

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

JULY 2023 -
DECEMBER 2023
VOLUME 64 - 34



**In Carville Love Conquered All
The Harmons Begin a 51-year Marriage**

CONTENTS

July 2023-December 2023 Vol. 64-34

In Carville Love Conquered All By Claire Manes	3
Reversing A Called Third Strike By José Ramirez, Jr.....	5
Two Stories, One Passion Lead to New Exhibit About Carville By Claire Manes	9
The Bergen International Conference on Hansen's Disease By Paul Johansen.....	10
Hansen's Disease Clinics.....	15

Cover Photo Courtesy of Johnny Harmon Collection

All correspondence concerning The STAR should be addressed to:

**Voiture Nationale
250 E 38th Street
Indianapolis, IN 46205-2644**

EDITORIAL BOARD

José Ramirez, Jr. -**Managing Editor, LCSW**
email: joseramirezjr@hotmail.com
Thomas (Tom) Adams, **RPh**
Claire Manes **PhD**
Mary O'Friel, **MA**
Erika Betzabe Ramirez, **JD**
David Scollard, **MD**
Mike Wood **BBA**

Stanley Stein

Founder - Editor, 1941 - 1967

The contents of this publication may be reproduced in whole or in part with credit given to **The Star**, Carville, Louisiana.

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," or when it is used as a medical term. We dislike the word "leprosy" intensely, but we dislike the practice of censorship even more. Furthermore "The Star endorses Section II, 13c of the United Nations Principals and Guidelines addressing discrimination of persons who have experienced Hansen's disease, that encourages the media to portray persons who have experienced the disease using 'dignified images and terminology.' "

MOVING SOON?

Please let us know six weeks before you move what your new address will be. Include your old as well as your new address.

**\$2.00 Per Year Domestic
\$5.00 Per Year Foreign**

National Hansen's Disease Program
9181 Interline Ave
Baton Rouge, LA 70809
Phone: (800) 642-2477
Website: www.hrsa.gov/hansens-disease

In Carville Loved Conquered All

by Claire Manes

Readers of The Star know Hansen's disease has often been misunderstood. There are erroneous ideas about its contagion, its severity, its link to the Bible. Judgment is made about those diagnosed with it; the curious and uninformed find it difficult to accept that those with Hansen's disease are simply persons with a treatable disease. There is speculation about the ordinary life and love of those with the condition.

When I first began writing about my family's life in Carville, I was occasionally met by a writer or would be writer who would say, "Oh, I'd love to write a novel about a romance in Carville." The implication seemed to be that such a story would be mysterious and exciting. I would usually smile politely or nod knowingly. I was wrong. I should have said, "Those stories have already been written and consummated." Patients met, fell in love, and married and their love endured.

Which story do you want? There is the story about the young man who would pedal across the Carville campus at noon to meet the young school teacher. Both had been patients at Carville and had children from previous marriages. Ray Elwood and Julia wed, raised their two families, and celebrated almost fifty years of marriage until death separated them. Their lives were devoted to their church, their family and their brothers and sisters in the Carville community.

Maybe your plot would center on the young girl who was twelve when she caught the eye of Johnny Harmon. As a child at Carville, Louise was lovingly cared for and protected by her surrogate parent, Gracee Choi. She spent her time with her brothers and other young patients, separated from the adult population. Johnny never forgot. He waited for Louise and when she was an adult, they married. The Harmons had a 51-year marriage, two children, several grandchildren, and a life both in and outside of Carville.

Another story that has already been written is that of the petite young Texas woman, Mary, who wrote letters for her Carville friend, Darryl Broussard, a tall gangly Cajun. As Mary told the story years later, when Darryl's love affair through letters ended, he wondered what he would do next. Mary suggested that he could write letters to her. It worked and they were married in Carville for life. He was "her honey." Their love supported them and nurtured others in the Carville community.

They accepted the responsibility of being surrogate parents for young patients at Carville. They were surrogate parents for the young Mexican American teen, Julia, who was separated from her family for six years. Later they nurtured another Mexican American, José Ramirez, a young college student from Texas whose condition removed him from his parents, 12 siblings, and girlfriend, Magdalena. Mary and Darryl's support for José along with Magdalena's daily letters, sustained the couple during his seven years in treatment. They married during José's last year in Carville. They have been married for 50 years and have two children and two grandchildren plus hearts full of love and activism for the Hansen's disease community.

There were others: Mary's sister Kitty also a Carville patient fell in love with Louis Boudreaux, a patient from a nearby parish (county) along the Mississippi River. Louis was the second editor of The Star, taking over the desk after Stanley Stein died.

Another Star editor who found love at Carville was Abel Aparacio, a Cuban refugee and the first Spanish editor of the paper. Abel met Yolanda within the Star office and married her.

Then there was the couple who was reunited and married in Carville. Laddie Bolden, the first black professional hired at Carville, a friend of mine and a friend of Sam, told me this story. Sam Wilson had been a band leader in his home country of Trinidad; Theresa had been his lead singer, but Hansen's disease separated them. Sam had been in Carville for several years blinded from his condition when Theresa arrived, disabled by the same disease and confronted with mobility issues. They were married. His vow to her was simple, "You be my eyes, I'll be your legs and carry



José and Magdalena Ramirez
Courtesy José Ramirez



Mary and Darryl on their wedding day
Courtesy NHDP Museum

you.”(Quest, p. 54) None of their challenges stopped them from dancing at every opportunity.

For many years the government did not sanction marriages between patients or provide housing for married couples, but love found a way. Couples would escape through the hole in the fence to marry and honeymoon, sometimes returning voluntarily to Carville; other times being returned by law enforcement. In a June 1956 Star article, Ann Page, herself one of the Carville couples, (husband, Hank) recalls the early maneuvers couples took to marry. The couple would plan their vacations together and with the help of family or friends on the outside declare their vows in a formal ceremony. Returning from their vacation, the couple would present their marriage certificate, a *fait accompli* to the Medical Officer in Charge (MOC).

Lacking private homes, some newly married couples were forced to divide their living between the dormitory type housing for men and women. A husband could visit his wife in her room in the women’s house until 10 pm when he would have to return to his bachelor’s quarters. Luckier couples managed to create their own community in Cottage City, also called Cottage Grove and Suburbia. This was a neighborhood of cottages built by patients and passed from generation to generation of residents. The houses cropped up on the hospital grounds, cobbled together with material bought with hard earned money or left over from building projects on the grounds. They were not palaces but provided couples and their friends places to reside and entertain.

My grandfather apparently had one such cottage. It has never been clear why he had it.. Perhaps he hoped his wife would come for conjugal visits or he may have lived with someone for a time. When he died in 1932 my grandmother inquired about its existence. Dr. Denny the MOC indicated that he knew of no such houses. It has been suggested that since these were unofficial residences the government had “no official” knowledge of them. Ironically, however, these non-existent houses all had fully connected utilities.

In the late 50s after much politicking by the patients and their political allies the federal government did provide houses or apartments for married couples on the premises. This meant the demolition of the hand built cottages in Suburbia and the loss of countless memories, but sturdy houses or apartments were provided for the couples.

The new housing coincided with the public health hospital’s new attitudes toward marriage between patients. In 1959 such marriages were sanctioned by the hospital and blessed by the churches. The Star represented this new attitude, covering weddings between couples in the pages of the paper. Accounts were given that were reminiscent of articles in any hometown newspaper. There were descriptions of the bride’s gown, the bridesmaids, flower girls, and best man as well as any reception held after the church celebration. According to the Star, a Greek Orthodox wedding was celebrated in the Protestant chapel on April 30, 1960, between two patients. The bride’s father a priest in the Greek Orthodox church officiated at the ceremony. The article,



1959 STAR announces new cottages



Mr and Mrs Scott
From The STAR May-June 1962

“Love and Marriage for Star Staffers,” reports on the young couple and also on the symbolism inherent in the Greek Orthodox celebration. (Love p. 11) An international wedding was blessed between Jose Casas a recently arrived patient from South America and Mrs. Esther Gomez a patient from Puerto Rico. Their marriage was celebrated on December 18, 1961 in the Protestant chapel. (Boy Meets p. 12) A picture of one Carville couple, Carma Jean Giggy and Tom Scott, was featured on the cover of the May-June 1962 issue of the Star and an article detailed the event. (A Spring, p. 8) An article the following year noted that their marriage received national coverage in Parade magazine, a Sunday insert in many newspapers of the time. In that same article the Star noted that there were 28 Carville couples living in the new houses or apartments. (Carville Couple p.1) The stories of falling in love in Carville are not the only stories. There are reports of divided love as well. In a 1928 letter my grandfather wrote to my grandmother about a woman whose husband was in Carville in the 20s and 30s. She came to Louisiana for an entire summer and visited her husband every day. (Manes, 119)

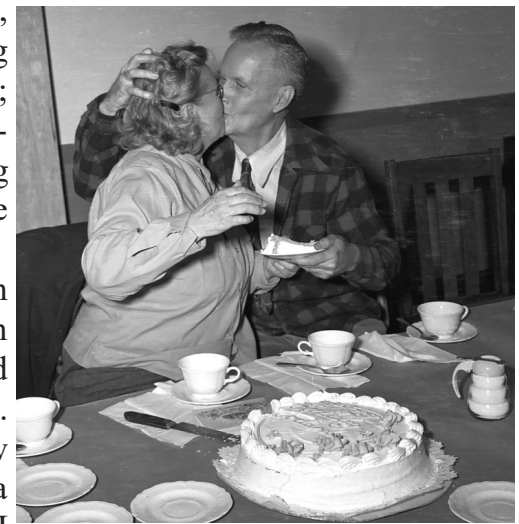
My grandfather also recalled the man who drove the rough roads to Carville two or three times a week and on Sundays to spend time with his wife. (Manes, 121)

Major Hans Hornbostel, a World War II survivor of the Bataan Death March, made international news when he revealed that he was being forbidden from living with his wife who was a patient at the Carville hospital. A compromise was reached; he rented a room in the Carville village and visited his wife daily during her confinement. Sometimes Carville residents who rose early would see him discretely leaving her apartment in the early hours of the morning, sneaking through the hole in the fence and returning again later in the day. (Fessler, 184)

Not all relationships were successful. Some faced separation or divorce which was legal for spouses of those with Hansen's disease. Such was the case in my own family. My great uncle Norbert's fiancé had written to him faithfully when he served in the Great War but broke off their relationship after his confinement in the hospital. My uncle Albert's wife filed for a divorce after they had been separated for a few years by his residence in Carville. It is not clear to me if the divorce was caused by a fear of Hansen's disease or the difficulty of maintaining a long-distance relationship. I am inclined to believe it was the latter. My grandmother and grandfather struggled mightily and often unsuccessfully to maintain a long distance relationship. He was understandably lonely and she was paralyzed by fear of his condition, worried for their two young children. Ultimately, they reached a reconciliation. She visited him in the last years of his life, was at his death bed in December 1932, and perhaps rode in the ambulance with his body to their hometown for burial.

I suggest these real-life stories to counter the all too frequent stereotypes of persons with Hansen's disease. There is no denying that incarceration and confinement of persons with Hansen's disease was wrong, but focusing only on their disease clouds the humanity of people within that community, and it was a community.

Hansen's disease is a curable bacterial condition, no more nor less. Stigmatizing persons with the disease is devastating to them and destructive of our humanity. Carville like any community had its stories of love, jealousy, intrigue. There were folks who were generous of spirit and those who were petty and mean spirited. Their stories are rich and multilayered not because they had Hansen's disease, but because they were human.



The Hornbostels
photo courtesy Johnny Harmon Collection

Works Cited

- "A Spring Wedding."* *The Star* vol. 21 no. 5 May-June 1962 cover and p8.
Bolden, Laddie conversation with the author. Mr. Bolden was employed at Carville from 1963 to 1993 and has shared Carville stories with me for many years.
"Boy Meets Girl at Carville—Wedding Bells." *The Star* vol. 21 no 3, Jan-Feb 1962 p. 12.
"Carville Couple Featured in Parade." *The Star* vol 22 no. 6 July-August 1963 p. 1.
Fessler, Pam. Carville's Cure: Leprosy, Stigma, and the Fight for Justice. New York Liveright 2020.
"Love and Marriage for Star Staffers." *The Star* vol.19, no 5 May-June 1960 p.11.
Manes, Claire. Out of the Shadow of Leprosy the Carville Letters and Stories of the Landry Family. Jackson UPM 2013.
Page, Ann. "Marriage Carville Version." *The Star*, vol.15, no 10 June 1956, p 4.
Quest for Dignity: Personal Victories over Leprosy/Hansen's Disease Published by IDEA. The International Association for Integration, Dignity, and Economic Advancement 1997 p. 54

Reversing A Called Third Strike

By José Ramirez, Jr.

In the game of baseball, when a home plate umpire calls a third strike on a batter for an out, the third strike is not reversible. It is also illegal according to baseball rules to argue the call. In our journeys through life many have experienced incidents when we have been "called out" due to unforeseen circumstances, or because of actions/words by others. Reversal of this "out" might not occur until later in life when destiny changes an initial negative outcome.

For me, a painful "out" was as a seventeen year old entering my senior year in high school in Laredo, Texas. I felt invincible with a belief that nothing could darken my senior year. I was wrong. On the first week of classes I received a slip from the principal's office to visit the school counselor. My initial thought was that I was being complimented for completing most of my credits for graduation. The school counselor, dressed in a beige sports coat, white shirt and light blue tie had me sit across from

his desk. His focus was on some papers on his desk. He slowly raised his head to stare at me without affect and said, “It is a good thing you have a strong back as you will be digging ditches the rest of your life.....you are not college material.” He asked if I had any questions. I silently stared back not knowing what to do nor say.

As I returned to my class I decided that I would be the first son to graduate from high school, make my parents proud. I mentally prepared myself to join the Marines the day after graduation and be sent to Viet Nam to fight the war at the time. I did graduate and I did make my parents proud, but I did not join the Marines. On the day of graduation I was speechless as I glanced at the graduation program and noticed my name as the recipient of a \$150 scholarship from the Laredo Classroom Teachers Association, enough money to pay for two semesters at Laredo Junior College.

I found out that one of my teachers had submitted my name to the association and thus changed my destiny. The teacher **reversed the “out” thrown at me nine months earlier** by one of her colleagues. The next night my girlfriend, Magdalena, also received a \$150 scholarship from her own high school. These unexpected scholarships projected both of us towards a college education, and not a lifetime of digging ditches.

Then, 20 months after graduation I received another “out” as a I was diagnosed with Hansen’s disease and involuntarily admitted to the national leprosy hospital in Carville, Louisiana, for seven years. The reversal of such was getting the opportunity to attend Louisiana State University and furthering my education while still a patient. This was made possible by four individuals advocating on my behalf: the hospital’s social worker, the hospital director, the Texas Rehabilitation counselor in Laredo, and one of the nuns who was an RN at the hospital. However, these two reversal of outs in my young life did not compare to the experiences of my fellow patients at the hospital in Carville, Louisiana.

One of the most dramatic reversals of an “out” occurred at Carville many years before my admission to the hospital. It was Carville’s own field of dreams. In the movie, “Field of Dreams,” a team comprised of professional baseball players labeled as outcasts is resurrected to redeem themselves and bring smiles to the living. In Carville in March 1951, another group of men stereotyped as “the living dead” because of the Hansen’s disease found in their bodies surprised everyone by becoming champions of the fast pitch Louisiana River League.

These champions, worthy of a display at the Baseball Hall of Fame, lived in isolation at the United States Public Health Service Hospital in Carville, Louisiana. This was the only hospital of its kind in the continental United States. It was located exactly 20 miles from the gates of Louisiana State University but millions of miles removed from acceptance by the general populace.

Hansen’s disease is an illness that has caused havoc to families, given rise to many myths, forced policy makers to capitulate to unfounded fears, isolated those diagnosed with the disease, and created a powerful stigma. Ironically, this same disease and its accompanying isolation meant that those with it also formed unending friendships, unconditional love and great pride in overcoming physical and emotional pain.

The hospital was located on property known in the 1800’s as the Indian Camp Plantation. The residents of the hospital lived in quarters that were located along a line where slave cabins once stood. The Mississippi River meanders around the property and alligator filled swamps hugged the 350 acre hospital grounds. The hospital was further enclosed by a 12-foot cyclone fence and a narrow gate for access/exit watched by a guard 24/7. The hospital was operated by the State of Louisiana from 1894-1920 and the federal government from 1921-1999. Congressional legislation originally created the hospital in 1917, but WW I held off the take-over of the facility from Louisiana.

In 1951 the hospital had its own post office branch known as Point Clair. In 1951 young men in their late teens and early 20’s diagnosed with Hansen’s disease were forced to live at the hospital. **They came together to form the Point Clair Indians softball team in** honor of those who had lived and died on the property many decades before.

Professional baseball had broken the “color line” with Jackie Robinson in the late 1940’s. The Carville Indians were a potpourri of colors. The team and coaches were comprised of a mixed race of patients. The coaches were Hispanic and Samoan. The infield had two Caucasians (Bob and Ray), one Hawaiian (Johnny) and one Japanese-American (Willie). The outfield had one African-American (Arthur) and two brothers of Japanese descent (Arthur and Ben). The catcher was Puerto Rican (Jack). The pitchers were Mexican-American (Mike) and African-American (Richard). Richard was featured in The STAR, Baton Rouge Advocate and EBONY Magazine. He was described as a “120 lb. youngster with a blinding fastball.” These were their Carville Indian names. In 1951 the practice among some patients was to change their names to protect their kin from the Hansen’s disease stigma. Therefore, **while their heroics on the baseball field may be long remembered, their true identities may not.**

Most of the players had not previously participated in organized sports, so their role models were older Carville patients. These older men used to play against each other prior to the birth of the Point Clair Indians. They were known as the “Reds” and “Blues.” Their bodies often had red and blue nodules resembling a physical beating that un-treated Hansen’s

disease can leave on the body.

The Point Clair Indians were allowed to play only “home” games as their institutional status forbid them to leave the property. All games were played under the lights as the Louisiana heat and humidity made it impossible for players and fans to make it through a day game. The brightness of the lights, intermingling with the fog from the river and swamps, made the majestic 100+ year old oak trees look scary with their dangling earth toned Spanish moss. If the inevitable mystery of the disease did not frighten the visiting players or their guests, then the gloomy surroundings might have intimidated them.

The softball field was ingeniously built on a nine-hole golf course called the “Patients’ Course.” The course was a challenge to play with traps, small brush, oaks, and cottages for married couples and frequent interruptions from squirrels, possums and nine-banded armadillos scurrying across the fairways. The Patient’s Federation, with the assistance of hospital staff, would annually host the Carville Golf Invitational.

Besides the quality of play by the Point Clair Indians on the combination softball field/golf course, the next most impressive event to occur on these sacred grounds was the participation of baseball great Mel Ott during the 1951 Invitational. Mel Ott lived in Gretna, Louisiana, and was on the Patient Golf Course when he received a phone call informing him of being voted to the Baseball Hall of Fame.

The first hole of the golf course was parallel to the right field chalk line, number two crossed center field and number nine allowed golfers to touch second base as they played the short game to reach the green. In order to play both sports throughout the year an outfield fence was never erected. This design favored the Point Clair Indians on defense with their speed and also running the bases after hitting line drives.



Carville’s “Field of Dreams. Note the absence of an outfield fence to accommodate the adjoining golf courses

The Carville Grandstand had a horseshoe design, going from first base to third base. The park had two levels, all made of timber, and an announcer’s booth high above home plate. The stands were in pristine condition, painted green and the envy of all visiting teams. The hospital had a practice of separateness for patients and staff/visitors: separate seating at the hospital cafeteria and two churches, and an imaginary line separating the staff houses and patient buildings. In earlier times this latter separation was denoted by a row of hedges dividing the property. This separation continued with seating in the grandstand.

The Carville administration, Patient’s Federation and outside teams comprised of all white or all Black players negotiated a truce on seating in the grandstand and playing games. It was agreed that competition between teams would be the focus during all “home” games. For visitors to the games, Blacks and whites would take seats in the grandstand along the third base line on a first come first served basis, and not on color basis. Patients sat along the first base line. Visitors to the games had similar access to water fountains and bathrooms. It is believed that in the 1950’s the Carville Grandstand was the only racially integrated public place in Louisiana.

One of the older patients was a ham radio operator. He used his skills to broadcast the games to the “Blind House” and others either in the infirmary or those unable to walk to the grandstand. Many of the patients who had been undiagnosed and thus untreated prior to hospitalization had nerve damage to their eyelids. Unable to blink, debris would collect on the eyes resulting in blindness. Fans were rooting for the Indians even though they were unable to see the unique speed of the pitches, but they could hear the roar of victory.

This same man was President of the Garden Club and a proud war veteran. He loudly played the National Anthem before announcing the line ups. The stars and stripes and anthem were highly respected by all even though Congress had denied the residents the right to vote up through 1946 simply because they were diagnosed with Hansen’s disease. Other populations institutionalized due to mental illness, mental retardation (cognitive issues) or incarceration were similarly denied voting privileges.

Another patient was the scorekeeper. He was trusted to keep an accurate record of the game because he served as the postmaster for the Point Clair Post Office on the hospital grounds. He also was President of the Patient’s Federation and Lions Club. This gentleman was abandoned by his family when diagnosed with the disease. He arrived at Carville as a teenager and quickly changed his name as he was deemed dead by his family. However, prior to his death he reverted to his given name and requested in his will that his obituary be published in his home town to share that he had many friends and did not die alone.

Each of the players had their own stories of lost dreams, lost love, lost families and lost lives. “The Law of Silence,” the

practice of ignoring the injustices of isolation and thus allowing stigma to flourish, could have petrified any thoughts of success for these young men. However, collectively they created an opportunity to reach for an imposing goal-----victory on a diamond.

Ray and his brother were escorted to Carville by law enforcement officers from Florida as teenagers. Besides having a batting average in 1951 of .402, he also excelled as the first resident at Carville to graduate from the hospital's high school, and became the first to attain the rank of Eagle Scout. Ray and Willie perfected the double play combination and frequently received applause from the fans, patients and visitors.

Tom was in the Army when diagnosed, discharged quickly, and escorted to Carville by two MP's (Military Police). He was a backup infielder and pinch runner to steal bases. He became a leader on the team and in the hospital community as Commander of the hospital's own American Legion Post # 188 and Manager of the Patient's Canteen.



Though not the champions this team mentored the Point Clair Indians

The two Japanese-American brothers saw their mother “arrested” in 1935 after being diagnosed with the disease and sent to Carville. They lost their home in California at the onset of World War II, were sent to an internment camp in Utah, and required to sign a “Loyalty Oath.” Similar to their mother, they, too, were sent to Carville after being diagnosed in 1948. One of the brothers became an expert in operating the print machinery for the Carville Star. The other brother left the hospital against medical advice and tried out for the Pelicans, a minor league team of the Pittsburg Pirates, was released on the last day of try outs and eventually returned to Carville. He made the hand propelled wheelchairs which he, too, used in later years. Bob was known for ripping the ball via line drives out of reach of the defense. He had big hands, large forearms and speedy legs a la Mickey Mantle. He ended up making jewelry boxes from discarded building materials and selling them to patients, staff and visitors.

Joe was small but agile and fast while patrolling center field. A ball hit in the gaps was deemed an automatic out. He learned how to make special shoes for those with feet deformities and ultimately made some for his own feet after his loss of sensation caused an infection and then amputation.

Mike, without a wind up, was able to put such a “vicious spin” on the ball that on several occasions he reportedly caused the hide on the catcher’s mitt to be ripped off. Later he would use his leadership skills to be elected President of the Mexican Club. The catcher, Jack, used three sets of mitts for the 1951 season. Richard had a blazing fastball and few opponents were able to solidly hit the ball.

The year 1951 was when young men at Carville were able to overcome high fevers, painful reactions, ongoing nerve damage and lengthy separations from family. Conversely they were able to earn acceptance as equals on the baseball diamond, battle stereotypes, attack discrimination and helped everyone living at the hospital feel victorious.

The grandstand, softball field and golf course no longer exist. Many of the Point Clair Indians still reside on the hospital grounds.....in the cemetery close to their life-long friends. The cemetery, protected by legislation, is situated in the back of the facility under tall and beautiful pecan trees. The cemetery, with perfectly centered white marble gravestones, looks like a mini Arlington National Cemetery located in Washington, D.C.

The property is now headquarters for the Louisiana National Guard and portable buildings stand on what used to be the Patients’ Golf Course and the Point Clair Indians Grandstand. The Hansen’s disease Museum, located at the entrance to the facility and open to the public maintains some of the memorabilia from the “Red” and “Blue” teams, and the glorious 1951 softball season.

Hansen’s disease, feared by millions throughout the centuries, forced a third strike upon the members of the Point Clair Indians and the other 385 residents at the hospital. However, united in strength they were able to reverse a called third strike and overcome great injustices through the power of a bat and ball. (Photos Courtesy of Johnny Harmon Collection)

Editor’s Note: *In 1971, twenty years after the victorious season, I was a senior at Louisiana State University. Following in the footsteps of other Carville Presidents, I was elected President of the LSU Sociology Club. I embarked on a journey of becoming more engaged in school activities and an advocate for my brothers and sisters with Hansen’s disease. One of my*

activities was to umpire slow pitch softball games just as I had done in my home town. I became close friends with the champions of the LSU Intramural Men's Softball League and invited them to play two exhibition games at Carville. The invitation was reluctantly accepted. The LSU team eventually embraced the challenge as they were educated by me about the uniqueness of the hospital and their opponents. Some of the members of the Point Clair Indians had passed and others lacked the youth and health to be competitive but their vigor and enthusiasm was not lost. The outcome of the two games has long been forgotten, but the memories of reversing a called third strike was evident among those of us who (again) played that night under the lights, and those who were eternal fans.

Two Stories, One Passion Lead to New Exhibit about Carville

By Claire Manes

Anne Harmon Brett and I connected through our common experience. Each of us had relatives who had been incarcerated in the United State Public Health Hospital #66 (later called the Gillis Long Hansen's Disease Center) because they had leprosy, now preferably called Hansen's disease.

Anne Harmon Brett's grandmother Louise Triche, her mother, Louise Anne, and three uncles Andre, Butch, and Claude had all been sent to Carville between 1934 and 1935. In my family my grandfather and his four siblings were patients there between 1919 and 1977.

In Anne's family her grandfather "Pere Pere Jack" Triche experienced the greatest loss. His wife was taken to Carville without his knowledge. He had no idea what had happened to her or why. He only learned of her disease and incarceration when the sheriff told him what had happened. Within two years he also lost his daughter and three of his sons. They were all taken to Carville, diagnosed with Hansen's disease. Mr. Jack "Pere Pere" Triche further experienced the stigma of the disease when the family home was burned down and he lived in a shed on the plantation where he worked.

Anne and her brother Johnny did not experience the stigma of leprosy that had affected their grandfather. Their mother, Louise Anne Triche, came to Carville at age ten. Years later she met and married another patient, Johnny Harmon. The couple had two children, Anne and Johnny. Although they could not raise their children in Carville, they were always connected to them. When their first child, Johnny (J.C.), was born, the Harmons found relatives by marriage who lived nearby. The Becnels cared for J.C and Anne as their own, but they never forgot that the children were precious to Anne and Johnny. The Becnels would bring the children to visit their parents on Sundays. The Harmon family would gather on the levee at Carville for Sunday picnics. Louise Anne and Johnny would escape through the hole in the fence carrying food and a camera. Perhaps it was these early pictures that instilled in Anne a love for her father's photography.

Leprosy was a word that was never used in the family. They only spoke about "the disease." Carville and its residents were familiar to both Anne and her brother.

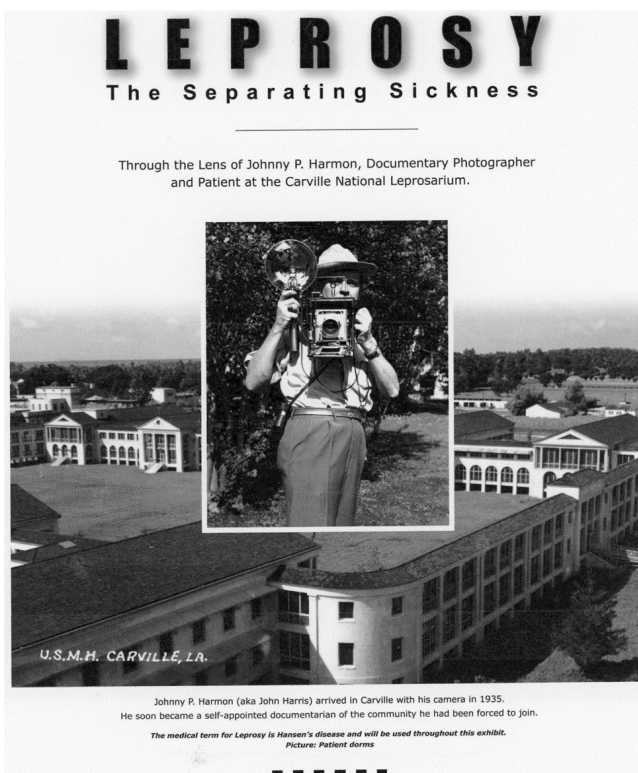
My own experience was quite different. My family never spoke about our grandfather or any other members of our family in the Carville hospital. "Carville" for us was a euphemism for leprosy. I learned at age nine that my grandfather, Edmond G. Landry (aka Gabe Michael) had lived and died in Carville because he had leprosy. However, the strongest message I received was that we did not speak about him. Only gradually did I learn what had happened to my grandfather's other siblings: Norbert (aka J.J) Amelie (aka Emma Lee Michaels), Marie, and Albert.

Anne and I had quite different experiences of Carville, but we shared a common passion—the desire to show the humanity of the men, women, and children forced to live their lives in the Carville hospital. A somewhat casual comment by Anne led us on a journey and learning curve to tell a Carville story. Anne said randomly, "I wish I could display my father's photography" and I naively replied, "Oh we can get a grant" not quite knowing what that entailed.

With the support of many, we received a Louisiana Endowment for the Humanities Rebirth grant and proceeded to create a photographic display to tell the story Leprosy the separating sickness. Anne's father took more than family photos on the levee. For more than fifty years as a photographic documentarian and patient, he chronicled the life of his fellow patients in the community at Carville. He recorded their joys and sorrows, their work and recreation through his lens and with his heart.

The result was a substantial collection of behind-the-scenes pictures that Anne and I culled to create the photographic exhibit, "Leprosy the Separating Sickness." The show includes photographs but also paintings and cartoons by this gifted man. The focus of the exhibit is the patients, ordinary people living in a community they did not choose. Pictures show them at play, at work, in celebrations, and in quiet moments. It does not forget the Daughters of Charity who were a significant part of the Carville story from 1896 until 2005, six years after the hospital closed. Some of the doctors are also featured as the exhibit

addresses the progress that was made in treating the patients. The goal we set for ourselves was to show not the wounds and scars of patients but the faces of men, women and children living full lives.



Opening panel of the exhibit of Johnny Harmon Photos

An invitation from Dean Thomas LaVeist of the Tulane University School of Public Health and Tropical Medicine gave us a venue for our first showing. Dean LaVeist had sought an exhibit that focused on the intersection of art and medicine. When he learned about Johnny Harmon's photography, he invited Anne to use Tulane as a venue. The grand opening there featured a welcome from Dean LaVeist, a presentation on Hansen's disease by Tulane professor Dr. Rie Yotsu, and brief remarks by Anne Harmon Brett and Claire Manes. Seeing the crowded gallery and hearing the remarks from visitors, Anne and I realized that we had fulfilled our goal and extended the work of the *Star*, radiating the truth about Hansen's disease. The 19 panel exhibit will be on display at Tulane University until early February 2024. In April and May of 2024, it will travel to the Jean Lafitte Acadian Cultural Center in Lafayette, Louisiana. After the presentation in Lafayette, it will be shown in June and July at the Jean Lafitte center in Thibodaux, Louisiana, just miles from Vacherie where Johnny Harmon had a photography studio after his release from Carville. The Bayou Teche Museum in New Iberia, Louisiana, will host the exhibit in late September. All exhibitions are free and open to the public. Additionally, pictures and articles related to the exhibit will be available on the website/Facebook: Friends of Carville Historic District.

The sustainability of the panels will enable it to be shown to interested groups in different venues after 2024.

The Bergen International Conference on Hansen's Disease

By Paul Mange Johansen

INTRODUCTION: Norway looms large in my psyche, as the country where my mother's parents were born and raised. In 1985 my brother and I visited Tjeldnes, the tiny island above the Arctic Circle where our grandfather grew up, and confirmed many of the outrageous stories he told us. I spent the summer of 1987 studying Norwegian at the University of Oslo. So, it was no surprise, when I had to write a term paper for a medical history course my senior year of college, that I chose Hansen's 1873 discovery of *Mycobacterium leprae*. What I couldn't know at the time, however, was that 35 years later I would still be studying this fascinating, challenging disease and the people impacted by it.



Presenters at the Conference

Last June I traveled to Bergen, Norway for the fourth time to attend the international celebration of the 150th anniversary of Hansen's remarkable, historic discovery (please visit www.Hansen2023.org for additional details about all of the information that follows, including recordings of all lectures). The two-day conference, held Wednesday-Thursday, June 21-22, was preceded by

numerous lead-up events, and followed-up by an international film festival. International Leprosy Congresses (ILC) have been held roughly every six years since 1897. Although this meeting was not an ILC, it was the third time Bergen served as host for an international conference on Hansen’s disease, the others (which were ILCs) in 1909 and 1973 (the centennial celebration). While it is impossible to summarize everything that happened there, I hope to convey the unique sense of community and commitment shared by the dedicated attendees from around the globe.

150TH ANNIVERSARY CELEBRATION–CONFERENCE STRUCTURE: The conference, under-written by the Sasakawa Leprosy Initiative, an offshoot of the Nippon Foundation, included six primary sessions, divided into three pairs addressing the topics of “**Medical Challenges**,” “**Human Rights and Dignity**,” and “**History Preservation – Learning from the Past**”. Each topic began with a Keynote speech, and each session included a Moderator and four or five panelists. We learned from nearly 50 experts -- scholars, medical personnel, people affected by Hansen’s disease, a novelist and a storyteller -- spanning 17 countries and 7 international organizations. Norway was the most heavily represented country (9 experts), followed by Japan (4 experts). In addition, the conference included a juried poster exhibition. A total of 20 posters spanned 12 countries, with the Philippines most strongly represented (4 posters). In addition to the juried poster exhibition, a second poster exhibition featuring the experiences of persons affected by Hansen’s disease, which can be viewed here:<https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/3938>.

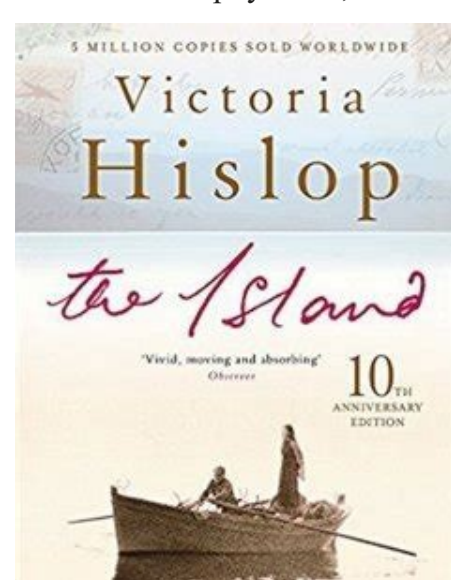
The conference began with greetings from meeting organizers from the University of Bergen (Margareth Hagen and Emmet McCormack) and the Sasakawa Leprosy Initiative (Yōhei Sasakawa), and dignitaries from the World Health Organization (Tedros Adhanom Ghebreyesus) and the United Nations (Volker **Türk**). We were treated to keynote speeches by Yōhei Sasakawa (also Chairman of The Nippon Foundation), Lorentz Irgens (University of Bergen) and Yuliati (PerMaTa Indonesia). Interestingly, Emeritus Prof. Irgens was the only living member of the committee that organized the centennial celebration in 1973. The opening session ended with greetings from the Norwegian Minister of Health and Care Services (Ingvild Kjerkhol).

Twice during the celebration we heard inspiring classical music performances by members of the Goldmund Quartet, who all performed on stringed instruments made by Antonio Stradivarius, owned and loaned by the Nippon Foundation.

Wednesday evening there was a special night tour of the Lepramuseet (Leprosy Museum), where many of Hansen’s patients lived and were treated. Since my last visit over 15 years ago, an entirely new portion of the museum had opened up, and was filled with detailed descriptions and artifacts covering all aspects of the history of Hansen’s disease (HD) in Norway. In addition to microscopic drawings, essays covered the Norwegian Leprosy Registry, the 1909 International Leprosy Congress held in Bergen, the issue of stigma, and numerous related topics. Importantly, the museum did not shy away from telling the full story of Hansen’s misuse of his authority as a physician. On November 3, 1879 Hansen “placed leprosy-infected material into the conjunctiva” the eye of Kari Nielsdatter Spidsøen without obtaining her consent, a clear ethical violation. He was trying to establish whether the more infectious nodular form of HD could be induced in a patient with the less contagious macroanaesthetic form. As a result he was relieved of his duties as a physician, but not as the Chief first Medical Officer for Leprosy in Norway. This episode suggests that Norway was as



Lepramuseet (Leprosy Museum)

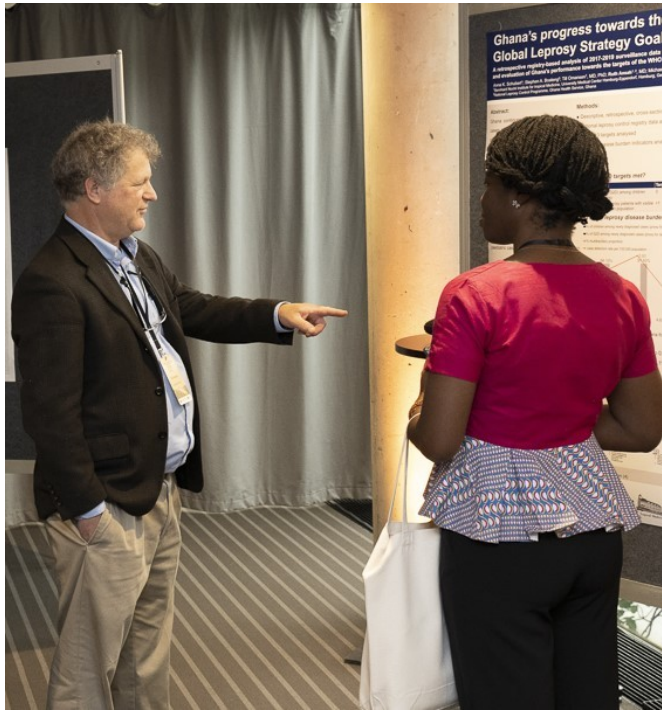


advanced in medical ethics as it was in microbiology in the late 19th century.

Thursday also included two Special Sessions, by British author Victoria Hislop (“The Island,” a novel about Spinalonga) and French-Norwegian story-teller Abbi Patrix (Hansen’s great-grandson). I was unfamiliar with Hislop’s best-selling novel, but appreciated her deep humility and genuine appreciation toward the HD community in Greece for allowing her to adapt “The Island” into a 26-episode drama that became “the most successful television series ever broadcast in Greece,” according to her website. She told a funny story about walking the streets of Greece one afternoon and being surprised at how quiet everything was, until she realized that most people were inside watching “To Nisi” (“The Island”).

Abbi Patrix was a pioneering and gregarious storyteller decades before discovering he was also Hansen’s great-grandson. His artist mother had a complicated relationship with Hansen, who died a dozen years before she was born. She was the family keeper of Hansen’s personal effects, and in 1997 wrote a book about him, in Norwegian. When she died in 2010, Abbi became the keeper of Hansen’s archives, including letters he exchanged with Bergen contemporaries composer Edvard Grieg, polar explorer Fridtjof Nansen, and other cultural luminaries of that period.

THREE KEYNOTE SPEECHES: 1. “Medical Challenges” Keynote Speaker Professor Paul Fine (London School of Hygiene & Tropical Medicine) set the stage by pointing out the inherent logistical challenges in trying to achieve



The Author discusses with Ruth Ansah her poster regarding Ghana's Progress Towards the Global Leprosy Strategy Goal

Zero Leprosy. “First the semantics: the word ‘elimination’...No longer is elimination defined for leprosy as ‘reduction of prevalence below 1 per 10,000,’ and it’s no longer defined as ‘elimination as a public health problem.’ And I say phew, thank goodness! That first target, set 32 years ago, without consultation, led to a lot of disagreement in the leprosy community: 1 per 10,000 was arbitrary. The phrase ‘elimination as a public health problem’ caused difficulties...If you’re a public health officer in a village somewhere and you have a leprosy case, you’ve got a public health problem! And it’s not helpful for WHO to say you don’t, because there’s only 1 per 10,000 in your country. We’ve moved on from that. “We’ve got another definition, and this one talks about ‘autochthonous cases.’ I think that formally means that *Mycobacterium leprae* infection is ‘locally acquired.’ Not always easy to recognize or to confirm in contemporary society where people move a lot...“And finally ‘interruption of transmission’...defined how? That phrase...is widely used in discussions of many infectious diseases, with a variety of different definitions, often not defined. “What is transmitted? Leprosy is not transmitted, although that phrase is used very widely as you all know. *Mycobacterium leprae* is transmitted, and sometimes causes leprosy in a certain proportion of infected individuals. And what proportion that is? My goodness there is a lot of disagreement about that, and very, very little data.

“So we’re talking about interruption of transmission of *Mycobacterium leprae*, but we can’t measure it!...We don’t have something like a tuberculin test with which you can get an annual risk of infection with *M. tuberculosis*. We don’t have that for leprosy; I wish we did. So, our indicator is disease, this thing that is not transmitted.”

Some degree of hope was provided by Paul Saunderson (American Leprosy Missions), who discussed promising early clinical trials of LepVax. While progress is slow, partly as a result of the slow growth of the bacterium, the Phase Ia results, completed in March, 2019, demonstrated that the vaccine was safe in healthy adults and induced a strong immune response. Enrollment in a Phase Ib/2a trial is currently underway, with results anticipated by March, 2026. This talk was particularly interesting to me, as I spent my early career working in Merck’s Vaccine Clinical Biostatistics department, and so am well aware of the potential pitfalls and disappointments of early clinical trials. I had a colleague at Merck from India, whose dissertation in the early 1980s focused on a vaccine for Hansen’s disease. *Mycobacterium leprae* remains a formidable opponent.



2. “Human Rights and Dignity” The second keynote speaker, Alice Cruz, is the first person to serve as the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. And she didn’t pull any punches. “If you go and talk to the new generation, you will see that their main concern is not the fact that some people may reject them. This is violence, let’s call it with the right word. It’s the fact that children affected by leprosy are expelled from schools; it’s the fact that people are fired from their jobs; it’s the fact that they never had access to the formal work market, so they don’t have access to social protection. And all of these are what we call social and economic rights, which are the very same rights that states find all the excuses not to guarantee, because they cost money. “Why is it so difficult to fulfill promises related to leprosy? I’m sorry for saying this. I admire medical experts very much, and I admire NGOs very much. But...that’s my job, to say the inconvenient truths. Leprosy has been mostly addressed either by a medical or by a charity-based approach. And neither of them ensures human rights...NGO’s do not ensure universal access to human rights; that is the state’s mission to do...We really need to change our mission and our strategies towards a rights-based approach to leprosy-related discrimination.”

Many people spoke of their personal experiences living with Hansen’s Disease during the remainder of these two sessions. Half presented in their native languages with the assistance of translators, including Portuguese, Hindi, Bengali and Ethiopian. These brave individuals had overcome their experiences to such a degree that they traveled Norway to present at an international conference. Their personal stories were compelling, and the support they received was an honor to witness.

3. “History Preservation – Learning from the Past” Having initially entered the world of Hansen’s disease through the lens of history, I was especially pleased and impressed with the third keynote speech. Associate Professor Magnus Vollset (University of Bergen) was also the primary organizer of the entire conference, a heavy burden that did not appear to weigh him down. He pointed out that the



Laurinda Rosa Maciel concludes her remarks with “I would like to end this presentation by reminding you that we must talk about it, write and listen to people who have been affected by leprosy, and preserve the objects that are part of this story and that tell it as a human and social phenomenon. If we don’t we run the risk of these traces of history disappearing. I am grateful for the opportunity to show what Brazil has done to preserve the history of leprosy in different aspects. Remembering is preserving and not forgetting so as not to repeat.

1897 Berlin conference “was the first global public health advice on leprosy, and the start of the fight for Zero Leprosy.” But he also did not pull any punches regarding Hansen’s mixed contributions to the field: “And this brings us to the third, and more sinister, interpretation of Hansen’s legacy.

From history, we know that while widespread stigma and discrimination against people affected by the disease was never universal. Faced with what was then an incurable and contagious disease, Hansen saw it as a logical consequence that the sick had to be identified and segregated. And to achieve this, the popula-

tion needed to be taught to recognize and fear those affected. Instead of combatting stigma, Hansen advocated spreading fear of contagion as a public health tool. As he put it at the conference in Berlin in 1897, ‘In Norway, we have succeeded. If a leper looks for a maid, he will not find one – no one wants to work for them for fear of contagion.’ “Hansen framed the fight against leprosy as a question of rights and duties. Those who were not affected, the healthy majority, had a right to avoid contagion. And the sick minority, those who had the disease, had a duty to accept restrictions on their freedoms...These policies were relatively effective, and at the time they were the only effective tool that existed. Still it is clear that the segregation Hansen advocated in many countries were practiced more strictly than necessary, lasted longer than necessary, and facilitated discrimination and abuse.

“Many of the outdated legislations that we still struggle to get rid of today were put in place with reference to recommendations made by Hansen. “These three interpretations [from superstition to knowledge, a scientific breakthrough, generating stigma for public health] are *all* true. And this, to me, is the first lesson of history. Preserving, studying, and communicating the history of leprosy teaches us to deal with ambiguities and the fact that different people can experience and interpret the same issues differently. “Here in Bergen we believe that for history to truly be a guide to the future we can’t merely celebrate past achievements. We must also identify and learn from past mistakes. This makes us better...to tackle difficult issues, and even unpleasant issues today...“When we, 50 years ago, marked the hundredth anniversary of Hansen’s discovery, this approach of looking for past success to learn from was widespread. Even the court case where Hansen was sentenced was presented with the emphasis on the silver lining. Yes, Hansen did something that was wrong, experimenting on a patient. But this only goes to show how progressive the Norwegian court system was. Supreme Court Justice Knut Blom argued, ‘While the rest of the world opened their eyes to the unethical abuses in medical experiments only after the horrors of the Second World War, Hansen’s case introduced the right to informed consent in Norway already in 1880’



Professor Vollset

History Preservation: Some Arguments from Professor Vollset

- 1—Shared Perspective...We are all historical Actors
- 2—History Invites Reflection and Distance
- 3— History Created Identity and Awareness
- 4— History Invited Curiosity and Learning
- 5— History of Leprosy is Special...Lessons for Other Issues
- 6— Our Last Chance to Learn

...Prof. Vollset ended his talk with both a warning and a reason for hope: “And the fourth reason is what we call the paradox of prevention. In countries like Norway where leprosy, or Hansen’s disease, is no longer a public health issue, it is no longer a priority. In some respects, leprosy is

a victim of its own success. The introduction of MDT [multidrug therapy], as you all know, changed leprosy into a firmly curable disease. And the elimination campaign galvanized support in the 1990s. But when we achieved the goals in the last two countries in 2005, the job was over.

“Great strides have been made in the 2000s in recognizing leprosy at the highest level of the United Nations. No other disease has a Special Rapporteur on [the elimination of] stigma and discrimination. However, in the aftermath of the elimination goal being reached, funding dried up, organizations left the field, and the main scientific journal was terminated, making the paradox of prevention quite apparent. “In recent years this has started to change, much thanks to a co-organizer, the Sasakawa Health Foundation, who have included history preservation as a target for funding opportunities. And to Yōhei Sasakawa’s relentless efforts as a Goodwill Ambassador for leprosy elimination.”

CONCLUSION: Over the course of the two-day conference, I continued to marvel at how advanced Norwegian society was 150 years ago. As Prof. Vollset noted, “Hansen’s discovery, as you all know, happened three years before Koch first observed the anthrax bacterium, and nine years before the discovery of *Mycobacterium tuberculosis*...Hansen’s discovery marks the dawn of the bacteriological revolution.” Not only was Hansen’s discovery of *Mycobacterium leprae* the very first human disease attributed to a

bacterium, but the Leprosy Registry, which first convinced him that “infectiousness was not paid sufficient attention by us [in Norway],” was another remarkable medical innovation that has become second-nature to epidemiologists. Norway also led the world in medical ethics, holding Hansen to account for failing to obtain informed consent from Ms. Spidsøen before operating on her eye. Finally, Norway was able to entirely eliminate Hansen’s disease by the 1950s, without benefit of modern drug therapy. As Paul Fine asked, “How did they do it? I wish I knew!” Why are these historical facts not better known, and not prominently featured in infectious disease textbooks? I wish I knew.

One challenge that was highlighted when discussing Zero Leprosy is how intertwined HD is with poverty. One speaker went so far as to say that HD will never be eliminated entirely until worldwide poverty is first eliminated. Another critical theme that was emphasized repeatedly through out the conference was, “Don’t Forget Hansen’s Disease/Leprosy”! The Sasakawa Health Foundation recently conducted an in-depth study of the many steps needed to combat the stigma and discrimination of HD. As summarized by Executive Director Takahiro Nanri, “In remote areas, there is social stigma and self-stigma, while professional stigma is common among new employees of the health profession.” The Sasakawa Health Foundation supported this conference in many ways, including travel support to persons affected by Hansen’s disease, and with free t-shirts and tote bags emblazoned with the “Don’t Forget Hansen’s Disease/Leprosy” logo, along with advance copies of Yōhei Sasakawa’s lengthy book, Making the Impossible Possible, and CDs of the wonderful musicians who performed at the conference.

Finally, Prof. Paul Fine also highlighted the crucial need for young researchers to enter the field. “We need new blood,” he pointed out. “The field will be around for awhile.” As older researchers are retiring and dying, their vital knowledge, experience and expertise must be passed on to a new generation of advocates. I was fortunate to meet three: Ruth Ansah, Emily Quilter, and photographer Tom Bradley, who are helping me remain optimistic for the success of future efforts on behalf of people with Hansen’s Disease.

Special thanks to Janet Staley for making my trip to Norway possible.

CELEBRATION WEBSITE <https://hansen2023.org> – Complete conference program, listing of juried posters, and lecture recordings from both days (over 10 total hours of video), as well as numerous lead-up events and a follow-up film festival in October.

*Johansen and Ansah Photo Courtesy of Thor Brodreskift
Other Photos and Conference Logos courtesy of the Conference and the author*

Author Paul Mange Johansen, MA currently works as the Biostatistician at Berkshire Medical Center, a rural hospital in Pittsfield, Massachusetts, USA. He has written for the The Star previously, most recently about the Penikese Island Leprosarium (1905-1921), in the July-December, 2021 and the January-June, 2023 issues. Another passion of his is mental health reform in higher education.

***** ATTENTION *****

Don’t let your subscription expire!

For a new or renewal **subscription** to The Star please fill out the subscription form below and mail your payment to :

Voiture Nationale 40&8
Attn: The Star Membership
250 E 38th Street
Indianapolis, IN 46205-2644

Subscribe to The Star

Name: _____

Address: _____

Address2: _____

City/State/ZIP: _____

Country: _____

Email: _____

\$2.00 per year domestic \$5.00 Per Year Foreign

Make checks payable to: Voiture Nationale

My enclosed check is for ____ years and for ____
subscriptions for a total amount of \$ _____



150 years

Discovery of the
Leprosy Bacillus 1873

**SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE**

日本
財団
**THE NIPPON
FOUNDATION**

笹川保健財団
**SASAKAWA
Health Foundation**

HANSEN'S DISEASE CLINICS

ATLANTA HD CLINIC

Emory TravelWell Center
550 Peachtree Street NE
7th Floor
Atlanta, GA 30308
PH: (404) 686-5885 Fax: (404) 686-4508
Physician –Dr Jessica Fairley
email: jessica.fairley@emory.edu
PH: (404) 686-5885
Public Health Nurse: Charlotte Varney, RN
Email: charlotte.varey@emory.edu

BOSTON HD CLINIC

Lahey Medical Center
41 Mall Road
Burlington, MA 01805
PH: (781) 744-5670 Fax: (781) 744-5687
Physicians - Dr. Julia Benedetti / Dr. Winnie Ooi
email: julia.benedetti@lahey.org
email: winnie.w.ooi@lahey.org
Public Health Nurse: Krista Langlois, R.N.,B.S.N.
email: krista.Langlois@lahey.org
PH: (781) 744-5670

CHICAGO HD CLINIC

University of Illinois at Chicago
Outpatient Care Center (OCC)
1801 W. Taylor Street, Suite 3E
Chicago, IL 60612
PH: (312) 996-8667 Fax: (312) 966-1188
Physician - Dr. Carlotta Hill
email: chhill@uic.edu
Public Health Nurse Yusuf Adegoke, RN
email: yadegoke@uic.edu
PH: (312) 996-0734

LOS ANGELES HD CLINIC

LAC+USC Medical Center
1100 North Start St. Clinic Tower A5B123
Los Angeles, CA 90033
PH: (323) 409-5240 Fax: (323) 441-8152
Primary Physician/Dermatology -
Dr. Maria T. Ochoa
email: maria.ochoa@med.usc.edu
Public Health Nurse - Jeffrey Phommasith, RN
email: jphommasith@dhs.lacounty.gov
Telephone: (323) 409-5240

MIAMI HD CLINIC

Jackson Memorial Hospital
1611 N.W. 12th Avenue
ACC East – 2nd Floor
Department of Dermatology
Miami, FL 33136-1096
PH: (305) 585-2511 / (305) 585-7348
Fax: (305) 355-2155 / (305) 585-6397
Primary Physician - Dr. Andrea Maderal
email: AMaderal@med.miami.edu
Public Health Nurse - Liliana Zucki, RN
email: Hansen-Program@jhsiami.org

Telephone: (305) 585-1111
Telephone: (305) 585-1111 Ext. 354026

NEW YORK HD CLINIC

Bellevue Hospital Center
Department of Dermatology
462 First Avenue, Room 17-N-7
New York, NY 10016
PH: (212) 562-6096 Fax: (212) 263-6423
Primary Physician - Dr. William Levis
email: doctorwilliamlevis@gmail.com
Public Health Nurse - Zina Jones, RN
email: Zina.jones@nychhc.org
Telephone: (212) 562-5671

PHOENIX HD CLINIC

Wesley Community Center Inc.
1300 South 10th Street
Phoenix, Arizona 85034-4516
PH: (602) 610-3169 Fax: (602) 257-4338
Primary Physician - Dr. Ronald Pust
Tucson Office: (520) 668-6441
email: rpust@email.arizona.edu
Public Health Nurse - Lynn Moriarty, RN
PH: (602) 610-3169
email: lmoriarty@wesleychc.org

SAN JUAN HD CLINIC

University of Puerto Rico Medical Sciences
Campus
School of Medicine - Dept. of Dermatology
P. O. Box 365067
San Juan, PR 00936-5067
PH: (787) 765-7950 Fax: (787) 767-0467
Primary Physician - Dr. Aida L. Quintero Noriega
email: dermatol.rcm@upr.edu
Email: aida.quintero@upr.edu
Public Health Nurse - Sonia Santos-Exposito, RN
PH: (787) 758-2525, Ext. 5503
email: sonia.santos@upr.edu

SEATTLE HD CLINIC

Harborview Medical Center
2 West Clinic – 359930, 325 Ninth Avenue
Seattle, WA 98104
PH: (206) 744-2213
Fax: (206) 744-5174
Physician - Dr. Jason Simmons
email: jasonds@uw.edu
Public Health Nurse – Chinh Tran, RN
email: tranc@uw.edu
Telephone: (206) 744-5112

SPRINGDALE HD CLINIC

Joseph H. Bates Outreach Clinic of Washington
County
614 E. Emma Avenue, Suite 247
Springdale, AR 72764
PH: (479) 751-3630 Fax: (479) 751-4838

Physician: Linda McGhee, MD
email: mcghee@umas.edu
Public Health Nurse - Ruby Lewis, RN
email: rubulewis@arkansas.gov
Telephone: (479) 8415779

TEXAS HD CLINICS Headquarters

Department of State Health Services
Hansens Disease Program
P. O. Box 149347, Mail Code 1939
Austin, TX 78714-9347
PH: (512) 806-4334
Fax: (512) 989-4010
Nurse Consultant: Elizabeth Foy, RN, BSN
email: elizabeth.foy@dshs.state.tx.us
Telephone: (512) 533-3144

Denton County Public Health

Denton Office
535 S. Loop 288, Ste. 1003
Denton, TX 76205
PH: (940) 349-2900
Fax: (877) 865-2587
Primary Physician – Dr. Javed Akram
email: Javed.Akram@dentoncounty.com
Public Health Nurse – Soila Gomez, RN
email: soilagomez@dentoncounty.com
Telephone: (972) 434-4706

UT Physician Dermatology – Texas Medical Center

Houston Office (Primary office)
Houston Med. Cnt. Professional Bldg.
6655 Travis, Ste. 700
Houston, Texas 77030
PH: (713) 500-8260
Fax: (713) 524-3432
Primary Physician: Dr. Steve Mays
email: Steven.Mays@uth.tmc.edu

Texas Center for Infectious Disease

2303 S. E. Military Drive
San Antonio, TX 78223
PH: (210) 531-4526
Fax: (210) 531-4508
Primary Physician - Dr. Adriana Vasquez
email: adriana.vasquez@dshs.texas.gov
And Dr. Annie Kizilbash
email: quratulainnie.kizilbash@dshs.texas.gov
Public Health Nurse - Trista Reglein, A.C.N.E.
email: tristareglein@dshs.texas.gov
Telephone: (210) 531-4576

VOITURE NATIONALE
250 E 38th Street
Indianapolis, IN 46205-2644

NONPROFIT ORG.
U.S. POSTAGE PAID
INDIANAPOLIS, IN
PERMIT NO. 963

The Star

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 dapson, 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