

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JULY - DECEMBER
2010
VOLUME 64 - 10**



Member of the Daughters of Charity, probably from the early 1960's, praying at the Sacred Heart Chapel at the National HD Hospital in Carville, Louisiana.

Photo by Johnny Harmon

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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.

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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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A Brief History of CARVILLE'S CATHOLIC CHAPELS

By: Elizabeth Schexnyder, Curator, National Hansen's Disease Museum

Any history of Carville's Catholic Chapel, Sacred Heart, begins with the arrival of the Daughters of Charity in April, 1896.

The State Board of control of the *Louisiana Leper Home* agreed to furnish sleeping and living apartments for the Daughters of Charity who were to arrange a room for a chapel, secure the services of a priest, and assume all responsibility for household and nursing details.

Sister Beatrice gave a minute description of the early chapel:

... one of the [slave] cabins, the only vacant spot, was fitted up in a hurry, as we must have Mass on Sunday... We took down the wooden partition, which gave us a floor space of twenty-six feet by fifteen and one-half feet. Then we brushed, swept and white-washed... we covered the ceiling and side walls with heavy white sheeting, drawing it... so firmly that on entering, one could get the impression of a new white plaster wall. Sister Agnes sent us linoleum from New Orleans to cover the floor. It is a very pretty pattern.

The Altar, benches and kneelers used was formerly used at St. Stephens and Hotel Dieu in New Orleans. On the twenty-ninth day of June of that first year the Stations of the Cross were erected in the little chapel. They, together with a tabernacle, a set of red vestments, small linens for the altar, and an altar cloth were sent by the Notre Dame Convent in Boston. The first Catholic priest stationed here was Fr. Michael Colton. The Chapel was small, especially on a Sunday, but the Sisters pledged to get along with it until a better one is built.

Although Dr. Dyer, the president of the Board of Control, was not a Catholic it was through his initiative that the second Sacred Heart Chapel was built. The Sisters report in 1905:

Some days ago, Dr. Isadore Dyer... visited the Home and incidentally attended services in the Chapel... he at once determined to do something towards providing better accommodations... At the close of the service he gave a check for \$1,000...

Dr. Dyer's generous gift brought others. The Daily Picayune of New Orleans widely publicized the movement and kept it before the public for many months--raising over \$7,000 for the fund.

Encouraged by the response, Sister Benedicta sought the architects, Messrs. Mackensie and Torre, who had the charge of the construction of the new cottages to be built by the State on the grounds. Plans were drawn up for a handsome chapel on the style of the California Missions.

June 3, 1907 marked the culmination of two years of effort on the part of the charitable people of New Orleans to provide the home with a chapel. A special train brought dignitaries from New Orleans to Carville for its dedication. Afterward eight patients received the Sacrament of Confirmation at the hands of the Archbishop. This Chapel stood until the present structure of brick was built in 1934 by the Catholic Church Extension Society of the United States. The ground breaking for the 3rd and last Sacred Heart Chapel took place on October 18, 1933.

Dr. O. E. Denney, Commanding Officer of the Hospital, and Sister Catherine Sullivan Superioress of the group of Sisters were present at the laying of the cornerstone. Abbot Paul Schauble, the resident priest, preached a Sermon.

Architects Wogan and Bernard of New Orleans drew up the plans for the 6229 square foot cruciform chapel. It has elements of the Spanish mission revival style evident in the fine brickwork. The twelve Promises of the Sacred Heart to St. Margaret Mary Alacoque adorn the side altar. The façade features a Romanesque arch over heavily coffered doors. The pitched roof is crowned with Ludivici clay tiles. The nave and transepts host stained glass windows that depict Biblical scenes emphasizing consolation of the sick donated by patients and their families. The fourteen marble bas-relief Stations of the Cross were donated by individuals and organizations. Plaques identify the donors.

On June 8, 1934, Feast of the Sacred Heart, Carville's new Catholic chapel was dedicated. Three principal agencies are credited for its erection. First to the Archbishop John W. Shaw, of New Orleans, second, the [Leper] Home Chapel Society, an organization of New Orleans women; third, the generosity of the Catholic Church Extension Society of the United States, without whose \$35,000 of aid the chapel would never have been built.

ONLINE COURSE: Awareness of Hansen's Disease In the United States: Basic Diagnosis, Treatment and Management of Complications

NATIONAL HANSEN'S DISEASE PROGRAMS, Education Department, 1770 Physicians Park Drive, Baton Rouge, Louisiana
Phone: 1-800-642-2477, E-mail: mtemplet@hrsa.gov

COURSE DESCRIPTION

This online course presented by the National Hansen's Disease Programs is designed to increase health care providers' awareness of this unique and misunderstood disease.

Although Hansen's disease (HD), more commonly known as leprosy, is not a common infectious disease, it has not been eradicated from the U.S. population. HD is endemic in the U.S., particularly in the Gulf Coast region, with 150 to 200 new cases diagnosed each year.

Fifty years ago, cases were detected in the port cities and the Gulf Coast region. These patients with the disease were institutionalized to the Gillis W. Long HD Center, located in Carville, Louisiana. Today, however, this is no longer the case and they are no longer institutionalized. HD is primarily treated on an outpatient basis and more cases are being detected in the heartland of the country. This fact increases the likelihood that those in the general medical community may encounter one or more cases of HD and find this information useful in the detection and management of the disease.

This online course is intended to:

- Provide private practice and academic healthcare providers with the basic knowledge necessary to diagnosis and treat HD.
- Introduce methods used to prevent the disabilities caused by HD.
- Aid in the clinical diagnosis and management of more complicated HD (Leprosy) cases.

AUDIENCE:

Doctors Nurses Nurse Practitioners Physician Assistants Public Health Workers Social Workers Therapists

UPON COMPLETION, THE PARTICIPANT SHOULD:

- Be able to access the services provided by the National HD Programs to healthcare providers
- Recognize the cardinal signs and symptoms of HD
- Understand the microbiology and pathology of HD before and after treatment
- Identify the varied clinical presentations of HD
- List two basic treatment regimens used in the U.S. for HD and how patients are classified into these two groups
- Learn the complications of HD and how to manage them

LECTURE SERIES

- Introduction, epidemiology of HD and the services provided by National HD Program (NHDP)

James Krahenbuhl, PhD, Director NHDP

- Basic microbiology and pathology of HD, pathologic changes seen during treatment and pathologic basis of complications

David Scollard, MD, PhD, Chief, Clinical Branch, NHDP

- Clinical presentations of HD, cardinal signs and symptoms, classification systems used in HD, treatment regimens & management of complications

Barbara Stryjewska, MD, Chief Medical Officer, NHDP

COST: NO FEE

CREDIT: 1 Contact Hour

C.M.E. APPLIED FOR:

(CME Credit is only available to physicians at this time)

This online course has been approved for 1.5 C.M.E. Credits by the American Academy of Family Physicians

- Application for CME credit has been filed with the Louisiana State Nurses Association (LSNA), an accredited approver by the American Nurses Credentialing Center, Commission on Accreditation

(AAFP Prescribed credit is accepted by the American Medical Association as equivalent to AMA PRA Category 1 Credit toward the AMA Physicians' Recognition Award).

WORLD LEPROSY DAY

By José Ramirez, Jr.

January 30, 2011 will be the 48th anniversary of World Leprosy Day as first declared by President Kennedy in 1963. This unique declaration came 4,000 years after several persons affected by leprosy were buried in a segregated gravesite. According to archeologists in Egypt, the 2009 discovery of skulls with disfiguring features linked to the disease verified the long history of fear that man has had of leprosy.

There are many stories, both factual and others based on hearsay, that the life of a person affected by leprosy has been one of psychological and physical torture. Unlike the torture inflicted by others, the torture experienced by persons with this misunderstood disease was believed to have been imposed by a god for sins committed against others. This has been perpetuated by various mandates which allowed this type of belief to flourish, such as the Ten Commandments for Persons with Leprosy. The first of these commandments states that persons with leprosy (described much more negatively in actual documents) shall not be “.....allowed to enter churches.....or into any assembly of people.” Ironically, centuries after these commandments were penned a person affected by leprosy, Father Damien, was canonized at St. Peter’s Cathedral.

In reality, the tortures against persons affected by leprosy have come not from God, but rather from mankind. It is man who has molded the brick and mortar (literally and figuratively) to build the isolated leprosarium throughout the world killing the identity of those suspected of having the disease; it is man who has crafted the shackles that bound those affected by leprosy to live in a petrified fashion; it is man who created laws to prevent marriage, voting, employment, education, and child bearing opportunities for those with leprosy; it is man who have been witness to the level of disabilities occurring with limited resources on prevention; and it is man who has given life to stigma-----an act of labeling, rejection or unexplained fear of a person.

Until the 1980’s, the world of leprosy was attracting a wide range of medical and research specialists and major discoveries were being published with abundance. During the following decade this trend took a different route as the “elimination campaign” dramatically impacted funding, and the collection of data (prevalence vs incidence), to the point that expertise in this field ceased to grow. With the onset of a new century, the stigma associated with leprosy started to be attacked by a large number of advocates throughout the world who were unwilling to remain silent about the direction of early diagnosis, prevention of disabilities and treatment. Many of these advocates have been persons affected by leprosy.

Historically, persons affected by leprosy have not been seen as individuals who can provide expertise in the world of leprosy. This has changed via the demands of empowerment, compliance with human rights and the written word (based on a per capita basis, the community of “Carville” may have more authors addressing the issues associated with leprosy than any other community in the world). During the last two years, persons affected by leprosy have been more actively involved in policy making endeavors as evidenced by their participation in the World Health Organization (WHO) sponsored meetings in Cairo, Manila and most recently in Geneva (the latter being the Eighth Expert Committee on Leprosy). This shift in advocacy though may not be enough to overcome the obstacles already created by the campaign as funding for research continues to be a major barrier

So, with all the challenges and advances that have occurred in leprosy, is there still a need for a World Leprosy Day (WLD)? The answer is absolutely **YES**, because leprosy is expected to be around for many, many more decades, and stigma is not expected to diminish. On January 30th, remind your religious leaders, your friends, your colleagues, your neighbors that leprosy is not hereditary. It is not a punishment from God. Disabilities can still occur. The disease can be cured quickly with multiple drug therapy. Early diagnosis and prompt treatment are the keys to cure and prevention of disabilities. Stigma can incapacitate persons affected by leprosy. World Leprosy Day is a time to not only celebrate steps taken forward, but also to identify and stop actions that may result in steps taken backward.

HANK KWIATKOWSKI—CHEF DE CHEMIN DE FER LA SOCIETE DES QUARANTE HOMMES ET HUIT CHEVAUX

‘HEAD FRED’ OF THE SOCIETY OF FORTY MEN AND EIGHT HORSES!

By George H. “Doc” Willis, Nationale Directeur, Carville Star

For those of you who have never heard of the Forty & Eight, I can only imagine what is going through your mind right now, however, if you have computer access, you can Google our organization by going on the web page www.fortyandeight.org. Enough though about that at this time—I would like to introduce our Chef de Chemin de Fer to you.



Elected at the 2010 Nationale Promenade is an outstanding veteran of the United States Military. Henry E. “Hank” Kwiatkowski (yes, Kwiat (Quit) kow (cow) ski) served our country during the Vietnam Era. He graduated from Paratrooper School and not only jumped out of perfectly good aircraft, he also served in the Field Artillery as a Captain in the United States Army.

Prior to being inducted into the service, Hank was born and raised in the great state of Pennsylvania. Following his tenure with the army, Hank returned to his home in Pennsylvania and began a career in industry. He accepted employment with the Singer Corporation as Quality Assurance Manager and then Industrial Engineering Manager. He was employed by Rockwell International as Plant Operations Manager being subsequently promoted and relocated to Texas as General Plant Manager. Following that assignment he relocated to Louisiana and accepted employment with UGC as Director of Engineering and Manufacturing. He later accepted employment with Columbia Broadcasting System as Director of Manufacturing Operations. After founding an automotive business, Hank operated it until retiring at age 50 (a lifetime goal). He remained in Louisiana after retirement and resides there today. Hank’s wife

Sharon is employed as confidential assistant to the Commanding General of the Air Force Global Strike Command. They have lived in Louisiana for more than 25 years.

Now, what does it take to become the “Head Fred” for the Forty & Eight Veterans’ Organization? Well, this is only a few of Hank’s activities and achievements from military service to the present time, leaving out what else he has to offer our country in the future. After induction into the U.S. Army, he accepted a commission as a 2nd Lieutenant, Field Artillery. Hank served as Commander of a Basic Training Company, Commander of a Transportation Company, Commander of a Special Troops Disciplinary Unit, Adjutant of a Specials Troops Brigade and Adjutant of a Basic Combat Training Brigade. While serving in the United States Army, he was awarded the Army Commendation Medal for outstanding service to his country. Following his departure from the army, he joined several veterans’ organizations in order to continue his service to other veterans in their transitions from military service to civilian life. One such service was the American Legion, the largest veterans’ organization in the world, with three million members in strength at one time. Hank volunteered for many jobs in the Louisiana American Legion—in his 37-year membership, he served as post, district, and state finance officer, then as Department Finance Officer, Department Adjutant, and Department Judge Advocate for more than ten years and still serving. During his “free” time, Hank also served as Editor of the Legionnaire Newspaper, “*The Louisiana Legionnaire*”. For his outstanding service, Hank was selected as Legionnaire of the Year for the state of Louisiana and was also presented an Honorary Life Membership in the American Legion by his Post.

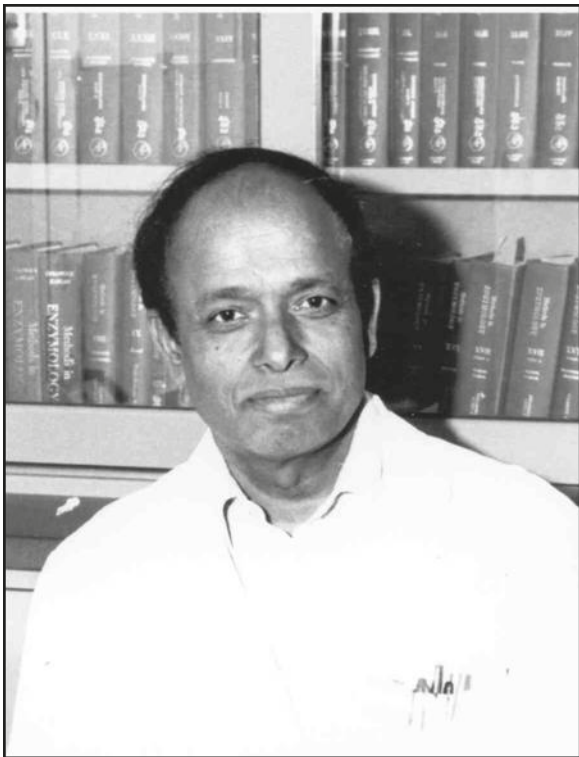
In 1988, while working diligently with the American Legion, Hank was invited to be a member of La Societe des Quarante Hommes et Huit Chevaux. Even though he continued his work in the American Legion, he accepted the challenge of performing similar duties in the 40 & 8. Hank served as L’Editeur of the *Koran Iron Horse* and received many awards for best local newsletter. He served as L’Editeur of *The Cajun Link* and received the best National Newsletter Award several times. On his progression to be the Nationale Leader of the Forty and Eight Organization, Hank gained great knowledge and led this organization by serving as Correspondant Locale, Commissaire Intendant (Treasurer) for 7 years, Chef de Gare Locale and in 2001 was Grand Chef de Gare de la Louisianne. He continues to serve as Grand Correspondant for the State of Louisiana 40 & 8 for over 14 years and also

served as Sous Nationale Directeur (assistant to the Nationale Directeur) for the National programs of Americanism, Membership, and Disaster Relief. He also served three years as Secretary/Treasurer for the National Box Car Association. He then was selected to serve as Sous Chef de Chemin de Fer in 2008. For his outstanding performance with the Forty & Eight, Hank was selected as Grand Voyageur of the Year for Louisiana in 1999, and in 2006, was chosen as Nationale Voyageur of the Year.

Hank has been very active with and supportive of our Carville Star program. The Forty & Eight Grand de la Louisianne has adopted this program and supports it 100%. Hank only has to be asked for assistance when special projects arise concerning our Hansen's Disease Museum and in 2008, Hank and the Grand de la Louisianne donated a generous amount of funds in order for our managing Editor Jose Ramirez to travel to Rome to witness the Canonization of Father Damien. He also highlighted the Carville facilities and programs, including pictures, personnel, and the museum, in a centerfold edition of the "Louisiana Legionnaire."

Hank Kwiatkowski was elected the "Head Fred" or Chef de Chemin de Fer for the Nationale Organization of La Societe des Quarante Hommes et Huit Chevaux in September, 2010, in Springfield, Illinois. He continues to live in Louisiana and he is married to Sharon Kwiatkowski. Hank is the father of two children and blessed with three grandchildren. His hobbies (in his free time) include fishing, house boating, restoring vintage cars, and traveling, which is good; because this year as Chef de Chemin de Fer he will travel many thousands of miles, representing our Forty & Eight organization and saying 'thanks' to all voyageurs for their outstanding support and work with our veterans and programs like the Carville Star Program. La Societe des Quarante Hommes et Huit Chevaux is blessed to have such a dedicated leader.

Kuchukungu Prabhakaran (1927 - 2010)



The leprosy community lost a pioneer in leprosy research with the death of Dr. Kuchukunju Prabhakaran who passed away Sunday, April 11, 2010 in Baton Rouge, LA. He was born in Anchal, Kerala, India in 1927, received his Ph. D in Biochemistry from the University of Bombay in 1965, joined the Laboratory Research Branch of the National Hansen's Disease Programs in Carville, LA, USA soon thereafter and retired from Carville after 33 years of service.

Dr. Prabhakaran contributed substantially to our understanding of the unique biochemistry of *M. leprae*. He discovered and characterized the enzyme diphenyloxidase (DOPA) in extracts of *M. leprae* and showed that the enzyme was not present in other known mycobacteria. The detection of DOPA oxidase was used early on as an *M. leprae*-specific marker providing a means to identify *M. leprae* in tissue smears. Dr. Prabhakaran identified *M. leprae*'s glutamine decarboxylase, an enzyme capable of generating gamma-aminobutyric acid (GABA), a chief inhibitory neurotransmitter in the mammalian central nervous system. He also demonstrated that *M. leprae* transports ATP from the host cell, explaining in part its host cell dependence. In his latter years he made seminal contributions to our understanding of *M. leprae*'s beta-lactamase enzyme providing a foundation for making ampicillin-sulbactam an effective antibiotic for killing *M. leprae*.

Dr. P, as he was known around the lab, was always cheerful and ready to help anyone in their scientific or personal pursuits. His memory will be greatly treasured by all who knew him.

Tom Gillis, Chief NHDP Laboratory Research Branch and Gene Harris, NHDP LRB biochemist (retired)

Order of St. Lazarus Scholarships for Training in Management of Hansen's disease (leprosy)

By: John Byrnes, KLJ, BrCrLJ - Hospitaller of the Grand Priory of America

The Military and Hospitaller Order of St. Lazarus of Jerusalem was pleased to provide scholarships for six nurses to attend a comprehensive seminar on the management of Hansen's disease (leprosy) at the National Hansen's Disease Programs (NHDP) October 19 – 21 in Baton Rouge, LA.

This comprehensive seminar concentrated on the differential diagnosis, treatment and management of the disease and its complications, and also included sessions on the history of the NHDP, the biology and epidemiology of the leprosy bacillus, unique immunology and histopathology of the disease and the psychosocial stigma of leprosy. The seminar was followed by 2 days of hands-on instruction concentrating on management of leprosy reactions, as well as the special physical and occupational therapy techniques applicable to individuals with nerve damage.

Each of the Order of St. Lazarus's six regional Commanderies selected a candidate to attend, and each nurse was reimbursed up to \$1,000 for travel expenses. While some of the scholarship recipients worked in NHDP Ambulatory Care clinics with hundreds of HD patients on their registry, others worked in private clinics with dozens of HD patients.

Commandery of the Atlantic: Stephanie Burns, RN, DNC, Lahey Clinic, Burlington, MA,
Commandery of the Southeast, Anjalie Graham, RN, MPH, Emory University School
Of Medicine, Atlanta, GA,

Commandery of the South, Deris Calderon, LPN, St. Francis House, Springdale, AR,

Commandery of the West, Vicky Crosby, APRN, Ocean view Health, Oceanview, HI,

Commandery of the Southwest, Dallas HD Clinic- Nancy Bernstein, BSN, Dallas County
Department of Health & Human Services, Dallas, Texas,

Commandery of the Midwest: candidate attended the spring NHDP seminar

The scholarship recipients were asked to provide a written narrative of their experience at the seminar, and all described not only how valuable the training was, but more importantly, how they in turn can better educate others in their clinics about the special considerations required in interacting with HD patients.

The Order of St. Lazarus traces its origin to the Crusades more than 1,000 years ago. The present day Military and Hospitaller Order of St. Lazarus of Jerusalem was founded by the Monks of St. Lazarus. Leprosy was the scourge of the fighting knights in the Holy Land, and the monks ran hospitals treating this disease and welcoming all, regardless of nationality or religion.

The primary purpose and activity of the Order of St. Lazarus is, and always has been, charity. Primarily, St. Lazarus has been world renowned as a Hospitaller Order in that its works have always been associated with medical care, primarily through the operation of medical facilities such as hospitals and clinics. The Grand Priory of America's current charitable works include both international and national activities.

Besides the charitable activities at the national level, many Subjurisdictions of the Grand Priory of America participate in local charitable activities of their own, such as these scholarship programs. The Subjurisdictions have their own websites describing the charitable activities that they are involved with in more detail. Click on the links in the website below to visit their respective charity WebPages to learn more about their regional work.

Our vision is to create awareness and to educate people in the importance of these programs in saving lives around the world, and to support projects that work towards these goals... For more information, please go to: www.st-lazarus.us

Tribute to Colonel Clyde Guidry (1946 – 2010)

Post Commander Gillis Long Center, Carville, LA



The staff and residents of the National Hansen's Disease Programs (NHDP) were shocked and saddened to hear of Colonel Guidry's sudden death on November 24, 2010. As the Post Commander of the Louisiana National Guard's (NG) Gillis Long Center which now operates the Carville Historical District, Colonel Guidry had oversight over NHDP clinic, residential and museum space. But Col. Guidry was more than a landlord; he was a close personal friend to many of our staff and all of our resident patients.

NHDP's Facilities Management Branch Chief Captain Jimmy Foto interacted on a weekly basis with the Colonel and always spoke highly of his diligence, flexibility and dependability in addressing our routine and urgent needs. As hurricane Gustav approached, our HQ in Washington sought reassurance that our patients would be safe. I was able to confidently tell them don't worry. They were part of the Colonel's family and had nothing to worry about. Carville was the safest place in LA

I have been with this program as researcher and director for >30 years and shared with many other old timers an anxiety about our relocation in 1999. We feared that the fantastic history of this special place, dating from 1894, might not be respected and would trickle away. We soon learned these fears were unwarranted, especially so under Col. Guidry who developed a personal interest in Carville's history. He became interested in preserving and restoring the unique and historic architectural features of Carville's buildings. The Forty and Eight's project to replicate and relocate the 1894-1921 stone memorial from its secluded site in the front quad to a prominent place in the cemetery was done with his strong collaboration. His keen interest in Carville's history was greatly welcomed by our curator, Elizabeth Schexnyder. Together they have searched the nooks and crannies of the vast Carville complex and discovered a number of relevant artifacts that have been researched and put on display. Colonel Guidry was delighted to be kept apprised of new documents uncovered in newspaper archive searches and gleaned from the National Archives and National Library of Medicine. He often would greet groups of museum visitors and share with them the broad scope of the NG current mission at the Center.

Colonel Guidry had a special relationship with our resident patients at Carville. He did all he could to meet their needs and they loved and trusted him. NHDP's Commander Connie Torrence-King testifies to his honor, integrity and compassion for those who chose to remain in "their home" in 1999. He learned each individual's full name, their origin, and enough about their personal lives to converse with them when they met in the hall or cafeteria. He knew and understood the circumstances that brought each of them to Carville. Ladies were greeted with a bear hug and men received a firm sincere handshake; gestures HD patients treasure especially.

I will always be enormously grateful to him for his support and compassion for our program and the Patients at Carville. The NHDP family extends its deepest sympathy to Colonel Guidry's family and his Gillis Long Center Staff.

James L. Krahenbuhl, Ph.D.
Director, NHDP

Simeon Peterson: *Where are you from and how did you get here?*

By: Elizabeth Schexnyder, Curator, NHDM

On Thursday evening, May 17, 1951, eighteen patients voluntarily transferred from the Leprosarium in the US Virgin Islands to Carville, the largest number of patients ever to be admitted to the hospital at one time. They ranged in age from twenty-three to seventy—twelve men and six women. They were flown here by the US Air Force in a huge cargo plane from St. Croix, VI, making the trip of 2,000 miles in twelve hours. Drs. Fredrick Johansen and Rolla Wolcott greeted them on the tarmac of Harding Field in Baton Rouge. Upon arrival at Carville, the newcomers were greeted by a large crowd of patients, nursing staff, and resident chaplains. A late supper was waiting. Twenty-three year old Simeon Peterson was among them. “I didn’t eat, I was so tired. We all were.” Simeon spent the next couple of months in the Infirmary. “My hands were in bad shape. I started the first of many surgeries to correct that right away.” Pete made a new friend, Oscar, during his first week. “Oscar was right down the hall. He used to send me things to eat and drink by his sister [who was also a patient]. We were close in age and became friends. We’re still friends today.”

Simeon, or “you can call me Pete” he instructs visitors, began hosting tours in the National Hansen’s Disease Museum in October of 2009. The diminutive man with a puckish wit arrived for duty sharply dressed with suspenders and a coordinating derby-styled hat. He listens with patience as visitors organize their thoughts, sorting through the myths and fictionalized versions of ‘leprosy’ that previously informed their understanding. *Where are you from and how did you get here?* Pete carefully answers each question as if it was the first time it was asked of him. He describes his former quarters at the Virgin Island leprosarium near Christiansted (built by the Danish government in 1910 and acquired by the US in 1917) as a run-down eight-acre complex that had a continuous odor from a rum distillery next door, bordered by the sea. He was five years old when first admitted. He also had a brother and sister who preceded him as patients. Pete is straight forward when describing the medical procedures he’s had to reduce the clawing of his fingers and increase his dexterity. “We’re here to educate,” he said. “That’s what I do.”

Especially affective with young visitors, Pete has a directness and approachability that they appreciate. When children arrive at the museum with their parents or teacher, they often appear reserved and hesitant. Uncertain as to what they are about to see or hear. Pete makes the National Leprosarium and Hansen’s disease human for them. An hour later, parents and teachers must coax the kids out the door for another event or appointment on their schedule. They will find their young charges clustered around Pete, chattering and smiling, as he holds court in the main exhibit hall.

Many book groups have planned tours based on Pete’s work schedule. When they learn that “Harry” (character inspired by Pete in the book *In the Sanctuary of Outcasts* by Neil White) will be giving the tour they arrive with books ready for his signature.

Always gainfully employed during his 59 years at Carville, Pete’s also been an elevator operator at the Infirmary (3 floors, 65 cents per hour) and worked in transportation, assisting patients in wheelchairs to get to their medical appointments, whether in Carville or Baton Rouge.

In addition to his museum duties Pete’s also the editor of The STAR magazine. In the 1950s, Pete volunteered at The STAR. He addressed magazines to far-flung subscribers. Stanley Stein was still leading the publication. The STAR staff had been in contact with the [VI] patients since 1942. “We [Virgin Islanders] first heard about Carville through The STAR. I liked Stanley, but didn’t know him very well. Stanley Stein was easy to talk to but hard on the doctors. He was looking out for us.”

A DAY IN THE LIFE OF DR. YASIN AL QUBATI

By: Yasin Al Qubati, M.D.

A strong desire obligated me to set aside the office work for a day. I had to visit the field again. This was something which I had done regularly for twenty years up until the time, a few years ago, when a team I had successfully built up, had been able to take over full responsibility for this task from me.

It was a story I had heard. There was a family living in miserable conditions in a remote area of Yemen, situated between its borders with the Sultanate of Oman and Saudi Arabia, called Al-Mahara. This is a desert area on the coast of the Indian Ocean facing the famous, natural and wonderful island of Socotra.

The four-wheel drive vehicle had to fight the desert of the Empty Quarter to reach our destination – a family home that had been abandoned because one of the had leprosy. It was a two-storied mud house with eight rooms. There was not a trace of furniture. Only the roof, ceilings and walls remained. A dusty picture of an old man hung from one wall.

We were shown around this house by the owner. This old woman told us: “We were all living together in this house with my husband and his father, who had leprosy. My father-in-law lived here for years until he died, hidden from the sight of other people. Since all the villagers knew that my husband’s father had had leprosy, after this death the pressure on us to move was great. Our neighbors believed our house was full of leprosy germs. We were forced to throw all of the furniture into the valley to be carried away by the next flood brought by the Indian Ocean. We then had to leave our home- with not a piece of furniture to our name. For the last three years we have been living together, cramped into one room. All twelve of us!”

Then I spoke: “Look Madam, there are no leprosy germs on any of these walls. They cannot survive outside the body for more than two days.” I touched my face to a wall of the house. Then each member of my team did as I had done and ran his face along the walls. “All of use will be affected if there is leprosy on these walls.” I added: “You have to return to your house with your children.” “No, Doctor, I cannot,” she replied. “Even my husband has left us. He emigrated to Saudi Arabia three years ago. He couldn’t face the village community.”

As we were all leaving the house, I asked the leader of the village to get every person in the village to gather at the mosque. When we were all there, I started a health education session. This lasted for the next two hours. I answered many questions.

I used many verses from the Holy Quran to convince the villagers that leprosy is not that serious a disease.

By then end of the day, the family was back in their home.

Dr. Yasin Al Qubati, Yemen Representative of German Leprosy and Tuberculosis Relief Association. Dr. Al Qubati is a member of the Eighth Expert Committee on Leprosy for the World Health Organization. This story was originally published by ILEP (International Anti-Leprosy Organization).

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At Harborview's leprosy clinic, doctors treat stigma along with the disease

By: [Rachel Solomon](#), Special to The Seattle Times

Harborview Medical Center has one of 15 federal clinics in America focused on patients with Hansen's disease, or leprosy, a disease most Americans think was eradicated long ago. For patients, most of whom are immigrants, the stigma is often the worst part of their diagnosis.

When the Filipina woman came to the small clinic at Harborview Medical Center, she was certain the skin lesions that darkened her body were lymphoma. That's what the doctors initially told her.

But when they took a skin biopsy, the doctors said it wasn't lymphoma — it was leprosy. Perfectly treatable, even curable if caught early. But the woman was devastated.

"She preferred lymphoma over leprosy," said Elizabeth Dobler, a fourth-year medical student working at Harborview. "Leprosy is totally treatable. A lymphoma could kill you."

Harborview's Hansen's Disease Clinic — a reference to the other name for leprosy — is one of just 15 federally funded clinics in the country dedicated to treating a disease most Americans think no longer exists.

Leprosy, an infectious disease that primarily attacks the skin and nerves, is not the terror it once was.

But to many of the clinic's 150 patients, most of them immigrants, the stigma is often tougher to swallow than the actual diagnosis.

"Despite the fact that this may be a forgotten disease by most Americans, it's still a very real concern," said James Harnisch, the dermatologist who has run the Harborview clinic since the 1970s. "But people here often just think of leprosy as destroying your hands and feet and eyes and leaving you totally disfigured."

Misconstrued ailment

It took almost a year of treatment and continued explanation before the woman's depression about her leprosy began to fade. Her case reflects the lingering fear linked to one of the world's most misunderstood infectious diseases.

Thanks to drug therapies, the prevalence of leprosy around the world has shrunk dramatically in the last few decades. The number of reported new cases dropped from 602,000 in 2002 to around 250,000 in 2008, according to the World Health Organization (WHO). But places like Brazil, India and islands in the Pacific still teem with the disease.

In the United States, there are only about 6,500 remaining cases, including about 200 new cases each year — numbers that have remained static since the 1980s. Harnisch said the Harborview clinic averages one new patient a month.

Back in the 1970s, around 75 percent of Harnisch's patients were Vietnamese refugees. As those patients got better, more Hispanics and then more immigrants from the South Pacific islands — the Philippines, Samoa, Micronesia — trickled in.

During the past 10 years, many of the clinic's new patients have come from India — including some professionals drawn here by the region's tech boom. "Once they're over here, they might bring their mother, their father, their sister or brother to live with them, and guess what? They have leprosy," Harnisch said. That's no surprise since nearly half of the world's reported leprosy cases are in India, according to the WHO.

Fear of leprosy is ancient. People thought that the physical deformities it could cause were a curse from God. Sufferers became outcasts, and leprosaria became their new homes.

"When there was no treatment, once you got it, you had it for life, and it got worse and worse and worse through life," said Philip Kirby, the clinic's attending dermatologist. "That's why those people were often confined to leprosaria."

But leprosy — also known as Hansen's Disease, after Norwegian doctor Gerhard Armauer Hansen who discovered the cause of the disease — isn't spread through a handshake or a sneeze. It's transmitted through close contact with an infected person over time, often facilitated by crowding, poor nutrition and bad hygiene.

Leprosy bacteria, which are in the same family of bacteria that cause tuberculosis, grow where it's cool, so nerves on the arms, legs and around the eyes are most vulnerable. Hands and feet may go numb, and patients can get cuts or burns or lose digits without even feeling it. Some go blind.

The disease can be controlled with a multidrug-treatment regimen over a few years, Harnisch said. And longer treatment time lessens the chance of relapse.

But doctors worry when patients refuse to accept their diagnosis, something that happens all too often. Then the patients don't take their medications or follow treatments, Kirby said.

So the doctors reframe the disease, introducing it first as a "temporary, curable infection," Kirby said. Then they ease them into the leprosy diagnosis.

"I can't say we've always been successful with that," Kirby said. "We've treated some patients who went for years without complying for treatment because that meant somehow they were buying into what we said they had."

For some patients, the trick is masking their leprosy from others — sometimes even spouses and children. Thinning and loss of eyebrows can be a telltale sign of leprosy, so doctors will color in bald spots with an eyebrow pencil or even transplant hair from a patient's scalp, resulting in long, bushy brows.

When patients lose sensation in their feet, they are urged to wear special shoes with extra depth and custom inserts.

"We've had people refuse to wear these protective shoes because they thought that was going to be recognizable by friends and family," Kirby said. "Anything that makes them look different can be something that they won't do."

And sometimes, the doctors lose touch with patients entirely. Their phones have been disconnected or they've returned to their home countries.

Fostering awareness

Leprology was a natural career path for Harnisch. He was interested in infectious disease, dermatology and internal medicine, and leprosy married all three. It was a challenge, and Harnisch liked that.

During his medical residency at Emory University's Grady Hospital in Atlanta, Harnisch saw a patient with mysterious plantar lacerations matching those described with leprosy. It turned out to be diabetes.

But Harnisch said the case left him fascinated with leprosy. Though he worked on sexually transmitted diseases for the next several years, any patient with leprosy was routed to him.

When the Harborview clinic was established by the federal government, Harnisch was picked to head it.

More than 30 years later, little has changed — except that funding has taken a dive. The clinic used to be open every Wednesday. Now patients are seen every other Wednesday morning.

Scheduling can be frantic. If one day, 12 patients are on the calendar; maybe only a few will show up. Or the opposite happens, and 20 will pack the waiting room.

But the clinic remains a place where patients can come out of hiding. During appointments, their leprosy isn't a secret, said Dobler, the medical student.

"We'll all touch them and examine them and we aren't afraid of them," Dobler said. "Touching means a lot to patients. They appreciate when multiple people go up and touch their arms."

Many of the students knew little about leprosy before beginning work at the clinic. That's another reason the doctors are here: to teach, to make visible the disease that's been forgotten by so many Americans.

"That's an important thing, to pass on that understanding, so later on there are other people that can take care of these patients," Harnisch said. "The disease is not going to go away."

Rachel Solomon, a University of Washington student, originally reported this story for a global-health-reporting class. She can be reached at rachel.l.solomon@gmail.com

Chef de Chemin de Fer Hank Kwiatkowski Homecoming

By George H. "Doc" Willis, Nationale Directeur, Carville Star

THE SPECIAL EVENT, MARCH 2011

The Chef de Chemin de Fer Homecoming,
The Cajun Wreck, and the Carville Museum Visit

During the first week of March 2011 there will be an event that will surpass any event the Forty & Eight has ever experienced. In Lafayette, Louisiana, Chef de Chemin de Fer Hank Kwiatkowski and the Louisiana Cajuns will host the Chef's Homecoming. Coupled with the homecoming will be a memorable trip to Baton Rouge, LA to visit the Carville Museum, along with an unforgettable Cajun meal hosted by the Directeur of the National Hansen's Disease Program and upon returning to the Lafayette hotel, you will become involved in and witness to the Cajun Wreck.

For those of our voyageurs and dames who have never had the opportunity to visit Louisiana, this will be a very memorable occasion and vacation. You will become acquainted with and introduced to some of the best Cajun food you have ever tasted; plus, I am told there will be many surprises upcoming at this celebration.

On Thursday, 03 March 2011, there will be buses available to transport those who wish to visit the Carville Museum. The visit will be open to all members of the Forty & Eight and La Femmes. We have arranged for Dr. James Krahenbuhl, Director of the Hansen's Disease Center in Baton Rouge, to meet our group at the Museum and he will present an oral summary of the Hansen's Disease Center, progress and history of treatment, and a slide show of how the diseases are treated. Information will also include the importance of our STAR publication and treatment centers throughout the United States and other areas where Hansen's is found.

Those individuals who have visited the Carville presentation and museum have a new realization of how important our Carville Star program and our donations are in eliminating the stigma of Leprosy, and also in distributing the research and development of the treatment of this disease.

Following the presentation by Dr. Krahenbuhl, we will visit the Carville Museum, meet and talk with our Ambassador, 'Mr. Pete', and also our museum curator, Elizabeth Schexnyder. She will give us a tour of the museum and cemetery and will answer any questions you have concerning the museum. The museum is constantly changing with more artifacts being acquired for display. Even if you have been before, there is much more to see about the life and history of the Hansen's disease residents who lived at Carville for years.

Following the tour of the museum, Dr. Krahenbuhl has arranged for all who visit the museum to enjoy a dinner of true Cajun cuisine, cooked by award-winning chefs. I am told that the ones preparing our meal have won many 'cook-offs' in the Baton Rouge area.

Returning to Lafayette, you will continue your adventure at the hotel with the Cajun Wreck and then our Chef de Chemin de Fer's Homecoming on 05 March 2011. This experience available to you will be one you will always remember and it will bring a new perspective as to what we are all about in the Forty & Eight Family.

We are looking forward to seeing you in Louisiana March 03, 2011 through March 06, 2011. Drive Safe!!

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
Fax: (832) 393-5247
Physician - Dr. Terry Williams/Dr. Steven Mays
Public Health Nurse – Marion Matsu, RN, CCM
Main: (832) 393-5173

Texas Center for Infectious Disease
2303 S. E. Military Drive
San Antonio, TX 78223
PH: (210) 531-4576
PH: (210) 531-4295
Fax: (210) 531-4508
Appointment Secretary (210) 531-4526
Physician - Dr. Robert N. Longfield
Physician - Dr. Adriana Vasquez
Physician - Dr. Lynn Horvath
Public Health Nurse - Ms. Debbie Mata, RN
Ph: (210) 531-4295

Department of State Health Services Region
(HSR) 11
601 W. Sesame Drive
Harlingen, TX 78550
PH: (956) 423-0130
Fax: (956) 444-3295
Physician - Dr. Richard Wing
Public Health Nurse – Grace Flores, RN

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RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

The **Forty & Eight**, an honor society of veterans created in 1920 and **The STAR's** primary funding organization, draws its origin from World War I. Millions of American soldiers in France were transported to the front in narrow French box-cars, called "Voitures," which would only hold 40 men or 8 horses. Remembering the close brotherhood of those box-car days, **La Societe des Quarante Hommes et**

Huit Chevaux (The Society of 40 men and 8 Horses) was formed and local Voitures began organizing as outstanding Legionnaires were invited into membership. Membership is still by invitation only.

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



FACTS ABOUT HANSEN'S DISEASE

What is HD?

Hansen's disease, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr. Gerhard 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