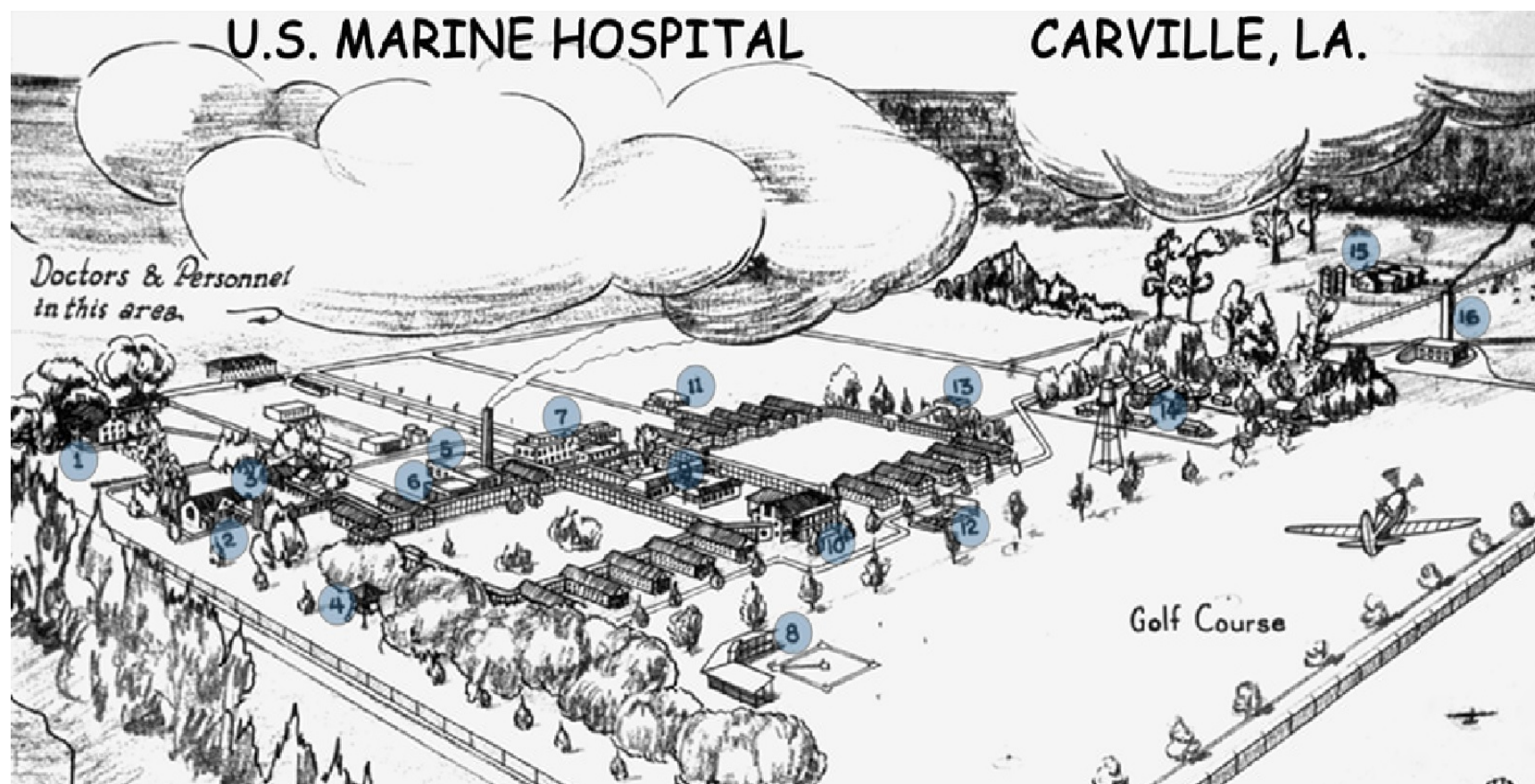


The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JANUARY - JUNE
2014
VOLUME 64 - 17**



1. SISTERS QUARTERS
2. PROTESTANT CHURCH
3. CATHOLIC CHURCH
4. OBSERVATION TOWER
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8. BALL DIAMOND

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16. INCINERATOR

Johnny Harmon's Drawing of Carville, c. 1940 was drawn using his gift for mechanical perspective. It was drawn without benefit of an aerial photograph. He positioned himself in an imaginary spot 1500 feet above the ferry landing and drew the center based on distances that he had paced off. And aerial photograph would overlap perfectly with that drawing. Few people notice the airplane over the golf course. Johnny drew a P 40 fighter plane, a WWII "tank buster" making a practice strafing run on the golf course which these planes, based in Harden field in Baton Rouge often did. This remarkable drawing graced the cover of the star in 1946.

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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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His HOLINESS DALAI LAMA Visits Leprosy COLONY in India

By Dr. P.K. Gopal



“Special visit to a leprosy colony in India.” L to R are Dr. P.K. Gopal, President of IDEA India; Mr. Yohei Sasakawa, Chair of Nippon Foundation Japan and WHO Goodwill Ambassador for the Elimination of Leprosy; and His Holiness Dalai Lama.

In India, persons affected by Hansen’s disease, more commonly known as leprosy, have started a national level organization called Association of People Affected by Leprosy (APAL). Dr.P.K.Gopal was the first Chairman of this organization. Now Mr.Narsappa, living in a leprosy colony in Hyderabad, is the Chairman. Mr.Yohei Sasakawa , chairman of the Nippon Foundation of Tokyo, Japan and the World Health Organization (WHO) Goodwill Ambassador for Leprosy Elimination, asked Dr.P.K.Gopal and Mr.Narsappa to organize the visit of His Holiness Dalai Lama visit to the leprosy colonies. Mr. Sasakawa had informed His Holiness about the situation of leprosy colonies and the stigma often associated with this disease. His Holiness expressed his wish to visit the leprosy colonies in Delhi.

The planning for this event started in early 2013. The Kasturba Leprosy Colony was selected for the visit. There are about 16 leprosy colonies in that area and so the leaders of all the leprosy colonies were involved in the preparation of the visit.

The Sasakawa India Leprosy Foundation is an organization working to improve the quality of lives of people living in the leprosy

colonies in India. This organization partnered with APAL in the planning process. The entire expenditure for this event was supported by The Nippon Foundation, Japan.

The Government and the Police also helped with the visit and provided the necessary security arrangements. APAL invited the Board Members, State level leaders and other people affected by leprosy from the 16 States of India to attend the function on March 20, 2014.

When His Holiness exited from his car he was received by Mr. Sasakawa, and Mr. Narsappa. His Holiness received a rousing reception from the crowd. Instead of going to the stage His Holiness first went to the people and spoke with many and blessed them. “He asked me if I was fine. He blessed me and asked me to stay well. I told him I have some problems with my eyesight. It felt really nice having spoken to him,” said P Virkkan Yash Bavadel, 60. He has been living in one of the colonies on the leprosy complex for almost 25 years.

According to 55-year old Jhali Devi, residents like her have been living in the complex for the past 30-40 years but the lack of facilities is still a problem. “We have many challenges making a living,” she said.

“Dear brothers and sisters, I am extremely happy to come here and see you,” the spiritual leader told a crowd of 500—made up of people affected by leprosy, journalists, government officials, and others—at the Kasturba Gram Colony in Tahirpur Leprosy Complex, New Delhi, on March 20.

The Dalai Lama delivered an address that resonated with his audience. “People should not look down on others. It is totally wrong. Discrimination is a sin.”

Discrimination is something that people affected by leprosy know only too well. Their disease pushes them to the margins of society, denying them opportunities for education and employment, destroying marriages and restricting access to healthcare and social amenities. Even after treatment, the stigma can last a lifetime.

In the face of leprosy’s challenges, His Holiness Dalai Lama urged his audience never to lose hope and to go forward with “courage and self-confidence.”

India has some 850 self-settled leprosy colonies that are home to around 200,000 people. Recognizing the need for these communities to speak with a common voice, in 2006 the Nippon Foundation supported the establishment of a nationwide network now known as the Association of People Affected by Leprosy.

While addressing the audience the Tibetan spiritual leader pledged his support for leprosy-affected people and promised to donate one million Rupees (\$16,700 U.S.) to the Kasturba Gram Kusht Ashram – a complex for leprosy affected persons in Delhi. “People who spend money in a luxurious way are foolish. They should spend money on people who are needy and poor. This is the best way to serve God,” the spiritual leader said.

In India, 1.35 new cases of leprosy per 10,000 were reported between April 2012 and March 2013. His Holiness expressed his willingness to help persons with leprosy over the next five years using the royalty his trusts receives from the sale of books written by him.

“A smiling person is always better than the one who is rich and healthy because they have forgotten to smile. Even if a person has physical difficulties, he is smiling and his brain is functioning properly. There is no reason to feel disheartened. Self-confidence and dignity is very important in a person’s life and if he has that there is no need to feel sad,” said the spiritual leader.

The media from Japan extensively covered the event. Mr. Sasakawa, who was instrumental in coordinating the visit, underlined its significance. “I am certain that the words we have heard today from His Holiness will give tremendous encouragement to people affected by leprosy and their families across India and throughout the world,” he said. The visit proved to be an unforgettable and stigma-bursting experience for those who attended the event with His Holiness. For residents of the complex, the visit was a delight.

“Leprosy is not hereditary. It is not highly infectious. It is not a dangerous disease,” said APAL’s president, V. Narsappa, “There is no need to isolate us. We are equal members of society.” He also called for the discriminatory term ‘leper’ not to be used. The event ended with a great surge of confidence among the 500+ present at this special gathering.

Memories of Carville

The following are two stories of children who grew up on the 350 acre facility while one of their parents worked at the hospital. The parents were federal employees with housing provided on the grounds as part of the “hardship pay” afforded to most of the employees in a supervisory role. After each story is a brief reflection on the times as recorded by persons who lived on the “patients’ side.”

Growing up at Carville, 1936-53 **by Shirley Harelson**

On July 30, 1936, I arrived into the world at the US Marine Hospital at Carville, Louisiana, on the last house on 2nd Street. The doctor from the neighboring community did not arrive and the first doctor to check me in was a Public health Service physician (probably Dr. Frederick Johansen). Although I don’t remember the first few years, I soon came to realize that this was a wonderful place to grow up from 1936 until we moved in 1953. As the roads to the hospital were gravel and folks only went into Baton Rouge about every 2 weeks, the hospital was a small village all its own. We were very fortunate to have electricity, steam heat, running water, and street lights, since electricity did not come to the surrounding communities until the mid to late forties.

As with any hospital, children under 12 were not allowed on the patients’ side. So I only saw patients when we went to church. However my dad, Alex Haase, worked in the Power Plant and sometimes when we brought supper to him, at work, he was chatting with a few patients outside the power plant.

My earliest memories are of walking to the end of our street with the boy next door to meet “Sugar Boy” who also worked in the power plant. His wife made the best biscuits, which he gave us when we met him. Of course, Dad had to call home and have my mama, Edith, bring a lunch for “Sugar Boy” as we had eaten his.

Many children lived at the Hospital and since it was fairly secluded, we were very close. We made kites and flew them on the golf course and on the levee. We also swam, skated, road bikes, put on plays in the ball-room and watched movies (in the old plantation). We also played baseball & softball, etc. We played up and down the street and no parent had a problem with correcting any child they thought needed it. On nights when there was no movie, often the adults (sometimes with children in-tow) would stroll around the block, visiting with each other. The Parish school bus did not take us to school. We were taken in a battleship-gray government bus, and when it was broken we went in a canvas covered supply truck. It was like arriving at school with 20 or so brothers and sisters. We formed a bond that still exists today.

During World War II, a look-out tower was erected on the levee near the front gate, and adults were assigned shifts to watch for aircraft. Every plane spotted was called in to a central site. We were given playing cards with U.S. and foreign planes on them to help us learn the aircrafts. I always went with my mom on her shift to keep her company. Also, Mrs. Faget, the Medical Officer-in-Charge’s wife, had all the females, including us little girls, making knitted items for the troops. The adults made more difficult items, but us little girls only knitted long olive-green scarves.

An organization provided first-run movies for the patients, which were also shown to the staff residents and their families. When we got old enough to date, we only went to movies to socialize with our friends, as we had seen these movies before they came to Baton Rouge. After midnight, the front gate at the hospital was locked for twenty minutes each hour, starting on the hour. Folks timed their return home, so as not to have to sit and wait for the guard to return.



The world was a much smaller place as people did not travel the way they do today, and there was no television, etc. However, since Carville was the national center for Hansen’s disease treatment, research and training, we children met people from all parts of our country, and many other countries of the world. We learned a lot about other cultures and places through them. I lived there from 1936 until 1953 shortly before my dad retired, and as most of the other “Hospital Kids” who had left, I missed living there. However I did return as an employee in 1968 and retired in 1995—another good experience.

Editor’s Note:

Carville was designed to be self-sustaining in an effort to not rely on outside resources. As a result the government employed highly skilled electricians, plumbers, carpenters, etc. While children on the “staff side” enjoyed many freedoms, the children on the “patient side” were assigned surrogate parents and did not have access to a formal education until the 1950’s. The practice of having guards patrol the corridors of the “patient side” from 9pm-6am continued until the late 1970’s, even though the routine of closing the gates stopped in the early 1960’s.

Carville Memories, 1942-49 **By Stewart Perry Butler**

In early 1942, shortly after the beginning of World War II, my father, mother, younger sister (by three years) and I (age eleven) moved to what was then known as the U.S. Public Health Service’s National Leprosarium. Since then the name of the disease that was known as leprosy has been changed to Hansen’s disease. My father was transferred to Carville to serve as its Maintenance and Supply Officer. We lived there until the summer of 1949.



We had our Victory Gardens to grow our own vegetables and there was a huge scrap pile for metal and rubber near the front gate. On the levee, was an elevated airplane watch tower which was staffed from dawn to dusk by volunteers, including teenagers, who called in all aircraft sightings as to speed, direction and type. There were practice air raid warnings and blackouts. The Civil Defense patrolpersons checked to make sure no lights could be seen. In hindsight I think these two things were unnecessary but were really designed for propaganda purposes to make us feel the war was closer to us than it was, thereby making us feel more personally involved.

Looking back on that period, especially after the War, I can best describe it as being like “Country Club” living. We had our own tennis court, swimming pool, nine-hole golf course, Ping-Pong room, a free movie every week and we explored the adjoining

woods and the batture behind the Mississippi River levee in front of the hospital grounds and our house.

The personnel were allowed on the patient side for medical treatment and specified occasions such as softball games and church. Both the Roman Catholic and Unified Protestant churches had personnel sections. The only rules were that we weren’t supposed to touch anything and to wash our hands upon our return to the personnel side.

We socialized with the medical staff, who lived in the front row of houses; the trades persons, who lived in the second and third rows of houses, and a few people living in the surrounding community.

Since my father was a commissioned officer in the U.S. Public Health Service, we lived in one of the four or so duplexes in the first row of houses. There were also two single houses, one of which the commanding officer Dr. Faget lived in and the other in which the second in command Dr. Johannsen lived. A wide parkway separated the first and second rows with a street between the second and third rows.

All the staff socialized with each other and members of the “outside” community. I remember the families of Drs. Prejean, Johannsen, Faget and Fite. Dr. Fite was a fellow stamp collector who played chess with me on the side while playing poker with the grown-ups and Mrs. Fite became a very close friend of my mother’s. Other staff families I remember were the Turners, Huevels, Nicolosis, Barbays, Rev. and Mrs. Rash and especially the Dubreuil’s whose son (Dave) became my closest friend. My father paid for the traps and bait Mr. Dubreuil used craw-fishing in the batture behind the levee in exchange for some of Mrs. Dubreuil’s delicious crawfish bisque.

And then there was the Sunshine Lady, so called because she lived in the wide place in the River Road on the way to Baton Rouge named Sunshine, La., or was it the other way around? In any case, once when her son was visiting, my mother asked him if he knew how to play poker, to which he drawled “Why Mz. Butler, I was borned under a poka table.”

Editor’s Note:

Over its years of operation, the USPHS hospital at Carville admitted 102 men who had served in the armed services during World Wars I & II. The veterans had an active American Legion chapter and often handled the Colors of the Guard at festivities held within the hospital grounds. Up until 1971 the practice of using two chalices for communion, one for staff and one for patients, was routinely followed during mass at the catholic chapel. The practice ended when one of the patients sat on the staff side and received communion from the staff chalice.

Michihiro Ko: A Role Model For Advocacy

By Kay Yamaguchi

The headline of the latest issue of Zen Ryo Kyo (All Japan Hansen's Disease Hansen's Disease Sanatoria Residents' Association) Newsletter reported the passing of Michihiro Ko who had led the Zen Ryo Kyo movement for nearly 50 years, leading the way in restoring dignity and rights of the people affected by Hansen's disease (HD) in Japan.

Mr. Ko was 80 when he died on May 09 in Kusatsu, a noted hot spring resort, where he was to attend the annual gathering of Hansen's Disease Association for the People (or Hansen's disease Citizens' Association). He was one of the co-founders of this association when it was created in 2005.

Mr. Ko had been quite confident of his health until recently. "I have never suffered any illness except Hansen's disease" he used to say, but recently had developed arrhythmia, or a heart rhythm disorder. He had taken a 24- hour Holter electrocardiography just two days earlier and was expecting a further check up after the meeting in Kusatsu.

Mr. Ko was known with the phrase "I will stake my life for the Zen Ryo Kyo movement." In fact, the last appeal he wrote for the Zen Ryo Kyo Newsletter, published after his death, was titled "Urgent Appeal – Rights to Life is Threatened - the realities in Hansen's disease sanatoria". Mr. Ko had been at the forefront of the fight to sustain the quality of day-to-day care for the aging residents of 13 national HD sanatoria throughout Japan in order to ensure a dignified life in the final years of the residents. The residents had been forced to live life in isolation due to the prolonged HD policy by the government, which had been totally condemned by a land mark court decision back in 2001. His last appeal concluded with the following phrase: "Zen Ryo Kyo is determined to fight through, until our swords are broken and our arrows are exhausted."

Michihiro Ko was born in 1934 in Kyushu, Japan in an established family but he was diagnosed with HD at age 17. Soon after, in 1951, he was admitted to the Oshima Seisho-en Sanatorium located on an island in the Seto Inland sea. Sulphones were already available, but it was only dispensed to "admitted patients" in the HD sanatoria. There was no option for him but to leave everything behind and enter a sanatorium. Upon admission he was strongly advised to adopt an alias. He named himself Masao Kosaki, the name which he discarded on April 1, 1996 when the prolonged Japanese Leprosy Prevention Law was finally abolished.

After this unjust law was repealed, he had the opportunity to leave the sanatorium and build a life of his own outside. Contemplating his future, and watching his fellow inmates, mostly older and with severe physical difficulties, abandoned by their families and living under harsh discrimination, his sense of comradeship did not allow him to think only of his personal pursuit. After pondering over his future, he finally chose the path to remain with them, to lead



the organization and to fight for better lives within HD sanatoria. Once having made up his mind there was no turning back.

He first led the Zen Ryo Kyo branch, based in Oshima, for more than 10 years. In 1995 Mr. Ko was elected General Secretary of the central body of Zen Ryo Kyo based in Tokyo. He shifted his base to Tama Zensho en in Tokyo and lived there until his death. The abolition of the Leprosy Prevention Law took place in 1996, followed by the nationwide expansion of law suits demanding government compensation. It all culminated as a total victory on the part of the plaintiff, the HD sanatoria residents, who had filed the case against the government. These were unprecedented years of confrontations, negotiations, arguments, dialogues and compromises. Mr. Ko's courageous leadership and that of his predecessors and fellow leaders such as Mr. Kazumi Sogano, also from Oshima and a senior to him, are well remembered in the history of Zen Ryo Kyo movement over these difficult years. Mr. Sogano was a plaintiff on the law suit and insisted that the Japanese government apologize for all of the injustices related to HD.

Mr. Ko was a brilliant orator. His presentations were always impeccably organized. He also had full understanding and sympathy for Japan's general aging population in general as well as those affected by HD and their families in Asia and throughout the world.

I had long wanted to introduce Mr. Ko to people living with HD outside Japan and also wanted him to share Japan's experiences with the rest of the world. In fact he had been a member of Sasakawa Memorial Health Foundation Board of Councilors for 6 years from 2005-2011. Due to his heavy work load with an enormous amount of travel and meeting other leaders from within and outside the world of HD, the opportunities to directly interact with his 'comrades' outside Japan were rather limited, but there were a few unforgettable scenes of him related to international interactions. In June 1998 Mr. Ko represented Zen Ryo Kyo at their first ever International Exchange Meeting of Persons Affected by Hansen's Disease – in Quest for Dignity and Living Together - held in Tokyo, where 9 persons with a HD background, representing 7 countries, joined 600 audiences, many from Japan's HD sanatoria, to commemorate Japan's change and share experiences. Mr. Ko was there to present the Tokyo Declaration. At a function held after the meeting, guests were entertained by Zen Ryo Kyo chorus in which Mr. Ko was on key-board demonstrating his skill of playing piano.

Also Mr. Ko participated at a World Health Organization (WHO) meeting in Manila in 2009, also attended by José Ramirez, Jr. and many others throughout the world affected by HD. It was to work out a draft document of WHO Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services. In his presentation he referred to a developing network of various social segments of people in Japan, who, he had hoped, would take over to further the legacies of HD affected individuals. These were the legacies of their struggle, their perseverance and achievements, in order for the future generations to find a value of society where every individual is entitled to his/her innate rights as individuals and every person is given recognition as an equal and valued member of society. History is for a dialogue between the past and the future. At this meeting he said "most of us who have lived with Hansen's disease will leave this world sooner or later, but the memories of how we lived, we want the future generations to remember in order for them to build their world a better one." I clearly remember him saying at the end of his presentation, "Fortunately, I think I have found an answer to this in Japan."

The Kusatsu meeting concluded by all of the attendees vowing that Mr. Ko's mission would be upheld by all, each in different segments of society.

Ms. Kay Yamaguchi is advisor to the Sasakawa Memorial Health Foundation
Tokyo, Japan

New Signs of Life at the Carville Historic District

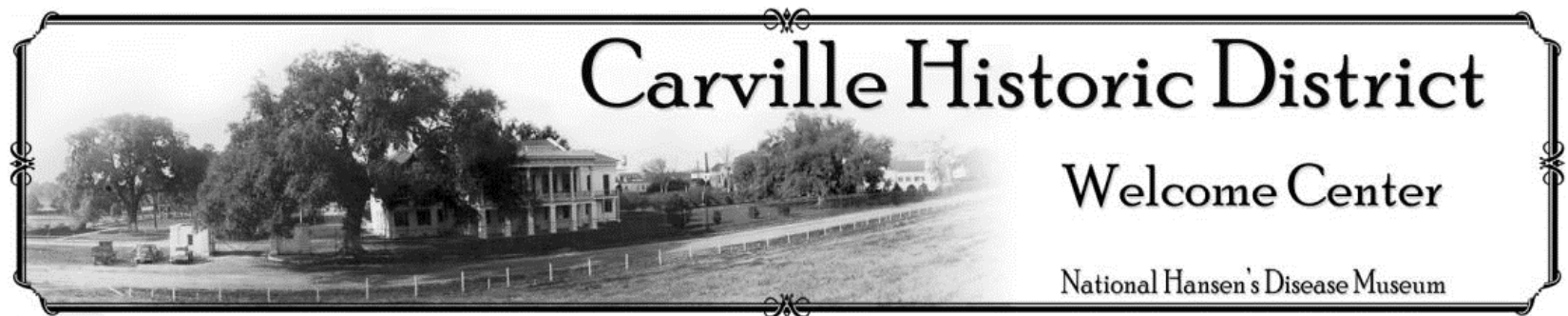
By Elizabeth Schexnyder

It's been a long time coming, but the new signs for the Carville Historic District and National Hansen's Disease Museum have arrived and are being installed.




The Carville Historic District Welcome Center gets a facelift.

The Welcome Center sign was designed using a panoramic image from the mid 1930's. Indian Camp Plantation sits on the old graveled Mississippi River Road flanked by a live oak and the hospital gatehouse. Antique vehicles can be seen parked out front.




Inside of the Welcome Center, two timelines will present the history of the leprosy hospital and a history of the development of the buildings. The hospital underwent many renovations over the decades to accommodate larger patient populations and upgrade to the latest technologies.



1941 Promin
"The Miracle at Carville"


Dr. Guy Faget

1940-1941 The hospital is rebuilt to provide individual rooms for 450 patients in 2-story dormitories. In addition, a new recreation center and separate living quarters for the Daughters of Charity are completed.



1940-1947 Guy Henry Faget, MD, Director, National Leprosarium, pioneers sulfone drug therapy. Dr. Faget and his staff demonstrates the efficacy of sulfone drugs, including Promin, Diasone and Promizole in the treatment of Hansen's disease (HD).

1943 The 40/8 veterans organization donates a new printing press to "The STAR" patients' magazine. This supportive relationship by US veterans to Carville's patients continues to this day.



Drawing by Howard Bayer, 1947

Detail of hospital history timeline.



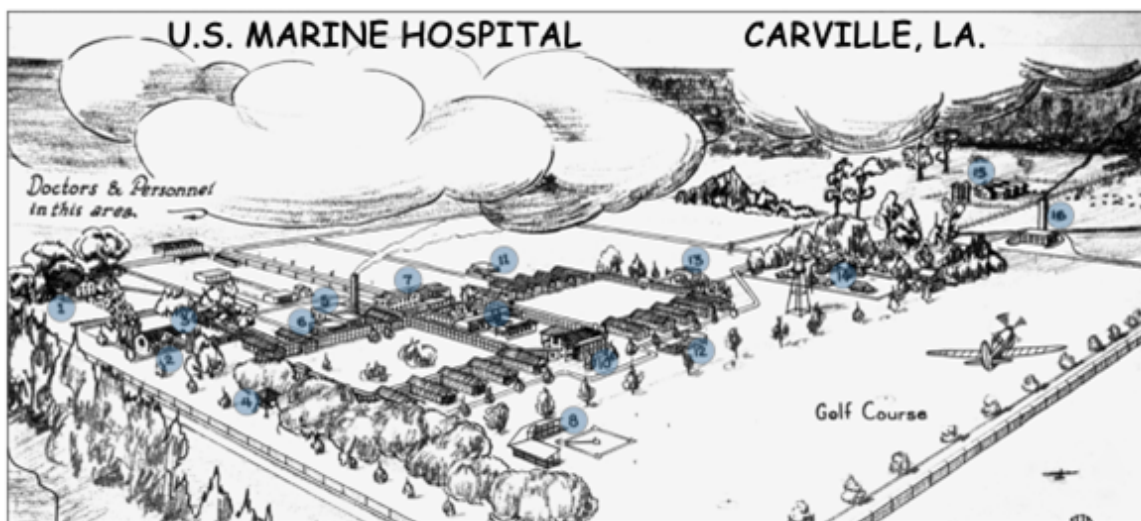
A new museum sign is going up on River Road, directly across from the Carville Historic District. Another has been installed directly in front of the museum.

Pictured: Louisiana Department of the Military employees installing sign.



Inside the museum enlargements of iconic Carville images enhance the visitors' experience.

Pictured, front to back: Promin Injection, Pressroom of the STAR, New Hospital Dormitories.



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16. INCINERATOR

Pictured: Johnny Harmon's drawing of Carville, c. 1940. One of four panoramic images now hanging in the museum's main exhibit room.



Nine new markers installed in the Carville landscape will clearly mark the self-guided audio driving tour.

Infirmary, US Public Health Service Hospital, Carville

Built 1933-34, under William H. Woodin, Secretary of the Treasury, Dr. Hugh Cumming, Surgeon General and James A. Wetmore, Acting Supervising Architect

Carville is significant because of the caring facilities built on site from 1894 to 1941 to treat Hansen's disease (leprosy). The great discovery of sulfone drug therapy, called "The Miracle at Carville", took place here.

The Infirmary was perhaps, the most complex building at Carville with various departments and services:

- 75 bed general hospital
- Doctors' offices
- Nursing Department
- Examination rooms
- Operating rooms
- Laboratory
- Medical Records
- X-Ray
- Pharmacy
- EENT & dental clinics
- Physical & Occupational T
- Autopsy room & morgue

Medical Records was the first stop for new patients. Because of the stigma associated with leprosy, many patients chose an alias upon admission, to protect their families from discrimination.

Originally, the Infirmary was designed with open wards, men upstairs and women downstairs.

Over the years, renovations created individual rooms with private baths. Although the screened porches were lost in the process, the screening remains across the facade and preserves the integrity of the 1933 design.

In 1999, the National Hansen's Disease Programs relocated from Carville to Baton Rouge and title to the hospital property and buildings were transferred to the State of Louisiana.

In 2005, the old Infirmary was renovated by the State of Louisiana as a conference center and hotel.

U.S.P.H.S. HOSPITAL INFIRMARY

Original Architectural features of the Infirmary:

- Steel and masonry construction
- 41,207 square feet
- Open wards (1 for men, 1 for women)
- Screened porches spanning the width of facade, on both 1st & 2nd floor.
- Rooftop arbor for patients to enjoy fresh air and a view
- Building dedication plaque, front entrance

To identify important buildings, individual interpretive panels were designed and will mark the hospital Infirmary, Sacred Heart Chapel, Union Protestant Chapel, and 1st Patients' Cemetery.

Planning is underway to provide additional buildings in the historic district with interpretive identification panels in the future.

Open Letter to Pope Francis

By José Ramirez, Jr.

Your Holiness, as you know there are many words throughout the world that intentionally or unintentionally create images in one's mind. These words result in a label that scars individuals as much as the hot metal used to brand cattle.

One word that has had a branding effect in my life is the word leprosy. This word is immediately linked to "leper" or the "L" word...contagion, open sores, sin, outcast, etc. Even when written in reverse it still spells rejection, i.e., repel. The image created for me is resurrecting the sobbing that my mother - mi madre - did on my chest on the day I was diagnosed with Hansen's disease, more commonly known as leprosy.

My mother cried so profoundly that I did not know how to stop her tsunami of tears. Her pain was so intense that I became petrified with fear. Her shaking was so strong that my hospital bed rattled from the attack of metal-on-metal. My mother was asking for my forgiveness for the sins she had committed because she firmly believed that God was punishing her through me, and my diagnosis of leprosy. Her unwavering and devoted faith in God and the Catholic Church was insufficient in bringing her solace. I had no idea how to console her and simply hugged her and cried as a solitary confused thought overwhelmed my mind - God, how can you be so cruel to my mother?!

Thirty-two years later, after my 750 mile journey in a hearse "because hearses are for the dead and ambulances are for the living", declared part of the "living dead" and a seven year institutionalization in the leprosarium in Carville, Louisiana, my mother told me "Now I can die with a clean soul." My mother was in the advanced stages of Alzheimer's but after I shared with her some important words from Pope John Paul her face lit up, she smiled and kissed me on the forehead. Pope John Paul told the world in 2000 that "persons diagnosed with leprosy are my brothers and sisters."

Now dear Pope Francis, I dread that my mother's pain is being felt even inside her casket. I dread that you have compared her loving son and all of his brothers and sisters with those who care more about their career than for their faith. I dread that you have compared us to the stifling bureaucracy that exists in the Vatican Court. And finally, I dread, as all of my brothers and sisters, that you have placed us on the same road to hell as pedophiles. My mother would be screaming if she were alive.

Dear Pope, we are not "a leprosy." We are fathers, mothers, brothers, sisters, aunts, uncles, grand parents, friends, colleagues and much much more. We are not "lepers" nor "a leprosy."

I have asked the millions of persons currently affected by leprosy who have metaphorically taken a painful journey in a hearse and have been impacted by the stigma that accompanies this disease to pray for guidance, patience and resolution to the misuse of labels and myths which can cause so much pain.

Leprosy does not discriminate as it crosses all borders, cultures, socio-economic walls and ages. So regardless of where my brothers and sisters reside, we look forward to the elimination of the indiscriminate use of the word leprosy and its sibling, "leper."

I remain a devout Catholic and pray that God continues to give you the physical strength and wisdom to serve as Our Holiness.

Sincerely Yours,

José Ramirez, Jr.
Managing Editor
The STAR

MY THOUGHTS ON COURAGE, STIGMA, AND FATHER DAMIEN

By Joseph Steil

My initial plan was to write an article on the Cajun Wreck and Carville Tour. The Cajun Wreck is an initiation into the 40&8 that is held every year in Lafayette, Louisiana. A tour of the Carville Historic Area is always a part of the Cajun Wreck, and this year was no exception. The tour went very well with excellent support by Elizabeth Schexnyder, Dr. David Scollard, and Capt James Figarola. And the Cajun Wreck raised \$436 for Carville Star. The foundations of a good article.

But I couldn't sleep one night about a month ago, so I got up to watch a little television. Flipping through the channels I stumbled upon the movie "Molokai: The Story Of Father Damien". This movie was produced in 1999, and has a star-studded cast including David Wenham as Father Damien, Sam Neill, Peter O'Toole, Leo McKern, Kris Kristofferson, and Derek Jacobi. For those who haven't seen the movie, here is a review from IMDB.com:

"Exile to Molokai was the means with which leprosy was dealt with in the Hawaiian Islands during the late 1800s. Molokai was an untamed isle located between the islands of Oahu and Maui. Abandoned for all extents and purposes, the lepers attempted to scrape out a living in their squalor without outside aid or care. Enter the courageous Father Damien. He was the first priest to go to Molokai. And even though his bishop strictly warned him that "he must not touch anyone," Father Damien risked his life and health to reach out to the suffering.

Gradually, Father Damien was able to gain the trust of the lepers. Additionally, and more importantly, his cries for additional help were heard and heeded by others. The success of his appeals was unbelievably dismaying to superiors who were more interested respect and riches than reaching out to the suffering.

Eventually, as expected Father Damien was also afflicted. This, however, only seemed to provide him with an even greater drive to ameliorate the conditions of his now "fellow" lepers. After collapsing during Mass, he was carried to the very hospital that he himself had established where he died. There is a touching scene when all gather to pray for him at the hospital's entrance."

I was very moved by this movie. I knew the story of Father Damien. Jose Ramirez Jr., The *Star* Managing Editor, traveled to Rome in 2009 to attend the canonization of Father Damien. Jose also wrote articles about Father Damien in the July-December 2009 issue of The *Star*. But knowing the story doesn't always give you the whole picture or really 'hit you where you live'. I was particularly impressed with two ideas I took from the movie: courage and stigma.

Nelson Mandela said "I learned that courage was not the absence of fear, but the triumph over it. The brave man is not he who does not feel afraid, but he who conquers that fear." I am sure Father Damien felt fear when he volunteered and especially when he arrived at Molokai in 1873 and saw the squalor there. But he was determined to treat the afflicted with dignity and all the human compassion he had. He dressed ulcers, built homes and furniture, made coffins, and dug graves. Father Damien's arrival was a turning point for the community as after his arrival basic laws were enforced, shacks became painted houses, working farms were organized, and schools were established. And he also had courage dealing with his superiors and government officials, most of whom just wanted the Molokai story to remain hidden from public view.

Four priests volunteered to go, and the bishop's plan was for the volunteers to take turns assisting the inhabitants. Father Damien was the first priest to volunteer and was only supposed to stay at Molokai a short time. But Father Damien stayed for 16 years until his death in 1889. To me that speaks directly to the courage of Father Damien. And also to the courage of everyone who worked with those at Molokai, Carville, and everywhere else that those afflicted were and are currently shunted off to. Suffering was alleviated and a cure was finally found because of the courage of many, many people. But there are still many afflicted worldwide who need courageous people to battle for them.

When Father Damien went to Molokai, Hansen's Disease was incurable. And the stigma of 'leprosy' was palpable throughout the movie. Yet even today with a cure and the knowledge that 95% of people cannot get Hansen's Disease, there is still a large stigma attached to it. To me, that is very sad. Over 100 years later and with a cure, we are still dealing with the stigma.

Jose Ramirez Jr. wrote about stigma in the July-December 2011 issue of The *Star*. I think it is worthwhile to end with his "Ten Practices for Overcoming Stigma" and for all of us to persevere to have these practices followed around the entire world:

- I. Thou shall be forbidden to label anyone.
- II. Thou shall be forbidden to reject anyone with different abilities.
- III. Thou shall not fear someone simply because they are different.
- IV. Thou shall embrace the U.N. Article I., Declaration of Human Rights.
- V. Thou shall refer to a person with different abilities using person first language.
- VI. Thou shall work to eliminate the negative effects of stigma on others.
- VII. Thou shall educate others about stigma.
- VIII. Thou shall advocate on behalf of others.
- IX. Thou shall work to overturn the Law of Silence.
- X. Thou shall strive for inclusion.

My Road to Dignity

By Miyoji Morimoto

My life has changed since I decided to speak openly about my history with Hansen's disease, more commonly known as leprosy.

I was diagnosed with leprosy in 1952, at age 14, and isolated at a national leprosy sanatorium. The secret of my leprosy lasted for 44 years.

In 1996, the abolishment of Japan's Leprosy Prevention Law, allowed thousands of us affected by leprosy to regain our life, human rights, freedom and dignity. My wife and I decided to share with others our experience of isolation, by writing a book titled Testimony: Mistakes of the Japanese and used our real names as authors.

The release of our book received much publicity throughout all outlets of the media and became widely known throughout Japan. My family was outraged with the publicity and verbally abused us with harsh words such as, "Take cyanide and die."

For eight long years, my family refused any contact with me, even after the courts declared that the Leprosy Prevention Law had been illegal. Finally, they were able to understand that shame and leprosy are not siblings. With their acceptance, I became more comfortable sharing my story of isolation. To date I have made over 900 presentations in the community, academic circles and temples, raising awareness about the disease and gaining new friends.

After living a life of the living dead, this changed to a life with meaning. So, in 2004 I established the Japanese Chapter of IDEA (Integration, Dignity and Economic Advancement). IDEA is a worldwide organization of persons affected by leprosy. The Japan Chapter has 300 members and supporters. IDEA Japan supports the education of children of those affected by leprosy in China, Indonesia, Nepal, Philippines and Thailand. I have discovered that, when I believe in myself, I can move straight to where I want to be, regardless of my past with leprosy. At age 75, every day and every life is endearing.

Currently, there are approximately 2,000 persons still residing at the 13 sanatoria in Japan. Their average age is 82 and many live lonely lives as they have no contact with their families. Upon their death, they will be buried in community cemeteries at the sanatoria. By the year 2020, the number of residents is expected to decrease to 600. No new cases are being admitted to the sanatoria.

Those still living at the sanatoria are starting to experience medical problems, due primarily to the aging process. However, with fiscal challenges, there is a shortage of medical staff to care for their needs. The residents wish to maintain a positive quality of life and have threatened to go on a hunger strike if funding for medical care is not restored.

The 13 sanatoria are no longer institutions. They have been integrated into the community due, in large part, to the efforts of Zen Ryo Kyo, the national network of residents affected by leprosy. By having this open concept, the sanatoria can continue their existence and allowing the residents to live a life filled with dignity and re-

spect. Recently pre-schools were opened in the sanatoria, bringing much joy to the residents as they were denied the right to have children during the era of the Leprosy Prevention Law.

Over 1,300 persons have left the sanatoria to live in the community. I am one of these. However, only ten have publicly discussed their history with leprosy and their lives at the sanatoria. Unfortunately, stigma is still deeply rooted in our mindset, even though we were cured years ago. It is still difficult to reveal this past with our families. However, I believe that we should find a venue to narrate our history so that future generations can understand our painful road to attaining dignity.

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Atlanta, GA 30308

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PH: (404) 686-5885
Public Health Nurse: Roberta Dismukes, RN
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PH: (404)-320-7668 PH: (404) 686-7668

BOSTON HD CLINIC

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41 Mall Road
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CHICAGO HD CLINIC

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Physical Therapist - Louis Iannuzzi, P.T., C.Ped.
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PH: (602) 372-1407
email: brendacabrales@mail.maricopa.gov
Physical Therapist - Tracy Carroll, MPH
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Seattle, WA 98104
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Toll Free: (877) 520-5000
Fax: (206) 744-5109
Primary Physician - Dr. James Harnisch
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Public Health Nurse – Chinh Tran, RN
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Other Clinics

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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 2008 the World Health Organization reported that there were 212,802 new cases of HD worldwide. In 1993, there were 591,000 new cases reported, and in 1992, 690,000 new cases. The largest numbers of Hansen's disease patients continue to be in Southeast Asia and Central Africa with smaller numbers in South and Central America. The largest number of patients in the Western Hemisphere are in Brazil.

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. There were 150 new cases reported to the registry in 2008. California, Hawaii, Louisiana, Florida, Massachusetts, and New York contributed the largest number of cases in 2008.

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 dapsons, 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