts of the human body. Because of this, researchers decided to attempt to infect armadillos since they have a lower body temperature and live long enough, roughly twelve to fifteen years, for the typically slow-moving disease to progress.[170] In 1971, two armadillos had developed HD. This meant that the bacilli could be collected "in quantities adequate for exhaustive biochemical analyses and physiological investigations." New treatments would no longer have to be tested on patients first.[171]

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[169] "Leprosy Legislation," Carville Rules and Regulations Collection, Hansen's Museum.
[170] "Dr. Kirchheimer Reports On Armadillos," *The Star* 32, no. 5 (May-June 1973), 2, accessed October 17, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A6036#page/15/mode/2up. It was not discovered until 1975 that armadillos in the wild could contract Hansen's disease naturally. These armadillos seemed to be concentrated in the same areas where large numbers of human cases occurred, mostly in the southern United States. Ilanna Vanessa Pristo de Medeiros Oliveira, Patricia Duarte Deps, and Joao Marcelo Azevedo de Paula Antunes, "Armadillos and leprosy: from infection to biological model," *Revista do Instituto de Tropical de Sao Paulo* 61 (2019), accessed April 7, 2021, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6746198/#.
[171] "Hails Armadillo as Lab Model," *The Star* 32, no 5 (May-June 1973), 12.

In 1980, the leprosarium received a name change. The facility would then be called the Gillis W. Long Hansen's Disease Center after the Louisiana Congressman who fought to keep the institution open while other Public Health Service hospitals began closing in 1981.[172] The new multidrug therapy (MDT) treatment, a combination of dapsone, rifampicin, and clofazimine, as well as the various outpatient clinics now open in multiple states meant that the hospital's usefulness was nearing its end.[173] Even the most serious cases of HD were cured with the new treatment available in nine to twelve months. Without the fear of being shut away in an institution, people suspected to have HD could utilize the clinics to ensure an earlier diagnosis before the disease progressed to the point of disability. These clinics changed what it meant to receive a diagnosis of HD since they provided outpatient treatments that would not greatly disrupt patients' lives.

By 1990, patient numbers had dropped to 185. A creative plan was devised to utilize the empty beds now available. In an ironic twist of fate, Carville was to become a federal prison. In 1990, the federal Bureau of Prisons was low on space, especially for inmates with who were older or were ailing. Initially, the plan was to transfer two hundred inmates, from Springfield, MO and Fort Worth, who were unable to navigate a normal prison institution due to their conditions.[174] However, eventually around five

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[172] John Parascandola, "An Exile in My Own Country: The Confinement of Leprosy Patients at the United States National Leprosarium," *Journal of History of Medicine* 10, no 1 (1998), 122. The #66 was dropped from the leprosarium name in 1951.

[173] Ramirez, Jr., *Squint,* 208-209. Outpatients clinics are located in Arizona, New York, Florida, Washington, Texas, California, and even one in Puerto Rico.

[174] Associated Press, "Leprosy Center to Take 200 Ill U.S. Prisoner," *The New York Times,* December 2, 1990, accessed October 17, 2020, https://www.nytimes.com/1990/12/02/us/leprosy-center-to-take-200-ill-us-prisoners.html.

hundred inmates shared space with the patients at Carville.[175] A spokesman for the Bureau of Prisons stated "obviously we're not going to mix civilians in with convicted felons."[176] That is, however, exactly what happened. Though there was some effort to separate the patients and inmates, they did share the grounds and some of the common spaces within the facility and could easily interact with one another. This experiment did not last long. The inmates were removed from Carville in 1994 after it was determined that the situation was not ideal for the patients.[177] Although this was not a lengthy period in Carville's history, it shows that the leprosarium still was not viewed by outsiders or administration as the home that it was for the patients.

The leprosarium officially closed in 1999; "a victim of its own success."[178] The Gillis W. Long Hansen's Disease Center was moved to Baton Rouge and reduced in size.[179] Eighty-four patients remained at the facility, many of whom had lived at Carville for the majority of their lives.[180] The average patient age was eighty-five.[181] The federal government had given back the property to the State of Louisiana and the state planned to use the site for a Louisiana National Guard at-risk youth program, so patients had to leave. Many of the patients took the offered annual living stipend of $33,000 and left the hospital. Other patients staged a protest in March 1999 stating that "we were separated

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[175] Neil White, *In the Sanctuary of Outcasts* (New York: HarperCollins, 2009), 113.
[176] Associated Press, "Leprosy Center to Take 200 Ill U.S. Prisoner."
[177] White, *In the Sanctuary of Outcasts,* 308.
[178] Reeves and Reeves, "Carville-One Hundred Years of Public Health," 31.
[179] Elizabeth Schexnyder, "Carville: Silos for Dairy Barn and Armadillo Research," New Orleans Historical, accessed October 17, 2020, https://neworleanshistorical.org/items/show/632?tour=55&index=8.
[180] Schexnyder, "Carville: Annual Patient Census," 4, Hansen's Museum.
[181] Ramirez, Jr., *Squint,* 102.

from our families and forced to create a new family…If we are moved as planned, we will be uprooted and once again separated from our families…To do this to us a second time is not only cruel, but unjust."[182] The situation received widespread media attention and sympathy for the patients; a sign that the tide might have turned on the stigma against this once dreaded disease. The government finally relented and allowed the patients who wanted to stay the choice to do so.[183]

The National Hansen's Disease Museum opened in 2000 in the old staff cafeteria of the facility to preserve the fascinating history of the institution and HD in the United States. With patient numbers continuing to dwindle, the Daughters of Charity "officially ended their mission" at Carville in 2005.[184] The last two patients finally left the facility in 2015 when they moved into a nursing home in nearby Baton Rouge. As the institution began its new life as a Louisiana National Guard installation, it would be easy to think that this chapter of American medical history is behind us. However, with the recent emergence of COVID-19 worldwide, familiar themes are beginning to resurface. The stigma and fear surrounding COVID-19 and the uncertainty that continues to shroud its transmission and impact is the same as the ambiguity that surrounded HD. As countless nations quarantine in an attempt to stifle the progress of COVID-19, individuals are

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[182] Gaudet, *Carville*, 163.

[183] Pam Fessler, "Confined by Leprosy, But Open To The World: Remembering 'Ambassador' Mr. Pete," *NPR*, December 28, 2017, accessed October 17, 2020, https://www.npr.org/2017/12/28/573844426/confined-by-leprosy-but-open-to-the-world-remembering-ambassador-mr-pete.

[184] Elizabeth Schexnyder, "History of the National Hansen's Disease (Leprosy) Program: Carville Hospital Timeline," Health Resources and Services Administration, last updated July 2018, accessed October 18, 2020, https://www.hrsa.gov/hansens-disease/history.html.

feeling a small taste of what patients at Carville experienced as "these types of separation do give birth to grief as losses of employment, home, family, and love mount up."[185] Hopefully, as we continue to fight this global pandemic, we will be able to use the lessons that Carville and similar institutions have taught us about the importance of community and the dissemination of accurate medication information.

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[185] Jose Ramirez, Jr., "COVID-19 and Hansen's Disease: Similarities and Differences," *The Star* 64, no 27 (January-June 2020), 4, accessed October 19, 2020, https://static1.1.sqspcdn.com/static/f/741376/28330736/1596114896950/The+Star+2020-7-13.pdf?token=uDXNSwxwtanSOpS72GCjEBqyCXw%3D.

CHAPTER 3

Digital Museum Exhibit Theory and Application

Daniel J. Cohen and Roy Rosenzweig in *Digital History: A Guide to Gathering, Preserving, and Presenting the Past on the Web* were among the first historians to explore the question "in what ways can digital media and digital networks allow us to do our work as historians better?"[186] The widespread availability of the internet has provided museums, especially smaller institutions with less resources and funding, with more avenues to reach potential patrons and researchers than ever before. Increasingly user-friendly applications make it possible for museum workers with little knowledge of newer technology to expand their offerings to the public and to connect with patrons in more engaging and modern formats. The recent pandemic has shown that digital offerings for museums may no longer simply be optional to supplement physical exhibits but will become expectations by the public. Museums that resist advancements into digital exhibitions will find themselves falling further behind other institutions and unable to stay relevant in the increasingly digitally based twenty-first century.

The Library of Congress launched the first known online exhibit, titled *Revelations from the Russian Archives*, in June 1992. Although the exhibit was difficult

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[186] Daniel J. Cohen and Roy Rosenzweig, "Introduction," *Digital History: A Guide to Gathering, Preserving, and Presenting the Past on the Web,* accessed January 17, 2021, https://chnm.gmu.edu/digitalhistory/introduction/.

to navigate and had little interactivity, this attempt provided a lot of promise for the future of digital exhibits and intrigued users.[187] Due to the complexity of developing early electronic content, only larger institutions and universities were initially able to afford the specialized staff and technology needed to create digital exhibits. As the ubiquity of the internet grew, increasingly sophisticated technology and easy to use software was developed in the late 1990s and early 2000s. With these advances, smaller museums and archives have been able to successfully incorporate online exhibits into their repertoire.

Many museums, especially smaller institutions, were at first hesitant to develop digital exhibits for fear that patrons would no longer physically visit the museums they could access electronically. However, as long as museums create digital content that works in tandem with their physical exhibits, rather than just providing information in two formats, it has been shown that institutions can reach wider audiences rather than cannibalizing existing patron numbers.[188] Originally started in 1995, the Smithsonian Institution Libraries' website houses the "Library and Archival Exhibitions on the Web" guide, which currently lists "over 3000 links to online exhibitions from libraries, archives and museums around the world."[189] It is clear that digital exhibits are not just a fad.

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[187] Aleksandr Gelfand, "If We Build It (and Promote It) They Will Come: History of Analog and Digital Exhibits in Archival Repositories," *Journal of Archival Organization* 11 (2013), 66, accessed January 29, 2021, https://www.tandfonline.com/doi/full/10.1080/15332748.2013.882160.

[188] Gelfand, "If We Build It (and Promote It) They Will Come," https://www.tandfonline.com/doi/full/10.1080/15332748.2013.882160.

[189] "About this Site," Library and Archival Exhibitions on the Web, accessed January 29, 2021, https://www.sil.si.edu/SILPublications/Online-Exhibitions/about.htm.

There are many benefits, especially for a museum like the National Hansen's Disease Museum, in creating digital exhibits. For one, the museum currently has no additional area to expand its physical exhibit space. The museum is housed in the former leprosarium's staff cafeteria while the Louisiana National Guard operates the remainder of the former institution. It is unlikely that the museum will receive additional room for exhibition expansion. A digital exhibit would require very little square footage in the existing space. Also, museums can create any number of digital exhibits of any size while still not encroaching on additional physical space. Electronic storage can be purchased at increasingly larger intervals with minimal extra cost. This is a viable option for museums such as the National Hansen's Disease Museum with little space and a smaller, fixed budget.

Digital exhibits and digitized materials also provide patrons and researchers with greater accessibility.[190] Many museums and archives house extensive collections that go largely undiscovered by visitors. Also, there might be some documents and items that are too delicate to be displayed in a traditional analog exhibit. Electronic exhibits also lend themselves more to different types of media, like audio and video files, that are less likely to be incorporated in traditional physical exhibits in smaller museums. Digital exhibits that are shared online can also create more interest in and knowledge about the

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[190] Tim Grove, "History Bytes: Online Exhibits," *History News* 59, no. 3 (Summer 2004): 5, accessed March 28, 2021, https://www.jstor.org/stable/pdf/42653965.pdf?ab_segments=0%252Fbasic_search_gsv2%252Fcontrol&refreqid=excelsior%3Aefe040792cb764518a870194f9cb0a4b.

institution. As stated in previous chapters, the National Hansen's Disease Museum is, even today, very isolated. It is not located in a large town nor is it advertised widely as a tourist attraction, as other museums are. A greater online presence, especially one that included digital exhibits, could spark interest in visiting the museum in person or would allow researchers to access information from around the world. Online exhibits can also create a more engaging space, allowing for visitors to discuss collections and even creating a place to capture public memory about the subject of the exhibit.[191] There has been a resurgence of conversation about the importance of accessibility due to the recent pandemic.[192] With the recent push for remote and online learning, online and digital offerings can assist schools in building more diverse curriculums covering topics that would not have previously been covered.[193] The National Hansen's Disease Museum has been closed since mid-March 2020 with no definitive time frame of when it will be able to reopen. Their limited online digital exhibits have been of great assistance to me in my research over the past year, providing me a way to interact with the museum and archive when I am physically unable to do so. Access to digitized holdings could also entice

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[191] Cohen and Rosenweig, "Exhibits, Films, Scholarship, and Essays," *Digital History,* accessed January 27, 2021, https://chnm.gmu.edu/digitalhistory/exploring/4.php.

[192] Deborah Agostino, Michela Arnaboldi, and Melisa Diaz Lema, "New Development: COVID-19 as an accelerator of digital transformation in public service delivery," *Public Money and Management* 41, no 1 (2021), accessed January 27, 2021, https://www.tandfonline.com/doi/full/10.1080/09540962.2020.1764206. Elizabeth Merritt, "Digital Tools for Pandemic Times," *Center for the Future of Museums Blog*, November 18, 2020, accessed January 27, 2021, https://www.aam-us.org/2020/11/18/digital-tools-for-pandemic-times/.

[193] Allyson Mitchell, Sarah Linn, and Hitomi Yoshida, "A Tale of Technology and Collaboration: Preparing for 21st-Century Museum Visitors," *Journal of Museum Education,* accessed March 27, 2021, https://www.tandfonline.com/doi/epub/10.1080/10598650.2019.1621141?needAccess=true.

visitors to make the journey to discover what else the museum has to offer once it reopens.

Despite all of the advantages of digital exhibits, there are some drawbacks in utilizing electronic formats. One of the disadvantages of digital media is that as technology becomes obsolete, the cost of storing electronic files increases in the future. There can be a significant capital outlay in obtaining new technology. Means of digital storage has shifted from floppy disks, to CDs, to flash drives in a relatively short amount of time.[194] Some institutions are now utilizing cloud software to store their data and digital collections. Electronic files are also susceptible to corruption and damage in different ways than material collection items are. However, museums can avoid some of these pitfalls by creating "a disaster recovery plan that details the process of recovering data and information technology systems (both hardware and software) after a natural or man-made disaster" and maintaining regular backups of digital files.[195] Digital exhibits could also alienate older or less-technically savvy museum patrons.[196] Museums should consider their audience when creating exhibits, both analog and digital. Easily navigable digital exhibits will be more enjoyable for visitors across the spectrum of technical skill levels. By utilizing the tenets of universal design and creating a logical and easy to use

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[194] Daniel Cohen, "The Future of Preserving the Past," in *The Public History Reader*, ed. Hilda Kean and Paul Martin (New York: Routledge, 2013), 220.

[195] Edward M. Corrado and Heather Lea Moulaison, *Digital Preservation for Libraries, Archives, and Museums* (Boulder, CO: Rowman & Littlefield, 2014), 4, accessed January 29, 2021, https://ebookcentral.proquest.com/lib/sfasu-ebooks/reader.action?docID=1676304.

[196] Cohen, "The Future of Preserving the Past," 216.

site, a digital exhibit can be created that not only accommodates those with disabilities, but is "usable by all."[197] Also providing both physical and digital exhibits will help keep visitors' interest as well as allowing patrons to interact with the information at their own comfort level.

While the format and execution of creating a digital exhibit may present different challenges than a physical exhibit, the planning process remains the same. David Dean presents a project model for exhibition development in *Museum Exhibition: Theory and Practice* that I have utilized to create a digital exhibit for the National Hansen's Disease Museum (Figure 16).[198] This model consists for four phases: conceptual, development, functional, and assessment. The conceptual phase begins when ideas for new exhibits are generated and decided upon by an institution. The development phase includes gathering resources and presenting the exhibit. These first two stages will be the phases that I will mainly focus on as the last two, functional and assessment, largely emphasize how the visitors are responding to the new format and whether or not the museum has achieved its goal with the exhibit. Once the digital exhibit is in place, the National Hansen's Disease Museum can complete the last two phases of the exhibition development model to gauge

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[197] Valerie Fletcher, Betty Siegel, and Ray Bloomer, "Going Beyond: What Does Universal Design Look Like?" *American Alliance of Museums,* October 1, 2010, accessed March 27, 2021, https://www.aam-us.org/2010/10/01/what-does-universal-design-look-like/.
[198] David Dean, *Museum Exhibition: Theory and Practice* (New York: Routledge, 1996), 17, accessed January 28, 2021, http://web.a.ebscohost.com/ehost/ebookviewer/ebook?nobk=y&sid=50e8c836-bfff-42af-8fb5-780230d2b455@sessionmgr4008&vid=3&format=EK.

whether they should maintain or expand their offerings in this format or revert to largely analog exhibits.

The conceptual phase of the exhibition project model begins with developing exhibit ideas that anticipate audience needs and wants and follows the mission of the museum.[199] According to their website, the National Hansen's Disease Museum's mission states, "supporting the National Hansen's Disease Program (NHDP), the museum: interprets the history, treatment and rehabilitation of leprosy in the US, honors those who lived at the national leprosarium as patients, and celebrates health care professionals who made medical history as they battled leprosy."[200] Since the building was originally a staff cafeteria, it does not have an ideal configuration for its current use. The museum design features thematic exhibits broken up by room. For example, there is a room dedicated to the Daughters of Charity staff who worked at the facility and another room dedicated to the many organizations that were a part of community and patient life at the leprosarium. Because of the thematic design, there is no chronological reference for visitors. I have designed an exhibit that not only incorporates the history of the facility in a linear timeline, but includes personal stories of those who lived and worked at the facility to create a more personal connection with the former institution and tie into the museum's mission (Figures 17 – 24).

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[199] Dean, *Museum Exhibition: Theory and Practice* (New York: Routledge, 1996), 18, accessed January 28, 2021, http://web.a.ebscohost.com/ehost/ebookviewer/ebook?nobk=y&sid=50e8c836-bfff-42af-8fb5-780230d2b455@sessionmgr4008&vid=3&format=EK.

[200] "The National Hansen's Disease Museum," Health Resources and Services Administration, last modified September 2020, accessed January 29, 2021, https://www.hrsa.gov/hansens-disease/museum.

The museum's audience should also be taken into consideration when building a new exhibit. Dean states that visitors "will react negatively to an environment in which he or she is not physically or intellectually comfortable."[201] Because this exhibit is digital, the same considerations of physical flow and space throughout the museum are not as important as they would be in an analog exhibit design. However, patrons' skill and comfort level with technology become much larger factors to consider with an online exhibit. The National Hansen's Disease Museum has recently acquired a large touchscreen television that has been placed in the center of the main exhibition room. Currently, the touchscreen features a slideshow of photographs. The curator has expressed interest in a digital exhibit that would provide patrons and researchers with additional photographs as well as audio files and transcripts of oral histories previously only available in the museum archives. The existing physical exhibits have remained on the walls that line the main exhibition room, so visitors can choose to interact with the digital exhibit or just view the analog exhibits depending on what type of experience they would like to have. Since the digital exhibit will be interactive, patrons will be able to move throughout the exhibit at their own pace or be able to access certain files types or specialized information if they should so desire.

The content discussed at the National Hansen's Disease Museum can also make visitors uncomfortable. The entire institution commemorates a facility that, for a long

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[201] Dean, *Museum Exhibition*, 29.

period of its history, held patients suffering from a stigmatizing disease against their will. Although there are bright spots in its history, like the discovery of a cure for Hansen's disease and the community that patients created while living there, many of the stories and pictures can be difficult for patrons to digest. In *Interpreting Difficult History at Museums and Historic Sites*, Julia Rose discusses how museums can help patrons reconcile the problematic and challenging history that some sites hold. Rose uses Commemorative Museum Pedagogy (CMP) to describe the difficulty some visitors have accepting unsettling history. CMP posits that when patrons are faced with historical narratives that are uncomfortable for them, what they are really experiencing is grief and loss. The grief that visitors can feel might be due to loss of self-identity, a feeling of helplessness or guilt, or conflict with what they believed to be the truth.[202] Many of the patrons to the National Hansen's Disease Museum visit because they have a familial tie to the institution and wish to learn more about a family member's life. These visitors can find certain aspects of the facility's history difficult and may need time to reflect and process what they learn.

Rose proposes a few suggestions in order to ease visitors into difficult history narratives. First, build empathy in visitors by sharing face-to face narratives. This means putting faces to the history rather than discussing groups of people exclusively in exhibits. Sometimes visitors have a difficult time accepting history that does not fit

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[202] Julia Rose, *Interpreting Difficult History at Museums and Historic Sites* (Lanham, MD: Rowman & Littlefield, 2016), 73.

within their preconceived notions because they are unable to tie that story to an individual. Freeman Tilden discusses this same idea in his principles of interpretation. He states that "the purpose of interpretation is to stimulate the reader or hearer toward a desire to widen his horizon of interests and knowledge, and to gain an understanding of the greater truths that lie behind any statements of fact."[203] Since the National Hansen's Disease Museum is organized thematically, it focuses on institutional history and the typical everyday lives of patients and hospital staff. The digital exhibit emphasizes individual patient and staff stories so that museum visitors will connect the narratives with actual people who lived and worked at the facility. Rose also suggests using active voice when possible over passive voice in exhibits and interpretation to humanize the narrative and make the individual the subject of the story.[204]Another benefit of the exhibit being in a digital format is that if patrons feel uncomfortable with the information provided, they will be able to easily skip around within the exhibit, leave the exhibit to reflect and return where they left off, and share the online exhibit with loved ones around the world to help process the difficult emotions that might arise.

The second section of Dean's exhibition project model is the development phase. This phase consists of two stages, planning and production. The planning stage entails setting the goals for the exhibition, determining exhibit design, and evaluating museum resources, such as the budget available for the project and deciding which archival

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[203] Freeman Tilden, *Interpreting Our Heritage* 3rd ed (Chapel Hill: The University of North Carolina, 1977), 33.
[204] Rose, *Interpreting Difficult History at Museums and Historic Sites*, 102-103.

collections will be featured in the exhibit.[205] The goals of this digital exhibit are threefold. One objective is to share personal stories of people who lived and worked at the leprosarium which will help the museum in meeting its mission to honor and celebrate these individuals. Another goal of the digital exhibit is to infuse the existing space and exhibitions with a modern twist that will hopefully attract new visitors. In my experience visiting the National Hansen's Disease Museum, many of the visitors were older. A digital exhibit will appeal to a different demographic of visitor. The final goal is to bring attention to interesting pieces within the archive that the public does not typically have access to without a research appointment. In assessing the resources available for this project, the museum already has a sizeable portion of photographs, oral histories, and transcripts stored digitally so there has not been a large investment of time converting these objects into an electronic format. Also, when the museum decides to update or add to the exhibit, they already have an in-house scanner with high resolution capability.

Beverly Serrell discusses the concept of having a "big idea" for a successful exhibit in *Exhibit Label: An Interpretive Approach.* A patron to a museum is more likely to walk away from an exhibit with retained knowledge and a positive experience if an exhibit has a clearly defined scope and goal. The National Hansen's Disease Museum already has a tremendous amount of information available in analog form on-site.

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[205] Dean, *Museum Exhibition*, 22.

The title or "big idea" of the exhibit will be Stories from Both Sides of the Hedge. This title, as Beverly Serrell suggests, states a clearly defined idea of what the visitor can expect from the exhibit.[206] The use of the words "both sides of the hedge" implies that there were differently lived experiences on and separation even within the walls of the institution created specifically for these patients. The use of the word "stories" should indicate that personal narratives will be the main focus of the exhibit. There is a short introductory page or "label" the describes the intent of the exhibit. Consistent fonts have been used on all title, group, and caption texts to maintain a sense of cohesion throughout the exhibit.[207] In order for the flow of the narrative to be uninterrupted, I have clearly defined characters and active rather than passive language to create meaningful stories in each of the three sections of the exhibit; Life at the Louisiana Leper Home, Life at the National Leprosarium, and the Gillis W. Long Hansen's Disease Center.[208] Each section will focus on patients and/or employees of the facility, with the majority of the narratives concentrated on the time period of the national leprosarium. This is due to the fact that this time period has the most information and archival material available as well as being the longest span of time in the facility's history. Information on each page has been split into easily readable blocks of text rather than longer paragraphs. Bullet point lists have been included to further break up larger sections of text.[209]

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[206] Beverly Serrell, *Exhibit Labels: An Interpretive Approach* (Lanham, MD: AltaMira Press, 1996), 2.
[207] Serrell, *Exhibit Labels*, 22-24.
[208] Serrell, *Exhibit Labels,* 14.
[209] Serrell, *Exhibit Labels,* 26.

Dean discusses six key elements that should be considered when designing an exhibit; value, color, texture, balance, line, and shape. Value is the level of lightness and darkness but not referencing color specifically. Darker values are attributed to heaviness while lighter values have a lighter weight.[210] Due to the heavy subject matter of this exhibit, I have focused on a neutral to darker value, however, I have chosen not to have the overall value of the exhibit be too dark so as not to have a depressing or unappealing effect. Colors also convey emotion. Many of the photographs used towards the beginning of the exhibit are black and white, but some colorful photographs are used later in the exhibit, which gives a feeling of hope and progress. The text will almost exclusively be white, black or gray in order to maintain a high level of contrast and in a sans serif font, which makes reading easier on a screen.[211]

Texture involves roughness or smoothness which provides visual interest in exhibits. This element is hard to achieve in an electronic format, but a version of texture has been attained in this digital exhibit by layering text over photographs to create a sense of depth.[212] Photographs that capture the spirit of the corresponding exhibit page have been included under each title label to provide complexity to an otherwise flat medium. Similarly, variety in shape provides interest to an exhibit by mixing geometric and

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[210] Dean, *Museum Exhibition,* 37.
[211] Cohen and Rosenzweig, “Text,” *Digital History,* accessed January 27, 2021, https://chnm.gmu.edu/digitalhistory/designing/2.php. San serif fonts can be seen as less serious than serif fonts, but I have chosen to prioritize readability. There are many san serif fonts available, and due to the subject matter of the exhibit, a more professional san serif font was chosen.
[212] Dean, *Museum Exhibition,* 39.

organic figures to the content.[213] Shape is another element that can be difficult to vary in an online exhibit, so I focused more on flow and balance. Balance describes how content, either text or objects, are distributed in the exhibit space. Symmetrical exhibits, which are arranged where objects of "equal size and weight match across a mid-point," are considered formal, while asymmetrical exhibits have a more informal feel.[214] This digital exhibit is organized in a more asymmetrical format to create a more interesting flow. Patient and employee narratives are split into columns, separated by "the hedge" as they were in real life at the leprosarium, on each exhibit page. This allows the visitor to view the different experiences of both the patients and staff simultaneously for comparison. Multiple modalities are used through each exhibit page; singles pictures, slideshow galleries, text, and block quotes, in order to break up the information in more interesting and visually appealing ways. The last element, line, is similar to balance in that it deals with the use of space to suggest directionality for the user.[215] Since this exhibit is digital, it will behave as a webpage does, with content being linear and movement through the exhibit will take place by vertical scrolling.

The production stage of the development phase is where all of the planning stages come together to create the actual exhibit. I have decided to showcase this digital exhibit using the webpage creator site Weebly. This site provides multiple free templates that are cost effective for small museums like the National Hansen's Disease Museum. These

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[213] Dean, *Museum Exhibition*, 40.
[214] Dean, *Museum Exhibition*, 39.
[215] Dean, *Museum Exhibition*, 40.

templates also require little technical skills or no knowledge of coding to use which is good news for museums without specialized staff members. I chose Weebly over other more traditional programs for digital exhibit creation due to its intuitive platform and because the finished product will be similar to something all visitors have utilized before. Other content management systems (CMS), like CONTENTdm and Omeka, are more suited for displaying objects rather than the largely interpretive style of exhibit I felt was needed for the National Hansen's Disease Museum.[216] These CMS programs, particularly the free versions, are difficult to navigate and do not have the narrative flow that a website provides. Also, initially at least, the digital exhibit will only be accessible in the museum itself. Hopefully, the National Hansen's Disease Museum website will house this exhibit as well but because the museum website is operated through a federal agency, the Department of Health Resources and Services Administration, all content on the website must go through extensive approvals. Once the exhibit has been approved however, the Weebly site should prove to be a smoother addition to the existing webpage than a CMS program.

The exhibit is organized by time period, with either health care workers and/or patients and their stories representing that particular era in the institution's history. The time periods are separated largely by changes in the institution's title, when the facility

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[216] Emily Marsh, "Chickens, aprons, markets, and cans: How the National Agricultureal Library uses Omeka as its content management system for digital exhibits," *Digital Library Perspectives* 33 no 4 (2017), 4, accessed January 29, 2021, https://www.emerald.com/insight/content/doi/10.1108/DLP-03-2017-0009/full/pdf.

was the Louisiana Leper Home, while the institution was known as the national leprosarium, and then when the hospital transitioned to largely a research facility known as the Gillis W. Long Center. Martin R. Kalfatovic in *Creating a Winning Online Exhibition: A Guide for Libraries, Archives, and Museums* suggests providing visitors multiple avenues through an online exhibit because viewers tend to skip around within exhibits of this format. However, all paths through the exhibit should be accessible to the visitor at all times.[217] Tabs with all portions of the exhibit will be visible at the top of the webpage, no matter what part of the exhibit a visitor is currently viewing, so that patrons can move freely within the sections with ease. The touchscreen that the exhibit will be featured on in the museum is also already in use and at eye level to the average visitor. Since the television screen is large and the pages can be manipulated by scrolling, this exhibit can be accessible at eye level for a wider variety of heights than an average static analog interpretive panel would be.[218] This should hopefully reduce visitor fatigue and increase the amount of time a patron is willing to spend on this exhibit.

The last two phases of the exhibition project model, functional and assessment, are undertaken once an exhibit has been presented to the public. The functional phase consists of maintaining and terminating the exhibit. The continuation of the exhibit should be easy for the National Hansen's Disease Museum since all of the items and media utilized within the exhibit are museum-owned so the exhibit will not be dependent

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[217] Martin R. Kalfatovic, *Creating a Winning Online Exhibition: A Guide for Libraries, Archives, and Museums* (Chicago: American Library Association, 2002), 84.
[218] Dean, *Museum Exhibition*, 41.

upon loan agreements from other institutions. The exhibit also need not be terminated if the museum feels that it is a beneficial addition to the rest of its offerings. This leads next to the assessment phase where the museum will evaluate if the exhibit accomplished its goals. If the museum conducts a survey about its exhibits and finds helpful suggestions to improve the digital exhibit, those changes can be quickly and easily made in the Weebly format. There is no need to spend money printing additional interpretation panels or images and allocating time reorganizing a physical exhibit since pages can simply be added, removed, or updated online and published immediately.[219]

As museums have changed over the years, so too have visitors, and institutions that wish to survive in an increasingly competitive environment have to meet the needs of a new generation of digital natives. The advantages of adding a digital exhibit to the National Hansen's Disease Museum's offerings far outweigh any drawbacks. The museum has had the same exhibits for many years, and since they have no additional space and all of the existing exhibits are integral to telling the story of the institution, it would be hard to remove any one of them in order to replace it with something new. Technology has come a long way and it is easier and more cost effective than ever for a small institution to start incorporating modern ideas and techniques into their repertoire. Digital exhibits can be changed and updated much more quickly than analog exhibits, meaning that the exhibit can be shaped to meet the expectations of visitors in a timely

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[219] Dean, *Museum Exhibition*, 25.

fashion and provide an incentive for patrons to visit the museum more regularly. In addition to sharing their collections with others online, the internet has allowed for museums and organizations to share their experiences and findings with similar institutions about what works best in this relatively new medium. Online exhibits have allowed smaller institutions to now operate in the same space that was previously only available to much larger museums and universities.

CONCLUSION

In the November-December 1944 edition of *The Star,* which commemorated the 50th anniversary of the institution, the editor wrote "if *The Star*, in reviewing the past, did not take proper cognizance of it and give credit where credit is due, then we should be guilty of ingratitude, the basest of all human frailties."[220] Memorializing our past, even if it is difficult and somewhat dark, is important. The medical staff who dedicated their lives to the care of others and the patients who fought for the rights of their fellow HD sufferers deserve to be remembered. The importance of the lessons taught by these exhibits, whether it is closure for a visiting family member, a cautionary message for the future, or teaching human empathy, cannot be understated. Museums like the National Hansen's Disease Museum should continue to seek out ways to share their collections and stories in new and creative methods to reach as many people as possible.

Chapters One and Two focus on the history of the leprosarium from its inception in 1894 until its official closure in 1999. The institution was a microcosm, subjected to the same historical movements that impacted the rest of the United States. It came under federal authority as the country moved from rugged individualism to the progressive idea

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[220] Stanley Stein, "Past Progress – Future Goals," *The Star* 4 no 3 (November-December 1944), 15, accessed January 31, 2021, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A1183#page/17/mode/2up.

that a nation had a duty to care for its sick. Decades later patients fought for their basic rights such as voting, marriage, and homeownership as much of the country struggled for those same freedoms during the more well-known civil rights movements. While the institution did isolate its patients from the outside world, in some cases against their will, it also became a home for many. This dynamic created a complicated and interesting relationship between patient and institution.

Chapter Three explored digital exhibition theory and its application for this project. Although David Dean's exhibition project model is traditionally used for the creation of physical exhibits, many of the components were applicable to digital exhibit design as well. Since online exhibits are contained on a screen, there are not the same concerns with space, flow, or directionality in a digital exhibit. However, there is similar focus on the readability, movement, shape, balance, and color usage in a digital exhibit. If an electronic exhibit is thoughtfully designed, it can easily be expanded to include additional narratives and content. The "big idea" for this exhibit, as discussed by Beverly Serrell in *Exhibit Labels: An Interpretive Approach*, is to synthesize the tremendous amount of information available at the museum and in the archive and create a chronological narrative flow using the stories and words of the people who lived the experiences as both patient and employee.[221] Tying the history and culture of the national leprosarium to individuals and their personal stories will hopefully not only keep visitors

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[221] Serrell, *Exhibit Labels*, 1-2.

interested, but to have them empathize with and care about the people who lived and worked at this very special place. The main goal of this exhibit, in the words of Freeman Tilden, is “not instruction, but provocation.”[222]

In the midst of a worldwide pandemic, the stories of the patients and medical staff of the national leprosarium have never been more relevant. As people across the world seek out entertainment, distractions, and avenues for remote learning during this trying time, museums should be meeting visitors where they are and providing them with access to familiar digital options that patrons utilize in other aspects of their lives. Museums now attract a wide range of visitors, from generations more comfortable with analog exhibits to digital natives who expect engaging and interactive content. Over the years, there have been an increasing amount of academic article and trade publications dedicated to utilizing digital technologies and online content. Museums do not have to abandon tried and true physical exhibits, however in an increasingly competitive and post-pandemic world, they must embrace change. As Aleksandr Gelfand writes, “rather than being in opposition to each other, a symbiotic relationship between analog and digital is an ideal that should be aimed for. If done properly, online exhibits may encourage distant viewers to visit in person and persuade a local visitor to turn to the online component.”[223]

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[222] Freeman Tilden, *Interpreting Our Heritage*, 3rd ed. (Chapel Hill: The University of North Carolina, 1977), 32.

[223] Aleksandr Gelfand, “If We Build It (and Promote It) They Will Come: History of Analog and Digital Exhibits in Archival Repositories,” *Journal of Archival Organization* 11 (2013): 77, accessed January 28, 2021, https://www.tandfonline.com/doi/pdf/10.1080/15332748.2013.882160?needAccess=true.

Online exhibits can easily be built with accessibility and universal design in mind. The idea behind universal design is to create the best exhibit possible for all visitors regardless of their ability and skill level. Font sizes, color contrast, and alternate text can be manipulated and applied to interpretative text and captions for visitors with visual impairments, subtitles or transcripts should be provided for audio and video files for patrons who are hard of hearing/deaf, and easily navigable websites will make a digital exhibit more enjoyable for all. Digital exhibits also lend themselves to better accessibility due to the fact that there is no physical space for a patron to navigate which can be a barrier for visitors with a variety of impairments. Incorporating universal design from the onset of exhibit development should not only consider serving those with different skill levels, but different learning styles as well. Giving visitors the ability to interact with an exhibit in multiple ways, formats, and from various angles allows for all learning types to absorb and understand the information being provided to them.[224] Not only are these capabilities often already incorporated into newer website design builders, such as Weebly, they are easy to utilize for curators unfamiliar with creating digital content.

This digital exhibit will be given to the National Hansen's Disease Museum for use in its main exhibition room and on its website. I have worked with the museum's curator, Elizabeth Schexnyder, to create a digital exhibit that will be useful for the museum but can also be used as a media database for researchers. Including a space to

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[224] Valerie Fletcher, Betty Siegel, and Ray Bloomer, "Going Beyond: What Does Universal Design Look Like?" *American Alliance of Museums*, October 1, 2010, accessed March 27, 2021, https://www.aam-us.org/2010/10/01/what-does-universal-design-look-like/.

showcase the countless oral histories that have been collected by the museum in addition to a more traditional digital exhibit will allow the archive to be utilized in a way that it never has been before. Researchers and visitors alike will be able to hear in depth narrative directly from the people who actually lived them. With a small staff and limited available time, the museum might not have been able to create this type of exhibit but with the framework available to them, the exhibit can be easily enhanced to include much more information and depth.

It is my hope that the exhibit not only meets the needs of the museum by adding personalized stories of individuals who had a great impact on the national leprosarium but that it also provides a connection between visitors and a truly unique piece of American history. The evolution of the patients' lives, from victims of societal stigma to finding their voice and shaping their own language and culture, show the tenacity of the human spirit. Even when the laws changed and the federal government relinquished authority over the institution, many patients clung to the community that was created at Carville. Even as quickly as the world is changing and growing, the location of the National Hansen's Disease Museum is still very isolated. This digital exhibit will broadcast the fascinating history that the museum holds to an entirely new group of visitors and provide inclusivity to a site historically known for its exclusivity.

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BIBLIOGRAPHY

Primary

Carville Historic District. Digital Image. CDC Public Health Image Library (PHIL). Accessed November 18, 2019. *https://phil.cdc.gov/Details.aspx?pid=8920*.

Entrance to Indian Camp Plantation, 1890's. Photograph. New Orleans Historical. Accessed November 18, 2019. https://neworleanshistorical.org/items/show/621?tour=55&index=0#&gid=1&pid=2.

"Hope House," patient dormitory at the Louisiana Leper Home, 1906." Photograph. New Orleans Historical. Accessed November 18, 2019. https://neworleanshistorical.org/items/show/621?tour=55&index=0#&gid=1&pid=12.

Legislative History of Leprosy. National Hansen's Disease Museum and Archives. Permanent Collection. Carville, Louisiana.

"Leprosy: Fact Sheet." World Health Organization. 2018. Accessed August 6, 2018. http://www.who.int/news-room/fact-sheets/detail/leprosy.

Manes, Claire. *Out of the Shadow of Leprosy: The Carville Letters and Stories of the Landry Family.* Jackson: University Press of Mississippi, 2013.

Martin, Betty. *Miracle at Carville*. Edited by Evelyn Wells. Garden City, New York: Doubleday and Company, Inc., 1950.

Oral Histories. The National Hansen's Disease Museum and Archives. Permanent Collection. Carville, Louisiana.

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

———. "A Day at Carville: My Home—*Mi Casa*." *Public Health Reports* 123 (2008): 222-224. Accessed August 6, 2018. https://www-ncbi-nlm-nih-gov.steenproxy.sfasu.edu/pmc/articles/PMC2239333/.

Slave Quarters on Indian Camp Plantation, 1894. Photograph. New Orleans Historical. Accessed November 18, 2019.

https://neworleanshistorical.org/items/show/637?tour=55&index=7#&gid=1&pid=2.

Stein, Stanley and Lawrence G. Blochman. *Alone No Longer: The Story of a Man who Refused to be One of the Living Dead.* New York: Funk & Wagnalls Company, Inc., 1963.

The STAR. The Louisiana Digital Library, available online at http://www.louisianadigitallibrary.org/cdm/landingpage/collection/p15140coll52.

US Congress. Senate. Letter from the Secretary of the Treasury, transmitting Letter from the Surgeon-General of the Marine-Hospital Service Presenting a Report relating to the Origin and Prevalence of Leprosy in the United States. 57th Cong., 1st sess., 1902. S. Doc. 269. Accessed June 22, 2019. https://babel.hathitrust.org/cgi/pt?id=loc.ark:/13960/t2r50sm6c&view=1up&seq=7.

White, Neil. *In the Sanctuary of Outcasts.* New York: HarperCollins Publishers, 2009.

Secondary

Agostino, Deborah, Michela Arnaboldi, and Melisa Diaz Lema. “New development: COVID-19 as an accelerator of digital transformation in public service delivery” *Public Money and Management* 41 no 1 (2021) : 69-72. Accessed January 27, 2021. https://www.tandfonline.com/doi/full/10.1080/09540962.2020.1764206.

Alcabes, Philip. *Dread: How Fear and Fantasy have Fueled Epidemics from the Black Death to Avian Flu.* New York: PublicAffairs, 2009.

Bridal, Tessa. *Effective Exhibit Interpretation and Design.* Lanham, MD: AltaMira Press, 2013.

Cauvin, Thomas. *Public History: A Textbook of Practice.* New York: Routledge, 2016.

Cohen, Daniel J. and Roy Rosenzweig. *Digital History: A Guide to Gathering, Preserving, and Presenting the Past on the Web.* Philadelphia: University of Pennsylvania Press, 2006. Accessed October 27, 2018. http://chnm.gmu.edu/digitalhistory/digitizing/1.

Dean, David. *Museum Exhibition: Theory and Practice.* New York: Routledge, 1996. Accessed August 1, 2018. http://web.a.ebscohost.com.steenproxy.sfasu.edu:2048/ehost/ebookviewer/ebook?sid=66100bed-0ff9-4a72-a176-4dc1702dc476%40sessionmgr4007&vid=0&format=EK.

Demaitre, Luke. *Leprosy in Premodern Medicine*. Baltimore: The John Hopkins University Press, 2007. Accessed August 6, 2018. http://web.b.ebscohost.com.steenproxy.sfasu.edu:2048/ehost/ebookviewer/ebook?sid=a12914a9-0b95-40f5-bb43-0f19a951230d%40pdc-v-sessmgr04&vid=0&format=EB.

“Department of the Treasury.” U.S. Department of the Treasury. Accessed September 21, 2019. https://www.treasury.gov/about/education/Documents/brochure%20(1).pdf.

Doull, James A. “Laws and Regulations Relating to Leprosy in the United States of America.” *International Journal of Leprosy* 18, no. 2 (1950): 145-154. Accessed September 19, 2020. http://ila.ilsl.br/pdfs/v18n2a02.pdf.

Duffy, John. *The Sanatarians: A History of American Public Health.* Urbana, IL: University of Illinois Press, 1990.

Elwood, Julia Rivera, ed. *Known simply to the rest of the world as Carville…100 Years.* N.p.: Department of Health and Human Services, 1994.

Faget, G. H. “The Story of the National Leprosarium (U. S. Marine Hospital), Carville, Louisiana.” *Public Health Reports* 57, no. 18 (May 1, 1942): 641-652. Accessed September 18, 2020. https://www.jstor.org/stable/4584083?read-now=1&seq=14#page_scan_tab_contents.

Fairchild, Amy L. “Leprosy, Domesticity, and Patient Protest: The Social Context of a Patient’s Rights Movement in Mid-Century America.” *Journal of Social History* 39 (2006): 1011-1043.

———. “Community and Confinement: The Evolving Experience of Isolation for Leprosy in Carville, Louisiana.” *Public Health Chronicles* 119 (May-June 2004): 362-370. Accessed August 6, 2018. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497625/pdf/15158116.pdf.

Fletcher, Valerie, Betty Siegel, and Ray Bloomer. “Going Beyond: What Does Universal Design Look Like?” *American Alliance of Museums.* October 1, 2010. Accessed March 27, 2021. https://www.aam-us.org/2010/10/01/what-does-universal-design-look-like/.

Fricker, Jonathan, Donna Fricker, and Patricia L. Duncan. *Louisiana Architecture: A Handbook on Styles*. Lafayette: University of Southwestern Louisiana, 1998. Accessed February 23, 2019. https://www.crt.state.la.us/cultural-development/historic-preservation/education/louisiana-architecture-handbook-on-styles.

Garcia-Muina, Fernando E., Laura Fuentes-Moraleda, Trinidad Vacas-Guerrero, Juan Jose Rienda-Gomez. “Understanding open innovation in small and medium-sized museums and exhibition halls: An analysis model.” *International Journal of Contemporary Hospitality Management* 30 no 11 (2019). Accessed January 18, 2021. https://www.emerald.com/insight/content/doi/10.1108/IJCHM-03-2018-0260/full/pdf.

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

–––––. “The World Downside Up: Mardi Gras at Carville.” *The Journal of American Folklore* 111, no 439 (Winter 1998): 23-38. Accessed September 29, 2020. https://www.jstor.org/stable/541318?Search=yes&resultItemClick=true&searchText=the+world+downside+up+marcia+gaudet&searchUri=%2Faction%2FdoBasicSearch%3FQuery%3Dthe%2Bworld%2Bdownside%2Bup%2Bmarcia%2Bgaudet%26filter%3D&ab_segments=0%2Fbasic_search_solr_cloud%2Fcontrol&ref

reqid=fastly-default%3A54bd5afde34059510bf0ad88bd5b6c12&seq=1#metadata_info_tab_contents.

Gelfand, Aleksandr. “If We Build It (and Promote It) They Will Come: History of Analog and Digital Exhibits in Archival Repositories.” *Journal of Archival Organization* 11 (2013): 49-82. Accessed January 29, 2021. https://www.tandfonline.com/doi/full/10.1080/15332748.2013.882160.

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

Grove, Tim. “History Bytes: Online Exhibits.” *History News* 59, no 3 (Summer 2004): 5-6. Accessed March 28, 2021. https://www.jstor.org/stable/pdf/42653965.pdf?ab_segments=0%252Fbasic_search_gsv2%252Fcontrol&refreqid=excelsior%3Aefe040792cb764518a870194f9cb0a4b.

Guder, Christopher. “Universal Design and the Library Website.” In *Public Services Quarterly* 10 (2014), 229-237. Accessed April 15, 2017. http://www.tandfonline.com/doi/full/10.1080/15228959.2014.931784?scroll=top&needAccess=true.

Hannefin, Daniel D.C. “The Daughters of Charity at Carville: 1896-1981.” *Vincentian Heritage Journal* 2, no 1 (1981): 55-80. Accessed September 29, 2020. https://via.library.depaul.edu/cgi/viewcontent.cgi?article=1004&context=vhj.

Hernandez, Barbara. “Inside View of Carville: Oral Histories of Patients and Staff from the Last United States Leprosarium.” *American Journal of Health Studies* 31 (Summer 2016): 176-189. Accessed August 6, 2018. http://go.galegroup.com.steenproxy.sfasu.edu:2048/ps/i.do?p=HRCA&u=txshracd2557&id=GALE|A484973417&v=2.1&it=r&sid=summon.

Hernandez, Barbara, Lorraine Michiels, Rasika Vengurlekar, Abhishek Kelkar, and Gincy Thomas. “The Legacy of Carville: A History of the Last Leprosarium in The U.S.” *American Journal of Health Studies* 24 (2009): 314-325.

Jackson, Joy J. *New Orleans in the Gilded Age: Politics and Urban Progress 1880-1896.* Baton Rouge: Louisiana State University Press, 1969.

Jay, Venita. “The Legacy of Armauer Hansen.” *Archives of Pathology and Laboratory Medicine* 124, no. 4 (April 2000): 496-497. Accessed January 27, 2020.

https://meridian.allenpress.com/aplm/article/124/4/496/61853/The-Legacy-of-Armauer-Hansen.

Jensen, John. "Before the Surgeon General: Marine Hospitals in Mid-19th-Century America." *Public Health Reports* 112, no. 6 (November-December 1997): 525-527. Accessed September 18, 2020. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1381932/?page=1.

John, Heather Varughese. "Translating Leprosy: The Expert and the Public in Stanley Stein's Anti-stigmatization Campaigns, 1931-60." *Journal of the History of Medicine and Allied Sciences* 68 (2013): 659-687.

Kalfatovic, Martin R. *Creating a Winning Online Exhibition: A Guide for Libraries, Archives, and Museums.* Chicago: American Library Association, 2002. Accessed August 17, 2018. http://web.b.ebscohost.com.steenproxy.sfasu.edu:2048/ehost/ebookviewer/ebook?sid=7633b7ed-b8c8-4335-962d-e823c93722ba%40sessionmgr102&vid=0&format=EB.

Kalisch, Philip A. "The Strange Case of John Early: A Study of the Stigma of Leprosy." *International Journal of Leprosy* 40, no 3 (1972): 291-305. Accessed June 22, 2019. http://ila.ilsl.br/pdfs/v40n3a09.pdf.

Kisacky, Jeanne. *Rise of the Modern Hospital: An Architectural History of Health and Healing, 1870-1940.* Pittsburgh: University of Pittsburgh Press, 2017.

Klinger, Jerry. "Searching for Stanley Stein." *Texas Heritage* 3 (2018): 14-18.

Laiche, Reagan. "The Daughters of Charity: From New Orleans to Carville." *New Orleans Historical.* Accessed September 17, 2019. https://neworleanshistorical.org/items/show/1280.

"Leprosy in the United States." *Public Health Reports* 27, no 24 (June 14, 1912): 941-946. Accessed June 23, 2019. https://www.jstor.org/stable/4567988?seq=6#metadata_info_tab_contents.

Lopez, Raul Necochea. "Arresting Leprosy: Therapeutic Outcomes Besides Cure." *American Journal of Public Health* 108, no 2 (February 2018): 196-202. Accessed June 22, 2019. https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2017.304177.

Lord, Barry and Gail Dexter Lord. *The Manual of Museum Exhibitions*. Walnut Creek, CA: AltaMira Press, 2001.

Manes, Christopher Lee. “The Letters of Norbert and Edmond Landry.” *Louisiana History: The Journal of the Louisiana Historical Association* 44 no 3 (Summer 2003):325-338. Accessed September 29, 2020. https://www.jstor.org/stable/4233939?read-now=1&seq=3#page_scan_tab_contents.

Marsh, Emily. “Chickens, aprons, markets, and cans: How the National Agricultural Library uses Omeka as its content management system for digital exhibits.” *Digital Library Perspectives* 33 no 2 (2017): 361-377. Accessed January 17, 2021. https://www.emerald.com/insight/content/doi/10.1108/DLP-03-2017-0009/full/pdf.

Martha, Sister and Sister Catherine. “The National Leper Home (U. S. Marine Hospital, No. 66).” *The American Journal of Nursing* 24, no. 10 (July 1924): 795-800. Accessed September 26, 2020. https://www.jstor.org/stable/3406541?seq=1#metadata_info_tab_contents.

Matassa, Freda. *Organizing Exhibitions: A Handbook for Museums, Libraries, and Archives*. London: Facet Publishing, 2014. Accessed August 17, 2018. http://web.a.ebscohost.com.steenproxy.sfasu.edu:2048/ehost/ebookviewer/ebook?sid=b4bcb398-d8a3-4cc8-a86d-0a233e7bcc1a%40sessionmgr4006&vid=0&format=EB.

Mitchell, Allyson, Sarah Linn, and Hitomi Yoshida. “A Tale of Technology and Collaboration: Preparing for 21st – Century Museum Visitors.” *Journal of Museum Education* 44, no. 3 (2019): 242-252. Accessed March 27, 2021. https://www.tandfonline.com/doi/epub/10.1080/10598650.2019.1621141?needAccess=true.

Mizell-Nelson, Michael. “Treated as Lepers: The Patient-led Reform Movement at the National Leprosarium, 1931-1946,” *Louisiana History: The Journal of the Louisiana Historical Association* 44, no 3 (Summer 2003): 301-324.

Moran, Michelle T. *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*. Chapel Hill: University of North Carolina Press, 2007. Accessed February 1, 2016. http://web.b.ebscohost.com/ehost/ebookviewer/ebook?sid=604b933d-2f2e-487b-8848-36e3d962147d%40sessionmgr114&vid=0&hid=118&format=EB.

National Register of Historic Places Registration Form. State Epileptic Colony Historic District. Abilene. Taylor County, Texas. National Register #91001539.

"The Only World They Know." *Newsweek*, March 28, 1999. Accessed June 22, 2019. https://www.newsweek.com/only-world-they-know-163686.

Parascandola, John. "Chaulmoogra Oil and the Treatment of Leprosy." *Pharmacy in History* 45, no 2 (February 2003): 45-57. Accessed June 23, 2019. https://www.researchgate.net/publication/277597573_Chaulmoogra_Oil_and_the_Treatment_of_Leprosy.

———. "From Germs to Genes: Trends in Drug Therapy, 1852-2002." Sesquicentennial meeting of the American Pharmaceutical Association, Philadelphia, March 17, 2002. Accessed January 26, 2020. https://www.lhncbc.nlm.nih.gov/system/files/pub2002042.pdf.

———. "PHS Chronicles: The Gillis W. Long Hansen's Disease Center at Carville." *Public Health Reports* 109 (1994): 728-730. Accessed October 1, 2016. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1403572/?page=1.

Peters, E. S. and A. L. Eshiet. "Male-female (sex) differences in leprosy patients in South Eastern Nigeria: females present late for diagnosis and treatment and have higher rates of deformity." *Leprosy Review* 73 (2002):262-267. Accessed August 6, 2018. https://www.lepra.org.uk/platforms/lepra/files/lr/Sept02/Lep262_267.pdf.

Quimby, Lauren. "Rising from the Ashes: Hansen's Disease, Carville, and Patient Identity in 20th Century America." Senior Independent Study Theses, The College of Wooster, 2014. Accessed June 23, 2019. https://openworks.wooster.edu/cgi/viewcontent.cgi?article=6985&context=independentstudy&httpsredir=1&referer=.

Reeves, Sally K. and William D. Reeves. *National Register Evaluation: Gillis W. Long Hansen's Disease Center.* Carville, La: Gillis W. Long Hansen's Disease Center, 1991.

Risse, Guenter B. *Driven by Fear: Epidemics and Isolation in San Francisco's House of Pestilence.* Springfield, IL: University of Illinois Press, 2016.

–––––. *Mending Bodies, Saving Souls: A History of Hospitals.* New York: Oxford University Press, 1999.

Rose, Julia. *Interpreting Difficult History at Museums and Historic Sites.* Lanham, MD: Rowman & Littlefield, 2016.

Satcher, David. "The History of the Public Health Service and the Surgeon General's Priorities," *Food and Drug Law Journal* 54, no 1 (1999): 13-19. Accessed

September 15, 2020. https://heinonline.org/HOL/Page?collection=journals&handle=hein.journals/foodlj54&id=57&men_tab=srchresults.

Schexnyder, Elizabeth. “Carville Patients’ Cemetery, The National Leprosarium.” *New Orleans Historical*, accessed June 23, 2019, https://neworleanshistorical.org/items/show/637?tour=55&index=7.

———. “Federal Staff Housing, Site Utilities, The National Leprosarium.” *New Orleans Historical*, accessed June 23, 2019, https://neworleanshistorical.org/items/show/808.

———. “Infirmary, National Leprosarium, Carville, Louisiana.” *New Orleans Historical*, accessed June 23, 2019, https://neworleanshistorical.org/items/show/770.

Serrell, Beverly. *Exhibit Labels: An Interpretive Approach*. Lanham, MD: Rowman & Littlefield, 2015.

Simmons, John E. *Museums: A History*. Lanham, MD: Rowman & Littlefield, 2016.

Smillie, W. G. “The National Board of Health, 1879-1883.” *American Journal of Public Health and the Nation’s Health* 33, no 8 (August 1943): 925-930. Accessed January 5, 2020. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1527526/?page=1.

Smithsonian Institution. *21st Century Roles of National Museums: A Conversation in Progress*. Washington, DC: Office of Policy and Analysis, 2002. Accessed Januarys 17, 2021. https://www.si.edu/content/opanda/docs/rpts2002/02.10.21stcenturyrole.final.pdf.

———. *The Making of Exhibitions: Purpose, Structure, Role and Process*. Washington, DC: Office of Policy and Analysis, 2002. Accessed January 17, 2021. https://www.si.edu/content/opanda/docs/rpts2002/02.10.makingexhibitions.final.pdf.

Sodaro, Amy. *Exhibiting Atrocity: Memorial Museums and the Politics of Past Violence.* Camden, New Jersey: Rutgers University Press, 2018. Accessed August 17, 2018. https://www-jstor-org.steenproxy.sfasu.edu/stable/j.ctt1v2xskk.1?refreqid=excelsior%3A129b42408a39f97cf90dce87ed089a73&seq=4#page_scan_tab_contents.

Sorrell, Melanie, Derek Norton, Jeff McAdams, Rachael Winterling, and Kathleen Dipple. “Creating an Online Scientific Art Exhibit Formatted for People with a

Visual Impairment." *Journal of Web Librarianship* 11, no 2 (2017): 105-123. Accessed August 17, 2018. https://www-tandfonline-com.steenproxy.sfasu.edu/doi/pdf/10.1080/19322909.2017.1300788?needAccess=true.

Tilden, Freeman. *Interpreting Our Heritage.* 3rd ed. Chapel Hill: The University of North Carolina, 1977.

Trautman, J.R. "A Brief History of Hansen's Disease." *Bulletin of the New York Academy of Medicine* 60, no 7 (September 1984): 689-695. Accessed June 15, 2019. https://www-ncbi-nlm-nih-gov.steenproxy.sfasu.edu/pmc/articles/PMC1911721/?page=1

U.S. Congress. Senate. Report of the Committee on Public Health and National Quarantine United States Senate on S. 4086. 64th Cong., 1st sess, 1916. Report No. 306. Accessed January 27, 2020. https://curiosity.lib.harvard.edu/contagion/catalog/36-990039103920203941.

U.S. Department of Health and Human Services: Health Resources and Service Administration. "Frequently Asked Questions." Hansen's Disease. Accessed April 7, 2016. http://www.hrsa.gov/hansensdisease/pdfs/faq.pdf.

Williams, Ralph Chester. *The United States Public Health Service, 1798-1950.* Washington, D.C.: Commissioned Officers Association of the United States Public Health Service, 1951.

Wright, Russel O. *Chronology of Public Health in the United States.* Jefferson, NC: McFarland & Company, Inc., 2005.

APPENDIX

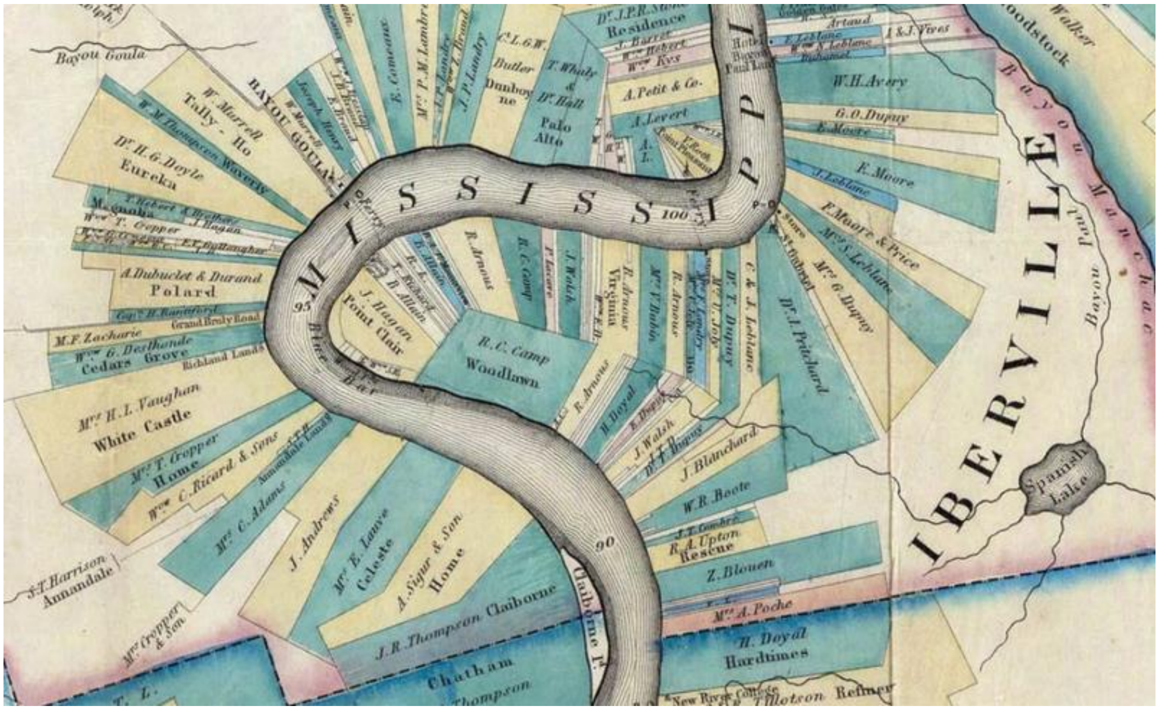


Figure 1. “Persac’s Map of the Mississippi, 1858,” map, New Orleans Historical, accessed November 18, 2019, https://neworleanshistorical.org/items/show/621?tour=55&index=0#&gid=1&pid=1. The property was originally named Woodlawn by owner Robert Camp, but called Indian Camp by locals. It is mostly referred to as Indian Camp in the historical accounts of the national leprosarium.

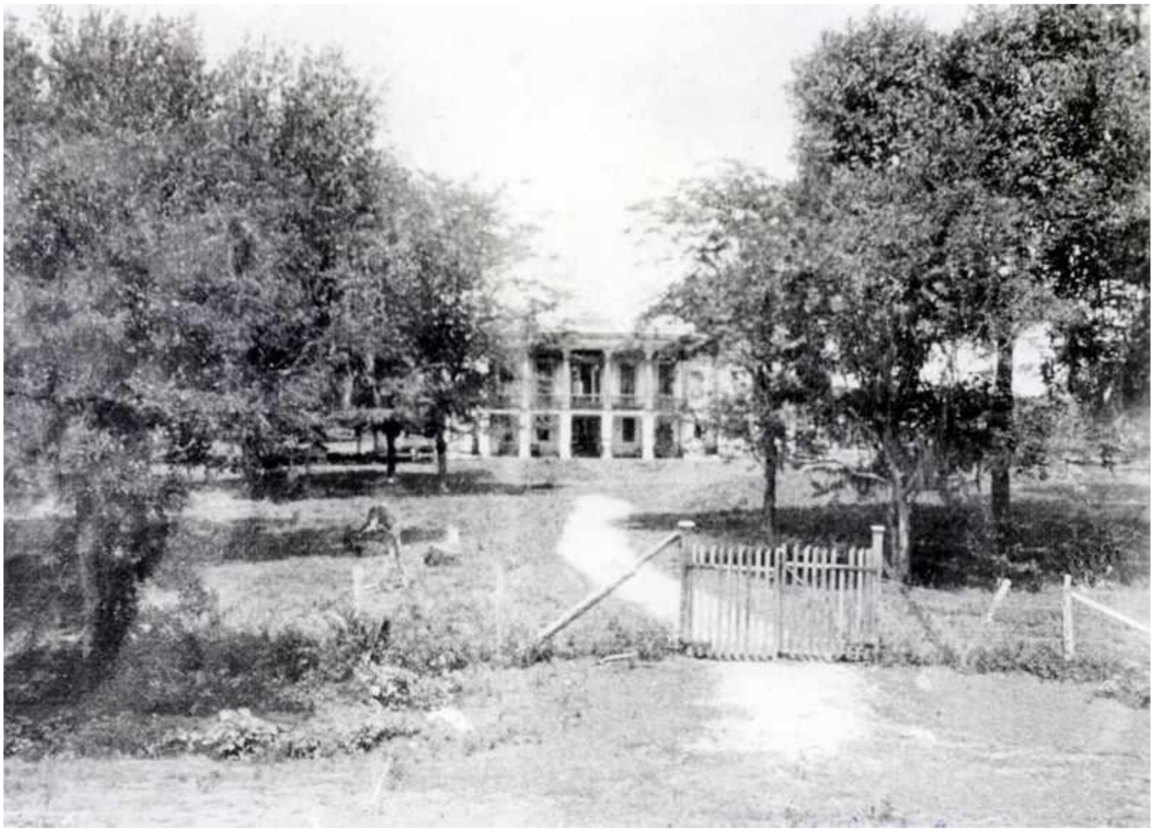
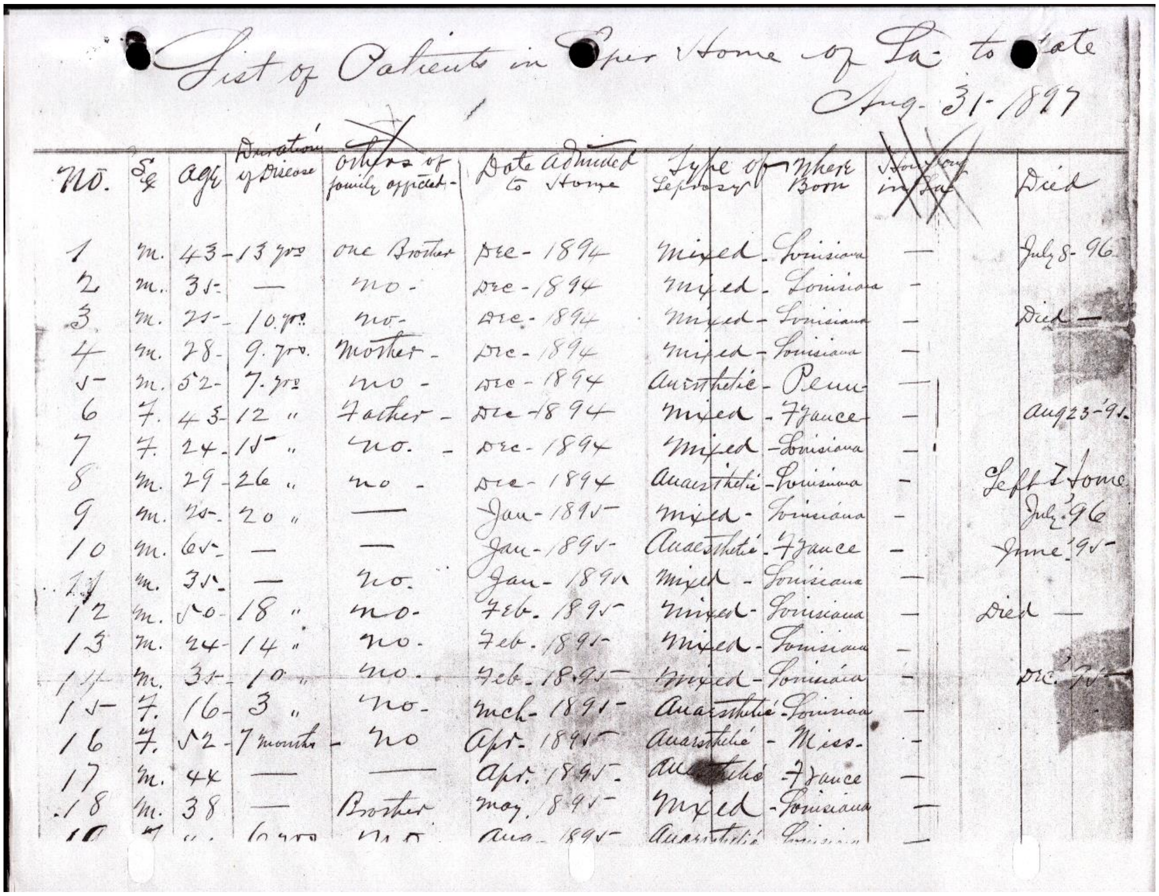


Figure 2. "Entrance to Indian Camp Plantation, 1890's," photograph, New Orleans Historical, accessed November 18, 2019, https://neworleanshistorical.org/items/show/621?tour=55&index=0#&gid=1&pid=2.

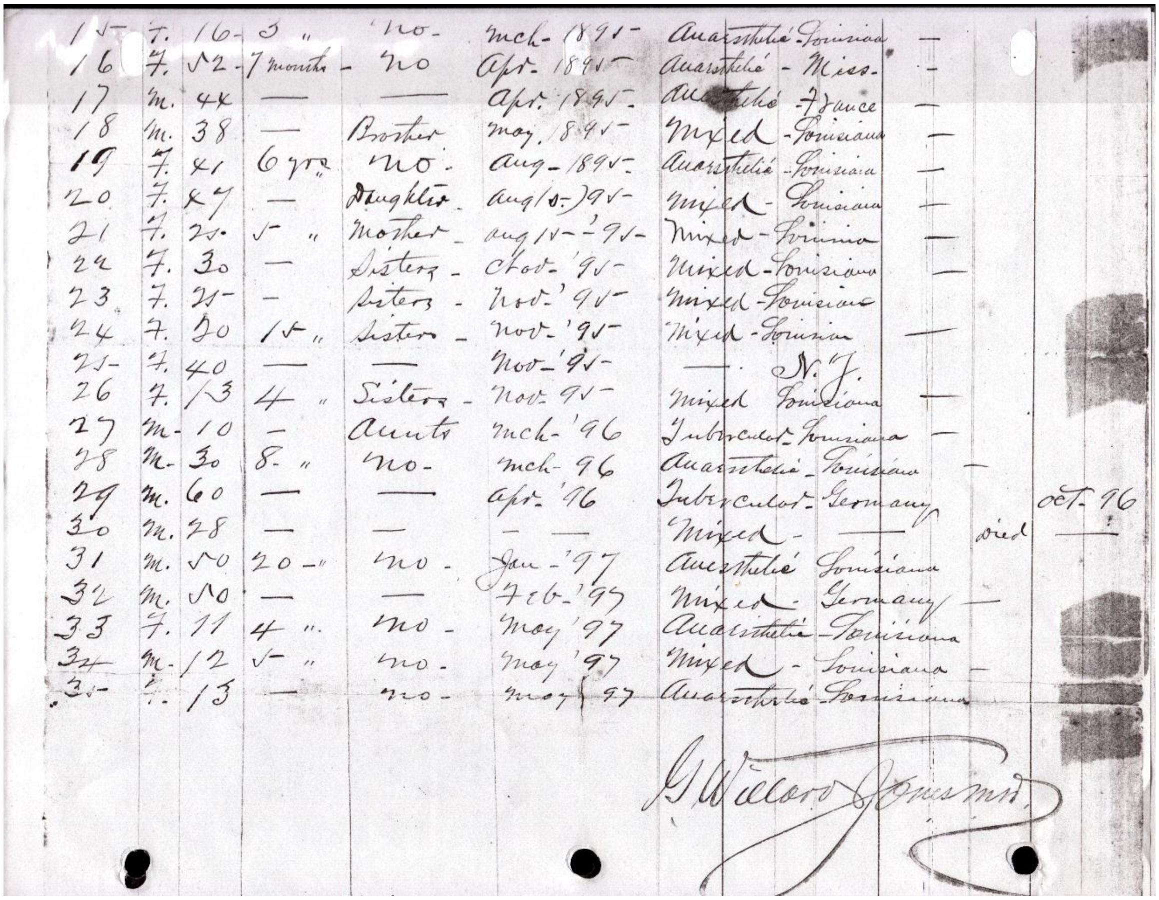
Figure 3. "Slave Quarters on Indian Camp Plantation, 1894," photograph, New Orleans Historical, accessed November 18, 2019, https://neworleanshistorical.org/items/show/621?tour=55&index=0#&gid=1&pid=7.



List of Patients in Leper Home of La to Date
Aug-31-1897

No.	Sex	Age	Duration of Disease	Others of family affected	Date admitted to Home	Type of Leprosy	Where Born	~~How long in La~~	Died
1	m.	43	13 yrs	one Brother	Dec-1894	mixed	Louisiana	—	July 8-96
2	m.	35	—	no	Dec-1894	mixed	Louisiana	—	
3	m.	25	10 yrs	no	Dec-1894	mixed	Louisiana	—	Died —
4	m.	28	9 yrs	mother	Dec-1894	mixed	Louisiana	—	
5	m.	52	7 yrs	no	Dec-1894	Anesthetic	Penn	—	
6	F.	43	12 "	Father	Dec-1894	mixed	France	—	Aug 23-95
7	F.	24	15 "	no	Dec-1894	mixed	Louisiana	—	
8	m.	29	26 "	no	Dec-1894	Anaesthetic	Louisiana	—	Left Home
9	m.	25	20 "	—	Jan-1895	mixed	Louisiana	—	July 96
10	m.	65	—	—	Jan-1895	Anaesthetic	France	—	June 95
11	m.	35	—	no	Jan-1895	mixed	Louisiana	—	
12	m.	50	18 "	no	Feb. 1895	mixed	Louisiana	—	Died —
13	m.	24	14 "	no	Feb. 1895	mixed	Louisiana	—	
14	m.	35	10 "	no	Feb. 1895	mixed	Louisiana	—	Dec. 95
15	F.	16	3 "	no	Mch-1895	Anaesthetic	Louisiana	—	
16	F.	52	7 months	no	Apr. 1895	Anaesthetic	Miss.	—	
17	m.	44	—	—	Apr. 1895	Anesthetic	France	—	
18	m.	38	—	Brother	May. 1895	mixed	Louisiana	—	
19	F.	"	6 yrs	no	Aug-1895	Anaesthetic	Louisiana	—	

Figure 4. "List of Patients in Leper Home of La to Date, Aug, 31, 1897," Daughters of Charity of St. Vincent de Paul collection, Hansen's Museum.



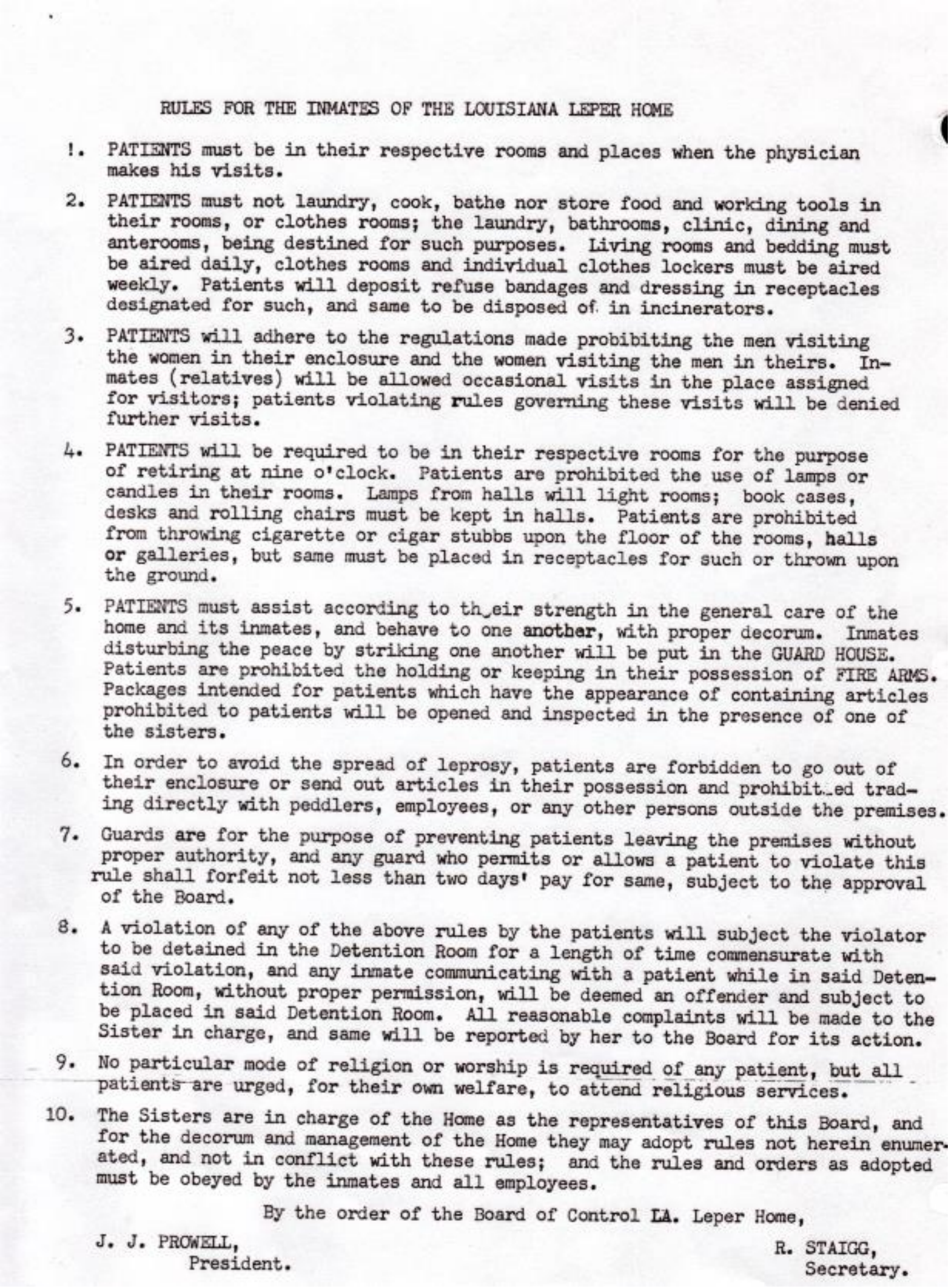
15	F.	16	3 "	no	mch- 1895-	Anaesthetic	Louisiana	—		
16	F.	52	7 months	no	Apr.- 1895-	Anaesthetic	Miss.	—		
17	M.	44	—	—	Apr. 1895.	Anaesthetic	France	—		
18	M.	38	—	Brother	may. 1895-	Mixed	Louisiana	—		
19	F.	41	6 yrs "	no.	aug.- 1895-	Anaesthetic	Louisiana	—		
20	F.	47	—	Daughter	aug 15- '95-	Mixed	Louisiana	—		
21	F.	25	5 "	Mother	aug 15- '95-	Mixed	Louisiana	—		
22	F.	30	—	Sisters	Nov.- '95-	Mixed	Louisiana	—		
23	F.	25	—	Sisters	Nov.- '95-	Mixed	Louisiana			
24	F.	20	15 "	Sisters	Nov.- '95-	Mixed	Louisiana	—		
25	F.	40	—	—	Nov.- '95-	—	N.J.			
26	F.	13	4 "	Sisters	Nov.- 95-	Mixed	Louisiana	—		
27	M.	10	—	Aunts	mch- '96	Tubercular	Louisiana	—		
28	M.	30	8 "	no	mch- 96	Anaesthetic	Louisiana	—		
29	M.	60	—	—	apr.- '96	Tubercular	Germany			oct. 96
30	M.	28	—	—	—	Mixed	—		died	—
31	M.	50	20 "	no	Jan.- '97	Anaesthetic	Louisiana			
32	M.	50	—	—	Feb.- '97	Mixed	Germany	—		
33	F.	11	4 "	no	may '97	Anaesthetic	Louisiana			
34	M.	12	5 "	no	may '97	Mixed	Louisiana	—		
35	F.	13	—	no	may '97	Anaesthetic	Louisiana			

J. Willard Jones md.

Figure 5. "List of Patients in Leper Home of La to Date, Aug, 31, 1897, page 2,” Daughters of Charity of St. Vincent de Paul Collection, Hansen’s Museum.


1906

Figure 6. " 'Hope House,' patient dormitory at the Louisiana Leper Home, 1906," photograph, New Orleans Historical, accessed November 18, 2019, https://neworleanshistorical.org/items/show/621?tour=55&index=0#&gid=1&pid=12. The covered walkway can also be seen in the background between the buildings.



RULES FOR THE INMATES OF THE LOUISIANA LEPER HOME

1. PATIENTS must be in their respective rooms and places when the physician makes his visits.

2. PATIENTS must not laundry, cook, bathe nor store food and working tools in their rooms, or clothes rooms; the laundry, bathrooms, clinic, dining and anterooms, being destined for such purposes. Living rooms and bedding must be aired daily, clothes rooms and individual clothes lockers must be aired weekly. Patients will deposit refuse bandages and dressing in receptacles designated for such, and same to be disposed of in incinerators.

3. PATIENTS will adhere to the regulations made probibiting the men visiting the women in their enclosure and the women visiting the men in theirs. Inmates (relatives) will be allowed occasional visits in the place assigned for visitors; patients violating rules governing these visits will be denied further visits.

4. PATIENTS will be required to be in their respective rooms for the purpose of retiring at nine o'clock. Patients are prohibited the use of lamps or candles in their rooms. Lamps from halls will light rooms; book cases, desks and rolling chairs must be kept in halls. Patients are prohibited from throwing cigarette or cigar stubbs upon the floor of the rooms, halls or galleries, but same must be placed in receptacles for such or thrown upon the ground.

5. PATIENTS must assist according to their strength in the general care of the home and its inmates, and behave to one another, with proper decorum. Inmates disturbing the peace by striking one another will be put in the GUARD HOUSE. Patients are prohibited the holding or keeping in their possession of FIRE ARMS. Packages intended for patients which have the appearance of containing articles prohibited to patients will be opened and inspected in the presence of one of the sisters.

6. In order to avoid the spread of leprosy, patients are forbidden to go out of their enclosure or send out articles in their possession and prohibited trading directly with peddlers, employees, or any other persons outside the premises.

7. Guards are for the purpose of preventing patients leaving the premises without proper authority, and any guard who permits or allows a patient to violate this rule shall forfeit not less than two days' pay for same, subject to the approval of the Board.

8. A violation of any of the above rules by the patients will subject the violator to be detained in the Detention Room for a length of time commensurate with said violation, and any inmate communicating with a patient while in said Detention Room, without proper permission, will be deemed an offender and subject to be placed in said Detention Room. All reasonable complaints will be made to the Sister in charge, and same will be reported by her to the Board for its action.

9. No particular mode of religion or worship is required of any patient, but all patients are urged, for their own welfare, to attend religious services.

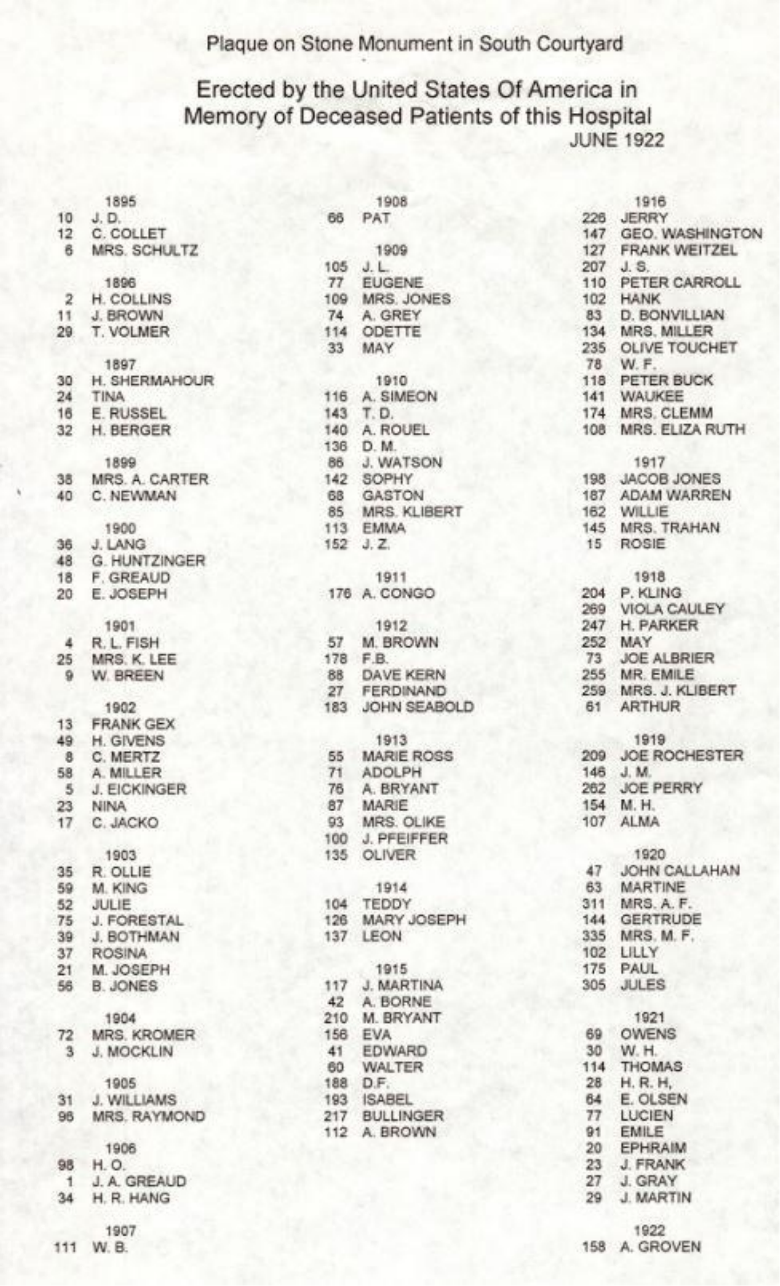
10. The Sisters are in charge of the Home as the representatives of this Board, and for the decorum and management of the Home they may adopt rules not herein enumerated, and not in conflict with these rules; and the rules and orders as adopted must be obeyed by the inmates and all employees.

By the order of the Board of Control LA. Leper Home,

J. J. PROWELL,
President.

R. STAIGG,
Secretary.

Figure 7. "Rules for the Inmates of the Louisiana Leper Home," Daughters of Charity of St. Vincent de Paul, Hansen's Museum.



Plaque on Stone Monument in South Courtyard

Erected by the United States Of America in
Memory of Deceased Patients of this Hospital
JUNE 1922

1895
10 J. D.
12 C. COLLET
6 MRS. SCHULTZ

1896
2 H. COLLINS
11 J. BROWN
29 T. VOLMER

1897
30 H. SHERMAHOUR
24 TINA
16 E. RUSSEL
32 H. BERGER

1899
38 MRS. A. CARTER
40 C. NEWMAN

1900
36 J. LANG
48 G. HUNTZINGER
18 F. GREAUD
20 E. JOSEPH

1901
4 R. L. FISH
25 MRS. K. LEE
9 W. BREEN

1902
13 FRANK GEX
49 H. GIVENS
8 C. MERTZ
58 A. MILLER
5 J. EICKINGER
23 NINA
17 C. JACKO

1903
35 R. OLLIE
59 M. KING
52 JULIE
75 J. FORESTAL
39 J. BOTHMAN
37 ROSINA
21 M. JOSEPH
56 B. JONES

1904
72 MRS. KROMER
3 J. MOCKLIN

1905
31 J. WILLIAMS
96 MRS. RAYMOND

1906
98 H. O.
1 J. A. GREAUD
34 H. R. HANG

1907
111 W. B.

1908
66 PAT

1909
105 J. L.
77 EUGENE
109 MRS. JONES
74 A. GREY
114 ODETTE
33 MAY

1910
116 A. SIMEON
143 T. D.
140 A. ROUEL
136 D. M.
86 J. WATSON
142 SOPHY
68 GASTON
85 MRS. KLIBERT
113 EMMA
152 J. Z.

1911
176 A. CONGO

1912
57 M. BROWN
178 F.B.
88 DAVE KERN
27 FERDINAND
183 JOHN SEABOLD

1913
55 MARIE ROSS
71 ADOLPH
76 A. BRYANT
87 MARIE
93 MRS. OLIKE
100 J. PFEIFFER
135 OLIVER

1914
104 TEDDY
126 MARY JOSEPH
137 LEON

1915
117 J. MARTINA
42 A. BORNE
210 M. BRYANT
156 EVA
41 EDWARD
60 WALTER
188 D.F.
193 ISABEL
217 BULLINGER
112 A. BROWN

1916
226 JERRY
147 GEO. WASHINGTON
127 FRANK WEITZEL
207 J. S.
110 PETER CARROLL
102 HANK
83 D. BONVILLIAN
134 MRS. MILLER
235 OLIVE TOUCHET
78 W. F.
118 PETER BUCK
141 WAUKEE
174 MRS. CLEMM
108 MRS. ELIZA RUTH

1917
198 JACOB JONES
187 ADAM WARREN
162 WILLIE
145 MRS. TRAHAN
15 ROSIE

1918
204 P. KLING
269 VIOLA CAULEY
247 H. PARKER
252 MAY
73 JOE ALBRIER
255 MR. EMILE
259 MRS. J. KLIBERT
61 ARTHUR

1919
209 JOE ROCHESTER
146 J. M.
262 JOE PERRY
154 M. H.
107 ALMA

1920
47 JOHN CALLAHAN
63 MARTINE
311 MRS. A. F.
144 GERTRUDE
335 MRS. M. F.
102 LILLY
175 PAUL
305 JULES

1921
69 OWENS
30 W. H.
114 THOMAS
28 H. R. H,
64 E. OLSEN
77 LUCIEN
91 EMILE
20 EPHRAIM
23 J. FRANK
27 J. GRAY
29 J. MARTIN

1922
158 A. GROVEN

Figure 8. "Plaque on Stone Monument in South Courtyard," Document number NHDM-1629, Hansen’s Museum. Patients are listed by patient number, name, and year buried. Many chose to be buried under their “Carville name.”

Figure 9. "Patients' Cemetery at Carville, the National Leprosarium," photograph, New Orleans Historical, accessed November 18, 2019, https://neworleanshistorical.org/items/show/637?tour=55&index=7#&gid=1&pid=2.

Figure 10. Patient owned beauty shop, photograph, Johnny Harmon Photograph Collection, document number JH120-13, Hansen's Museum.

Figure 11. "Infirmary completed in 1934," photograph, New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/770?tour=55&index=3#&gid=1&pid=2.

Figure 12. “Patients’ Dormitories, constructed 1940-1941,” photograph, New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/636?tour=55&index=4#&gid=1&pid=3.

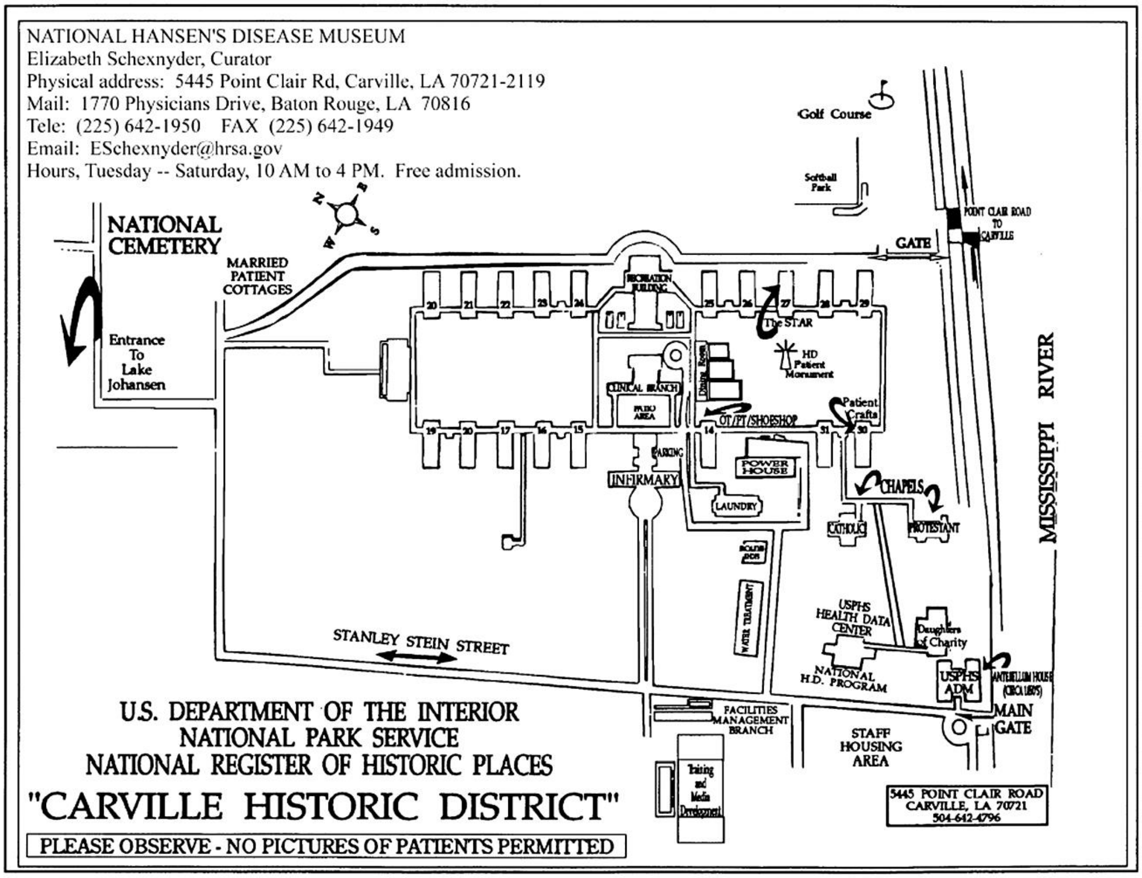


Figure 13. “Carville Historic District,” digital image, CDC Public Health Image Library (PHIL), accessed November 18, 2019, https://phil.cdc.gov/Details.aspx?pid=8920.

THE STAR

RADIATING THE LIGHT OF TRUTH ON HANSEN'S DISEASE

Oscar Lamp, National Head of the Forty anb Eight (center) with Sam Rubin (left) and Chas. Mitchell (right), prominent Voyageurs of the Grand Voiture of Louisiana pictured on their recent visit to Carville. Madamoiselle Metaire in the background.

September 1944

Figure 14. September 1944 issue of *The Star* featuring the Forty and Eight, digital image, Louisiana Digital Library, assessed October 1, 2020, https://louisianadigitallibrary.org/islandora/object/lsuhsc-p15140coll52%3A1181.

Figure 15. “Before and After Sulphone Drug Treatment,” digital image, New Orleans Historical, accessed September 20, 2020, https://neworleanshistorical.org/items/show/634?tour=55&index=2#&gid=1&pid=4. These series of photographs show a patient’s progression from 1943-1947.

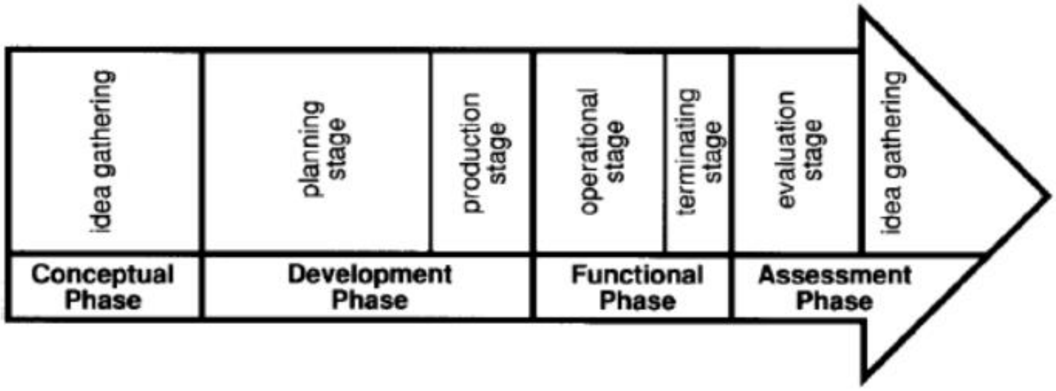


Figure 16. “Exhibition project model,” digital image, *Museum Exhibition: Theory and Practice* (New York: Routledge, 1996), 17, accessed January 28, 2021, http://web.a.ebscohost.com/ehost/ebookviewer/ebook?nobk=y&sid=50e8c836-bfff-42af-8fb5-780230d2b455@sessionmgr4008&vid=3&format=EK.

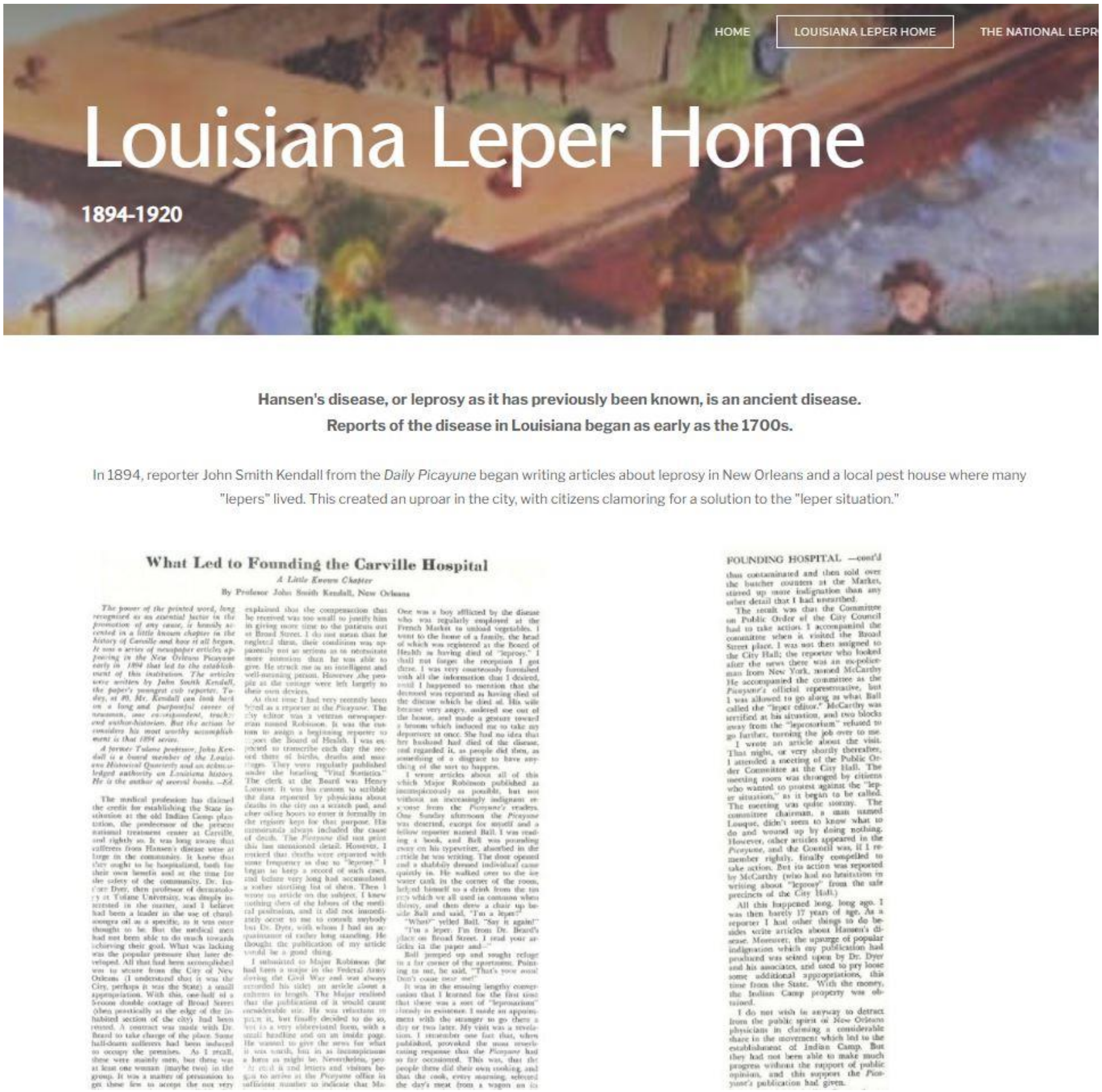
Stories From Both Sides of the Hedge

"Welcome to a community unlike any other in the world..."

The national leprosarium has a long history. From its beginning in 1894 until its closure in 1999, thousands of people diagnosed with Hansen's disease (previously known as leprosy) lived within its walls. Though separated from the outside world due to their stigmatizing illness, patients at Carville created a community with its own culture, traditions, and language.

In addition to the many patients who lived and were treated at Carville, many medical staff left their marks on the institution as well. Local doctors, nurses from the Sisters of Charity of St. Vincent de Paul order, and United States Public Health Service officials all worked tirelessly to care for their patients and research this dreaded disease. Eventually, a cure was discovered, the "miracle at Carville," ushering in the end of the policy of forced isolation.

Figure 17. "Proposed Home Page," digital image.



Louisiana Leper Home

1894-1920

Hansen's disease, or leprosy as it has previously been known, is an ancient disease.
Reports of the disease in Louisiana began as early as the 1700s.

In 1894, reporter John Smith Kendall from the *Daily Picayune* began writing articles about leprosy in New Orleans and a local pest house where many "lepers" lived. This created an uproar in the city, with citizens clamoring for a solution to the "leper situation."

What Led to Founding the Carville Hospital

A Little Known Chapter

By Professor John Smith Kendall, New Orleans

FOUNDING HOSPITAL —cont'd

Figure 18. "Proposed Louisiana Leper Home Page," digital image.

Life at the Louisiana Leper Home

> "Inside the fence and past the administration building you come upon a narrow stone walk lined with hedges...the deadline beyond which no patient may go..."
> --Sam Jones, Louisiana State Commander of the American Legion, in American Legion magazine

What was life like for those living and working at the Louisiana Leper Home?

During the state ownership of the leprosarium, a hedge was planted separating the patient and staff side of the facility. What were the experiences on both sides of the hedge?

Norbert Landry
1919-1924

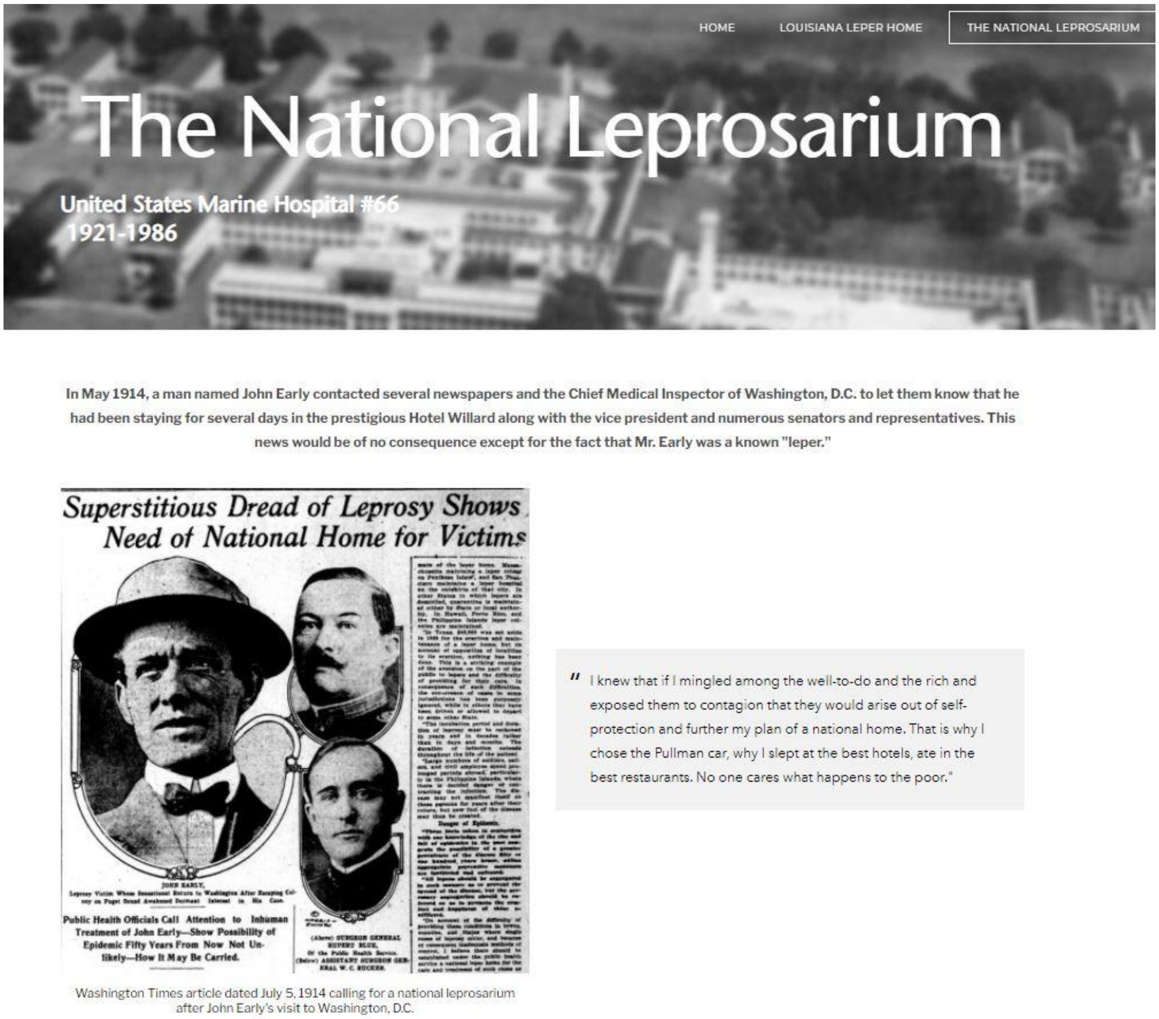
Norbert entered the Louisiana Leper Home as a patient in July 1919. He was a native Louisianan, from New Iberia, and a veteran of World War I. Norbert witnessed the institution as it transitioned from a state-run facility to the national leprosarium managed by the United States Public Health Service.

Sister Beatrice Hart, Sister Superior
1896-1901

> "When I offered myself to serve the lepers, I was sure that my Superiors would understand that I responded to the call of God and that they would accept me; I am not surprised and I experience a joy and a happiness beyond the power of words to express."

Sister Beatrice was among the first group of sisters assigned to the Louisiana Leper Home.

Figure 19. "Proposed Life at the Louisiana Leper Home Page," digital image.



The National Leprosarium

United States Marine Hospital #66
1921-1986

In May 1914, a man named John Early contacted several newspapers and the Chief Medical Inspector of Washington, D.C. to let them know that he had been staying for several days in the prestigious Hotel Willard along with the vice president and numerous senators and representatives. This news would be of no consequence except for the fact that Mr. Early was a known "leper."

Superstitious Dread of Leprosy Shows Need of National Home for Victims

JOHN EARLY,
Leprosy Victim Whose Sensational Return to Washington After Escaping Colony on Puget Sound Awakened Dormant Interest in His Case.

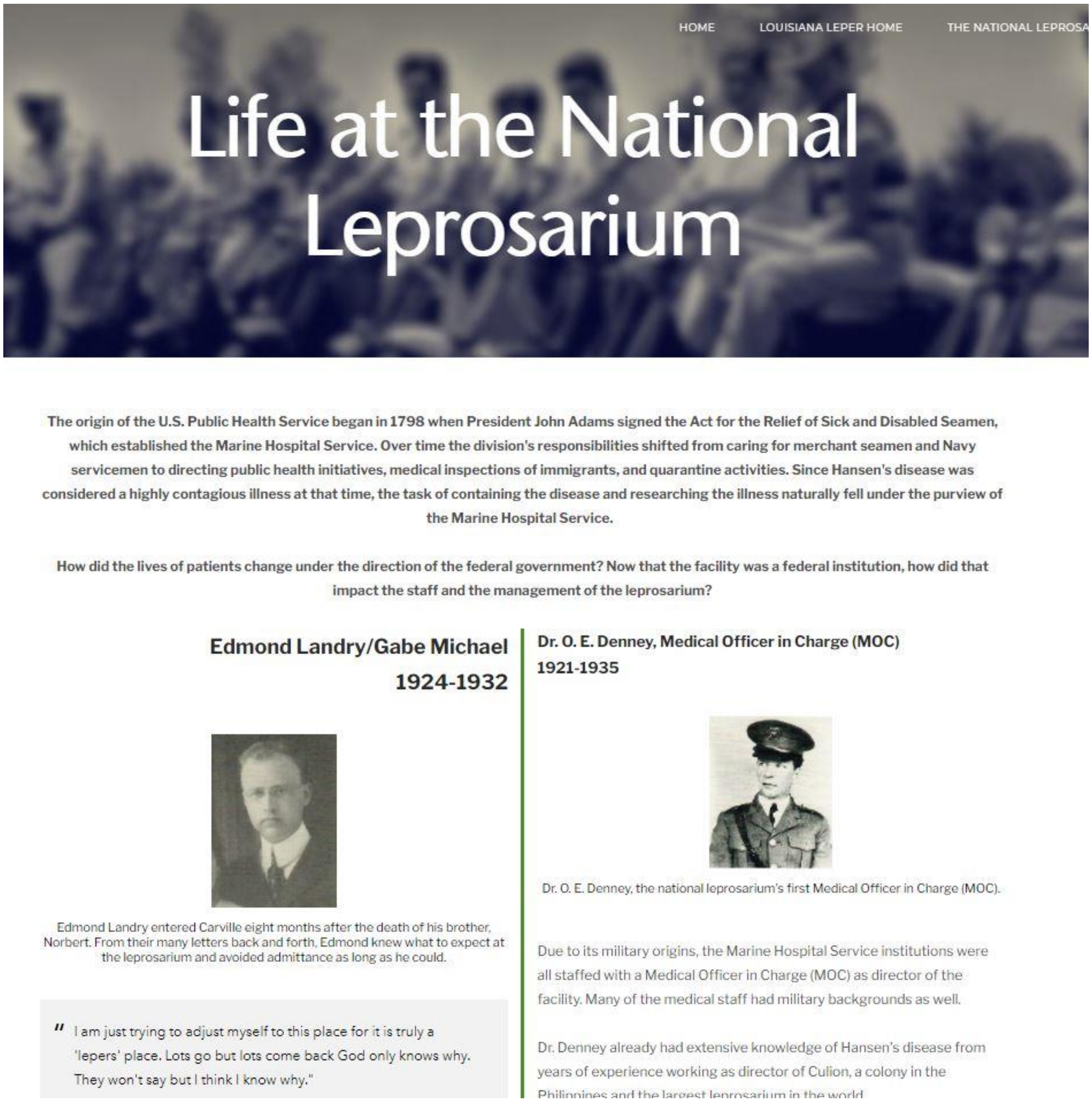
Public Health Officials Call Attention to Inhuman Treatment of John Early—Show Possibility of Epidemic Fifty Years From Now Not Unlikely—How It May Be Carried.

(Above) SURGEON GENERAL RUPERT BLUE,
Of the Public Health Service.
(Below) ASSISTANT SURGEON GENERAL W. C. RUCKER.

Washington Times article dated July 5, 1914 calling for a national leprosarium after John Early's visit to Washington, D.C.

> " I knew that if I mingled among the well-to-do and the rich and exposed them to contagion that they would arise out of self-protection and further my plan of a national home. That is why I chose the Pullman car, why I slept at the best hotels, ate in the best restaurants. No one cares what happens to the poor."

Figure 20. “Proposed The National Leprosarium Page,” digital image.



Life at the National Leprosarium

The origin of the U.S. Public Health Service began in 1798 when President John Adams signed the Act for the Relief of Sick and Disabled Seamen, which established the Marine Hospital Service. Over time the division's responsibilities shifted from caring for merchant seamen and Navy servicemen to directing public health initiatives, medical inspections of immigrants, and quarantine activities. Since Hansen's disease was considered a highly contagious illness at that time, the task of containing the disease and researching the illness naturally fell under the purview of the Marine Hospital Service.

How did the lives of patients change under the direction of the federal government? Now that the facility was a federal institution, how did that impact the staff and the management of the leprosarium?

Edmond Landry/Gabe Michael
1924-1932

Edmond Landry entered Carville eight months after the death of his brother, Norbert. From their many letters back and forth, Edmond knew what to expect at the leprosarium and avoided admittance as long as he could.

> " I am just trying to adjust myself to this place for it is truly a 'lepers' place. Lots go but lots come back God only knows why. They won't say but I think I know why."

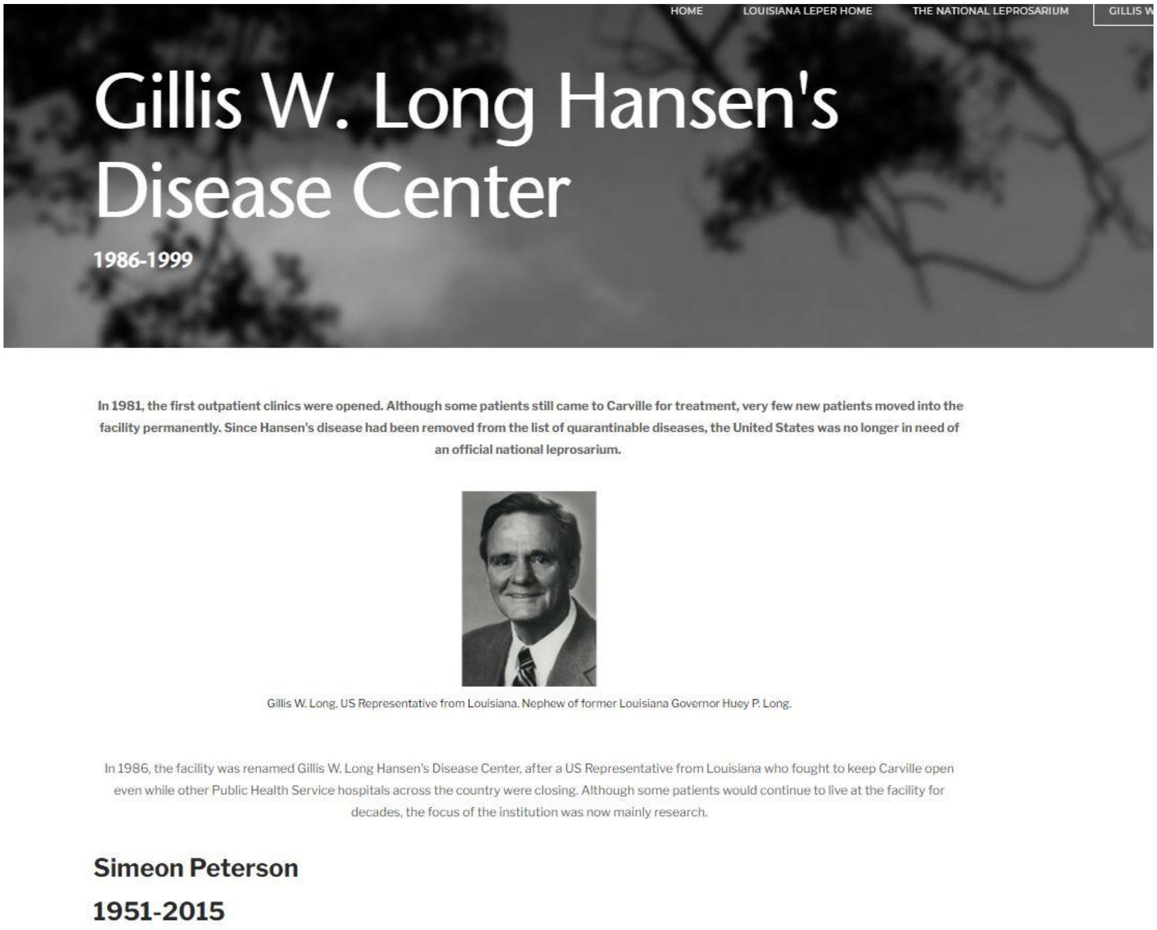
Dr. O. E. Denney, Medical Officer in Charge (MOC)
1921-1935

Dr. O. E. Denney, the national leprosarium's first Medical Officer in Charge (MOC).

Due to its military origins, the Marine Hospital Service institutions were all staffed with a Medical Officer in Charge (MOC) as director of the facility. Many of the medical staff had military backgrounds as well.

Dr. Denney already had extensive knowledge of Hansen's disease from years of experience working as director of Culion, a colony in the Philippines and the largest leprosarium in the world

Figure 21. "Proposed Life at the National Leprosarium Page," digital image.



Gillis W. Long Hansen's Disease Center

1986-1999

In 1981, the first outpatient clinics were opened. Although some patients still came to Carville for treatment, very few new patients moved into the facility permanently. Since Hansen's disease had been removed from the list of quarantinable diseases, the United States was no longer in need of an official national leprosarium.

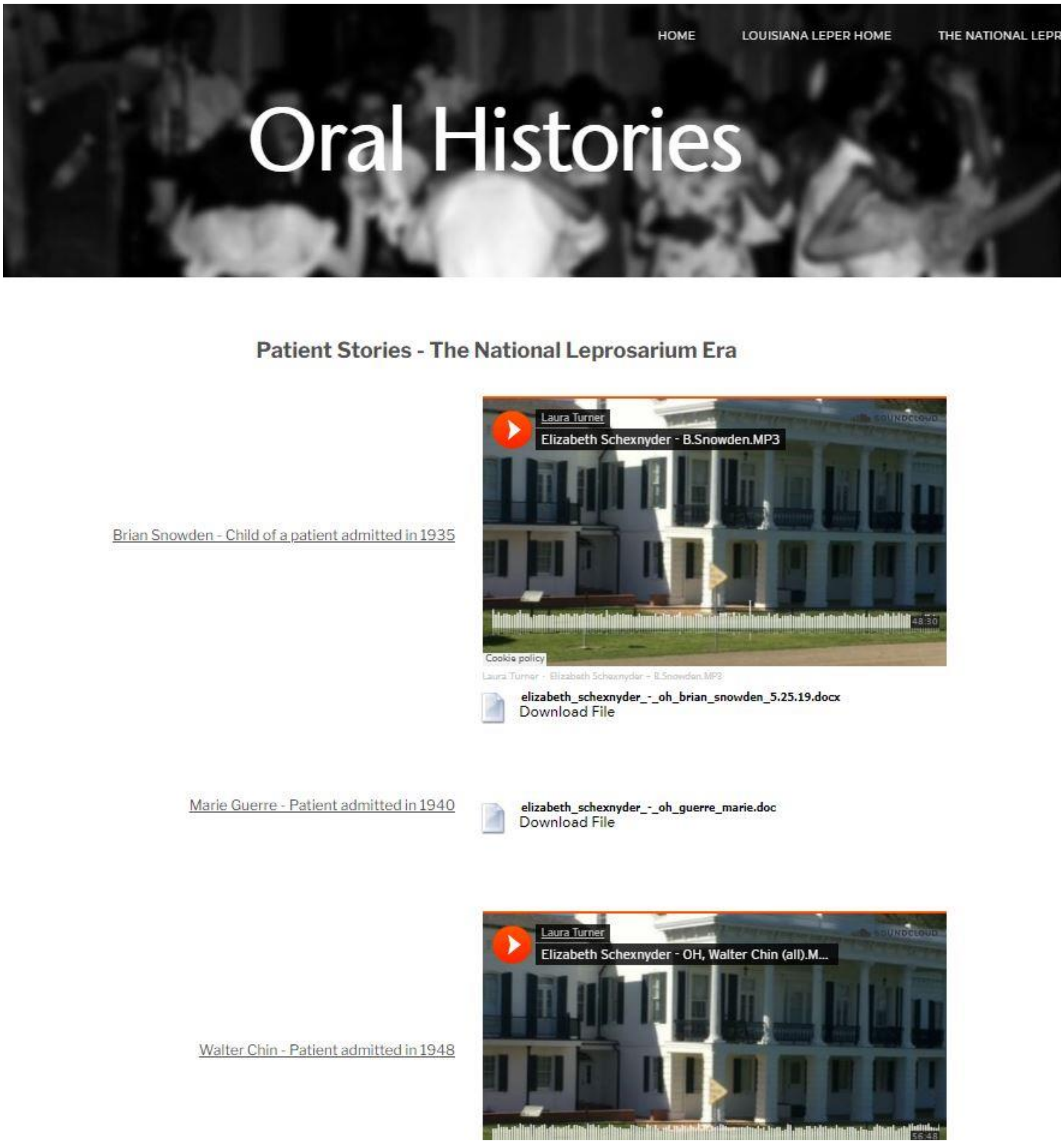
Gillis W. Long, US Representative from Louisiana. Nephew of former Louisiana Governor Huey P. Long.

In 1986, the facility was renamed Gillis W. Long Hansen's Disease Center, after a US Representative from Louisiana who fought to keep Carville open even while other Public Health Service hospitals across the country were closing. Although some patients would continue to live at the facility for decades, the focus of the institution was now mainly research.

Simeon Peterson

1951-2015

Figure 22. “Proposed Gillis W. Long Hansen’s Disease Center Page,” digital image.



Oral Histories

Patient Stories - The National Leprosarium Era

Brian Snowden - Child of a patient admitted in 1935

Elizabeth Schexnyder - B.Snowden.MP3

Laura Turner · Elizabeth Schexnyder - B.Snowden.MP3

elizabeth_schexnyder_-_oh_brian_snowden_5.25.19.docx

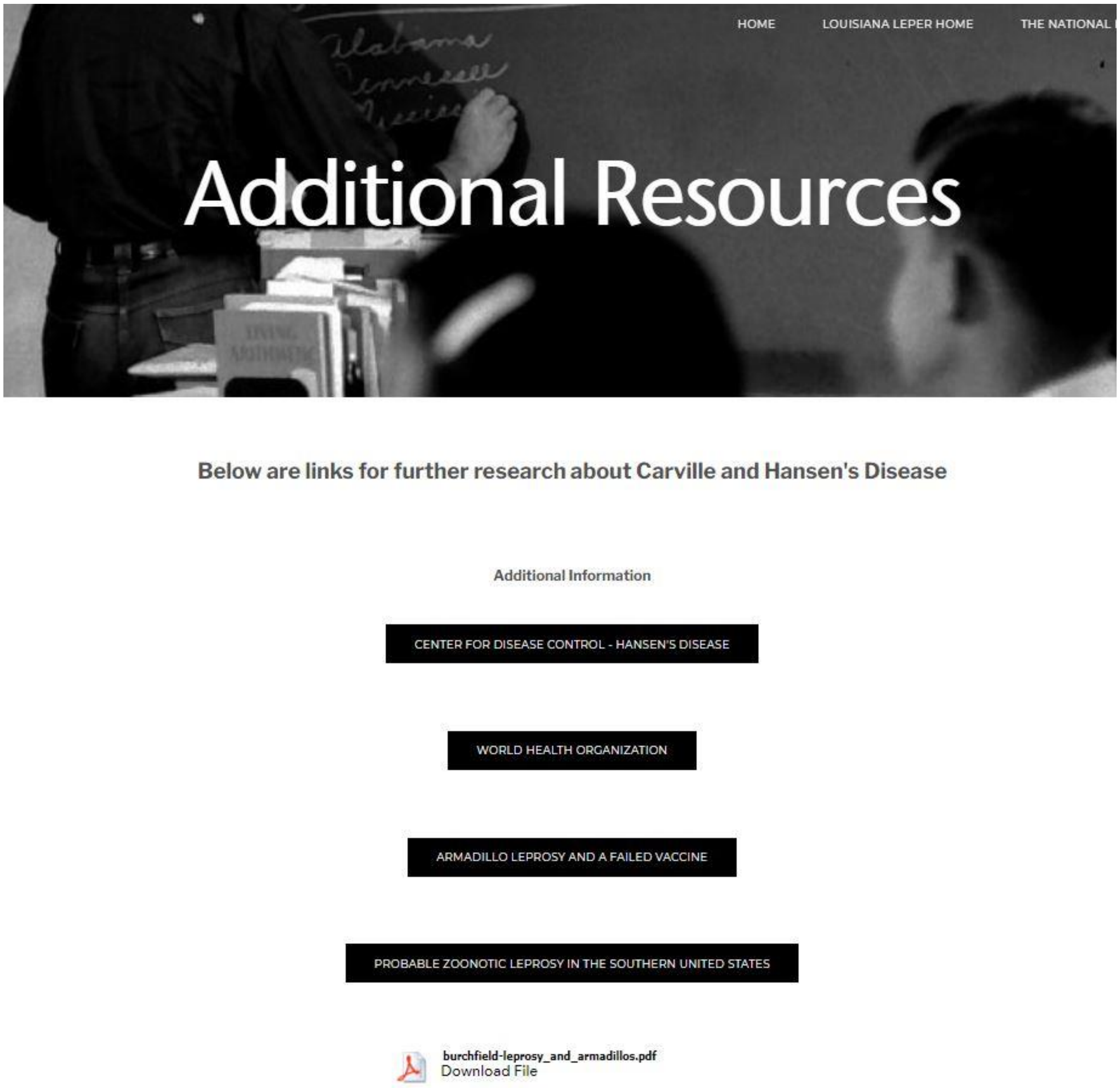
Marie Guerre - Patient admitted in 1940

elizabeth_schexnyder_-_oh_guerre_marie.doc

Walter Chin - Patient admitted in 1948

Elizabeth Schexnyder - OH, Walter Chin (all).M...

Figure 23. “Proposed Oral Histories Page,” digital image.



Additional Resources

Below are links for further research about Carville and Hansen's Disease

Additional Information

Figure 24. “Proposed Additional Resources Page,” digital image.

VITA

In 2005, Laura Turner entered Stephen F. Austin State University and completed her Bachelors of Business Administration in International Business in 2009. She continued her studies by enrolling in the Masters of Business Administration at SFA and completed the program with a degree in Management in 2011. She took a break from her studies and worked as a Coordinator in the Office of Disability Services at SFA. In 2015, she enrolled in the Masters of Arts in Public History program. During her time in the program, she attended multiple history conferences and even won the Portia Gordon Award for Best Graduate Student Paper at the October 2017 East Texas Historical Association Conference. While working on her degree, she accepted the position of Budget Analyst for University Affairs at Stephen F. Austin State University. Laura graduated from the Public History program in May 2021.

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The Chicago Manual of Style. 17th ed. Chicago: The University of Chicago Press, 2017.

This thesis was typed by Laura Turner.