

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JANUARY - JUNE
2011
VOLUME 64 - 11**



**Dr. Samuel Moschella, A Man Dedicated to his Family, Friends, Staff and Persons Affected by Hansen's disease.
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*All correspondence concerning **The STAR** should be addressed to:*

Voiture Nationale
777 North Meridian St Suite 300
Indianapolis, IN 46204-1420

EDITORIAL BOARD

Simeon Peterson -**Editor**
José Ramirez, Jr -**Managing Editor**

CONTRIBUTORS:

George H. "Doc" Willis
Irma Guerra
Ymelda Beauchamp
James Krahenbuhl, Ph.D.
Elizabeth Schexnyder, NHDP Museum Curator

Stanley Stein

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease, 2.) Furnish vocational rehabilitation for interested patients.

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

Editorial Policy On Terminology

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

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Moschella Receives Humanitarian Award

By David M. Scollard, M.D., Ph.D. Chief, Clinical Branch, NHDP

Dr. Samuel Moschella, a dermatologist at the Lahey Clinic in Burlington, MA, who also serves as a regular guest lecturer at the National Hansen's Disease Programs biannual symposium, was recently selected to receive the Arnold P. Gold Foundation Humanism in Medicine Award by the American Academy of Dermatology. The Award was presented to Dr. Moschella at the annual meeting of the Academy in New Orleans earlier this year.

Dr Moschella "Sam," an internationally esteemed dermatologist, is a long-time friend of many Hansen's Disease (HD) patients in the United States being a strong supporter of the NHDP's training and clinical missions. He is a past president of the American Academy of Dermatology, editor of a major 2-volume textbook of dermatology, and a much sought-after lecturer internationally.

For all of his travels and professional activities, Sam has always had a special concern for patients with HD. He first encountered the disease in the late 1940's when he was a medical officer in the United States Navy, stationed in Cuba. He diagnosed the disease in several military dependants and began treating them. He carried this interest with him in his assignments to U.S. Naval Hospitals, first in Chelsea, MA, and later in Philadelphia, and finally in his academic career at Harvard Medical School.

Dr. Moshella is not only a brilliant physician but is also a naturally gifted teacher. During a series of events honoring his teaching career at Harvard a few years ago, the chairman of his department introduced him repeatedly as, "The gold standard for teaching at this medical school – not this department, but this medical school." He has brought this talent for teaching with him in his lectures at Carville, and now at the NHDP in Baton Rouge, where our seminars are attended by residents in dermatology, physicians, and nurses.

His extensive international travels have also afforded Dr. Moschella many opportunities to consult on HD in many countries, including fellowships from the World Health Organization that enabled him to visit HD programs, ranging from the All Africa Leprosy Training Program in Ethiopia to the Brazilian National Hansen's Disease Center in Bauru, Sao Paulo where he has conveyed to the physicians and residents he has encountered, his concern for providing proper treatment and rehabilitation for HD patients.

Dr. Moschella is also no stranger to the pages of *The Star*. He was a key organizer of HD seminars for military dermatologists that started at Carville in 1964, and soon accepted civilian physicians, as well. In this effort he collaborated closely with Drs. Trautman and Jacobson, former Carville Directors, developing the curriculum and recruiting an outstanding faculty that has included experts on all aspects of HD. Many of these seminars have been reported in the *Star*, identifying Dr. Moschella as well as other guest faculty several articles and reviews he has written have been noted in its pages as well.

As described in an article by his nurse, Stephanie Burns, in this issue of *The Star*, Dr. Moschella continues to diagnose and treat HD patients at the Lahey Clinic in Burlington, MA, one of the NHDP's national network of outpatient clinics. He also continues to lecture at the NHDP Seminars each spring and fall, impressing another generation of physicians with the importance of recognizing the challenging clinical aspects of HD. At age 90 Sam is extremely fit, due in part to a sustained regimen of exercise; swimming and, recently, bicycling. We intend to have him as our featured speaker at our NHDP HD seminars for many years to come.



Past Present and Future = Today

By: José Ramirez, Jr.

The articles in the current issue of The Star are unique examples of how different generations can blend into one and create a powerful force to educate the world about Hansen's disease (HD). Beginning with the history that predates the discovery of the Americas, to the connection between man and animal, to the invaluable contributions made by one man in Boston, Massachusetts, the leprosy bacillus has affected millions throughout the centuries. In addition, it has also impacted billions because of its strong reluctance to divulge a long kept secret.....what are the other vectors besides the nine banded armadillo?

One factor of leprosy that has never been a secret is the undeniable strength of its stigma and the damage it can cause to the psyche of those affected and their extended families. This stigma-----an act of labeling, rejection or unexplained fear of a person-----refuses to die or weaken. It wrecked havoc on our ancestors who felt compelled to die with their diagnosis kept a secret from their friends and families. It continues to present barriers to employment, marriage and travel. And, it appears that leprosy will affect millions for many more generations.

How can The Star readers make a difference TODAY? In my opinion, one way is to use the power of the pen, or in today's world, the power of email. By "writing" to those holding elected offices in our respective countries and requesting that they partner with other leaders to establish one World Leprosy Day (WLD), in order to avoid a fragmented attack on stigma. By requesting support for one global WLD from organizations who focus on services specific to persons affected by HD, a unified frontal attack on stigma can break down walls of ignorance. By asking our friends, neighbors and colleagues to similarly embrace and contribute to this campaign, the world can hold hands one day and discard the belief that one gentle touch will transmit the disease.

So, please join the campaign to have one unified WORLD LEPROSY DAY. Please share with us your efforts to make this dream a reality.

The Magic of Sharing

by Elizabeth Schexnyder

In a chance meeting at a Institute of Museum and Library Services www.ims.gov funded preservation workshop hosted by the Historic New Orleans Collection I met Maureen Knapp, Reference Librarian and Manager of Digital Projects for LSU Health Services Center (LSUHSC). www.lsuhs.edu/no/library

Maureen immediately inquired about the Nat'l HD Museum's collection of The STAR. Was it complete? (yes) Did we have an index? (yes, again) and, most notable "are you interested in having a complete set of The STAR digitized, searchable AND available on the Internet?" (YES!!!!)

Since answering yes to all of Maureen's questions, we met again at the LSU Health Services Center Library in New Orleans to review the steps needed to make a digital, searchable set of The STAR (1941 to the present) available online. They estimated the work will be complete by October 1, 2011. LSUHSC has received approval from The 40/8 to link to the online copies of The STAR already in digital format at www.fortyandeight.org/the-star Now I am awaiting approval form HRSA to give Maureen the green flag to "go"!

Moral of the story: continuing education certainly pays and so does a little old-fashioned networking. The web address to The digital STAR will be hosted through another non-profit entity whose mission is to help Louisiana cultural treasures go digital, The Louisiana Digital Library (LDL). www.louisianadigitallibrary.org. LDL's purpose is to make unique historical treasures from Louisiana institution's archives, libraries, museums, and other repositories accessible to Louisiana residents and to students, researchers, and the general public in other states and countries.

Grandfather Alexander

Gary W. Hietala and Diane E. Follmer Saint Paul, Minnesota



Alexander (1877-1939) and Lena (1875-1961)
Hietala on their wedding date, ca. 1905

Gary Hietala grew up not thinking very much about his Grandfather Alexander. His family was Grandma Lena; Mother and Dad and Brother; and Aunt Alice and Uncle Conrad, and no one mentioned Grandfather. As years passed, the family began to get smaller: Grandmother Lena died. Uncle, brother and dad died. Mother's memory was cloudy. When decisions had to be made about cemetery plots it became evident that we did not know where Grandfather Alexander was buried. Aunt Alice claimed not to know. We quickly deduced there was a mystery in the family.

After Aunt Alice's death, we set about filling in the blanks about Grandfather Alexander's life and death. We checked state records, historical files and institution records and found nothing. We knew only when Grandfather Alexander and Grandmother Lena had immigrated from Finland and their port of entry into the United States. We tracked their movement to the purchase of a farm in Minnesota. But there the trail turned cold for Grandfather Alexander for some time.

Then we went to visit Mrs. Irja Howe, a generous and jolly Finnish lady who grew up in the community. Yes, she remembered meeting Grandfather Alexander in the early 1930s, and did we know he had leprosy? No, we did not know, and we were glad we were seated on her sofa as the information from 80 years earlier came rolling out. She had seen him at the train station as he departed for Carville, Louisiana, one of two places people were sent after a diagnosis of Hansen's Disease.

We know more about Grandfather Alexander now. He was a large, strong man who worked in Minnesota iron mines until he and his wife could purchase their farm on the Mississippi River in northern Minnesota. We will never know if his life at Carville was eas-

ier because he was beside that same river. We know he spoke very few words of English and was always well groomed in his white shirt. We know the dates of his confinement. We know his last name was misspelled during his time at Carville. We know he carried a photo of his children that made him cry.

We know his Patient Number was 1134 and he died on October 2, 1939 of heart disease. We understand so much more about Hansen's Disease after spending time at NHDC and visiting the Museum. We wish Aunt Alice could have been relieved of the burden that she carried all her life because of lack of understanding of the disease..

Grandfather Alexander now rests in the peaceful cemetery at the National Hansen's Disease Center. Our hearts ache that he spent so many years far from the family and land he loved because of stigmas surrounding Hansen's Disease.. We are now erecting a gravestone in his honor near the family and land he loved in Minnesota. Welcome home, Grandfather Alexander.



Gary W. Hietala stands at the gravesite of
his grandfather, Alexander Hietala.

Imperialism and Armadillos

This article was written by Sophia Haase while completing a summer internship under the supervision of José Ramirez, Jr. in Houston Texas. Ms. Haase is a Junior at Rice University with a dual major in history and advocacy.

In 1492, Christopher Columbus introduced Europe to the “New World” of the Americas and claimed the newfound territory for the Spanish Empire. However, the Spaniards were not alone and brought with them a plethora of infectious diseases that the native Amerindians had no natural resistance to. The epidemics of diseases such as smallpox, typhus, influenza and diphtheria severely harmed the indigenous populations and are commonly cited as a central reason for the success of European colonization.

One unique disease often overlooked was likely carried across the oceans by slaves from Africa after being transported on crowded ships by Europeans. Hansen’s disease, otherwise known as leprosy, has almost always existed in Western society but was not present in the New World until the introduction of the Europeans. One of the most interesting aspects of leprosy is that unlike a disease such as smallpox, it was able to infect another indigenous population of the Americas: the armadillo. Armadillos are only found in the Americas and are the only currently known vector for Hansen’s disease. Because of this, leprosy provided the disease with the unique ability to spread in both directions.

Researchers at National Hansen’s Disease Center in Baton Rouge, Louisiana have recently confirmed the transmission of leprosy through armadillos and residents of the Americas have not known that the animals were carriers of the disease. Humans contributed significantly to the spread of armadillos and used them as pets and for food. During the Great Depression, Texans referred to them as “Hoover Hogs” because of their alleged pork-like flavor, and the animals have been promoted as a Texas souvenir since the 1890’s. Unbeknownst to the consumers and handlers of the armadillos, while Texans promoted the armadillo as a state symbol, they were simultaneously putting themselves at increased risk to contract Hansen’s disease. Mr. Ramirez who ate armadillos as a young adult has described the animals as tasting like chicken.

Leprosy in the modern Americas is as a direct consequence of the Conquest. Although history tends to emphasize the importance of the deaths that resulted from epidemics of other diseases, Hansen’s disease is still present in the Americas today and serves as a distant echo of the European invasion of the fifteenth century. In a final twist of irony, Dr. Robert Jacobson, previous Medical Director and Hospital Director at the National Leprosarium in Carville Louisiana has found no known cases of a Native American being affected by the disease. It appears that centuries ago, Europeans gave leprosy to armadillos and now they are returning the favor.

As a young child, my family visited Big Bend National Park in the Chihuahu Desert to see the various flora and fauna only found in that part of the world. Coming from my small hometown of Chester, New Jersey, I was excited to learn about all of the local animals like javelinas and cougars, but I was particularly enthused by the armadillos. Although I wanted to bring one home with me, my mother wisely decided that a stuffed animal version would be a better alternative and “Snuffles” became an omnipresent feature of my childhood. Years later, as part of my internship, I learned from my supervisor José Ramirez that armadillos had the hidden trait of being vectors for Hansen’s disease and I realized just how important it was that Snuffles was not a real armadillo that could have exposed me to the disease. After taking a virtual tour of the former Leprosarium and hearing stories about the history of leprosy, it is truly amazing that armadillos connect the past and present and continue to create history. As William Faulkner once said, “The past is never dead. In fact, it’s not even past.”

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In Memoriam

Sister Dorothy Bachelot, Daughter of Charity of St. Vincent de Paul, died on February 28, 2011 at St. Mary's Hospital in Evansville, IN, at the age of 83. Sister Dorothy was the last Daughter of Charity still working at the Gillis W. Long Hansen's Disease Center in Carville, LA, when the Hansen's Program was relocated to Baton Rouge, LA, in January, 2000.

Upon her retirement from the Center, Sister Dorothy was missioned by her Community to New Orleans, and then was transferred to Veronica House in Bridgeton, MO, in early 2008 when she was diagnosed with ALS. While there, she served her Community in the Ministry of Prayer. As her condition progressed, Sister Dorothy was transferred to Seton Residence in Evanston, IN in 2009, where she continued in her Ministry of Prayer until her death.

Sister Dorothy had been in her vocation as a Daughter of Charity for sixty-five years. She attended schools in New Orleans, and after graduating from St. Joseph High School in 1945, she entered the Daughters of Charity in St. Louis, MO. Sister Dorothy was admitted to St. Joseph Hospital's School of Nursing in Chicago, Ill, and on completing her OR post-graduate training at DePaul University in 1952, she received her BSNE.

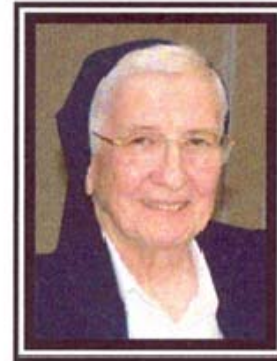
From 1952 to 1982, Sister Dorothy fulfilled her mission with the Daughters of Charity in her chosen field of nursing the sick. She served in a variety of healthcare facilities in Evansville, IN, in San Jose, San Francisco, and Los Angeles in California, and Lafayette, LA.

In 1983, Sister Dorothy was sent by her Community to the Gillis W. Long Hansen's Disease Center in Carville, LA, to minister to the residents there. The Daughters of Charity have a long history with the care, treatment, and research at the Center. They were the first nurses on site in 1896 to minister to the people with Hansen's disease brought in by barge from New Orleans to fend for themselves at the abandoned Camp Plantation.

She was one of three children born to Eula Istre and Webster Bachelot. She was preceded in death by her parents, her brother, Webster Joseph, and her sister, Lois Bachelot Landry, and is survived by nieces, nephews, and her Sisters in the Community of the Daughters of Charity of St. Vincent de Paul.

All of us at the National Hansen's Disease Program dearly miss Sister Dorothy's cheerful face and beautiful smile as she labored tirelessly, caring for patients, staff, and her sisters in Community, but know she continues with us in spirit. (Courtesy of Daughters of Charity of St. Vincent de Paul)

IN LOVING MEMORY OF



Sr. Dorothy Bachelot, D.C.

May. 6, 1927 – Feb. 28, 2011

SELF-GUIDED CARVILLE HISTORIC DISTRICT DRIVING TOUR

By: Elizabeth Schexnyder

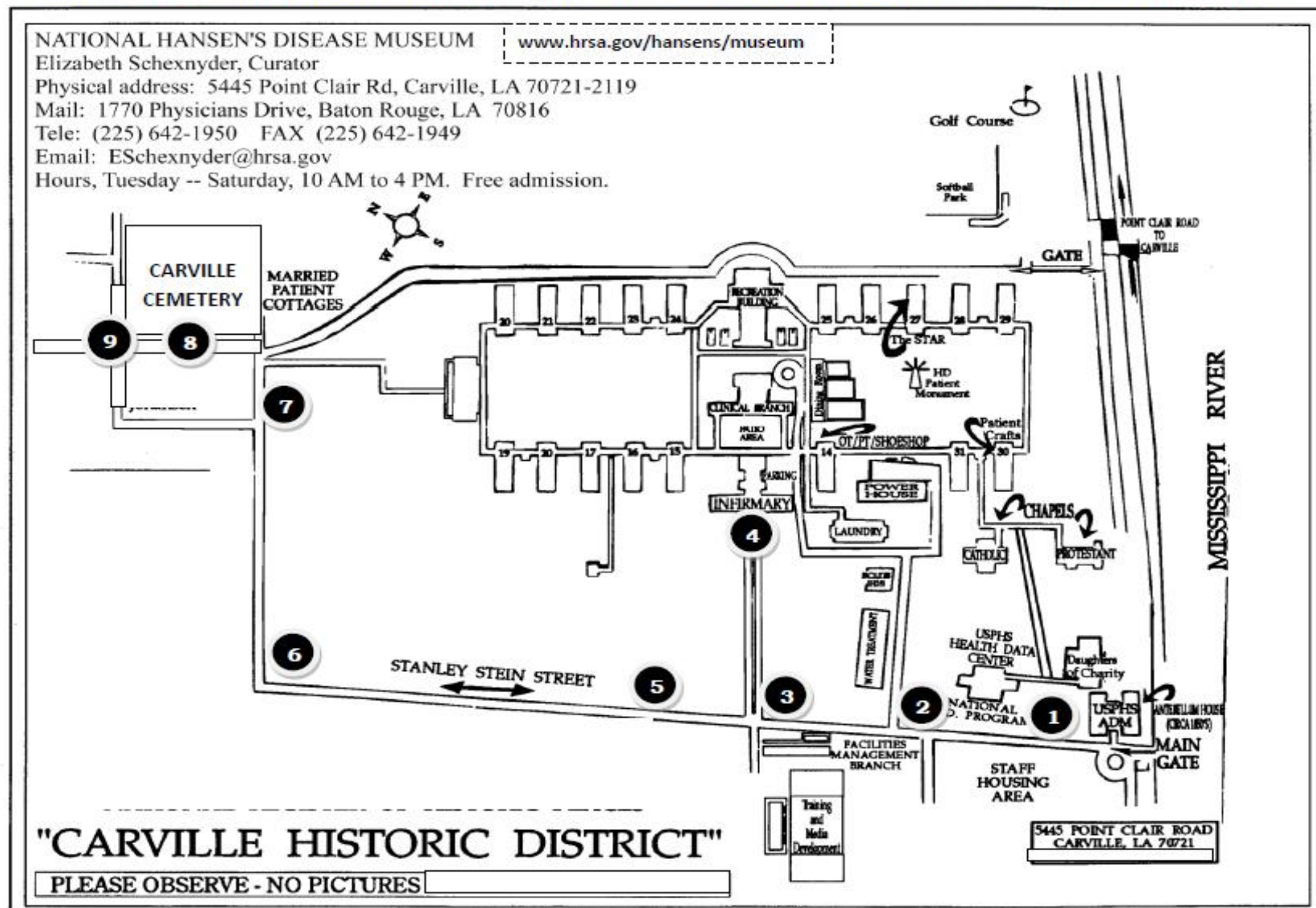
It's official. As of March 2011 all visitors need for a narrated tour through Carville's 400-acres of history is a cell phone and about 20 minutes of their time. How is this possible? By calling 225-756-3828 and choosing from options 1-9.

The Nat'l HD Programs Museum Committee and Col. John Angeloz, Installation Commander of the Gillis W. Long Center, collaborated with the museum curator Elizabeth Schexnyder to create a tour that allows visitors insight into "Carville History" even when the museum is closed. The 9-stop self-guided driving tour through the grounds is available rain-or-shine, 7 days a week. You don't need a reservation.

But the 9-stop tour is designed to accompany the visitor on a leisurely drive through the Carville Historic District. Each stop features a 2 minute narration highlighting a different aspect of the hospitals' history including: Hansen's Disease, Public Health Service, Quarantine, The Infirmary, Patients' Housing & Recreation, Armadillo Research and The Patients' Cemetery. At the Cemetery stop, the visitor is invited to park and take a contemplative walk among the 750 burials.

Now, if you should stop by when the museum is closed (Sundays / Mondays /FED holidays) ask the guard at the gate for a copy of the Driving Tour Map (see map) and you're on your way to a deeper understanding of the National Leprosarium. All from the comfort of your car.

SELF-GUIDED DRIVING TOUR: Carville Historic District Call 225-756-3828, options 1-9 for narrated history



Boston Hansen's Disease Clinic

By: Stephanie Burns, RN, Coordinator

In 1998, Dr. Samuel Moschella convinced the Lahey Clinic in Burlington, MA, (a suburb of Boston), to assume responsibility for the care of patients with Hansen's disease. Lahey Clinic acquired its first patients from Brighton Marine Hospital in Brighton, MA. Brighton Marine Hospital held the federal contract for the treatment of patients with Hansen's disease prior to Lahey Clinic. At that time the active Hansen's disease patient census in New England was approximately 35 and consisted mostly of immigrants from Cambodia, Vietnam, and Laos. The Hansen's clinic started with one doctor, Dr. Moschella, one nurse and one Khmer interpreter.

As news spread throughout the local communities that the Hansen's Disease Clinic for the New England States had relocated to Lahey Clinic, new referrals from Worcester, Framingham, and New Bedford, MA, and Rhode Island, Vermont, and New Hampshire increased our patient count quickly. The majority of our patients are now immigrants from Brazil.

Since 1998 the Hansen's disease team has also grown. In addition to Dr. Moschella, we now have Dr. Danielle Miller, Dermatology; Dr. Winnie Ooi, Infectious Disease; Dr. Kathleen White, Internal Medicine; Victoria Garcia-Albea, NP; Stephanie Burns, RN and Coordinator of the Hansen's Disease Clinic; Susan Gragg, LPN. We also have our interpreters, Cassia Vieira and Marie Billies, Portuguese; and Pedro Pinheiro, Cape Verde; Sandra Montanes and Lydya Ulmashi, Spanish; and Julie Hak, Khmer. In addition, our staff includes Janet Skolnick, Occupational Therapist; Eric Schuster, Pedorthist; Jennifer VanDerLinden, Social Worker; and Jean Caiazza, Financial Councilor; as well as many residents and medical students who come to learn from one of the best teachers, Dr. Samuel Moschella.

The Hansen's Disease Clinic is scheduled once a month on a Saturday when we see 20 to 40 patients. If any patient with Hansen's disease is unable to attend the Saturday clinic, appointments are also available Monday through Friday. They can also be scheduled with Ophthalmology for the ocular problems, Neurology for the peripheral neuropathies, and Infectious Disease for the comorbidities such as tuberculosis, hepatitis, strongyloidiasis and chagas.

We have one hundred three active patients. Thirty-eight of these patients still require chemotherapy. Our Hansen's clinic may have a small number of patients compared to the twelve other Hansen's clinics throughout the US, but our patients and staff are like family. Lahey Clinic's Hansen's disease team take great pride in knowing our patients receive excellent care, which is delivered with much compassion.

This is a picture of our staff at the Lahey Hansen's Clinic:

Third row: Naiara Vaz (Portuguese Medical Interpreter), Susan Gragg LPN, Eric Schuster (Pedorthist) and Elizabeth Schuster (Practice Manager, Boston Pedorthic)

Second row: Jean Caiazzo (Referral Management), Pedro Pinheiro (Portuguese, Cape Verde Medical Interpreter), Victoria Garcia-Albea NP, Cassia Vieira (Staff Portuguese Interpreter), Janet Skolnick (Occupational Therapist), Kathleen White MD (GIM), Jennifer VanDerLinden (Social Worker)

First row: Winnie Ooi MD (Infectious Disease), Samuel Moschella MD (Dermatology), Danielle Miller MD (Dermatology), Stephanie Burns RN



THE GENTLEMAN BEHIND THE STAR

by Ray and Julia Elwood

This is the first of a series of articles on Editors of the Star Introduction by Elizabeth Schexnyder, Curator of the Carville Museum

Stanley Stein – 1931 – 1967 Managing editor, “The Star”

Stanley began "publishing" the Sixty-Six STAR on mimeograph paper in 1931 (2 months after he arrived at Carville as a patient in March of 1931).

That early precursor of The STAR ran until 1934. Due to controversy over article LEPPER'S MASS which Stein reprinted from an outside contributor in 1934, his staff quit (they were all Catholic and the hospital's catholic chaplain was really mad about the article) and at the same Stein became very ill (he lost his sight slowly over the next 6 years).

In Sept 1941, The STAR was reborn with the mission "Radiating the Light of Truth on Hansen's Disease". The 40/8 gifted the STAR with a real printing press in Dec. 1944, and Stein remained editor until his death in December 1967

Comments by Ray Elwood

After graduation from high school I was employed by The Star magazine in the circulation department. The Star magazine is a patient-published international magazine whose motto has been “Radiating the light of truth on Hansen’s Disease,” and promoting the use of the term Hansen’s disease instead of the stigmatized word leprosy. Hansen’s disease was named after the Norwegian scientist, Dr. G. Armauer Hansen, who discovered the bacillus.

The Star was founded by Stanley Stein in the late nineteen thirties. The first copies were printed on a mimeograph machine. The magazine contained local news of the activities in the hospital. It also contained a bulletin of sport events, meetings of the various clubs, church services, local gossip, and some medical news. After a few years of publication under the original name, “Sixty-Six Star,” (named accordingly after the US Marine Hospital #66) ceased printing because Stein was struggling with serious eye problems which eventually led to blindness.

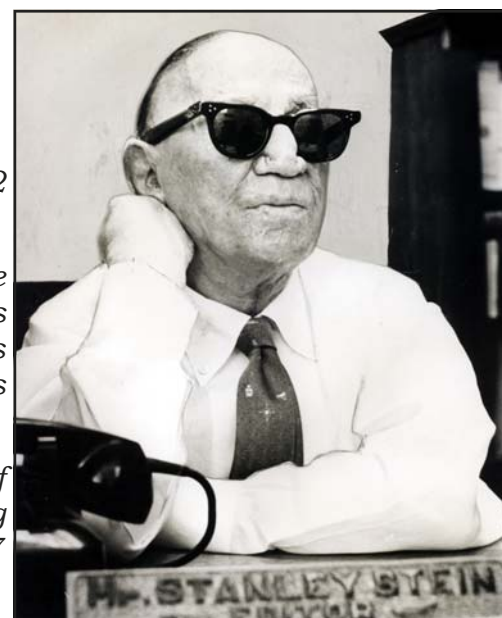
In 1941 as soon as Stein recovered from a tremendous setback, The Star was reborn. Stein was a veteran of World War I therefore was a member of the American Legion and the Forty and Eight. He was instrumental in organizing the local B. L. Spann American Legion Post #188 within the hospital. Stanley influenced the veteran’s organizations to take an interest in the small publication and they soon provided funds to purchase an old Heidelberg the first hand press. Stein were elated.

Stanley Stein did not stop there. He sought after the endorsement of the Forty and Eight (La Societe des Quarante Hommes et Huit Cheveaux), an honor society of the American Legion. This society’s name copied from the train boxcars which transported soldiers during World War I. Each boxcar contained 40 men and eight horses. This veteran’s organization took upon them The Star as a major national project. Not only did they fund equipment, supplies, postage, but they helped sell subscriptions. It was agreed that the cost would be \$1.00 per 12 monthly issues. (In 2011 it is \$2.00 for a winter and summer issue).

Stanley Stein was born, raised and buried in Boerne, Texas. A pharmacist by profession, he was the first public relations person at Carville. He sought and obtained connections with leaders of veteran’s organizations and a Jewish rabbi from Baton Rouge. The actress Tallulah Bankhead became his friend who wined and dined Stein whenever he visited New York. Ms Blankhead sent him a bronze bust of herself, after receiving it; Stein commented to her, “My Dear, I can’t even see it.” She responded in her deep and sensual voice: “But you can feel my bone structure, Dahling.”

In the course of the years The Star grew in circulation with subscribers behind the Iron Curtain, and in many foreign countries, especially in countries where HD was prevalent it became a respected semi-medical journal which was sometimes used as a teaching tool for HD field workers.

In addition to giving the patients something to do by producing Little Theatre plays, Stein was busy trying to eliminate the practice of



FROM THE COLLECTIONS OF THE
NATIONAL HANSEN'S DISEASE
PROGRAMS MUSEUM

the hospital sterilization of the outgoing mail. He was not successful until 1968 a year after his death.

Comments by Julia Elwood

After my graduation, (the class of 1957 was the largest class--six persons-- ever in the history of the Carville School), I wanted to start work. Someone told me that there was an opening as secretary for Stanley Stein, founder and editor of *The Star*. His secretary was being discharged and he was interviewing for the job. I became very nervous because I heard that he was a perfectionist. "Well," I told myself, "all he can tell me is 'no'." It took me a couple of days to build up courage to be interviewed. Stein was a man of small stature, receding hairline and fingers shortened by the disease, but he was a well dressed man who wore a suit and tie to work every day. When I entered his office he was behind his desk, we talked about my background, where I came from, my family, and numerous other things. He said that he would like to see how I worked, so he asked me to read his mail to him.

I did not want to make a mistake, so I was reading all the letters of a word and trying to pronounce them correctly. When I picked up the first letter from Tucson, Arizona, I pronounced it Tuck-son. As soon as I did that, he rose from his chair, pounded on his desk, raised his right hand in the air and said, "What kind of graduates are being put out by our schools nowadays? I can't believe you don't know how to say that word. That is Tucson." There was a long pause—I think it is called a pregnant pause—and I continued, "Would you like for me to read what's inside?" The rest of the mail was done correctly and I got the job. Six years after he yelled at me, Stein stood there at the same place and told me that if I had gone to college I would have graduated magna cum laude. He had been a good teacher to me and being my first boss I respected what he had to say.

Many times when he gave me more dictation than I could finish before the next day, he would really get after me. When I had had enough, I would quietly tell him that he was inconsiderate and really did not have any conception of how long it took to type letters, articles, correct them, and get them ready for mail and the pressroom. While I was talking, his expression would change. He would get a smile on his face and tell me, "It's good that you know when to tell me off. I need that once in a while." I could not stay angry at such a person.



Stein had a cottage in White City, which he called "Wit's End," and hired a very quiet Filipino man as his butler. Stanley was at work promptly at 8:30 a.m. and left at 2:00 p.m. During his years at *The Star*, Stein never received compensation. I worked with him for about five years, until I was discharged from the hospital in 1962. Stein had an awesome vocabulary and I learned a lot from him. He had a cousin, Trudy, in New York City, to whom he wrote every Monday morning. He kept her up-to-date on what he was doing.

There was a newspaper man, Jim Hughes, a reporter who later became City Editor of *The Morning Advocate*, Baton Rouge, Louisiana. Jim visited a couple of times a month to help Stanley. This five foot one reporter typed so fast with his two index fingers and made so many mistakes that I had to retype some of the articles. Jim also had the biggest and kindest heart of any man I have seen. And he cursed like a sailor when he and Stein were alone in the office. I shall never forget this "diamond in the rough." He gave me a great letter of recommendation which helped me when I was looking for a job after I left the hospital.

The *Star* staff was an international bunch. Ann and Hank were both Cajuns, married in Carville and lived in White City. Ann worked proofreading the magazine and Hank was in the pressroom. Hank used to say, "She makes the living, and I make the living worthwhile." They were wonderful loving persons who endeared themselves to many. Then there was this Californian Filipino, Nito, middle aged, quiet, intelligent, who worked in circulation. His office was next to mine, and when he passed to go in to work, he would always say, "How are you, Doll?" During my pregnancy he would always bring me a treat and say, "This is for the baby." He was fond of baseball and when the Dodgers were playing in the 1958 World Series, he had the radio on. It was the last game and a very close one. Most of the men were listening to the last inning. There were resounding yells of celebration because his team had won. There was also a tall and slender Chinese man named Jin, who hardly spoke and worked in the pressroom. He would move around his work area doing his job quietly and efficiently. Stanley and I were both from Texas, he a German Jew and I a Catholic Mexican-American. What a bunch!

Before he died, Stanley Stein revealed his real name a being Sidney Maurice Levysen, and also wrote his autobiography *Alone No Longer*. It is filled with history; facts about Hansen's disease and many stories of the old days at Carville. Stanley was a fighter for patients' rights, a trailblazer, and a hero to persons affected by HD. The main boulevard at the Center of Carville is appropriately named Stanley Stein Drive.

THE MISSION OF THE STAR

By George Willis

Many people in the world know about leprosy only from childhood memories of Bible stories and movies. I used to be one of those people. I remember going to a local church on Saturday evenings to watch Christian movies and remember one particular movie about “the ‘Leper’” touching Jesus’ robe and begging for help. The Biblical books of Leviticus, 2nd Kings, Matthew, and Luke of the Bible tell the stories of individuals suspected of having infectious skin diseases and leprosy, and that no one would associate with them because of this illness. Even today, society isolates individuals who have been diagnosed with Hansen’s disease because many still think the virus can be spread by touching, kissing, or from coming in contact with someone with the illness. Some people also think that the disease is not curable.

Can you imagine being diagnosed with leprosy, and not knowing how you contracted it? Can you imagine your knowledge of the disease being only what you heard as a child from Bible stories? And wait- there’s more! Your friends will know you have this condition and won’t want to talk to you, much less come in contact with you. Imagine!

The Carville Star program and our bi-annual publication of *The Star*, serves to educate those who do not know. The Carville Star is one of the oldest programs adopted by the veteran’s organization, La Societe des Quarante Hommes et Huit Chevaux (otherwise known as The Forty & Eight). The Forty & Eight also publishes *The Star* periodical to enlighten the public about Hansen’s disease, the treatment that has been developed for it, and the associated stigma. *The Star* publishes information not only to teach the doctors treating these individuals, but also to inform people affected with leprosy that there is help and a cure for them. *The Star* enlightens the community where the Forty & Eight members are performing an outstanding service by making this publication available to anyone who is interested in learning about leprosy. With the assistance of the Forty & Eight Voyageurs and Dames, *The Star* is distributed to almost 150 countries, including the United States where there are currently fifteen Hansen’s disease outpatient clinics.

We need your help! Please continue to support the Carville Star program and send *The Star* everywhere in the world.

You can assist the Carville Star by supporting the “Buy a Country” program or by sending copies of the *Star* to foreign countries where this disease is still prevalent and to the clinics in the United States. We are helping to get the word out to those individuals who are doing research to find a cure. *The Star* helps to diminish the stigma associated with Hansen’s disease.

Remember, stigma hurts.

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Armadillos and Leprosy in the Southern United States

by James L. Krahenbuhl, Ph.D. Director, National Hansen's Disease Programs



Dr. Richard Truman and friend

The April 28th issue of the widely read New England Journal of Medicine (NEJM) featured a paper that provided an authoritative answer to the 35 year old question, “Do armadillos transmit leprosy to humans?” The answer? “Without a doubt, yes!”

Many long time readers of the STAR might think, “So what’s new about that? We’ve read about leprosy in armadillos for over 30 years.” What’s new is the painstaking development by NHDP scientists of an advanced molecular biology tool that can characterize individual strains of *Mycobacterium leprae* and permit comparison of the strains isolated from either humans or armadillos.

The study was carried out by an international research team led by Dr. Richard Truman from the NHDP’s Laboratory Research Branch (LRB) with his colleagues Drs. Tom Gillis and David Scollard and included experts from the Global Health Institute and Swiss Institute of Bioinformatics (Lausanne), the *Institute Pasteur* (Paris) and the *Institute de Biomedicina* (Caraccas).

In brief, when the scientists compared the gene sequences of *M. leprae* samples taken from humans and armadillos in the Southern U.S., the findings showed that 64% of the *M. leprae* samples from humans had a DNA sequence that had never been seen before, and that strain was identical to the strain seen in 85% of samples from armadillos from the same region. These data confirm a long suspected link between armadillos and the 30-40 new cases of leprosy seen each year in native born Americans living in the Gulf Coast Area who have never lived or traveled abroad where the disease is prevalent.

It is important to stress that the findings do not change the risk of acquiring leprosy from armadillos. That risk remains extremely low. With approximately 30,000,000 people living in Texas and Louisiana and approximately 30 new cases per year from these states, the incidence of new cases is roughly “one in a million.” In fact, this study will actually decrease the already low risk by cautioning the public to avoid contact with armadillos.

Over 130,000 physicians subscribe to the NEJM and over 16,000 have downloaded the abstract of the article or requested reprints. Thus, perhaps the most important outcome of this publication will be to raise the awareness in U.S. private sector physicians that leprosy does exist in the U.S. It is not only found in individuals who are foreign born or who have lived in areas of the world where the disease is prevalent. Individuals born in the U.S. and living in the Gulf Coast Area with no typical travel history can acquire leprosy and armadillos are the likely source. Failure to diagnose and treat the disease early can have dire consequences; nerve damage, disability and deformity, the irreversible hallmarks of leprosy. Increasing the awareness of leprosy in the U.S. is a testament to the value of basic biomedical research on this disease.

Dr. Truman began his career at the NHDP with another seminal contribution to the armadillo leprosy story. In 1985, he put to rest misinformation that leprosy in Louisiana armadillos originated from the escape of infected animals from the two laboratories studying the animals. Using archived armadillo serum samples from Louisiana State University, Truman demonstrated that some of these animals had been infected with *M. leprae* at least 10 years before scientists attempted to infect them experimentally.

The NHDP maintains the only armadillo leprosy research unit in the world and continues to advance the use of these animals as an accurate model for the full clinical and pathological spectrum of leprosy including nerve damage. Whereas hundreds of immunological and molecular reagents are available in catalogs from the biotechnology industry for studying host immune responses in humans and laboratory animals such as mice and rats, there are no such commercial reagents available for armadillos. A strong collaborative effort between the multidisciplinary scientists in the NHDP LRB is meticulously developing a thin catalog of essential unique armadillo reagents designed to dissect the immune response of the armadillo. Progress will be described in future issues of the STAR.



Dr. Truman unmasked.

A TRIP TO CARVILLE

By George Willis



Greg Hall, Special Awards Nationale Directeur from Pierre, South Dakota walks along the historical cemetery at Carville during the 40&8 visit to the HD Museum in March, 2011.

Every year during March and July, the Nationale Directeur for the Carville Star program holds Editorial Board meetings in Louisiana to plan the next issue of *The Star*. Present at the meeting were Dr. Jim Krahenbuhl, Director of the Hansen's disease Center, Director of Outpatient Services Irma Guerra, Board member Ymelda Beauchamp, the Curator of the Carville Star Museum Elizabeth Schexnyder, Editor Simeon Peterson and from Texas, Managing Editor of the Star José Ramirez, Jr. Ms. Beauchamp was unable to attend the last meeting.

The meeting in March, 2011 corresponded with Chef de Chemin de Fer Hank Kwaitkowski's homecoming and the famous Louisiana Cajun Wreck. Since my residence is in northern North Carolina, this would be a thousand mile trip one way, and with my luggage for a week and my family consisting of my wife and 3 furry pets, I found it necessary to drive to the meeting that was scheduled for March 2nd in Baton Rouge. After two "delightful" (if that's possible) days on the road, we arrived at our hotel in Lafayette, Louisiana where the Cajun Wreck was to be held. Monsieur Red Miller, Grand Carville Star Directeur for Louisiana arranged our lodging at the Holiday Inn.

Following a good night's rest, I headed out for our meeting in Baton Rouge. Upon arriving at the National Hansen's Disease Center, we completed plans for the upcoming *STAR* publication and the visit to the Carville grounds the following day. Normally the Forty & Eight members meet with the residents and staff at the Baton Rouge Care Unit, but this year the residents had been moved to a skilled nursing/assisted living facility. We were also informed that a skilled cobbler who had made shoes for the residents was killed in an unfortunate automobile accident the previous year and there was still no replacement found.

March 3rd started out as a challenge when buses to transport more than one hundred Voyageurs and Dames to Carville did not arrive. We decided to improvise and several dedicated Voyageurs and Dames loaded their vehicles with riders and our caravan headed to Carville.

Once in Carville we headed to the theater on the facility where we were welcomed by Colonel McCall, the Commanding Officer of the National Guard Compound. We were then given a very informative presentation by Dr. Krahenbuhl on the strides that have been made in the diagnosis and treatment of leprosy. Elizabeth Schexnyder gave an overview of the Carville Museum and the future devices that will be available when visiting Carville such as audio explanations as visitors travel to various sights in their own car. Following these presentations, everyone headed out on a tour of the Star Museum and the cemetery.

At noon we were treated to a special lunch of Jambalaya prepared by famous Chef Byron Gautreau. It was fantastic!—more than we could have asked for! We will never be able to thank Dr. Krahenbuhl enough for that!

Immediately following the meal, José Ramirez, Jr spoke about his life as a resident at Carville and his experiences with the stigma of leprosy. Jose has authored many articles and one book on the subject. This was a great day for our Carville Star program as many of our members and guests have a greater appreciation for our Forty & Eight and the projects we sponsor.

After our visit to Carville, we had time to relax and get ready for a real Cajun evening with more great Cajun food and Cajun music at Mulates, a local restaurant where one can experience a genuine Cajun atmosphere.

Friday was a day on our own. But the evening was filled with party goers at the Early Bird Party followed by the Kangaroo Kourt. During the Kangaroo Kourt, the Grand du Louisiana raised funds for various Nationale programs in the Forty & Eight, and \$1700 was raised for the Carville Star.

On Saturday we initiated "The Wreck". This is when guest veterans become Voyageurs in La Societe des Quarante Hommes et Huit Chevaux. Lunchtime brought more delicious Cajun food prepared by our Louisiana Voyageurs Dudley LeBlanc and Ray Dupree, followed by an afternoon of entertainment provided by the "Sharecroppers", a local Cajun musical family. The evening brought was celebrated with a Cajun Banquet and our Chef de Chemin de Fer Hank's homecoming celebration.

Sunday morning brought on the unhappy task of re-packing our SUV. After ten years with the Carville Star program, this has been the best celebration yet. I would like to thank everyone for their outstanding support of all our programs.

HANSEN'S DISEASE CLINICS

BOSTON HD CLINIC

Lahey Medical Center
41 Mall Road
Burlington, MA 01805
PH: (781) 744-5670
Fax: (781) 744-5687
Primary Physician - Dr. Samuel Moschella
Public Health Nurse - Ms. Stephanie Burns, RN,
D.N.C.

CHICAGO HD CLINIC

University of Illinois
College of Medicine at Chicago
Department of Dermatology, (MC 624)
808 S. Wood, RM 376 CME
Chicago, IL 60612
PH: (312) 996-0734
Fax: (312) 355-0870
Primary Physician - Dr. Carlotta Hill
Public Health Nurse – Gladys Lee, RN

LOS ANGELES HD CLINIC

LAC+USC Medical Center
1200 N. State St.
Clinic Tower A5B123
Los Angeles, CA. 90033
PH: (323) 409-5240
Fax: (323) 441-8152
Primary Physician - Dr. Thomas Rea
Public Health Nurse - Ms. Helen Mora, RN
Occupational Therapist - Rob Jerskey

MARTINEZ HD CLINIC

Contra Costa Regional Medical Center
Outpatient Specialty Clinic
2500 Alhambra Avenue
Martinez, CA 94553
PH: (925) 313-6726
Fax: (925) 313-6465
Primary Physician - Drs. Sutherland/Saffier
Public Health Nurse - Ms. Elise Judy, RN
PH: (925) 370-5868
Fax: (925) 370-5529

MIAMI HD CLINIC

Jackson Memorial Hospital
1611 N.W. 12th Avenue
ACC East – 2nd Floor
Department of Dermatology
Miami, FL 33136-1096
PH: (305) 585-7348
Fax: (305) 585-6397
Primary Physician - Dr. Anne Burdick
Public Health Nurse - Ms. Gail Chepenik, RN

NEW YORK HD CLINIC

Bellevue Hospital Center
Department of Dermatology
Room 17-N-7
462 First Avenue
New York, NY 10016
PH: (212) 562-5670
Fax: (212) 263-6423
Primary Physician - Dr. William Levis
Public Health Nurse - Ms. Trudy Spencer, RN
PH: (212) 562-6096
Physical Therapist - Mr. Louis Iannuzzi, P.T.,
C.Ped.

PHOENIX HD CLINIC

Maricopa County Health Department
1645 East Roosevelt Street
Phoenix, Arizona 85006
PH: (602) 506-6650
Fax: (602) 372-3862
Primary Physician - Dr. Ronald Pust
Public Health Nurse - Eileen Smith, RN
PH: (602) 506-5070
Physical Therapist - Tracy Carroll, MPH

SAN DIEGO HD CLINIC

HHSa, North Central Regional Center
5055 Ruffin Road
San Diego, CA 92123
Mail Stop: N-513
PH: (858) 573-7338
Fax: (858) 573-7325
Primary Physician - Dr. Erik O. Gilbertson
Public Health Nurse – Ms Gina Sandoval, RN,
PHN

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. Pablo Almodovar
Public Health Nurse - Ms. Sonia Santos-Exposito,
RN
Ph: (787) 758-2525, ext. 5503

SEATTLE HD CLINIC

Hansen's Clinic at Harborview Medical Center
2 West Clinic - 359930
325 Ninth Avenue
Seattle, WA 98104
PH: (206) 744-2128
Fax: (206) 744-5109
Primary Physician - Dr. James Harnisch
Public Health Nurse – Marlene Skinnell, RN
Physical Therapist - Tom McClure, PT, CHT

TEXAS HD CLINICS

Department of State Health Services
Hansen's Disease Program
P. O. Box 149347
Austin, TX 78714-9347
PH: (800) 252-8239
Fax: (512) 458-7787
Nurse Consultant: Ms. Linda Brown MS, RN
PH: (888) 963-7111 Ext.: 6331
Officer Administrator: Kirbi Woods
PH: (888) 963-7111 Ext.: 6608

Dallas County Health & Human Services
2377 N. Stemmons Freeway, Suite 522
Dallas, TX 75207-2710
PH: (214) 819-2010
Fax: (214) 819-6095
Physicians - Dr. Jack Cohen/Dr. Sharon Nations
Public Health Nurse - Ms. Nancy Bernstein, RN,
BSN,

Houston Hansen's Disease Clinic
Northside Health Center
8504 Schuller Street
Houston, TX 77093
PH: (832) 393-4804
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Main: (832) 393-5173

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Physician - Dr. Lynn Horvath
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(HSR) 11
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Harlingen, TX 78550
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Fax: (956) 444-3295
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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 Amaner 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 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 noncommunicable 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