

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JULY - DECEMBER
2007**

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Picture at July Star board meeting are: standing, Dave Rabius Nationale Correspondant 40 et 8, Jose Ramirez Managing Editor The Star Mike Wood Nationale Directeur Carville Star 40 et 8, and seated is Captian Irma Gurrea NHDP Consultant.

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Stanley Stein

Founder - Editor, 1941 - 1967

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

Views expressed in **The Star** are those of patients of the Gillis W. Long Center at Carville, Louisiana, except in the case of direct quotations or signed articles.

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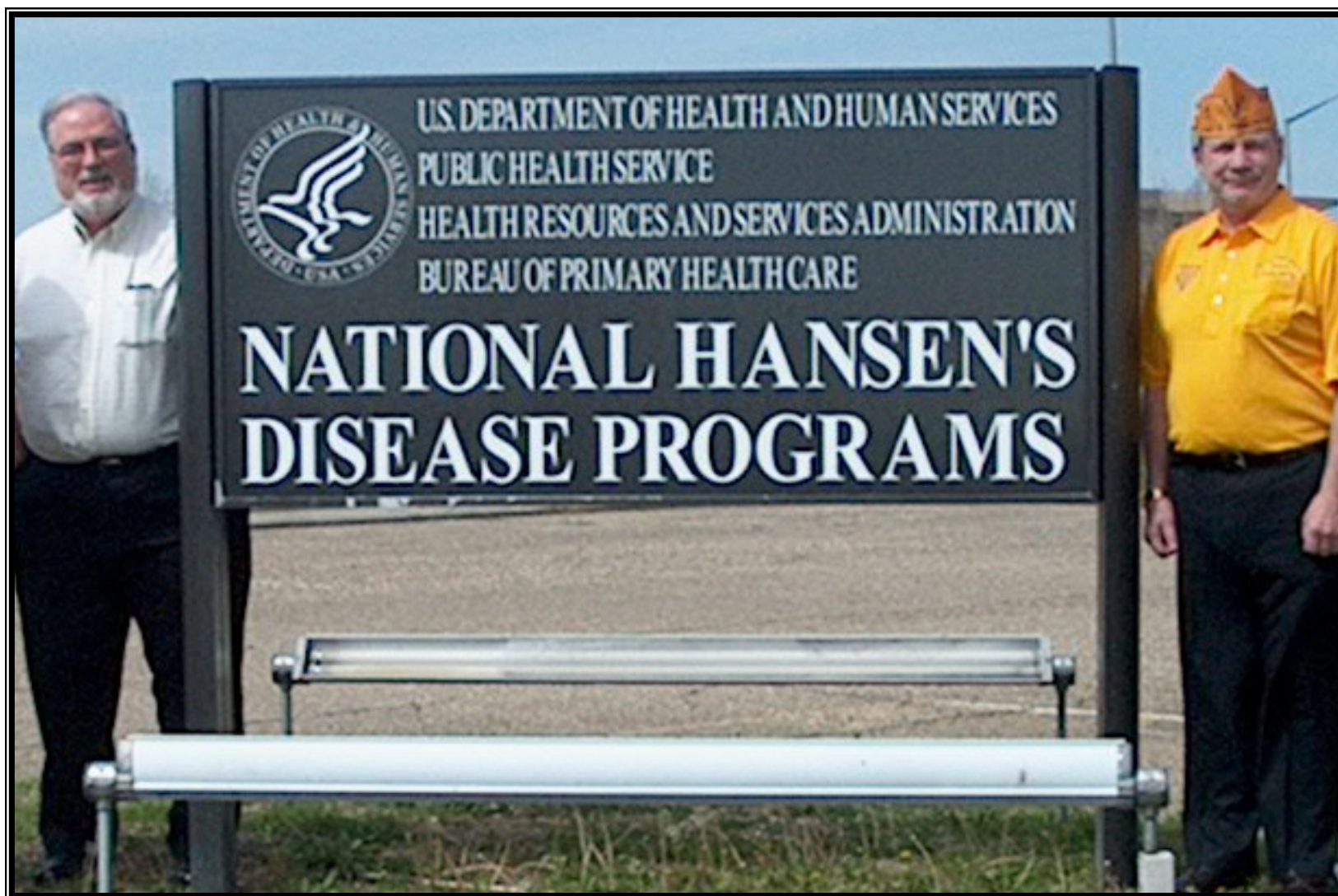
Editorial Policy On Terminology

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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MOVING SOON?

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At the last Star board meeting at the NHDP Center in Baton Rouge, LA on 12 July 2007 a new managing Editor of The Star was elected. His name is Jose Ramirez. Jose brings to The Star a first hand knowledge of life at The Gillis W. Long Center in Carville, LA. because he is a previous resident there and Hansen's Disease patient. Jose has written articles regarding Carville and Hansen's Disease in the past for other publications and shared one with us at this meeting. It was about the formation of the Carville baseball team and the experiences that they faced. We were amazed in the difference in reading an article written by someone that was there rather than by a third party. He is also a much in demand speaker on Hansen's Disease. Jose will assemble The Star and has promised to include editorials from his point of view, knowledge and experiences. Jose is a most welcome addition to The Star. Jose now makes his home in Houston, TX. Tanya Thomassie is not leaving completely, she will stay on and serve as a consultant.

Picture at July Star board meeting are: standing, Dave Rabius Nationale Correspondant 40 et 8, Jose Ramirez Managing Editor The Star Mike Wood Nationale Directeur Carville Star 40 et 8, and seated is Captian Irma Gurrea NHDP Consultant.

Mike Wood
Nationale Directeur Carville Star

The National Hansen's Disease Program

The National Hansen's Disease Program (NHDP) is located in Baton Rouge, LA. The Program, formerly at Carville, LA, relocated its services in January, 2000. Inpatient services for Hansen's disease (HD) are provided at Ochsner Medical Center, and the Ambulatory Care Program serves outpatients through eleven (11) Hansen's Disease Clinics throughout the United States and Puerto Rico.

The NHDP also promotes research in HD through the Laboratory Research Branch at the Louisiana State University School of Veterinary Medicine.

Eligibility for Services

Any person in the United States and Puerto Rico diagnosed with HD is eligible to receive healthcare services related to the diagnosis and treatment of HD and its related complications.

Services

- Confirmation of diagnosis through skin biopsies
- Medical care
- Medications for treatment of HD
- Inpatient treatment and Rehabilitative services
- Clinical consultation

Professional and patient education materials and conferences

Other Services

Persons who elect to receive their care for this disease from their private physician can receive HD medications through the NHDP at no cost, as well as processing of skin smears and skin biopsies. Private physicians may consult with medical and ancillary staff at NHDP.

Ambulatory Care Program

Outpatient HD services are provided in Arizona, California, Florida, Illinois, Massachusetts, New York, Puerto Rico, Texas, and in the state of Washington.

A list of these clinics is included in every copy of The STAR.



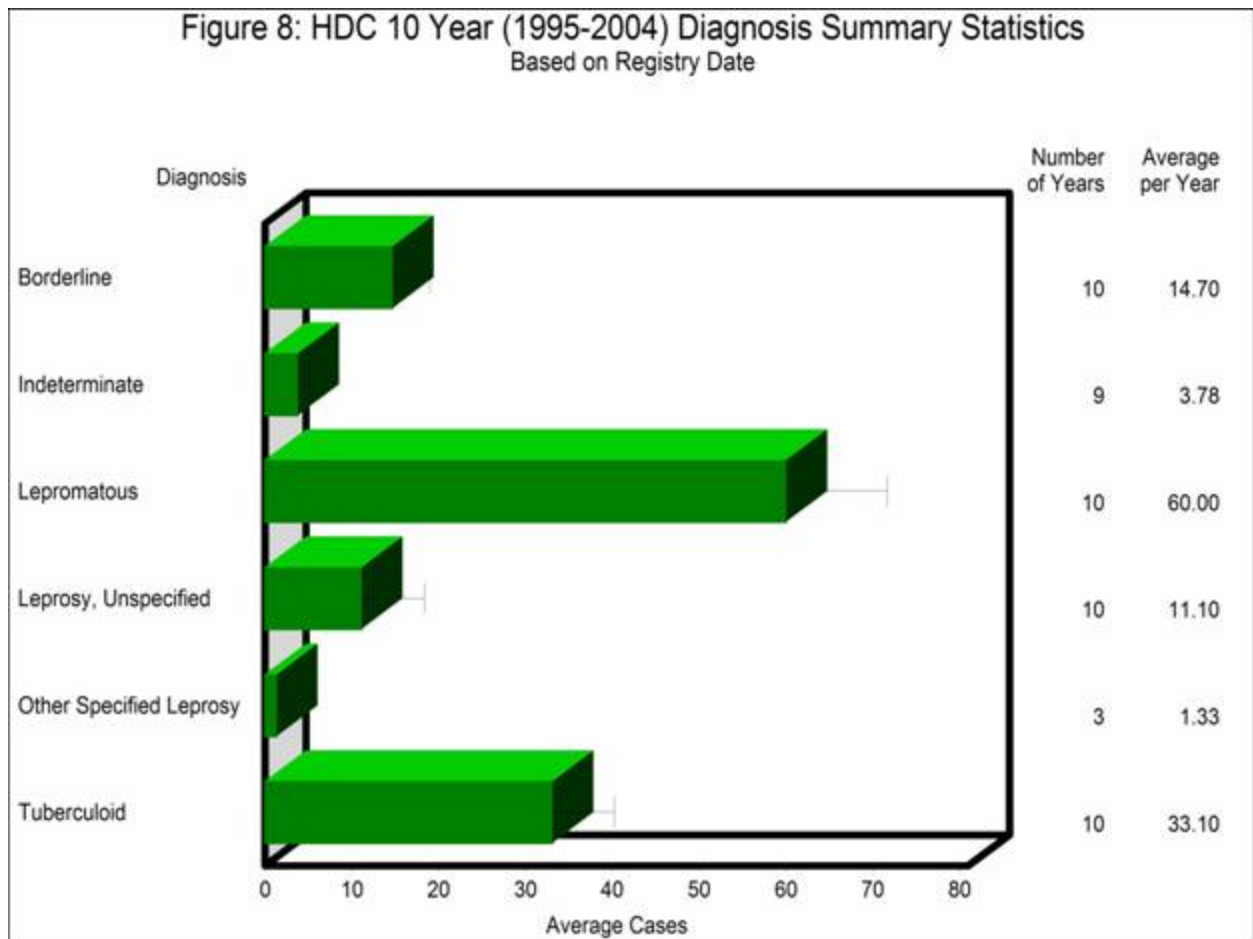
Disease Classification

The Hansen's disease surveillance form provides for initial classification of the disease into one of six categories which correspond to the universal ICD-9-CM diagnosis codes for leprosy (030.0-030.3, 030.8, and 030.9). This method of reporting classification is completed more consistently than other disease classification methods on the

Leprosy Surveillance Form in the U.S. The diagnosis code distribution of classifications registered in 2005 is shown in Table 4a. The majority (131/166, 79%) of U.S. cases are coded as either 030.0 or 030.1 and correspond to either lepromatous (59%) or tuberculoid (20%) respectively. Comparing these percentages to the ten year trend of reported codes (Table 4b) shows no significant variation, and these 2005 reports are in keeping with earlier observations.

Most leprologists prefer the Ridley-Jopling classification system, which includes both the lepromatous and tuberculoid ends of the spectrum as well as the associated borderline- lepromatous, borderline-tuberculoid and an indeterminate classification. Unfortunately, Ridley-Jopling classification data is frequently omitted from the surveillance form. Some clinicians may not know the disease classification when they report the case and others may be unaware of this classification system. Consistent with the diagnosis code data the majority (51/105) of U.S. cases are classified a lepromatous.

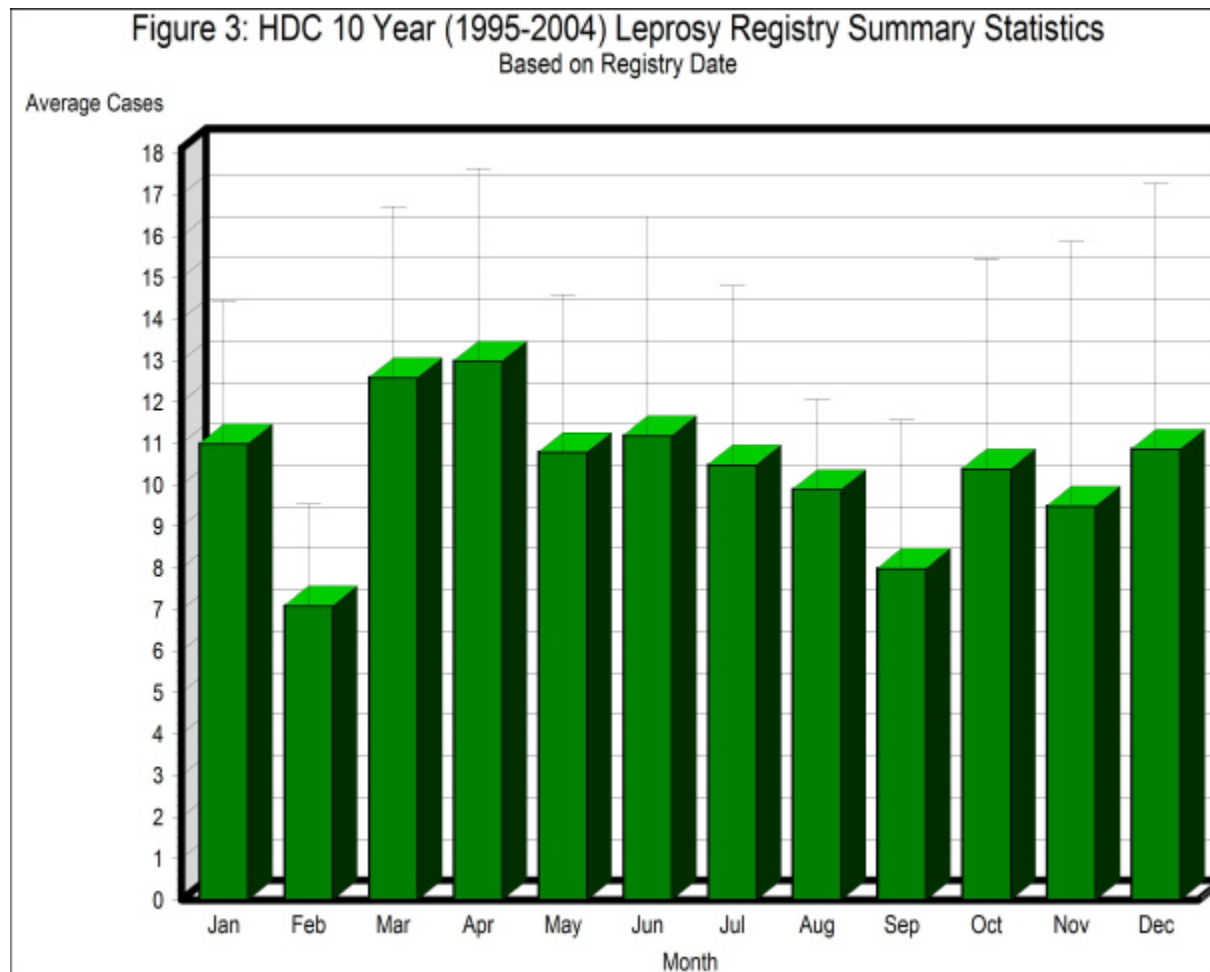
The WHO assess cases only as 'Multibacillary' or 'Paucibacillary'. A category of Multibacillary cases can be created by combining the Borderline and Lepromatous classes from the ICM-9 codes. Likewise, Paucibacillary cases can be identified by grouping the remaining categories. For 2005, 112 (67.4%) of the reported cases are grouped as Multibacillary and 50 (30.4%) as Paucibacillary according to this classification scheme (Tables 6a). These data are in keeping with the ten year trend of reporting as summarized in the preceding 10 year period in Figure 8.



Summary Statistics

A total of 166 cases were reported to the National Hansen's Disease Registry (NHDR) in 2005, representing a $> 20\%$ increase over the number of cases reported in the previous year (2004, $n=131$). This clearly reverses the declining trend in registered cases seen in recent years. Temporal variation in presentation is not uncommon with chronic diseases and can be influenced by a variety of factors. The decline in case registrations seen in the previous three years was coincident with the geographic relocation of our program from Carville, Louisiana to its current Baton Rouge campus, and it is possible that this programmatic disruption had some impact on case reporting.

The monthly number of cases registered in 2005 ranged from a low of 5 in December to a high of 33 in June (Figure 2). There is no pertinent epidemiological reason that a slow chronic disease might have variable reporting rates throughout the year, and these fluctuations in registration are probably the result of other operational issues. Among the operational concerns that might have influenced case registration in 2005 was transfer of our Registry data between incompatible computer platforms, which likely created some bottlenecks in recording. The Hansen's Disease Registry is now available as a SAS dataset, making it much easier to compare reporting trends. Comparing monthly registration trends over the last ten years shows that registration reports tend to be returned at a fairly constant rate throughout the year, and there is no substantive intra-year temporal trend for reporting cases to the HD Registry (Figure 3).



THE 40 & 8 AND THE CARVILLE STAR, THE BEGINNING

The involvement with the Carville Star began in 1931 from a visit by the Louisiana State Commander of the American Legion, Sam Jones of Lake Charles, LA. He was there to visit 23 veterans at Carville, and a number of other Legionnaires accompanied him. They had come to listen to the grievances from this group of 23 Hansen's Disease veterans gathered under a group of oak trees. Mr. Jones heard their complaints and needs. They were asking for a decent infirmary building, a recreation hall, more contact with the outside world, and baseball and golf to be played on the grounds at Carville. Sam Jones told them that he would do the best that he could, but advised them to form an American Legion Post. He explained that there is strength in numbers and that 23 veterans were not a force, but with a million Legionnaires behind them there would be unity. Sam Jones later attended the first meeting of the new Carville American Legion Post, and also went on to become the Governor of the state of Louisiana. The 40 & 8 became involved with the new Carville Star program immediately, and as The Star's founder and first editor said of the 40 & 8, "It was their adventure in humanity, and there is no way that we can ever thank the 40 & 8 for all they have done." From The Star's outset the 40 & 8 provided the modern equipment needed to produce a professional looking publication. When they needed a linotype machine, a printing press, or a bundling machine, the 40 & 8 always provided the funds. In 1944 the 40 & 8 took over the Carville Star program exclusively and has maintained it to this day, making it the second oldest program in La Societe. The creator and first editor of The Star, Stanley Stein, was himself a member of that original American Post.

The first issues of The Star were called "The 66 Star," because the site which is now the Gillis W. Long HD Center, was originally designated as Marine Hospital 66.

It has come a long way since the time that "leprosy victims" as they were referred to then, were ferried up the Mississippi River in the middle of the night and dropped off at a plantation dock in Carville, LA, then referred to as The National Leprosarium. Those patients were confined behind a high fence topped with barbed wire, and patrolled by armed guards. They were not allowed to vote, or marry, and visits with their families were doled out sparingly. They were told bluntly when they arrived "That you will die here." That site is now the Gillis W. Long Center for Hansen's Disease in Carville, LA. It still sits on the banks of the Mississippi River as it did then with the differences being that the dock is gone and an earthen levy stands between the gates and the river to protect against flood. Also gone are the armed guards and the fences topped with barbed wire, now replaced with treatment, research, understanding and progress in Hansen's Disease, due in a large part to the support of the 40 & 8.

Mike Wood, Nationale Directeur Carville Star



Alone No Longer		Stanley Stein \$4.00
Carville...100 Years		Carville Centennial Celebration 1894-1994, Julia Elwood, Editor \$10.00
Carville: Remembering Leprosy in America		Dr. Marcia Gaudet \$28.00
Miracle at Carville		Betty Martin \$23.00
No One Must Ever Know		Betty Martin \$21.00
With Love in Their Hearts		The Daughters of Charity of St. Vincent de Paul 1896-1996, Julia Elwood, Editor \$10.00
Love Me, Somebody		D. J. LeBeaux \$12.00

U.S. Book Purchases Please mail personal check or money order (include appropriate shipping charge).	Please address book inquiries or purchases to: <i>National Hansen's Disease Museum</i> 1770 Physicians Drive Baton Rouge, LA 70816 ATTN: Book Sales	Overseas Book Purchases Please E-mail book purchase request to NHDPmuseum@hrsa.gov Postage will be calculated by shipping destination and weight. Payment must be received prior to shipping.
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A Walk Through Hospital History

By Elizabeth Schexnyder

For The STAR Magazine

Submitted to Tanya Thomassie, October 2007

Hansen's Disease in the United States is a twice yearly seminar presented by the National Hansen's Disease Program Training Department. The target participants are health care professionals, in particular dermatologists, who want to learn more about identification and diagnosis of HD.

On the roster at the October 2007 seminar were expert presenters Dr Robert Jacobson, leprologist; Dr Samuel Moschella; dermatologist; Dr. Leo Yoder, leprologist and Dr. Ebenezer Daniel, ophthalmologist. Twenty participants from around the country filled the conference room at the Ochner Hospital campus in Baton Rouge.

In order for the seminar participants to understand the history of Carville and Hansen's disease in the US more fully, the group attended a jambalaya dinner in the ballroom of the Recreation Center in the Carville Historic District after the first day of classes. The 45-minute drive from the Baton Rouge hospital underlines the still isolated location of the nations' only quarantine hospital for leprosy. Tonight, Carville history is on the menu in addition to local cooking. Elizabeth Schexnyder, museum curator, served the group some background on the historic recreation center (where they were dining) culled from the National Hansen's Disease Museum archives:



Figure 1 Carville c. 1936. Wooden patient dormitories in foreground. Photo by Charles Marshall.

Louisiana's governor Sam Houston Jones was the honored guest at the formal opening of the new recreation building, a part of the five-million dollar building program completed in 1941. Governor Jones describes his visit to Carville—"You could not appreciate Carville's leprosarium now unless you had seen it a few years back, a cluster of crude wooden buildings. Now there are magnificent concrete, fire-proof structures, equipped with all the latest hospital improvements...my interest in this institution is beyond all politics".



Figure 2 Carville c. 1941. Federal government "fireproofs" the buildings. 2 1/2 miles of corridors connect all patients quarters. View of Buildings 15-19, women's dormitories.



Figure 3 Holiday entertainment for patients in the recreation center ballroom. 1940s. Photo by Johnny Harmon.

After dinner, the curator guided the group on a 30-minute walking tour through the hospital corridors. On the walk, the curator circulated historic photographs and told anecdotal stories to illustrate Carville history. The group passed the old 65 bed infirmary (recently renovated into a conference center), the patients' dining hall (a common cafeteria built was built in the 1980s), the patients' dormitories (male and female patients slept in separate dorms), the Quonset huts once used as Carville's school and occupational therapy work area, and the first Carville patients' cemetery. Finally, the group entered the "original staff dining hall and kitchen" (the museum). Museum exhibits include Carville history, Patients Recreation & Organizations, Patients' Stories, the Public Health Service, "Under the Pecans" (patients' cemetery), The STAR Magazine, the Daughters of Charity and Medical Artifacts.

Visiting the museum and treading the old halls of the hospital gave the HD seminar participants a visceral taste of Carville's history and a feeling for the patients' experience that is difficult to impart by words and training alone.



MARDI GRAS

Carville's celebration of Mardi Gras began in the 1930's, probably by patients from New Orleans who wanted to continue their tradition of carnival.

Mardi Gras for the Krewe of Carville follows the general structure of urban Mardi Gras celebrations in Louisiana, with costumes and masks, a parade with music, food and drink, favors, or tokens being thrown or begged for, general revelry, role reversal and symbolic inversion. It is unique, however, in that the participants are residents or staff members of the Gillis W. Long Hansen's Disease Center (formerly called the National Leprosarium) in Carville.

Patients' organizations, like the Lions Club, American Legion Auxiliary, Patients' Federation, American Legion Post, and the Mexican Social Club, started working months ahead planning and preparing for the carnival celebration. Patients and staff built floats out of anything with wheels-decorating bicycles, tricycles,

wheelchairs and various carts to compete for prizes. A parade rolled through the 2 ½+ miles of covered walkways (connecting the patients' dormitories, infirmary, cafeteria) and ended in the recreation center where the

King and Queen of Mardi Gras were toasted and a ball was held by the masking patients.

Doubloons minted in the 1990's commemorate important dates to Carville History: 1921 marks the federal take over of the facility, 1994 for the 100year commemoration of the arrival of the first HD patients, 1996 for the arrival of the Daughters of Charity who came to care for the patients. The armadillo, an important animal in HD research (pictured on the doubloons) became mascot of the celebration.

In the 1980's and 1990's the parade moved to the ballroom of the recreation center to accommodate older Carville residents. Since the hospital's relocation to Baton Rouge in 1999, the celebration of Mardi Gras continues at the Summit Hospital.



MARDI GRAS

February 21, 1950

For the first time since before the World War, the patients planned a big Mardi Gras celebration, with all the trappings and regal splendor of King, Queen, Court, floats, costumes and parade and a grand ball. The patients are to be commended for their efforts in making up artistic floats for which all kinds of hospital equipment has been put into use, from old beds on wheels to carts on wheels and bicycles.

After a parade on the walks the floats entered the ball room in the recreation building for the awarding of prizes. The first prize for floats motif "Justice" was awarded the Mexican Club - second prize an Irish theme by the B

Natural Music Club won second prize; the American Legion representing a hugh horn of plenty won third prize. There were costumes of gypsies, Spanish señoritas, clowns, mandarins, pirates, etc., all joining in the parade. Music was furnished by Jimmy Fisher and his New Yorkers from Baton Rouge. It was a very nice affair and a very fine miniature representation of the world famous Mardi Gras in New Orleans.

**Text from album Mardi Gras in Carville: Parades and Dances, Daughters of Charity Archives.*



Laboratory Research: Genetics and Cultivation

Gene expression, regulation and pseudogenes in *M. leprae*

Investigator: Diana Williams, Ph.D .

Fundamental to understanding the pathogenicity of *M. leprae* is identifying the genes needed for survival, growth and virulence in man. The completion of the *M. leprae* genome sequence has provided information capable of supporting studies aimed at better understanding *M. leprae* and the disease it causes.

The genome appears highly degraded and possesses the largest repertoire of pseudogenes compared to other bacteria as well as a large number of deleted genes. This large-scale loss of gene function has resulted in a genome that is occupied by less than 50 percent protein-coding genes and comparative genome analysis has identified deficits in several general cellular metabolic families. The National Hansen's Disease Program has used the *M. leprae* genome sequence data, bioinformatics and surrogate genetics in several mycobacterial hosts to study specific *M. leprae* genes associated with drug resistance, gene regulation, virulence, and growth.

The Program has also used this information, in collaboration with investigators at Colorado State University, to characterize the first *M. leprae* global DNA microarray, consisting of all open reading frames and pseudogenes.

Dr. Williams' work continues to be at the forefront of understanding *M. leprae* genetics and has resulted in molecular tests useful for diagnosing Hansen's disease and determining *M. leprae* 's susceptibility to antileprosy drugs.

[Dr. Williams' research interests and publications](#)

Genotyping *M. leprae* using variable number tandem repeats

Investigators: Tom Gillis, Ph.D and Richard Truman, Ph.D.

Understanding the mode(s) of transmission of leprosy is a major goal of leprosy research. Defining this epidemiologic parameter should help clarify risk of infection and may help direct public health intervention strategies aimed at controlling leprosy.

Mycobacterium leprae is an obligate intracellular pathogen that is widely distributed around the globe. There are no recognized sub-types and the bacillus exhibits little genetic diversity as judged by common DNA sequence structures. The only documented highly variable sequences are associated with variable number tandem repeat (VNTR) sequences distributed throughout the genome.

The National Hansen's Disease Program's primary goal for the VNTR studies is to establish a panel of reliable markers to be used in the field to track *M. leprae* within endemic communities with the aim of determining transmission links within that community.

Initial studies have been focused on establishing standards for assessing VNTR polymorphisms, integrating studies in selected field sites to validate the use of the VNTR marker panel(s) and coordinating the international consortium to implement this kind of testing in sites where leprosy remains a problem. Field studies are set for sites in India, Brazil, the Philippines and Bangladesh.

- [Dr. Gillis' research interests and publications](#)

[Dr. Truman's research interests and publications](#)

***Mycobacterium leprae* cultivation**

Investigators: James Krahenbuhl, Ph.D. and Tom Gillis, Ph.D.

Well over a century after its description by Hansen, *Mycobacterium leprae* has yet to be cultivated in vitro, making it one of the most intractable microorganisms to study.

Experimentally, it can be cultivated reliably only in mouse footpads or the nine-banded armadillo, achievement of significant numbers of organisms requiring 6 months to 2 years, respectively.

The recent completion of the sequence of the *M. leprae* genome indicates the deletion or partial deletion of multiple genes, notably those involved in respiratory chains, iron acquisition, and catabolic processes. Since these deletions would not necessarily preclude culture medium supplementation with defined growth factors, along with investigators at Colorado State University, the National Hansen's Disease program is designing different media formulations (e.g., different carbon, nitrogen, sulfur and phosphorous sources) taking cues from the *M. leprae* genome and other biochemical studies and then evaluating those formulations for their growth potential using radiolabeled reporter molecule as an indicator for metabolic activity.

If culture supplements are not sufficient to produce enhanced metabolism leading to sustained cultivation, then newly developed genetic tools are being evaluated for introducing genes into *M. leprae* with the goal of enhancing metabolism with sustained cultivation potential.

- [Dr. Krahenbuhl's research interests and publications](#)
- [Dr. Gillis' research interests and publications](#)
- [Dr. Truman's research interests and publications](#)

STIGMA HURTS

By Jose' Ramirez, Jr. *

Presented on Monday, January 28, 2008 at the Royal Society of Medicine in London, England.

Good afternoon. It is a great pleasure to be addressing this group one day following World Leprosy day, and one day preceding the opening of the International Congress on Leprosy in Hyderabad, India.

The wonderful comments made by Ambassador Sasakawa and other distinguished guests reflect a recent change in the tone and acceptance towards persons affected by Hansen's disease, more commonly known as leprosy. I say "recent" because for the last 30 centuries, words and actions have been directed at my extended family which project fear, ostracism and discrimination. My extended family, persons affected by the greatly misunderstood leprosy bacillus, have lived in all seven continents and experienced the pain of stigma.

My definition of "stigma" is.....an act of labeling, rejection, or unexplained fear of a person. Stigma is an action equivalent to lowering the forehead of an individual affected by leprosy into a kettle of boiling water. This symbolic mark has resulted in the unflattering description of persons affected by leprosy in all of the 46 major languages of the world.

Communication obviously has been a means of treating me and my extended family differently. Communication is also a means to reverse this trend. Therefore, your signatures on the document, "The Global Appeal to End Stigma and Discrimination," is an important step to achieving this goal.

For me, the effort to attain this goal started 39 years, 11 months and 25 days ago when I was diagnosed with leprosy in Laredo, Texas. The memories of feeling the impact of stigma after being informed of the diagnosis is still fresh in my mind. My diagnosis was communicated to me at a hospital in Laredo after many years of declining health and efforts by my parents to find a cause for my high fevers and difficult-to-heal sores. Modern medicine, alternative medicine, home remedies, and prayer were all attempted by my loving parents.

Immediately following my diagnosis, I was placed in isolation and visitors were mandated to enter my room shrouded in a surgical cap, gown, gloves, and mask. My parents always capitulated to authority figures; however, they were uncharacteristically defiant to this order. They proceeded to enter my room in their regular clothes to offer their spiritual support as I was informed on my illness.

* *Mr. Ramirez is an international advocate for persons affected by leprosy; a licensed social worker working with persons with mental and developmental disabilities in Houston, Texas; Managing Editor of the STAR; USA Coordinator for IDEA; and Board member of the American Leprosy Mission.*

My dignity and respect was challenged in the presence of my parents and girl friend as I was referred to by a horribly pejorative word I will simply reference as the "L" word. This five letter "L" word is the most offensive way to describe those of us affected by leprosy as it is often associated with words and phrases such as a pariah, strongly disliked, shunned for moral reasons, corrupt person, outcast, untouchable, and many more.

An epidemiologist sent to my bedside by The Texas Department of Health quizzed me about my personal life related to sex and diet. The belief that leprosy was a sexually transmitted disease had been disproven many decades earlier, yet the subject was still mentioned with embarrassing effects. To this date, no one has been able to prove how the leprosy bacillus is transmitted. There would be many other times when words and actions demeaned my existence as a human being.

(continued on page 14)

Without realizing the significance of their actions, my parents refused to keep my diagnosis a secret. The common practice of keeping one's diagnosis of leprosy a secret was unknown to my parents. Years later, they explained their actions by telling me that they did not wish to deny my existence. My parents' decision to inform my friends of my hospitalization by placing a 50-word article in the local newspaper helped pave the way for my recovery and advocacy.

My parents, however, were not immune to the stigma associated with leprosy. As devout Catholics, they were aware of the writings in the Bible. The references to leprosy state that this illness is considered a punishment for sins committed. As a result, they felt a great sense of guilt. Both tearfully apologized to me for unknown sins. They were convinced that God was punishing them, through me, with this feared disease.

Many faiths besides Catholicism have in their beliefs references to leprosy and sin. This is a powerful reference in Catholicism as leprosy is the most often mentioned illness in the Bible.

Within 24 hours of my diagnosis, I was placed in a hearse for a 750-mile trip to the only leprosarium in the continental United States located in Carville, Louisiana. The short trip on a stretcher from my hospital room to the hearse was like a death march as my parents, adult siblings and girl friend followed a priest quietly praying what seemed like the last rites. Ironically, the last rites were administered during the Middle Ages to person considered to have leprosy and deemed "the living dead."

I was declared one of the "living dead" after my parents sought assistance from the local funeral home owners who also operated the ambulance service. Their response was, "Ambulances are for the living, hearses are for the dead."

Considering that I could only see the inside of my transport, I did not find out about the hearse until years later. However, my girl friend, six brothers and sisters did see me as I was placed inside the hearse. They believed that I was being taken to my grave. Regrettably, every person with leprosy has symbolically taken a ride in a hearse, resulting in labeling, rejection and fear.

My stay at the leprosarium lasted for 3,476 days. This was a short time compared to a lifetime of institutionalization by many others in leprosariums throughout the world.

Years after discharge from the leprosarium, my mother heard me repeat the words said at the Vatican by Pope John Paul II, "Persons with leprosy are my brothers and sisters." Mom responded by telling me, "I can now die with a clean soul." Mom carried a sense of guilt in her soul for 33 years. Dad went to his grave believing that God punished me with leprosy for his alleged sins. Unfortunately, stigma has survived for over 3,000 years.

As I have traveled the world visiting with my extended family and recording some oral histories, I have encountered a common theme. I consistently hear the words, "I want to live, and die, with dignity and respect," and "Stigma hurts."

My visits have been to Brazil, China, St. Giles Leprosarium in England, Greece, Hawaii, Italy, Japan, Mexico, South Africa, Spain, Sweden, Turkey, Ukraine, and United States. Many of these places have enacted laws that deny basic human rights to person affected by leprosy. However, it has been the cruelty of fear, rejection and labeling that has allowed unwritten laws to flourish. Unwritten laws are what I call the "laws of silence." These laws are practiced by anyone who does not take a stand against stigma and discrimination. Therefore, we must join hands and attack stigma as it embraces the graves of those who have lived with leprosy. We should also attack the stigma that stands beside the people we love, the people we serve and the people we have yet to meet. We must never forget that persons affected by leprosy are brothers, sisters, fathers, sons, daughters, mothers, aunts, uncles, grandparents, advocates, artists, bankers, painters, psychologists, singers, social workers, students, teachers, writers and much more. My daughter, Erika, who is here with me today, understands the importance of acceptance as she has accepted me as her father unconditionally.

In closing, I challenge each of you to educate others about the stigma confronting my brothers and sisters throughout the world.

Muchas gracias. Thank you very much

SOURCES OF HD TREATMENT IN THE UNITED STATES

THE NATIONAL HANSEN'S DISEASE PROGRAMS (NHDP) provides HD care to persons in the United States at 1770 Physicians Park Drive, Baton Rouge, LA 70816 and through the Ambulatory Care Program, which includes the following Outpatient HD Clinics

NATIONAL HANSEN'S DISEASE PROGRAM

AREA	FACILITY	ADDRESS	PHYSICIANS / NURSE	APPOINTMENTS
BOSTON	Lahey Medical Center	41 Mall Road Burlington, MA 01805	Samuel Moschella, MD Stephanie Burns, RN	781-744-5670
CALIFORNIA (Los Angeles)	LAC.USC Medical Ctr Attn: Section of Dermatology Room 8440	1200 North State St Los Angeles, CA 90033	Thomas Rea, MD Helen Mora, RN	323-226-5240
(Martinez)	Contra Costa Regional Medical Center Outpatient Clinic	2500 Alhambra Dr Martinez, CA. 94553	Sutherland/Saffier, MD's Eliso Judy, RN	925-370-5270 1-800-495-8885 (In State only)
(San Diego)	North San Diego Health Center	2400 Grand Ave San Diego, CA 92109	D A Lopez, MD Carmen Rodriquez, RN	358-490-4400
CHICAGO	University of Illinois College of Medicine Dept. of Dermatology	803 South Wood St Room 376 CME Chicago, IL 60612	Carlotta Hill, MD Ann Przepiora, RN	312-996-0734
MIAMI	Jackson Memorial Hospital	Ambulatory Care Ctr 1611 N. W. 12th Ave. Miami, FL 33136	Anne Burdick, MD Gloria Ingle, RN	305-585-2600
NEW YORK	Bellevue Hospital Ctr Dept of Dermatology Room 17-7	462 First Ave New York, NY 10016	William Levis, MD Aloys Cabrera, RN Louis Iannuzzi, PT, C.Ped	212-562-6096
PHOENIX	Maricopa County Health Dept	1825 E. Roosevelt St Phoenix, AZ 85006	Ronald Pusi, MD Bill Cooper, RN	602-372-6661
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FACTS ABOUT HANSEN’S DISEASE

What is HD?

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

HD is essentially a disease of the peripheral nerves, but it also affects the skin and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, muscles, bones and 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 1994 the World Health Organization estimated that there were 2.4 million cases of HD worldwide with 1.7 million cases registered on treatment. The estimates for 1985 were 10 - 12 million and 5.4 million respectively. According to these estimates, in 1994, 70% of those who should be on treatment are now being treated. In 1992 there were 690,000 new cases reported and in 1993, 591,000 cases. There are also an estimated 2 - 3 million cases who have completed treatment but who still have residual disabilities who are not included in the above 1994 totals. 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 and still living. The number of cases with active disease and requiring drug treatment is approximately 600. There are 200 - 250 new cases reported to the registry annually with about 175 of these being new cases diagnosed for the first time. The largest number of cases in the US are in California, Texas, Hawaii, Louisiana, Florida New York, and Puerto Rico. There are still approximately 23 cases at the Gillis W Long Center at Carville, LA. Most patients in the US are treated under US Public Health Service grants at clinics in major cities or by private physicians.

(See listing of clinics.)

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 90% 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 the rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Usually rifampin and sometimes clofazimine or ethionamide are given in addition to dapsone. Treatment rapidly renders the disease noncommunicable by killing nearly all the bacilli and these dead bacilli are then cleared from the body within a variable number of years.

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RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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GET TO KNOW THE FORTY & EIGHT

The **Forty & Eight**, an honor society of legionnaires 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.

