

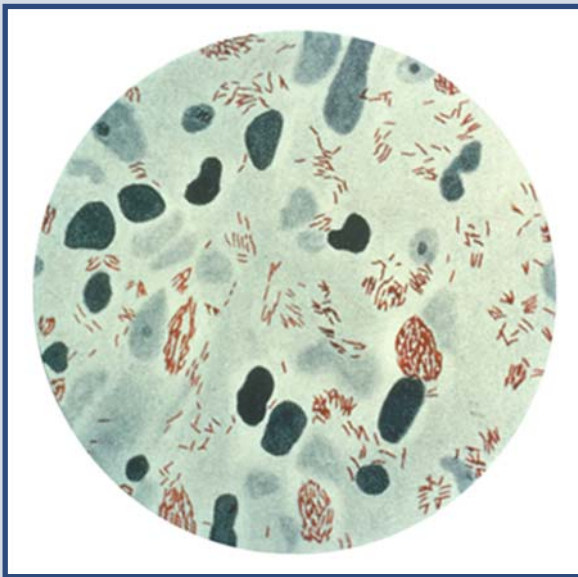
The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

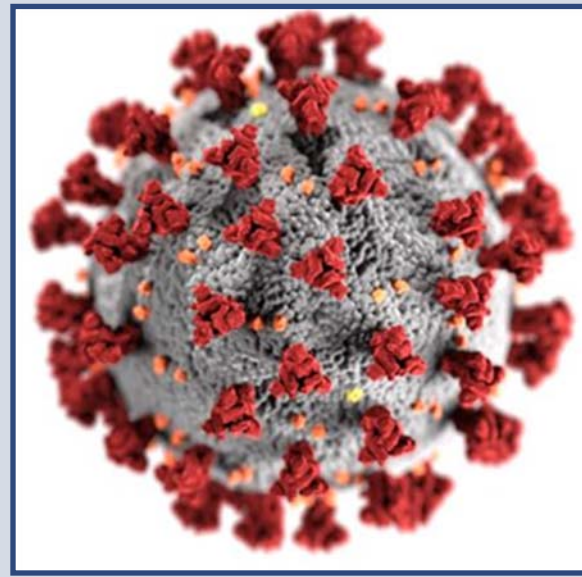
JANUARY 2020 -
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Hansen's Disease and COVID-19

Replacing Fear With Understanding



Microphotograph of Mycobacterium leprae, the small brick-red rods in clusters, taken from a skin lesion.



An illustration of ultrastructural morphology exhibited by coronaviruses. The illness caused by this virus has been named coronavirus disease 2019 (COVID-19).

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Stanley Stein

Founder - Editor, 1941 - 1967

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease. 2.) Serve as advocate for those who have experienced or been impacted by HD. 3) Foster self-empowerment of those who have experienced HD.

After you have read **The Star**, please pass it on to a friend and if **The Star** reaches you at a library, please place it conveniently for readers.

Editorial Policy On Terminology

The Star stands firm in its opposition to the use of the term "leprosy." We shall never abandon our campaign to secure general acceptance of "Hansen's disease." Nevertheless, the word "Leprosy" does appear in **The Star** under circumstances which we feel are unavoidable, namely: when signed articles are authored by someone who does not agree with us or when material discusses the disease prior to the introduction of the term "Hansen's disease." We dislike the word "leprosy" intensely, but we dislike the practice of censorship even more.

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Restored Column Capital Becomes Earliest Museum Artifact

By Tom Adams

The storied history of the property and grounds of what ultimately became a United States Public Health Hospital dedicated to Hansen's disease dates back to the early 1800's. That's when the area along the East bank of the Mississippi River (16 miles south of Baton Rouge) was labeled "Indian Camp" by European settlers. In 1825 this tract of land was purchased by Robert Coleman Camp to grow sugar cane using the labor of 100 enslaved Africans. In 1859 Mr. Camp built Indian Camp Plantation House on the land. In just 35 years the abandoned plantation was abandoned and was sold to the state of Louisiana to become its leprosarium. In 1894 the first seven patients were brought from New Orleans to the former plantation under cover of night via barge pulled by a distant tug boat. The patients were housed in slave quarters that proved more habitable than the once majestic plantation house. It is ironic that land once home to the enslaved again became home to a people enslaved because they had the misfortune of being persons affected by Hansen's disease.



Indian Camp Plantation House circa 1894

The state-run leprosarium operated until 1921 when it was taken over by the United States Public Health Service (USPHS). Today, the only surviving property from Indian Camp's days as a sugar plantation is the renovated Indian Camp Plantation House. No buildings from the "campus" constructed by the state remained following USPHS's aggressive building campaign of the late 1930's and early 1940's. In 1992 the plantation house and the complex of buildings constructed under USPHS's watch were added to the National Register of Historic Places and became the Carville Historic District.



damaged capital from storage



remnants from storage



artisan delivers to museum- capital seen positioned upside down

It remains a mission of the Forty and Eight's Carville Star Program to support the National Hansen's Disease Program Museum and the Carville Historic District. About 16 years ago, the museum was given a damaged capital and remnants of other capitals believed to be from the original 1859 Plantation House before its renovation to grandeur. (Simply put, a "capital" is a decorative piece found at the top of column.) The Carville entry to the National Register includes this description: "Column capitals are fashioned from double rows of acanthus leaf carvings with volutes or scrolls springing from the centers." Elizabeth Schexnyder, museum curator, located an artisan in nearby New Orleans who reconstructed a complete capital from the damaged capital and remnants provided. The Carville Star Program of the Forty and Eight funded the project, and the finished work now resides at the museum as the only artifact of the earliest days at Carville.

The National Hansen's Disease Museum at Carville is located at 5440 Point Clair Road, Carville LA 70721 (GPS address) and is open Tuesday through Saturday from 10:00 a.m. until 4:00 p.m. and closed on federal holidays. In lieu of the Covid-19 pandemic, check for updates to museum accessibility and operating hours.

COVID-19 and Hansen's Disease: Similarities and Differences

By José Ramirez, Jr.

Coronavirus (COVID-19) and Hansen's disease (HD), more commonly known as leprosy have much in common. The tiny bacillus of HD and the even smaller virus of COVID-19 are siblings in the spread of fear. HD and COVID-19 enter the body through the nose as minute droplets of moisture. Both can live in the body without showing any symptoms of their respective illness, or explode unexpectedly causing damage to the nerves (HD), lungs (COVID-19) and one's psyche.

Neither can be stopped from navigating across borders, rivers, oceans or mountains. Both attack twice as many men as women although they do not discriminate based on age, gender, race, religious beliefs or socio-economic status. Both do make it much more difficult for those affected by socio-economic disparities to locate and receive appropriate medical care, further widening inequality in society. Both are impacted by a fence, COVID by an imaginary one and HD by a real one with barbed wire.

Both can result in social distancing and quarantine, except those with HD the illness has historically caused long-term, involuntary separation from society. These types of separation do give birth to grief as losses of employment, home, family, and love mount up. When separation is not enough governments will build colonies/leprosariums and thus contribute to stigma, an act of labeling, rejection or unexplained fear of a person.

These institutions throughout the globe stopped accepting new patients as recently as 1999. Many have been converted to retirement homes for persons with HD who were in isolation. The COVID-19 theme of "we are all in this together" has a much different meaning for those who have experienced HD. Unlike those at the U.S. National Leprosarium in Carville, Louisiana during its 105 year history, COVID-19 isolation is expected to last for months and not decades.

As soon as the World Health Organization (WHO) declared COVID-19 a "pandemic," it distributed a document titled "Advice about leprosy and COVID-19." The document stated that "when epidemics or pandemics occur, poor people, in particular those with leprosy are usually affected disproportionately." The pandemic quickly enhanced HD's connection to neglected tropical diseases (NTD) and the lessening of case detections.

Two of the six recommended interventions by WHO included: "...advocate with authorities to allow selected health and social workers to visit persons with known problems due to disabilities, stigma, anxiety, or depression," and "set up a social media platform where people can find/share information about HD and COVID-19 for peer support."

Quickly recognizing the plight of persons who have experienced HD, including the approximately 250 new cases in the United States, members of an international organization of persons who have HD commenced a virtual journey. The organization, Integration, Dignity and Economic Advancement (IDEA) based in the U.S. started utilizing Zoom, similar to those affected by COVID-19. The group decided to merge IDEA's mission, "...to network with persons who have experienced HD..." HD with social work values, "connecting with persons traumatized during a crisis." The outcome has been a weekly gathering (support group) of persons from 23 different countries using multiple interpreters and separated by thousands of miles.

The weekly gathering has evolved from a problem sharing hour to a problem solving hour. An uplifting constant of those participating on the calls report a great sense of resilience. Persons on the calls have all taken steps to address some emotionally charged basic needs of persons who have experienced HD.

Some of the common themes have included: limited access to clean water and soap, need for food, need for transport to clinics for medications and hospitals for wound care, increased domestic violence, and need to counseling/therapy as the separation from loved ones and society in general has triggered many about past experiences of isolation. An unexpected effort from some countries was an attempt to declare former colonies/leprosaria as places to isolate those throughout the country who tested positive for COVID-19. Immediate and effective advocacy from those who lived in these "retirement" homes provided to be too much for those government officials hoping to further marginalize HD brothers and sisters.

These findings, and actions taken have been shared with the United Nations (UN) Special Rapporteur on Leprosy, UN Special Ambassador for Leprosy and the Global Partnership for Zero Leprosy (GPZL). With so many global links, the hope is that the stigma filled "fence" encircling HD, and its distant cousin COVID-19, will gradually collapse.

Family Passion for Truth Creates Two New Carville Works

The Disease: One Man's Journey through a Life with Leprosy by Anne Brett Harmon

Johnny Harmon had dreams that were bigger than his home state of Texas. In high school he took college correspondence courses toward a degree in engineering; he intended to become a Texas A&M engineer, but fate and a microbe called *Mycobacterium leprae* intervened. Johnny Harmon had leprosy and spent most of his adult life in Carville, Louisiana, at the United States Public Health Hospital. Although his life was changed, he was undeterred in his desire to live a full and productive life.

In *The Disease: One Man's Journey through a Life with Leprosy* his daughter Anne Harmon Brett tells her family's story in her father's voice, photographs, cartoons and art work. As she remarks, it is the story of a horrible disease, but more importantly it is the life story of her parents who fell in love at the Carville hospital. It is the story of a gregarious Texan with a wide range of interests in engineering, air planes, photography, classical music, poetry, and writing and the gentle, quiet determined Cajun girl Anne, twelve years his junior, who stole his heart. They were married with the support of the Catholic chaplain in Carville when marriage between patients was still forbidden.

Johnny had worked on his memoirs for several years at the end of his life. He composed multiple accounts of his fulfilling existence. After his death, his daughter Anne meticulously organized and synthesized her father's story into a warm human series of vignette like chapters. She complemented that with her mother's story and the account of herself and her brother who were cared for by a family in Vacherie, Louisiana where her family finally resided.

The Disease adds to the rich and important library of stories by and about those who transcended their diagnosis of Hansen's disease. It is available through Amazon and from <https://store.bookbaby.com/book/the-disease>.

Carville's Cure: Leprosy, Stigma, and the Fight for Justice by Pam Fessler

For most of his life Matthew Benjamin Koll knew only that his grandfather and namesake had died in an unnamed military hospital of some unknown tropical disease. This was the story that his family had perpetuated all of his life. In 1998 Matthew's father Harold Koll, tired of the secrecy that had surrounded his family, revealed that his father had had leprosy and had died in Carville, La. where he spent the last three years of his life. At that point Pam Fessler, Matthew's wife, promised her father in law to tell the story that had been hidden for decades.

That promise yielded an important new work *Carville's Cure: Leprosy, Stigma, and the Fight for Justice*. Pre-publication reviews attest to the value and readability of this new work. Pam Fessler brings her gifts as a researcher and her narrative skills from her work as an NPR correspondent to this important new work. Dr. David Scollard, retired director of the National Disease Program, says of the work,

“By turns heart-wrenching, inspiring, and infuriating, this is a fast-paced and highly readable account of attempts by patients, their families, doctors and American society in general to deal with the world's most misunderstood disease. Written with the eye of an experienced journalist and the voice of a novelist, this book tells the story—stranger than fiction—of the patients, nuns, doctors, movie stars, and politicians who have struggled to come to terms with the stigma and discrimination attached to leprosy. The book is painstakingly researched and documented, and unfolds dramatically through the words of the patients and other participants through their letters and personal papers as well as newspaper accounts and interviews.”

The book was released on July 14, 2020. Check the W.W. Norton website <https://wnorton.com/books/9781631495038> for locations for purchasing the book.

Two Pharmacists at Carville...Different Paths to Remarkable Successes

by Tom Adams

As I write this article, a pandemic is sweeping our world and pharmacists find themselves on the front line of engagement with an unseen enemy. The Oath of Maimonides is the traditional oath taken by pharmacists before starting their professional career. It begins "The eternal providence has appointed me to watch over the life and health of Thy creatures. May the love for my art actuate me at all times." During the Covid-19 pandemic it has been common to recognize pharmacists as members of an essential profession. Pharmacists have been challenged to creatively and safely meet the medication needs of their patients. Additionally, pharmacists are acknowledged for their roles in research and development of Coronavirus therapy and vaccine development. In the current crisis and throughout the history of the profession, pharmacists have played critical roles in promoting health and relieving pain and suffering. Two Carvillians, a patient and a staff member, lived the pharmaceutical oaths they had taken.

At the United States Public Health Service Marine Hospital No. 66, Stanley Stein and Sister Hilary Ross were pharmacists whose pharmacy careers and tenure at Carville took them down different paths to remarkable successes.

Sidney Maurice Levysen's (aka Stanley Stein) true career passion lay in theater or journalism. During his high school years, he wrote articles for two local newspapers and attended tent shows as frequently as possible. Upon high school graduation, Sidney wanted to pursue higher education in either career, but his pharmacist-father summarily rejected such aspirations. Instead, Sidney graduated from pharmacy school at the University of Texas Galveston and went to work in his father's drugstore in Boerne, Texas.

It was just after Sidney began working with his father in Boerne that he first noted puffiness of his face and eyes, the earliest symptoms of what would later be diagnosed as Hansen's disease (HD). Shortly thereafter, his father's health declined greatly leading to the sale of his drugstore and a family move to San Antonio. At the drugstore in San Antonio Sidney enjoyed great professional successes and a medical challenge. A dermatologist (Dr. McGlasson) who frequented the store noted a red spot on Sidney's wrist. He scheduled an office visit for Sidney; a test was performed that confirmed a diagnosis of HD.

Sidney's employment in San Antonio was cut short by the untimely death of his father in December 1921. He moved his mother back to Boerne but found employment at a drugstore in San Antonio owned by his two great uncles, all the while paying regular visits to Dr. McGlasson for chaulmoogra oil injections. Needing a vacation, in 1923 Sidney accepted a wedding invitation to Detroit for the marriage of a cousin. Scheduled as a few week's respite, the visit lasted five months, with Sidney taking a job at a local drugstore to support his extended stay.

Sidney returned to San Antonio invigorated and in high spirits. He purchased a drugstore in an affluent neighborhood of San Antonio using money left to him by his father. Personal and professional successes abounded but were short lived. Patches appeared on his face and his eyes became severely inflamed. The patches on his face became so unsightly that he could only work nights at the drugstore when customers were absent from the store. Not surprisingly, business suffered in his daytime absence and he was ultimately forced to sell the drugstore in 1930.

Secretly, Sidney and his mother left San Antonio for an apartment in New York, which was the home of his mother's relatives and also the place for the best of medical care and liberal statutes concerning management of HD patients. However, the New York dermatologist to whom Sidney was referred insisted that patients with HD lesions could not be treated in New York. The dermatologist reported Sidney to the apartment complex manager who evicted Sidney and his mother. With no assurance that his lesions would heal to the extent that he would become eligible for treatment, Sidney turned himself into the New York health department which admitted him to a hospital for isolation and about two months later arranged for his admission to Carville (United States Public Health Service Marine Hospital No. 66).

Arriving at Carville on March 1st, 1931, Sidney was required to assume his new name, Stanley Stein. His previous personal and professional life was now behind him. HD had already blinded him in his left eye and his face was marked by its characteristic nodules. After a few weeks of difficult adjustment to life at Carville, the patient leader of a minstrel suffered a "reactive episode" and Stanley was serendipitously asked to replace him. This opportunity rekindled the theatrical passion of his earlier life. The minstrel was a great success, and resulted in his recognition among patients and staff as a "naturalized citizen" of Carville. His success in this also led him to participate more in the patient life.

Like other patients, Stanley sought a job for a source of income. Because the Carville pharmacy served both patients and staff, Stanley was not allowed to practice as a pharmacist. He eventually landed a job as a dental assistant and a dispenser of medication to patients.

Although he was unable to continue his profession, Stanley maintained a pharmacist's concern for the "life and health of Thy creatures" and reprised his love of journalism. This became his motivation to start a publication to address common problems and interests among patients. He found an editor and staff and named himself managing editor of a patient newspaper. Using stencils, mimeograph and a typewriter loaned to the staff by Dr. Denney (Medical Officer in Charge), Stanley began the two-page 66 Star (the 66 from the hospital name, and Star from the name of the Boerne paper to which Stanley previously contributed.) The first 66 Star was dated May 16, 1931, just two and one-half months



Stanley Stein behind his editor's desk

after Stanley's arrival at Carville. It was a huge success and the paper quickly grew from two to twelve pages. Subscribers quickly rose to 250, nearly all of the patient population.

The 66 Star was sent to USPHS leadership in Washington, marking its first distribution beyond Carville. One official there noted the paper's appeal for state-of-the-art movie equipment and the debate over how to raise money to pay for such equipment in the absence of budgeted funds. Twice the official sent meat to Carville from USPHS facilities where livestock were grown, freeing funds designated for meat purchases and allowing purchase of movie equipment. The 66 Star's successful quest for this equipment marked the beginning of its influence in ultimately promoting and achieving far more impactful improvements for the common good of Carville patients.

Printers ink was again in his veins and Stanley felt the pull of the stage. He became director of the Carville Little Theater with performances attracting audiences of over 500. The theater closed when Stanley's decline in health forced a reduction of his activities. However, thanks to Stanley, the theater proved its value as something that patients could do for themselves that nobody could do for them. Later elected to entertainment director of Carville, he instituted the first large scale Mardi Gras celebration at Carville a tradition that remained until the final years of the hospital.

Just before the first anniversary of the 66 Star, Stanley was elevated to editor. Publication difficulties caused the 66 Star to cut back to a monthly publication. In 1934 publication ceased when the 66 Star fell victim to a controversy between the paper and its staff members who were also members of the Catholic Church.

In the late 1930s Stanley progressively lost vision in his right eye, plunging him into total blindness. Regardless of the ravages of HD requiring frequent hospitalizations, his tenacious optimism was never deterred. The Star was reborn in 1941 when patient spirits were at an all-time high due to the massive building boom at Carville that included an infirmary, patient quarters, dining hall and kitchen, recreation center and more. The new Star served the patient population and beyond with a motto of "Radiating the Light of Truth on Hansen's disease." By its tenth anniversary in 1951, The Star had a worldwide circulation of 4,000 that grew to over 14,000 in the 1963. The Star's educational campaign of the 1960's promoted and achieved worldwide changes in medical and social aspects of HD. By 1973 subscribers to The Star numbered 54,000 blanketing every state and 109 foreign countries. Continuously published since 1941, today The Star is mailed to 40 foreign countries and reaches countless readers who access The Star via internet.

Always searching for the common good Stanley determined to reach out to government agencies capable of changing undue restrictions on Carville patients. He created the United Patients' Committee for Social Improvement and Rehabilitation. This led to the creation of the Surgeon General's Advisory Committee on Leprosy to address 15 recommendations drafted by Stanley's committee. Action on these recommendations resulted in positive corrections to the archaic restrictions on the lives of Carville patients.

Stanley's passionate efforts for the needs of HD patients worldwide was recognized by the Damien-Dutton Society in 1953 when he received the first Damien-Dutton award for his efforts in the conquest of HD. The legacy of Sidney Maurice Levysen (Stanley Stein) is of a greatness that must forever be remembered. Stanley said "Instead of bemoaning the things that I have lost, I try to make the most of what I have left. In his essay on Compensation, Emerson says, 'For everything you have missed, you have gained something else.'" While HD altered the course of his life, Stanley Levysen responded by exercising his immense talent and ability for the benefit of many. His career as a pharmacist was short lived, but he continued to fulfill the pharmacist's oath until his death in December 1967.



Sister Hilary in the Chemistry Lab



Sister Hilary Photographs a Patient



Sister Hilary on cover of the Star

In 1893 Mary Ellen Ross was born in Berkeley, California, to her mother from Finland and her father from Sweden. She was the second of seven children. Her sea-faring father drowned in 1905 and about six months later the family lost everything in the San Francisco earthquake of

1906. She entered the workforce after finishing the eighth grade. While working at a clothing store she frequently attended mass and was encouraged to pursue a religious vocation. During a mass she experienced a "miracle of guidance" that directed her to the Daughters of Charity whose devotion to the sick and the poor inspired her. (The Monitor May 9, 1958 online.) She then pursued her professional education as Sister Hilary Ross.

In the May/June 1991 edition of *The Star* Cynthia M. Gould records "Of the scores of missionary and medical personnel who labored to eradicate the bacterium and the social stigma of Hansen's disease (HD), one stands out as an exemplary figure, Sister Hilary Ross. For 37 years this remarkable nun worked to eliminate the ignorance and misunderstanding at Carville through her humanity and compassion for patients, her role in the pharmacy and laboratory research during the sulfone era, and her contributions to professional organizations on both local and international levels."

She initially pursued a career in nursing, but a surgical procedure left her with facial nerve paralysis and removed her from her study of nursing. (Sister Hilary carried the associated disfigurement and chronic pain throughout her life.) She attended the University of Wisconsin from 1919-1921 before being assigned to the hospital at Carville. The hospital needed a pharmacist when she arrived in 1922 so for ten months she studied pharmacy at Charity Hospital in New Orleans and became certified in pharmacy when she passed the State Board Examination at Tulane.

As a pharmacist, she endeavored to make chaulmoogra oil palatable by masking its taste, incorporating it into varied flavoring agents, including chocolate. Unfortunately her efforts did little to help patients tolerate the oil and thus enhance their compliance with this mainstay of HD therapy. Sister Hilary achieved slightly better results by putting the oil in gelatin capsules consumed orally but bypassing gastric secretions. Through her efforts the ill-equipped pharmacy she inherited gained new equipment in 1924 with the acquisition of a 25-pound electric mixer for making ointments, a double boiler for formulating disinfectants and percolating jars for the removal of active ingredients from vegetables. Sister Hilary formulated intramuscular chaulmoogra oil in the Carville pharmacy, thus saving its very costly purchase from the Philippines.

Sister Hilary relinquished her pharmacy duties in 1928 when Carville needed a laboratory technician and sent her for training in that discipline. Upon return to Carville, she trained patients to conduct routine laboratory tests, giving them meaningful work and freeing her to pursue research projects. Because of her interest in blood chemistry and immunological problems, one of her first studies was an investigation of the relationship of calcium and phosphorus metabolism to bone changes in HD patients. It became the first of over 40 of her studies on blood chemistry and immunology reported in the medical literature.

In July 1940 Dr. Guy H. Faget was named Medical Officer in Charge of the USPHS Hospital at Carville. Dr. Faget experimented with toxoids, sulfa drugs, and high temperature therapy on patient volunteers - all without success. Success did come in 1941 when Dr. Faget first injected 6 patient volunteers with the sulfone, Promin. From the outset of sulfone use, Dr. Faget was challenged to determine the correct dosage to administer, the route of administration (oral, intramuscular, or intravenous), and the frequency of administration. To help him answer these concerns Sister Hilary devoted countless hours conducting laboratory tests on the blood and urine of sulfone patients. This laboratory data led to appropriate dosing guidelines, reduction of side effects, and the conclusion that daily intramuscular injections were in order.

In 1946 at the Pan-American Leprosy Congress, Sister Hilary presented her photographs of patients captured during their course of sulfone therapy. She also presented papers at the Sixth and Seventh International Leprosy Congresses.

In 1958 Sister Hilary received the Damien-Dutton Award "for outstanding scientific contributions as well as a lifetime of personal service and devotion on behalf of Hansen's disease patients." According to *The Monitor*, May 9, 1958, Sister Hilary credited the award to the patients at Carville "whose cooperation made it possible."

In August 1960 Sister Hilary's retirement concluded her time at Carville. Her retirement citation from the United States Public Health Service read: "On the occasion of her retirement from the Public Health Service Hospital, Carville, Louisiana, and in recognition and appreciation of her 37 years of faithful service, her outstanding contribution to the care and welfare of patients with leprosy, and her dedicated effort in the development and communication of scientific knowledge concerning this disease."

The final paragraph of a farewell article in *The Star* (My 37 Years at Carville) Sister Hilary wrote: "In leaving Carville I leave behind a host of friends who have been loyal to me over the 37 years. These have been most happy years. The patients have been most generous and cooperative in research projects and it is to them that I owe whatever I have accomplished during my years of service. I shall miss Carville but it will be ever in my thoughts and prayers. Though the ocean will divide us and me no more you see, remember your dear friend Sister Hilary will always be thinking of you."

Cynthia Gould ends her *Star* article about Sister Hilary with these words attributed to Sister Hilary's friend Dr. Wolcott: "Sister was a great lady. She enriched many along the way. The World was much better for her having passed this way."

Norbert Landry: One Man's Life in the Louisiana State Home for Leprosy

By Claire Manes

(author's note: Norbert Landry, a Louisiana resident and devout Catholic, wrote letters home to his family from 1919 to 1924. The letters give the account of one man's life and express his appreciation for the care and religious solicitude of the Daughters of Charity. It must be said, however, that not all patients had the same response to the religious women's discipline and care. Early in the home's history some patients objected to the strict segregation of the sexes imposed by the Daughters of Charity. Others, while appreciative of the medical care, had reservations about what they perceived as the nuns' proselytizing. This then is only one man's experience.)

Leaving a New Orleans restaurant in July 1919, Norbert Landry spied his cousin Paul Landry, a medical student at Tulane University. Norbert rolled up his sleeve and pointed to the strange patches on his arm, "Paul, tell me what you think." Taking one look at Norbert's arm, he directed him to see a doctor immediately. Paul then turned to his wife and told her to go at once to wash her hands thoroughly. The patches on Norbert's arm were leprosy and by July 29, 1919, Norbert Landry a veteran of the Great War and a resident of New Iberia, Louisiana, was on his way to the Louisiana State Home for Leprosy in Carville, Louisiana.

A letter from Dr. Saucier to Dr. Isadore Dyer began the process which moved quickly. "Mr. N. T. Landry would like to go to the State Leper's Home voluntarily, and is anxious to get a letter from you as to the management of said institution. Thanking you for any consideration shown the gentleman, I am Yours truly. M.E. Saucier, M.D." Norbert was the first of five siblings to reside in the leprosarium between 1919 and 1977, but the only one who lived in the State Home for Leprosy.

Norbert Landry was my great uncle and the first of his siblings to be diagnosed with leprosy. He had returned from France in April of 1919 with the intention of re-connecting with his family, celebrating his safe return home, finding employment, and proposing to his fiancée Louise. Leprosy stopped all of that. By July 31, he was a patient at the Louisiana State Home and by August 8, 1919 he had written to his brother Edmond that this was a "lonesome place... [where the] only joyous pastime is to go to church and pray for a cure....They have benediction and the Rosary every evening. So we go and pray for our cure."

Besides prayer Norbert relied on fidelity to medication and good hygiene. As he told Edmond, "I take my medicine regular and my bath, too." He told his mother that he took 50 drops of that oil (chaulmoogra) and he followed the dictum of Sister Regina who recommended that it "was better to keep ourselves neat and clean at all times." He also believed that hard work was good for him because it "sweated all that sickness out of me."

In Norbert's view this protocol of prayer, medication, and good hygiene was helping him. On more than one occasion he wrote home that he was seeing progress in his healing and that he would be home soon. He quoted the doctor and the Daughters of Charity who seemed to encourage him in his hope. In one letter he reported,



The second Sacred Heart Chapel (1906-1933). The Daughters of Charity, the employees and the patients would pray here. Norbert went to the chapel frequently to "pray for a cure." He reported in 1919 that it had been repainted and looked like a cathedral inside. (Photo courtesy of the National Hansen's Disease Museum, permanent collection.)

“Friday when the Dr. came in my room he went near the window and told me to come to the light so he could see me good. He again said to the Sister, ‘this boy is certainly improving.’ This makes me think that I am well. But will continue to pray to God for my early cure. And I will also go to communion as often as I can.” Unfortunately he did not see the results he longed for as he died in Carville in February 1924.



Norbert and other residents of the State home lived in wooden houses such as this. In 1923 after the federal takeover and again in 1940 new structures that were built were fireproof. (Photo courtesy of the National Hansen's Disease Museum, permanent collection.)

Most of Norbert's letters were written between 1919 and February of 1921 when the hospital was a state institution. They offer one man's perception of the State Home under the ecclesiastical control of the Daughters of Charity who according to Stanley Stein's later description “ran the show without interference, instituting a curious blend of tender care and iron monastic discipline.” A doctor came once a week to Carville from New Orleans, but the Daughters of Charity maintained the home. As I read Norbert's letters, I believe he saw the state institution as a home, one he wanted to leave, but one that offered compassionate care. He was receptive to the medical and religious care dispensed by the sisters. As a Catholic he was grateful for the medals and prayers the sisters gave him for his family in New Iberia and appreciative of their attention to his needs.

His letters also indicate a more relaxed atmosphere than when the home became the United States Public Health Hospital #66. One's identity was secret in the home but rather informally so, “We all call each other by any old names some call me Albert, some Norbert and others Sisero.” Chores were shared much as they would be in a family, everyone pitching in. Norbert accepted this as his participation in the running of the household. He wrote, “sister gives us little jobs every day to clean up or cut grass or fix chairs. So she had me cleaning up under one of the houses and cutting grass around it with a few other boys.”



“Sister had us cutting grass and cleaning under the houses.” (Norbert Landry) From the earliest days of the home, patients participated in the upkeep of the institution. When the home was federalized, many patients still maintained gardens around their living quarters. During World War II victory gardens became quite popular with the patient population. (Photo courtesy of the National Hansen's Disease Museum, permanent collection.)

Rules about pets were also much more relaxed in the home. Norbert's parents sent him a little dog, Zip, which was loved by him and the other patients as well as by the sisters and the priest. “ Zip is growing pretty much. He is pretty big now. He surely does like the Priest. If he can hear the Priest talk any how he's blocks away he will quickly run to Father. This is because the Priest takes him on the other side and for a walk nearly every day.”

Zip was not the only entertainment for the men. There were outings organized by the sisters. “Last Sunday the sister took us boys out for a walk back in the woods looking for some pecan trees. We certainly had a good time and a good exercise too. She brought a package of apples and oranges and gave it to us on the way. We each had a couple to eat.”



“We look like a little army” when we go out to hunt. (Photo courtesy of the National Hansen’s Disease Museum, permanent collection.)

This walk in the woods might have inspired the “boys” to go out on their own. “I have gotten myself a Rifle to shoot at the black birds and pass my time when I feel like taking some exercise. There are seven fellows who each have one just like mine. It looks like a little army when we all start out for a hunt. The only thing we can’t go far enough to get anything good to shoot at except Jay birds and Red birds. We all took our Rifles yesterday to go on our walk. We only saw a Rabbit but didn’t get it.”

He was also personally appreciative of the solace offered him by the Daughters of Charity, particularly Sr. Regina. When his fiancée Louise broke up with him in November of 1919, Sr. Regina’s solicitude proved to be beneficial. Louise and Norbert had been together long before the war. She was faithful to him in the war, writing letters attesting to her love and keeping him apprised of news from home. In his early months in Carville Louise wrote to him sending Novenas, stamps, and writing paper, but in November she broke their engagement. Norbert wrote his brother, “It’s a shame what that girl done to me.” Sr. Regina’s consolation and advice were valuable to Norbert in his pain.



Patients who tried to run away were jailed in the institution’s jail should they return or be caught. This jail was a fixture of the institution until the 1950s, but even beyond that there was a place of isolation for patients who needed such.(Photo courtesy of the National Hansen’s Disease Museum, permanent collection.)

There were other dark times in the institution that confined so many, separating them from family, loved ones, and the public. Norbert wrote of those who ran away never to return, those who attempted suicide, and those who ran away and were jailed upon their return. In one letter Norbert’s comments reflected the impossibility of detaining those who would not be kept in the home. “I forgot to tell you that there are two more fellows ran away from here. One of them had just ran out of here about two months ago but he had come back on business to see his Mother. He was lucky they didn’t keep him in jail long on account of it being Christmas. They let him out for him to take Communion on Christmas and the next day he was gone with another fellow.”

Norbert wrote, too, of the material needs that the home could not fill. He asked for writing tablets, stamps, a few cigars, shaving soap, and a pocket knife. “Ed, I wish you would send me a medium pocket knife, nice one now. I feel lost without one in my pocket.”

Norbert's description of food at the home and at the federal hospital underscored the financial struggle of the state institution. The Daughters of Charity ran the home with discipline and compassion, but they ran it on a shoestring. Letters from the Daughters of Charity reflected their ongoing struggle to get sufficient funds for the needs of their home. Letters from Norbert address this in terms of food. The only references to food at the Louisiana State Home were in letters about meals at Thanksgiving and Christmas 1919. There Norbert reported on the wonderful meals: all the turkey we could eat, even enough for supper; oyster soup, rice and gravy, fruit for dessert and a cigar for each of us men. The federal government began its direction of the hospital in February 1921 and almost immediately Norbert wrote of the changes in food. "So now we are under the control of the Government. Let me tell you we have been having much better food since that and more of it too. Milk three times a day where we use to have it once a day. We get eggs nearly every day, once, and Irish potatoes which we hardly ever saw any but very seldom and now we get them also nearly every day. ... Tonight I was supposed to take some calomel but they had some fish for supper and ice cream for dessert so I went and ate a big meal and forgot all about the calomel that I had to take."

Other improvements occurred when the hospital was federalized. "Dr. Denny is back from Washington since last night, with lots of good news to our interest. He came around this morning to see 'my old men' and mention that he had gotten much more than he had asked for over in Washington in line of money and different things for the interest of the place. 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 that is a great thing for us. We are surely thankful for that. But I myself I hope that I don't have to stay here much longer."

Physical changes also occurred with the Federal takeover. More patients from around the country were moved to Carville and Norbert reported the building activities that occurred including temporary housing being moved in to accommodate the larger population. Burial in the old cemetery was ended the following year as Norbert noted. He recounted the first burial in the new location in May of 1922. The body and the pall bearers were moved by ambulance to the location that at some point came to be referred to as "under the pecans."

For Norbert there were some constants between the two institutions that he appreciated. The Daughters of Charity remained at Carville employed by the federal government serving with the same compassion and fidelity that they had shown when they were in charge of the institution. The religious rituals and practices that Norbert had enjoyed continued: Mass, Benediction, rosary and the Way of the Cross. He also mentioned some new activities, the celebration of Hospital Day and a softball game with a team from White Castle. Norbert acknowledged that he knew one of the players from school in Lafayette, but "I didn't talk to him;" a familiar reaction for many in Carville and for Norbert in particular. He was the most secretive in the family about his condition. He wanted them to come to visit by way of New Orleans so that no one in New Iberia would know where they were going. When he died in February 1924 his obituary indicated that he had died in a federal hospital, but did not mention the hospital's name or his disease.

Within eight months Edmond was admitted to Carville, followed in 1934 by his youngest sister Amelie and in 1941 by Marie and Albert. Their respective stories cover more than fifty years of life in Carville during the 20th century.

A Walk Through Carville and LSU

By José Ramirez, Jr.

The Gillis W. Long Hansen's Disease Center, formerly known as The National Leprosarium and the U.S Public Health Service Hospital # 66, and informally known simply as Carville, is exactly 20 miles from the gates of Louisiana State University. These two institutions greatly influenced by personal and professional lives as both helped me to heal and claim my dignity as a young man who happened to have HD.

Carville is a place that I did not know existed until I arrived in February of 1968 from Laredo, Texas in the back of a hearse. My parents had been told that "ambulances are for the living and hearses for the dead." Accompanying me were my parents, José (JP) and Rosa, Raquel one of my 12 siblings, and my girlfriend Magdalena. My family believed that with the last rites being administered as I was rolled into the hearse I would likely not live long after leaving Laredo. As a result my mother packed a small bag with one pair of white socks, one pair of blue jeans and one white t-shirt, and no shoes. I have since donated the bag to the HD Museum.

Little did I imagine that Carville would become my home for seven years and LSU would become my escape from the routine lifestyle of living in an institution. Carville was an institution known for both phenomenal research reaching all continents of the globe as it developed the "miracle" drug, a cure, and a place created to isolate up to 400 human beings at a time on a three hundred and sixty acre piece of land known as a "tongue." This "tongue" is one and half miles wide, five miles long with one lonesome road embraced by the mighty Mississippi River.

For many months during my hospitalization I was unable to appreciate the beauty of Carville's history pre and post leprosarium, the majestic mansion built in 1845 serving as offices for the administrators, and the aesthetic connection of twenty-one two story white stucco buildings with two mile long walkways or perambulators. I had to first acknowledge my situation and overcome my self-pity.

I realized that with a power plant, water treatment center, infirmary, surgery room, in-house PT, OT, dental and ophthalmology, dining halls, two chapels, farm, cattle, jail, post office, movie theater, school with grades 1-12, recreation center, incinerator for trash, morgue, cemetery, separate quarters for staff (twenty-one wood or brick veneer cottages), two nine hole golf courses, 400 dormitory rooms for patients, a separate building for the Sisters of Charity, and one front gate for entry and exit manned by guards 24/7, this "community" was designed to keep people inside the barbed wire fence which encircled the facility.

Seeing the fast paced activity of Carville and listening to languages spoken by patients from other countries fascinated me, but the long silence echoing loneliness during the evenings and weekends frightened me. The staff to patient ratio of almost 3 to 1 meant that there were many feet walking the concrete of the perambulators. These feet became non-existent after 5pm during the week and the walkways became highways for cockroaches and crickets.

For me, it seemed like the only time during weekends I would meet a large number of my brothers and sisters was when the dining hall bell would be rung. The bell would sound loudly promptly at 7:15am, 11:15am and 4:15pm, similar to the punctuality of the unwritten rule of compliance for "acceptable behavior." The clank, clank of the bell made us zombies as we walked without affect to the dining hall.

As my residence at Carville turned from weeks to months and then years, I was able to finally appreciate the work done to build a "community." Members of the Patient's Federation, hospital administrators, American Legion, and the Forty and Eight requested and received funds in 1940 to build a truly accessible "community" pre-dating the American Disabilities Act by half a century. The two-story walkways made it possible for any of the patients on wooden, hand propelled wheelchairs to maneuver throughout the huge institution. The walkways were raised four feet off the ground with openings of elongated windows or full-length bays allowing us to breathe the aromas of

magnolia trees and admire the Spanish moss dangling from the hundred year old trees. Without the efforts of so many, my brothers and sisters of Carville and I likely would have only had a ground level view of the never ending cyclone fence.

My “escape” from Carville and journey to Louisiana State University on a daily basis was accomplished by the unrelenting advocacy by the hospital’s director, Dr. John Trautman and the hospital social worker Vernon Bahlinger. Their work, according to my patient # 2855 medical records, far exceeded their normal responsibilities. They joined forces to persuade the LSU leadership to change policy and allow “a person with leprosy to attend the university.” Mr. Bahlinger inspired me greatly so I pursued a career in social work.

As a result of their advocacy I was able to receive my Bachelor of Arts and Masters in Social Work degrees. I attained a level of appreciation for the Indian Mounds on campus, the exquisite lines of architecture found on every building, the openness of the parade grounds, the beautiful clock tower, the large quadrangle surrounding the library, the gigantic oak trees with branches hugging the ground, the Alex Box baseball stadium, and the Romanesque type Tiger Stadium. My commute to LSU would end at the parking lot surrounding the enormous stadium. My lonely trip back to Carville would also commence next to the huge stadium walls.

The emotional connection between Carville and LSU lies in my medical treatment, and the “treatment” I experienced at LSU. I was on experimental medications of B-633 (Clofazamine) and Thalidomide. Since the Clofazamine turned my complexion dark I was yelled at by the “n” word by some of my fellow students who were members of the Ku Klux Klan (KKK). I heard the “l” word far too often and now I also felt the pain of the “n” word. Thalidomide is a sedative (100 mg QID for years) and required me being prescribed stimulants to keep me awake while driving and studying. Luckily the “experiment” with these medications ceased prior to my discharge from Carville. However, the stigma welded to HD continues. While the stigma continues, so does my activism for dignity for myself and my brothers and sister around the world.

In summary, my “walk” has been made possible by my parents, siblings, wife, children, granddaughter, special friendships at Carville and LSU, millions of persons who have experienced Hansen’s disease, and the thou-

sands who have touched me during my journey. This journey has been my “quest for dignity” as so compassionately voiced by my eternal friend Bernard Punikai from Kalaupapa Settlement on Molokai Island, Hawaii. This “settlement” was also created by a quirk of nature, a “tongue” comprised of lava. This “settlement,” like thousands of leprosaria throughout the world was manipulated by man to isolate other human beings when the tiny HD bacillus attacked the body. For me, it is a walk that helps me to garner strength to continue my steps of advocacy for HD awareness and as a social worker in Houston, Texas.

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RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

The **Forty & Eight**, an honor society of veterans created in 1920 and **The STAR's** primary funding organization, draws its origin from World War I. Millions of American soldiers in France were transported to the front in narrow French box-cars, called "Voitures," which would only hold 40 men or 8 horses. Remembering the close brotherhood of those box-car days, **La Societe des Quarante Hommes et Huit Chevaux (The Society of 40 men and 8 Horses)** was formed and local Voitures began organizing as outstanding Legionnaires were invited into membership. Membership is still by invitation only.

Dedicated to the needs of their fellowman, the **Forty & Eight** raises funds and support not only **The STAR**, but funds a national nursing scholarship program, various child welfare programs, provides aid to veterans and continues to promote Americanism at both local and national levels.



FACTS ABOUT HANSEN'S DISEASE

What is HD?

Hansen's disease, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr. Gerhard Armauer Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without difficulty and counteract most of the fears generated by the folklore surrounding this disease.

HD affects the skin, peripheral nerves, and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, and the testes.

There are both localized and disseminated forms of HD. If left untreated, HD causes nerve damage, which can result in loss of muscle control and crippling of hands and feet. Eye involvement can result in blindness.

Where is HD Found?

In 2016 there were 216,108 new HD cases registered from 145 countries according to World Health Organization official figures. The countries with the highest number of new diagnoses are India, Brazil and Indonesia followed by some of the African nations. More than half of all new cases of leprosy are diagnosed in India.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began who are still living. This includes approximately 3,300 cases currently receiving medical treatment for HD by the NHDP Ambulatory Care Program Clinics or private physicians with assistance from the NHDP. 178 new cases were reported in the U.S. in 2015. Most of the new cases were reported in Arkansas, California, Florida, Hawaii, Louisiana, New York, and Texas.

How Does HD Spread?

While this aspect of the disease remains a medical mystery, the most commonly accepted theory is that it is transmitted by way of the respiratory tract, and abraded skin. The degree of susceptibility of the person, the extent of exposure, and environmental conditions are among factors probably of great importance in transmission. Most specialists agree that 95% or more of the world's population have a natural immunity to the disease. Persons working with HD contract the disease only rarely. Cases of HD which respond satisfactorily to treatment become noninfectious within a short time.

How is HD Treated?

Although the sulfone drugs, introduced at Carville in 1941, continue to be an important weapon against the Hansen bacillus, Multidrug Therapy (MDT), which includes dapsone, rifampin, and clofazimine, is the recommended treatment for HD in the U.S. The rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Treatment rapidly renders the disease non-communicable by killing nearly all the bacilli within a few days, although it takes a number of years for the bacilli to be cleared from the body. This slow process is what can cause a condition known as "reaction," which can cause inflammation of the peripheral nerves, leading to nerve injury, pain, loss of sensation, and muscle atrophy. If not treated promptly, this process can cause deformity and disability.

NHDP SERVICES Website: www.hrsa.gov/hansens