

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

JAN - JUNE
2012
VOLUME 64 - 13



Dr. Tom Rea Retiring from Los Angeles Hansen's Disease Clinic -Story on page 3
photo by Richard Dominguez

CONTENTS

January-June 2012 Vol. 64-13

Dr. Tom Rea Retiring from Los Angeles Hansen's Disease Clinic <i>Helen Mora, Robert Jerskey, and Robert Modlin</i>	3
A Gesture of Respect to the Unconvinced <i>Elizabeth Schexnyder</i>	4
Father Germaine Lafontaine <i>Ann Clay and Betty Landreneau</i>	5
The Elwood Era <i>Ray and Julia Elwood</i>	6
Journey of Discovery <i>Nicole H. Holmes</i>	7
The Los Angeles Hansen's Disease Clinic <i>Helen Mora and Robert Jerskey</i>	8
Mr. Pete: I Remember When <i>Simeon Peterson</i>	9
Social Experiment on Stigma <i>Jory Nagel</i>	10
IDEA Presented Historic Preservation Media Award <i>Mary O'Friel</i>	10
KIZUNA – The Strongest of Bonds <i>Kay Yamaguchi</i>	11
Maude's Laugh <i>Ymelda Beauchamp</i>	12
Forty & Eight Activities <i>Joseph Steil</i>	13
Leprosy and Advocacy <i>José Ramirez, Jr.</i>	14
Hansen's Disease Clinics.....	15

All correspondence concerning The STAR should be addressed to:

Voiture Nationale
777 North Meridian St Suite 300
Indianapolis, IN 46204-1421

EDITORIAL BOARD

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

CONTRIBUTORS:

Joseph Steil
Irma Guerra
Ymelda Beauchamp
James Krahenbuhl, Ph.D.
Elizabeth Schexnyder, NHDP Museum Curator

Stanley Stein

Founder - Editor, 1941 - 1967

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

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

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

Editorial Policy On Terminology

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

MOVING SOON?

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

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

National Hansen's Disease Program
1770 Physician Park Dr.
Baton Rouge, LA 70816
Phone: (800) 642-2477
Fax (225) 756-3806
Website: www.hrsa.gov/hansens

Dr. Tom Rea Retiring from Los Angeles Hansen's Disease Clinic

by Helen Mora¹, R.N., Robert Jerskey¹, LOTR and Robert Modlin², M.D.

World renowned leprologist and researcher Dr. Thomas H. Rea, Jr. is retiring after 31 years as the Project Director for the Hansen's Disease (HD) Program at the Los Angeles County-University of Southern California (LAC+USC) Medical Center in Los Angeles. Previously, (1973-1981) he served as Chief of the HD service at the LAC+USC Medical Center after beginning his career caring for patients with HD in 1963 at Bellevue Hospital in New York. In these 49 years in the field Dr. Tom Rea has earned the respect and admiration of scientists and healthcare providers as an outstanding leprologist, teacher and researcher.

In his early days in the field at Bellevue he developed and has sustained an interest in HD type 1 and type 2 reactions especially the latter a.k.a. *erythema nodosum leprosum* or ENL. With only corticosteroids and the anti-HD drug clofazimine to combat ENL he recognized the dramatic efficacy of the controversial drug thalidomide in managing ENL and lobbied the FDA for approval of its use.

Dr. Rea completed his undergraduate studies at Oberlin College and his M.D. at the University of Michigan where he also did his internship and dermatology residency at the University Hospital in Ann Arbor. He went on to his fellowship training in the Department of Dermatology at the New York University, School of Medicine. His interests in research stem from the surrounding vibrant immunology research community at NYU, including scientists like Dr. Rudolph Baer, studying mechanisms of contact dermatitis and Dr. H. Sherwood Lawrence doing early work on immunologic memory.

In Los Angeles Dr. Rea began studying the immunology of HD, investigating the role of antibodies and cell-mediated immune (CMI) responses. He sought additional training (1980-1981) in CMI with Dr. John Turk at the Royal College of Surgeons in London and, while there, took advantage of the presence of Dr. Dennis Ridley to learn the complex Ridley-Jopling histopathological classification scheme for HD. Posing with his microscope on the front cover of *The Star* is highly appropriate for Dr. Tom Rea. His interests in research have resulted in >140 published, peer reviewed articles.

The HD Clinic at LAC+USC serves more patients than any of the other 12 NHDP Ambulatory Care Clinics. Dr. Rea is very active in direct patient care and his style of medical practice might be called old fashioned. His soft quiet demeanor, mellifluous voice and the sincerity of his hands on approach to each and every patient generates a feeling of trust and confidence that is so essential to ensure patient compliance in the partnership required for management of a chronic disease like HD. Dr. Rea's day at the clinic starts early with a cup of coffee and a pastry, enjoyed with his staff. He doesn't leave until the last patient has been seen. He engenders a broad level of enthusiasm and commitment from his multidisciplinary staff, which includes a podiatrist, dermatology residents, nurse, occupational therapist and an orthotist.

As a mentor Dr. Rea has always enjoyed teaching moments with a multi-generational field of clinicians, doctors, medical students, laboratory scientists and guests. His expertise is shared across a geographical area far larger than the LA clinic. From his early days in New York he has promoted the need for HD awareness in the U.S., believing that you can't diagnose the disease if you do not consider it. To this end he has assisted and consulted with numerous physicians in the private sector who are willing to manage a case of HD themselves. We have been very fortunate to have the privilege of working alongside Dr. Rea, a knowledgeable, compassionate physician, a gentleman.

Dr. Rea's "retirement years" should, nevertheless, be fulfilling. His leisure activities include more than a casual interest in Japanese and European art, botanical gardens, fine cinema and reading the history of many eras. He, and his wife of 47 years, Mary, both enjoy world travel. But nobody at the clinic is the least bit surprised when he drops in for an early cup of coffee. Dr. Rea remains an Emeritus Professor and is still very active in the HD clinic. Dermatologist Dr. Maria T. Ochoa, who has 14 years experience working with Dr. Rea is now the project Director of the LAC+USC HD Clinic.

¹ Hansen's Disease Clinic, LAC+USC Medical Center, Los Angeles, CA

² Chief, Division of Dermatology, Department of Medicine at the David Geffen School of Medicine at the University of California Los Angeles, CA.

A Gesture of Respect to the Unconvinced: A Brief History of Postal Sterilization at Carville's Hospital

Elizabeth Schexnyder, National Hansen's Disease Museum Curator

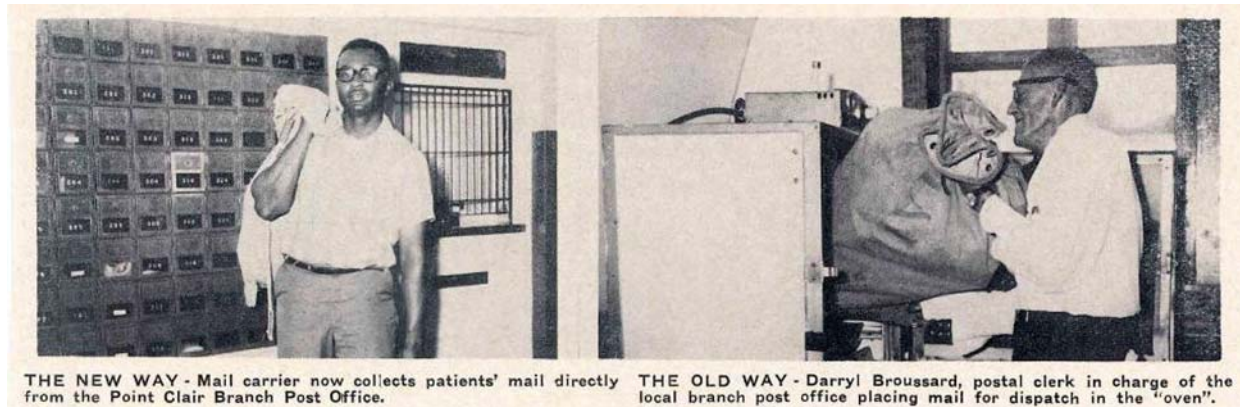


Figure 1 *The Star* September-October 1968 v28 n1

The U.S. mail was a lifeline to the outside world for a Hansen's disease patient quarantined to the federal leprosarium in Carville, LA. But patients' correspondence through the U.S. Post was allowed only if the public was satisfied of their safety.

The origins of sterilizing patients' outgoing mail is uncertain, but there are indications that it was begun at the turn of the century when Indian Camp Plantation grew into the Louisiana State "Leper Home." It was probably inherited by Dr. O.E. Denney, the first medical officer in charge, after the U.S. Public Health Service took over in 1921. When a Post Office was eventually established on-site, the patient-postmaster was in charge of sterilizing the outgoing mail in the laboratory oven. The staff sometimes forgot to turn off the heat until warned by the smell of scorched paper. One issue of *The STAR* was so charred that some copies crumbled before they got to subscribers. The *STAR* posted a footnote in all issues alerting subscribers to the "sterilization" process. In the July-August, 1950 issue the editor printed an illuminating letter from a disgruntled reader regarding the practice. (See Figure 2)

Efforts to abolish mail sterilization by hospital Director Dr. Edgar Johnwick and Stanley Stein, *The STAR* editor, stalled when both men died in 1967. Dr. John Trautman took over as Director of the hospital in 1968. *The STAR* asked him what his policy was in regard to patients' outgoing mail. The new Director was surprised to learn that letters and *The STAR* were still being baked. He immediately started the creaking wheels of bureaucracy turning, with the result that the archaic practice was reported over at last in the September-October, 1968 issue. Another milestone in Carville history.

From the start of the "Louisiana Leper Home" (1894-1921), the U.S. mail was distributed through an outside Post Office. In the early 1900's Chester J. Carville, the owner of the Carville General Store was awarded the contract to distribute mail for the community of what was then called *Island*, Louisiana. Because the mail was jumbled with regularity (Louisiana has many towns with identifiers of "Island"--Head of Island, Cat Island, Pecan Island, Cow Island, etc.) the Post Master General in Washington, D.C. officially gave the area the designation of Carville to untangle the mess in 1908.

I like your publication, "THE STAR", but frankly, there is one part of it which I do not like. That is the paragraph, in every issue, which reads:

"This paper, and all outgoing mail, is sterilized before leaving the hospital. This is done only as a gesture of respect to the unconvinced and not because there is any scientific necessity for it."

When you include that paragraph in any issue you send me, you don't respect me; you disrespect me. For this reason, as a special favor, will you please by-pass my copy from the "sterilization" process and send it to me just "as is," like any other publication?

Also, will you please cross out those lines, and write in underneath, "By special request of the subscriber, this particular copy of *THE STAR* has not been sterilized," over your signature as editor.

There are some things which human dignity forbids.

Robert H. Clary

Freeport, N. Y.

The patients' outgoing mail is baked for one half hour in a dry heat, 120 to 140 degrees Centigrade. On occasion mail, including batches of THE STAR, has been burned almost to a crisp, because of carelessness. This sterilization business is not our idea. It is "official" although once a high ranking U. S. Public Health Service doctor dubbed it "damned foolishness." The question is, should we or should we not tell the world about it. We could keep mum but the mail will continue to be sterilized until officialdom makes up its stubborn mind to quit paying homage to ignorance. A lot of local customs such as "sterilizing the mail" are hang-overs. It was done in 1894 when the place was opened and it is still going on in 1950. Through the years everything but the kitchen stove, and even that, has left this hospital without being sterilized, unofficially of course. If one could "catch" H.D. in that way more than half of this neighborhood would be inside the fence. ED.

Figure 2 *The Star*: Mailbag, July-August 1950 v9 n11

In January 1948, The STAR reported that the Post Office Department in Washington, D.C. authorized a Branch Post Office at the hospital. The new branch post office was established in the patients' recreation building after years of effort on the part of patients and their supporters. The hospital P.O. began its service on May 1st and was known as the Point Clair Substation. Darrell Broussard, a patient who had handled the hospital mail efficiently for many years, was appointed postmaster. The convenience of purchasing money orders or registered letters on the grounds rather than enlisting a 3rd party who *could* travel the 2 miles to the Carville P.O. was a great improvement for the hospital community where mail was so significant.

The Point Clair Substation is still in operation. The antique postal boxes have been stuffed full of mail daily by TK, postmistress for over 10 years. Residents can still stop in for a book of stamps and a friendly neighborly chat.

Father Germaine Lafontaine: *The Impact of One Unique Patient on Carville and the Community* By Ann Clay and Betty Landreneau

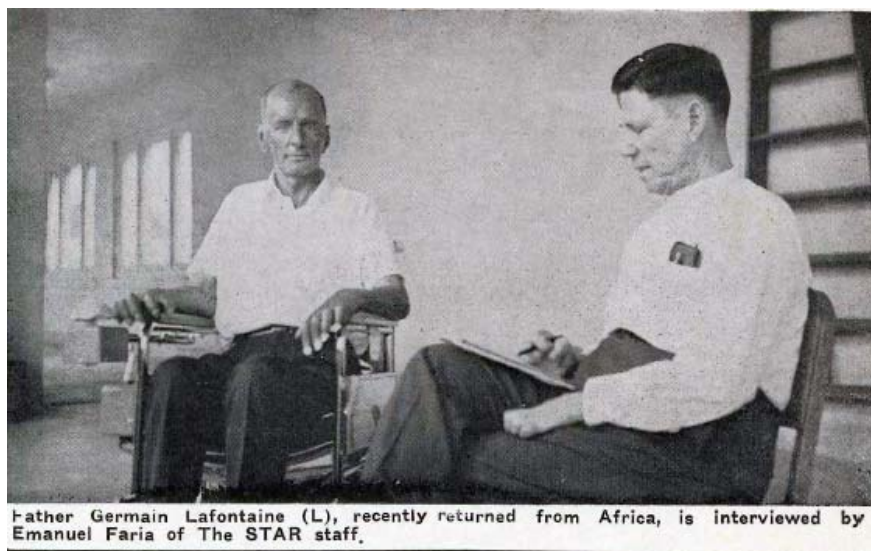
An article in the July 1969 Star entitled "Missionary Priest Becomes Carville Patient" could now be entitled "Carville Patient Becomes Missionary for Acceptance of Patients with Hansen's Disease (HD)". In 1969 when Father Germaine Lafontaine arrived at Carville, he was in need of assistance with activities of daily living, and was able to let orderlies and nurses provide this help with graciousness. He worked to be independent and as he got better many of the people received gifts of pieces of tapestry that he wove in therapy. The PT and OT allowed Father to learn to reuse his hands after surgery. He was an example to many other patients; taking the medication B663 that turned his skin a dark color. His example enabled others to accept the medication that was such an effective treatment for HD.

Father LaFontaine accepted his illness and did not hesitate to expand his interaction outside of the Carville Hospital. His confrere Father Luc Piette W.F., who accompanied Father LaFontaine to Carville, initially returned for a visit and was happy to see the friends and the influence Father Lafontaine had both in and outside the hospital. These ventures helped break the stereotypes people had of persons with HD.

Father Lafontaine traveled to the community of Pine Prairie in Evangeline Parish and became good friends with the local priest, Father Leslie Prescott. He visited so often that Father Prescott would say to the congregation "The cat is back" referring to Father Lafontaine.

When he visited in Lafayette and New Iberia, Father LaFontaine celebrated Mass in friends' homes. On one occasion in 1974 at the home of Sgt. Maj. Charles Clay he celebrated Mass and baptized Charles' younger sister, Agnes.

Father Lafontaine opened avenues for acceptance of persons with HD and for all persons he gave an example of how to be joyful in the midst of suffering. He loved to tell jokes often making a joke about him to make others laugh. He had the ability to make you feel like you were the most important person.



Father Germain Lafontaine (L), recently returned from Africa, is interviewed by Emanuel Faria of The STAR staff.

Editor's and Museum Curator's Notes.

Father LaFontaine blended into the community of the Carville in many ways besides the fact that he was experiencing challenges with experimental medication such as B663. This medication turned the color of one's skin to purple or black, with different levels of intensity depending on the amount of bacilli in the system. He liked to joke that he looked like a Black person, lived like a Cajun because of his fluency in French, and had the passion of a Mexican because of his love for the Catholic Church. To the 400 + residents in 1970, he was simply a gentle, loving and compassionate man who saw everyone as his friend.

He was discharged from Carville in 1973 and returned to Quebec, Canada. With his health restored he stayed busy preaching ministry in rotation in Lennoxville and Sherbrooke, beloved by parishioners and confreres alike. He died on January 24, 2004 in l'Hotel-dieu, Sherbrooke, Quebec and is buried in the family plot in St Michel cemetery.

Note from NHDP Museum Curator: Betty Landreneau served at Carville as Sister Helene Cole, Daughter of Charity, from 1969-1974. She is the sister of Ann Clay and aunt to Sgt. Maj. Charles Clay who currently works with the Louisiana National Guard at the site of the National Leprosarium, now known as the Gillis W. Long Center.

THE ELWOOD ERA

This is an on-going series of articles on editors of The Star written by Ray and Julia Elwood

Ray Elwood

My introduction to The Star came about 1948. As a Boy Scout at the Carville Hospital, our troop volunteered to help assemble the magazine. In the summer, I helped type the articles on printing forms that were prepared for the press room. This was rewarding because I discovered that I liked newspaper work.

After graduating from high school, I got a job at The Star working in the front office. At this time I had the privilege of working with the editor, Stanley Stein. I remember the first time that Ann Page, managing editor, told me to report to Stanley for dictation. I knew how to type but I had never taken dictation before. It was an experience that I have never forgotten. The man was using words that I had never heard before. After leaving his office I spent half of the day looking up the words in the dictionary.

I had an opportunity to move to the circulation room and later became manager of that department. From this point I was moved to the press room where I learned linotype and to handle the press. When the press room supervisor left, I was promoted to that position. I left the hospital in 1953.

In 1969, I had some complications that showed up and returned to the hospital. By then Stanley Stein had died and Louis Boudreaux was the editor of The Star. Louis asked me to stop by The Star to chat and he convinced me to return to work there. Louie knew I had experience with the process there so he asked me to help in the circulation department. Six months later, I found myself working as the managing editor. Louie and I worked well together and collaborated to enhance The Star's reputation as a world-wide magazine.

The Star had a circulation of 92,000 and printing of 94,000 issues. The magazine was mailed to 132 foreign countries. We even had copies going to doctors in Russia and China.

In the latter part of 1985, the Editorial Board named me the Executive Editor. This came about because Louis was in failing health. In early summer of 1986, Louie passed away and I became editor. The Star continued to grow with the help of the Forty and Eight organization, which continued to support The Star with subscriptions and donations to hospitals and doctors' offices in addition to public libraries.

It was difficult to maintain the subscription rate at \$1.00 per year. With the cost of paper, ink, photographic supplies and postage on the rise, we knew we would have to increase it to \$2.00 a year. This was one of the most difficult decisions the Editorial Board and I had to make, but with the support of the 40&8, it was put into effect.

As the years rolled by, I encountered a challenge with insufficient staff experience required in order to write stories and print The Star. Admissions to the hospital (started to dwindle and rumors circulated that the facility might close. We knew that someday the hospital might close. I recall reading about a representative in Congress back in the 1950's who tried to pass a bill to give the patients a stipend to leave the hospital and be able to care for themselves.

I started working with the Patients' Federation to prepare for the possible closing of the facility and decided to retire from The Star in 1997. I knew then that I was leaving The Star in very capable hands with Emmanuel Faria as the editor. After my retirement, I continued to work with the Federation in collaborations with the PHS Headquarters and U.S. Congressmen Richard Baker of Louisiana to introduce legislation in the U.S. Congress. We were successful in accomplishing this. Legislation was passed by Congress in 1997 for an annual stipend paid to patients who agreed to a voluntary discharge. Congress passed the legislation and the facility downsized, continuing to provide care to those who chose not to accept the stipend.

I enjoyed my years at The Star working with Stanley Stein and Louis Boudreaux, who were the real pioneers of The Star. I did what I could to continue their work and tried my best to educate the public about Hansen's disease.

Julia Elwood

Ray Owen Elwood Jr. was born in Key West, Florida, in 1932. He grew up a happy child who walked the sands of the lovely beaches there and rode his bicycle from one end of the island to the other. His ancestors had settled there from the Bahamas.

At 15 years of age, Ray was diagnosed with Hansen's disease and arrived at Carville as a patient in 1948. Even though society was cruel to him by burning his school books and desk, his early diagnosis prevented any signs of disfigurement when he started treatment.

Considering his young age when admitted to Carville, he was able to join other youngsters in games such as pool, badminton, baseball, miniature golf, tennis, and joined the Boy Scout group. He worked hard until he received his Eagle Scout, a feat he is proud of to this day. At Lake Johansen, which was located in the back of the compound, he would fish, ride the paddle boats, and go on picnics. He also swam there, even though this was forbidden.

He met his wife, Rose there and married her in 1953. They lived in San Antonio, TX, with their four children. After some years of being a successful business man and very active in his children's lives, he had a relapse of the disease and returned to Carville for treatment in 1969. He took several experimental drugs including Rifampin, Clofazimine and others until he was cured.

He met his second wife, Julia, a former patient, who had been hired as a teacher at the hospital school. After they married, they lived in a neighboring town with Julia's five children for 26 years.

Today, they make their home in a suburb of San Antonio, Texas. Both are enjoying their retirement.

JOURNEY OF DISCOVERY

by Nicole H. Holmes, MA, LAPC, NCC

It has been about fifteen years when I was first diagnosed with Hansen's disease (HD). Since that first day I have been through many transitions. I was a newlywed struggling with a chronic illness, wife, mother, and student. Now I am single with two sons. In the beginning, my experience living with HD and not knowing when the next painful reaction would occur caused me to doubt myself as a person. For a while I stopped believing I would ever be healthy and pain free. I went through a period of declining self-doubts due to rapid weight gain from taking high doses of prednisone and depression from the side effects of the medications. This was compounded by work, of being diagnosed with a stigmatizing illness, and unable to appreciate that things would get better.

I eventually found the best outlet for these doubts was to share my thoughts and struggles with others. This is when I started a website as a way to vent my frustration. Through my relationship with IDEA (<http://www.idealeprosodydignity.org>) and their assistance, I was able to help others across the country. I did this through my website, e-mail and by telephone, presenting my story to medical professionals and linking individuals to medical resources. In addition, I assisted individuals and families with understanding HD, providing them with a listening ear from someone who could validate their concerns and fears due to experiencing it firsthand.

Through all my experiences, I remain dedicated to educating others about HD, continuing to operate my website, and interact with individuals challenged by their diagnosis. I receive e-mails or phone calls every few weeks, some from individuals who found me through searching the Internet and others from referrals from the National HD Program (NHDP), IDEA or HD clinics. In one particular incident a nurse called and asked for my assistance in helping her reassure an individual recently diagnosed who was having reservations about going to NHDP for an evaluation. I was able to persuade the gentleman to go the NHDP and he is now doing well.

I saw the benefits of my support network and decided to complete my Masters degree in Community Counseling in order to become a stronger advocate. I graduated in December 2011, and am now a Licensed Associate Professional Counselor in Georgia. I also work at a crisis line and with a community organization assisting women in transition. I am currently working on updating brochures for Support for People with Hansen's Disease/Leprosy (<http://www.hansensdisease.org>), as well as the website.

The Los Angeles Hansen's Disease Clinic

Helen Mora, RN, and Robert Jerskey, LOTR

Hansen's Disease (HD) services at the Los Angeles County + University of Southern California (LAC+USC) Medical Center in Los Angeles, CA, have been provided since 1973 by Dr. Thomas Rea, Chief of Hansen's Services. When the HD Clinic at the U.S.P.H.S. Hospital in San Pedro, CA, closed in 1981, 225 patients in their HD service were transferred to the LAC+USC Medical Center in Los Angeles. At this time, the HD Clinic became part of the Ambulatory Care Program (ACP) through a contract with the National Hansen's Disease Program (NHDP) in Carville, LA. This clinic currently serves approximately 635 outpatients, and their service area extends to eight surrounding counties. It is the largest outpatient HD clinic in the country.

The clinic serves persons with HD, primarily from endemic countries in Latin America, Southeast Asia, the Pacific Islands, India, Africa, , and other parts of the world.

A primary objective of the clinics in the NHDP ACP is to prevent the deformity and disability that can be caused by HD. This is a challenge in a country of low endemicity like the United States, so professional and public education about HD is an important function of the HD Clinic. Since the LAC+USC Medical Center is a teaching hospital, resident MDs, medical students, and occupational therapy students rotate through the HD Clinic. Most are amazed to learn that leprosy can still be found in the U.S. as the disease was dropped from medical school and other *curricula* years ago. The clinic team serves as a resource of teaching and expertise for the medical and public health community in the area.

This clinic is a multi-disciplinary team of healthcare professionals dedicating their professional services to people affected by the disease, which though not highly communicable, has an entrenched history of severe stigma still associated with it. The goal of these dedicated providers is to educate patients and their families about HD. Full cooperation of the patient and his/her family is essential for the management of HD, which is a chronic illness. By countering the misinformation about leprosy that is widespread and by instilling a sense of optimism in the patient, their compliance and feeling of partnership with the clinic staff is greatly increased. The overall goal of the program is promotion of early diagnosis and treatment, thereby preventing the deformity and disability that leads to the stigma.

Services provided at the HD clinic include diagnosis of the disease, treatment, education, follow-up, and provision of ancillary services such as occupational and physical therapy, ophthalmology, and social services, as needed. Services and HD medications are provided at no cost to the patient, through a contract with the NHDP.

Contact information for the LA HD Clinic is :

LAC+USC Medical Center

1200 N. State. St.

Clinic Tower, Rm. A5B123

Los Angeles, CA 90033

Ph: 323-409-5240



Photo caption. Left to right: Helen Mora, RN, HD Program Nurse, Dr. Seth Vaccaro, Attending Physician, Robert Jerskey, LOTR, Dr. Maria Teresa Ochoa, Incoming Chief of Hansen's Disease Clinic, Dr. Thomas Rea, Outgoing Chief of Hansen's Services, and Greg Azatyan, Orthotist. Not pictured is Dr. David Bae, podiatrist. Photo credit: Richard Dominguez

Mr. Pete: I Remember When... My Career in Hospital Transportation

March 2012, by Simeon Peterson, as told to Elizabeth Schexnyder



Simeon Peterson and curator Elizabeth Schexnyder, National Hansen's Disease Museum, Carville, LA. Photo Laureen Lentz, 2012.

I began my career in hospital transportation when my job as the elevator man in the old Carville hospital Infirmary was eliminated around 1970. I had run the elevator for 5 or 6 years for 60 cents an hour before it was automated.

I moved into a transportation job right away. Now the trips I took were a little further than 2nd or 3rd floor in the Infirmary. My new job was to bring patients in wheelchairs to OT, PT, dressing clinics or anywhere the patients wanted to go on the Carville hospital campus. Dormitory buildings #17 and #18 were reserved for patients who could not walk well—because of amputations or blindness. Upstairs floors were for men and downstairs for women. All of the wheelchairs used at that time were of the hand-cranked kind. I don't remember the electric chairs coming in until the late 1970s.

I even worked on Sundays, a very busy day. I took trips to both the Protestant and the Catholic chapels—the two church services would start and end at different times so I juggled trips to get people to and from both chapels on time. I walked a lot but I think that is one of the main things that kept me going.

Patients regularly wanted me to take them to the *Reading Room for the Blind* where there was a whole library of Books for the Blind on phonograph records; patients would sit and listen. It was in the Recreation Center in the room where everyone plays dominoes and bingo today.

Betty and Harry Martin went to *Mass* every Sunday; I pushed Betty's chair while her husband Harry walked along with us. Harry wanted to do the wheelchair pushing but I told him, "Don't worry I get paid to do this!" Everyone loved Harry. He was a good man. If you came up short, he'd lend you money. He even did income taxes for free. Later on, when Harry died, we (the patients of Carville) wanted to go to his funeral but respected Betty's wishes to protect her family, so none of the patients attended the outside services.

Another patient I remember well was "Angel". He was from Louisiana; the disease made him blind. Every Thursday I took him upstairs to Bldg 15 to see Dr. Zaunbrecker. Dr. Z had converted to Catholicism and Angel stood as her sponsor during her Confirmation. But oh Lord, that Angel had "Big Words" for anyone who got in his way—he cussed at the hospital orderlies, the ladies who did his laundry—but never at me. I think he was angry because he was blind and couldn't take care of himself.

When the National Hansen's Disease Programs hospital moved to Baton Rouge in 1999, my job moved, too. I would catch the hospital shuttle at 8 AM from Carville and go to work at the Baton Rouge hospital where many of the HD patients were now living. I still took folks to OT/ PT appointments or to see the Social Workers.

When most of the patients moved to St. Clair Nursing Home in September of 2009 and my transportation job was done, Dr. Krahenbuhl, the NHDP Director, asked me if I would like to give tours at the Carville museum. I started that October and I'm still at the museum every day. I love it. I meet people from all over the country, all over the world. Australia, Denmark, Brazil, Japan. Ooo-wee! We never know who's coming through the door next.



Pete and Betty Martin. Photo Pam Parlapiano, c. 1994.

Social Experiment on Stigma

By: Jory Nagel

In your average classroom of high school students, teaching history of a disease might be packaged as a fairly standard lesson. Causes, symptoms, treatment, and epidemics can be conveyed in words, pictures, videos. When teaching on Hansen's disease (HD), however, there is an additional piece of the story that does not translate through these basic methods--stigma. That is why, when teaching History of Disease at a summer academic program through Johns Hopkins University's Center for Talented Youth, one class did not just address stigma's influence on disease by discussing it in the four walls of a classroom. They carried out a social experiment that asked them to engage their minds in some of the deeper questions underlying the force of stigma.

The social experiment was simple. After studying the etiology, pathology and clinical presentation of HD, students were presented with the task of testing the social response to HD in their camp environment. Students picked the cafeteria for their experiment site. Using sophisticated stage make-up, medical supplies, and real-life pictures of symptoms that have caused stigmatization for HD patients throughout history, each group selected a member to stand in as an HD patient for a day in the cafeteria. The groups then made a hypothesis on what reactions the HD patient might receive and developed a strategic plan for observing social reactions in the cafeteria. In some cases, groups may have elected more than one person to stand in as an HD patient so as to gain more data.

The results collected showed that students observed a range of reactions. Students documented stares, inquiries of what had happened to them, and even some peers asking them to go to the health office and/or offering to escort them there. One student group observed that staff in the cafeteria seemed agitated when students approached the food areas and one student even received a profane response from the cafeteria staff.

In the discussion that ensued, students who had offered to stand in as an HD patient expressed that, although they were conducting an experiment, they became ultra-conscious of reactions to persons around them, particularly when reactions demonstrated a sense of judgment or reluctance to associate with them. Some students remarked that they felt good when peers offered to take them to get health assistance, but then later realized that they would be frustrated with that as a longstanding response.

Editor's Note: Experiments like this will have a lifelong impact on the students as they begin to see persons with disabilities, and others stigmatized, as human beings deserving of dignity and respect.

IDEA Presented Historic Preservation Media Award

By: Mary O'Friel

The International Association for Integration, Dignity, and Economic Advancement, IDEA, has been awarded a 2012 Historic Preservation Media Award for their work on the exhibit "Absolute Faith: Saint Damien, Blessed Marianne and the People of Kalaupapa." Presented annually by Historic Hawai'i Foundation, this is Hawaii's "highest recognition of projects that perpetuate, rehabilitate, restore or interpret the state's architectural, archaeological, and cultural heritage." This exhibit forms the foundation for the new Damien-Marianne Heritage Center, established in Honolulu by St. Augustine by-the-Sea Catholic Church.

"Absolute Faith" focuses on the relationship between St. Damien of Molokai, Blessed Marianne Cope and the people of Kalaupapa. The exhibit includes historic photos and quotes by St. Damien, Blessed Marianne and Kalaupapa residents who knew them, as well as photographs from the canonization of St. Damien and the beatification of Mother Marianne, who will be canonized this October. It also features a portrait gallery of photos printed from rare glass negatives, of men, women and children dressed in their finest clothes, who lived at Kalaupapa in the early 1900s. Contemporary photographs of Kalaupapa residents in the late 20th century, as well as family members who are now carrying on their legacy, present a continuous history.

IDEA was responsible for developing the title, theme and flow of the exhibit; writing the narrative which includes many historical and contemporary quotations; selecting archival and modern photographs and identifying individuals in these photographs where possible; and conducting docent training.

Other organizations who received an award for their work on the exhibit include St. Augustine by-the-Sea; Mason Architects, Inc.; Barbara Pope Book Design; Heritage Resources, Inc.; Artifact Management LLC; James Erikson Studios; and Robert M. Kaya Builders Inc.

The exhibit opened March 2012 in Honolulu, Hawaii and is scheduled to remain on display until a permanent museum is built.

KIZUNA – The Strongest of Bonds

By Kay Yamaguchi

Over the past year, reports on the disaster and aftermath of one of the world's largest earthquakes never faded out of our sight. The scenes of the tsunami swallowing up everything were repeatedly broadcast on TV. The Fukushima nuclear power plant failure and accompanying damage posed a threat to our lives and Japanese society at large. These disasters have challenged all of us to realign our values and redefine the meaning of "progress and advancement."

One word that has been most ubiquitously heard since March 11, 2011 is "***Kizuna***", a bond or tie. This is an emotional word that touches everyone's heart in Japan and makes us realize the value of unity, and of bonding with the people living in the disaster stricken area.

Immediately after the disaster, many of us were very concerned about the residents at the sanatorium located near the disaster area, the National Hansen's disease (HD) Sanatorium Tohoku Shinsei en. Fortunately the distance from where the tsunami hit the coast line prevented any serious damage to the sanatorium but they had a five-day power loss and delays in supply deliveries.

There was an overwhelming amount of sympathy and goodwill extended to Japan from our friends overseas, including donations from individuals/families and communities with Hansen's disease. Jose' Ramirez, Jr. was one of the first persons who sent us messages and contributions.

The "***Kizuna***" unfolded one extraordinary chain of events in the tsunami hit town of **Karakuwa**, near the port of Kesen-numa in north-eastern Japan. Karakuwa was the hometown of **Shigeo Suzuki**, alias Fumio Tanaka (1912-1979), who spent 30+ years during the prime of his life at the Nagashima Aisei-en HD Sanatorium built on an island in the Japan inland-sea. More than 20 years after his death, a hand written autobiography of 2000 pages was found and later published.

Suzuki's life was extraordinary in many ways. His accomplishments were so many that this article is insufficient to describe the ways he touched the lives of others. We rejoice in knowing that he was able to inspire two very different generations.

Mr. Suzuki was diagnosed with HD when he was studying at one of the most prestigious universities in Tokyo. The diagnosis totally changed the path of his life as he left home and spent the next two years thinking of how to end his life. Fortunately he did not succeed with this plan – one of the few failures in his life and a great success for us.

He eventually was admitted to Nagashima Sanatorium. Mr. Suzuki quickly found his place as a leader of the Residents' Association in spite of facing confrontations with other leaders over their visions. He invited Yo Yuasa to teach English at the only high school in Japan opened within a HD sanatoria. His dream was to prepare the younger patients to aim for a higher education and a place outside the sanatoria. He also formed a committee to explore the rehabilitation of those cured and actively worked with authorities and other influential persons outside the sanatoria to make this happen. He was involved in many positive changes.

In the course of Suzuki's active involvement with outside supporters, which included high level government officials, intellectuals, media and influential leaders of his home town, he was asked to run for town mayor. The participation of a former resident from a HD Sanatorium in an election was simply something that was not expected, but the local community respected him so much that they decided to stake their future on this man. Suzuki would read The Star delivered to the Nagashima Sanatorium and remembered a story of a man affected by HD who had run for and was elected mayor of a small town in Mexico. He dreamed that something similar could be a reality in Japan.

He lost the election by a narrow margin as he had only a few months to campaign. However, he made it his life's mission to work for his home town of Karakuwa, a small fishing town in northern Japan. He helped to improve infrastructures, explored tourism potentials, and established a non-profit organization dedicated to assisting persons with mental disabilities. This organization was named the Senshin-kai Association and established in 1976. Today the Senshin-kai Association has a well established network of 9 welfare related institutions, all aiming for the enhancement of the quality of lives of the people who would otherwise face various social challenges.

One of the organizations Suzuki was involved while he was in Nagashima Sanatorium was the Friends International Work Camp (FIWC). FIWC was established in Japan in early 1950s with the mission to serve the people and community in need through volunteer work of college students. The highlight of FIWC's history was the construction of a 'Friendship House' in 1965 near Nara City. In light of stigma and the strong rejection of persons with HD those days, FIWC student volunteers took up the challenge to create a place

where people who wanted to visit the famous Nara City could stay safely. Mr. Suzuki strongly supported this idea and as a leader at the Nagashima sanatorium he persuaded some of the residents to join the FIWC students and worked together to build the Friendship House. Mr. Suzuki continued his relationship with FIWC after his return to his hometown of Karakuwa. Many FIWC members helped his election campaign when he ran for the town mayor and maintained a high level of respect for Mr. Suzuki, his courage, and determination.

On March 11, 2011, the strong earthquake and tsunami hit Japan. The port city of Kesen-numa was badly damaged and so was the neighboring town of Karakuwa. From all over Japan relief volunteers rushed to help the people and clear the huge volumes of debris. Among them were the student volunteers of FIWC. Knowing the town of Karakuwa was badly hit by the tsunami it was natural for FIWC student volunteers to choose Karakuwa for their work. They created a semi-permanent coordination station and came into contact with the Senshin-kai Association and its welfare facility network which was also badly damaged. There the young volunteers learned about the history of Senshin-kai Association and that of Karakuwa, the life of Shigeo Suzuki and FIWC and the creation of Friendship House. They all realized that this unique history is linked to Hansen's disease, connecting persons of different ages, residence and backgrounds.

Hansen's disease is sometimes called "A Separating Sickness," an illness that leads to isolation. However, it can also be a "Bond" or "**Kizuna**" that ties people beyond time and place, and creates the strongest of bonds. Through his life in the Nagashima Sanatorium and in the town of Karakuwa, Shigeo Suzuki was able to dramatically impact the lives of many people beyond HD, and beyond generations, helping "**Kizuna**" to blossom like a colorful flower of hope.

Maudes's Laugh

Ymelda Beauchamp

The last time I saw her – pushing a patient on a wheel chair to church on a Sunday morning – she was rushing down the hallways fixing the patient's hair as she walked, talked and laughed.....that contagious laugh.

Maude's laugh was a big beautiful laugh. A rumbling rainbow set free. It was so unrestrained in its honesty that you couldn't help but want to laugh along with her.

Living in a large facility like Carville with hundreds of people; people on wheel chairs and bicycles in the hallways, people coming and going all day long, workers as well as residents (patients) was a little overwhelming; lonely and depressing. Some days were better than others but always I sought the positive constant. The good things you can count on to alleviate the moments of pain and aloneness. For me it was Maude's laugh.

Maude was my friend. My good friend in Carville and she was kind to me at the lowest points in my life. She had worked in the cotton fields in Louisiana and while doing this lived in a one room shack where she brought her children along and gave birth to her last child all alone in deplorable conditions. She was diagnosed with leprosy and we met somewhere around 1970 when she came to Carville for treatment. Maude was never given a job in the hospital, nor received assistance from the Patients Federation as it was customary to patients in the infirmary and those who had no income. We never understood why and never questioned it. Many times she spoke of prejudice and racism but never dwelt on the matter, she earned money by washing clothes, and cleaning rooms. Many nights she came to my room and talked about the suffering of black people in the south, the hardships she herself had endured as a single black parent, poverty, abuse, and diagnosis of HD. And on some Saturday evenings she would drink herself to a state of stupor to drown her brokenness; but when Sunday morning came around Maude was up at the crack of dawn getting ready to wheel people to church. Taking one person, then another and another and when services were over she would take them back to their rooms. One at a time, laughing and joking.

I have been thinking a lot about Maude lately, maybe because she is also thinking of me wherever she is. Sometimes when I am standing in my kitchen cooking, weary and tired from work I need only to think of Maude's laugh burst forth from somewhere in those hallways in Carville. It never fails to put a grin on my gloomy face. Maude was one of the most compassionate, kindest people I have known. You just have to admire someone who laughs so joyously while working so hard at just living. Her laugh proudly announced her joy in life in spite of all the trials and tribulations that came her way.

She disappeared from my life years later, and much later while in California I received a note from one of her children notifying me of her death. Maude died of cancer, but before she did she asked that someone get in touch with me and give me her message which read: "*I miss you...*" *I miss you too Maude, my friend!*

Forty & Eight Activities

by Joseph Steil, Nationale Directeur, Carville Star



The Forty & Eight has been instrumental in maintaining the publication of The Star since 1943. The magazine is translated and distributed to any country and any U.S. clinic requesting the magazine through The Forty & Eight donor subscriptions and the **Buy A Country** plans.

We urge all Forty & Eighters to subscribe to The Star, and read it. You are not likely to give your support to a program, no matter how worthy, that you know very little about. Read your copy of The Star and be informed about the program. Become familiar with the facts about the program and Hansen's disease, which appears on the back of each issue of The Star. Once you do, there is no doubt that you will become a staunch supporter.

The Nationale Carville Star Committee is comprised of a Directeur, 4 Area Sous Directeurs, Treasurer, and Advisor. It is absolutely essential to the success of the Carville Star Program that each and every Voiture Locale and Grande support the Carville Star program to get the job done properly and ensure success. We also coordinate closely with our counterparts in La Society de Femmes.

La Society de Femmes is a fraternal organization of women founded in 1963 for the sole purpose of supporting the programs and principles of the Forty & Eight. La Presidente Nationale for 2011-2012 is Sandy Wood, and her Nationale Carville Star Chairperson is Joyce Willis. Joyce is married to George "Doc" Willis, who was the Forty & Eight Carville Star Directeur from 2008-2011. La Presidente Wood has named the Carville Museum as her Presidente's Project. Her goal is to raise \$5,000 for the Carville Museum before September 2012. La Presidente Wood has already raised funds by taking "pies in the face" at regional and state meetings and has challenged each Cabane and Grande Cabane to raise money for the Carville Star. All the Dames in Las Femmes will feel great pride in themselves and their organization when Sandy presents a check to the Forty & Eight at the Promenade Nationale.

The Promenade Nationale is the Forty & Eight's national convention. It is a time of renewed fellowship and election of new national officers. The 93rd Promenade Nationale will be held from 11-15 September 2012 in Fort Mitchell, Kentucky. Some of the activities include a Children's Party for disadvantaged children by our Boxcar Hobos, updates on our programs in-

cluding Carville Star, Americanism, Nurses Training, Child Welfare, POW/MIA, VAVS, and Youth Sports, and presentation of Americanism Award, Hero of the Year Award, and Law Officer of the Year Award.

The Voyageurs of The Forty & Eight, along with the outstanding support from the Dames of La Societe de Femme, are proud to have supported The Star from 1943 to the present. From the original presses and type setters, to the new modern full color format that is also available electronically, the Forty & Eight is ensuring that the research materials on Hansen's disease are distributed around the world.

*** ATTENTION ***

Don't let your subscription expire!

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

Voiture Nationale
Attn: The Star Membership
777 North Meridian St., Rm. 300
Indianapolis, IN 46204-1421

Subscribe to The Star

Name: _____

Address: _____

Address2: _____

City/State/ZIP: _____

Country: _____

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

Make checks payable to: Voiture Nationale

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

Leprosy and Advocacy

by José Ramirez, Jr.

This article was originally published in The Houston Chronicle on February 5, 2012.

In 1948, the United Nations adopted Article 1 titled Declaration of Human Rights, “All human beings are born free and equal in dignity and human rights.” This Article represents the values that all of us cherish but do not always show in every day practice.

With the continuing popularity of the social media and attention to adopted causes by celebrities, Article 1 does surface to the front page of entertainment news. These causes can be local, or international. However, unless these causes affect a specific group, their significance have a short life span. One cause that has a longer life span and is popular among the followers of teen entertainers, along with the residents of The White House, is bullying. Bullying is a phenomenon that gives birth to undignified and disrespectful behaviors. Bullying is a phenomenon that is learned by the stigmatizing comments made by adults.

Stigma is all about the negative perception of others, painful stabs through words, screaming insults and stares of dislike. Stigma, created by adults and imbedded in the minds of children, can rob those of us with different abilities or misunderstood illnesses of dignity and respect. The way to change this is via the art of advocacy.....lessons on refusing to remain silent when undignified and disrespectful actions occur. The myths surrounding the world of Hansen’s disease, more commonly known as leprosy, should not be allowed to flourish through our silence and exploitation of stigma.

Leprosy does exist in most parts of the world, including the United States. Since December millions of movie goers have seen the trailer for the movie titled “*The Pirates! A Band of Misfits*.” This trailer is intended for the young minds of the world, those who can be greatly influenced by the magic of movies. Unfortunately, they were exposed to myths about leprosy and pejorative labels. The screenwriter, actors who rented their voices to this movie, director and the film makers (Aardman Animations) created an image that depicts children with leprosy and their arms falling off-----nonsense in real life. Joking about children with different abilities is never funny.

How can the public possibly support bullying of those with different abilities in this manner? They should not and instead take a stand against stigma. Silence, regrettably, can only result in the art of advocacy lost due to neglect.

In this case, those of us affected by leprosy did not remain silent and instead took action. This was done by reporting on this horrible portrayal of our brothers and sisters in The Star, an international magazine created by our unique group. Additionally, a massive international campaign via email and letter writing was initiated. This resulted in support from the 40 & 8 (20,000 member organization of veterans in the U. S.), LEPRO (anti-leprosy organization), the World Health Organization, and the U. N. Ambassador for the Elimination of Leprosy.

The end result of our advocacy campaign and strong efforts to teach about the modern day existence of leprosy is that Aardman Animations agreed to issue an apology (“we decided to change the scenes out of respect and sensitivity for those who suffer from leprosy.... (and)honor the effortsto educate the public about the disabled”). They also agreed to edit the film to delete all insulting scenes and references to “leper,” (or the “l” word).

The “l” word is always defined in negative words, such as pariah, outcast, sinner. The “l” word is used in the public and social media to define us by the illness. The “l” word has resulted in fear that led to forced institutionalization, sterilization, loss of identifies, loss of due process and much more. To our knowledge, this is the first time that a film maker has responded to such an advocacy effort, agreed to changes and offered an apology.

Once these changes occur, those of us affected by leprosy can have a wonderful celebration for the 50th anniversary of World Leprosy Day on the last Sunday of January as declared by President Kennedy in 1962.

The dignity of those who died voiceless and nameless at the national leprosarium in Carville, Louisiana will continue to be remembered by those of us who spent many years separated from our friends and families at this one-of-a kind institution in the United States that opened in 1894 and closed in 1999.

The next challenge is to convince the members of the Academy Awards to better screen movie scripts that include references to us that denies dignity. Regrettably, several of the movies nominated this year for awards do violate Article 1 on Human Rights by callously using the “l” word.

HANSEN'S DISEASE CLINICS

ATLANTA HD CLINIC

Emory MidTown Hospital
550 Peachtree Street NE
7th Floor MOT
Atlanta, GA 30308

PH: (404) 686-5885 Fax: (404) 686-4508

Primary Physician – Dr. Phyllis Kozarsky
email: phylliskozarsky@emoryhealthcare.org
PH: (404) 686-5885

Public Health Nurse: Roberta Dismukes, RN
email: roberta.dismukes@emoryhealthcare.org
PH: (404)-320-6662 PH: (404) 686-7668

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
email: samuel.l.moschella@lahey.org Public Health Nurse
- Ms. Stephanie Burns, RN, D.N.C. *email:* stephanie.a.burns@lahey.org After Hours: (781) 744-8445

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
email: chhill@uic.edu

Public Health Nurse – Gladys Lee, RN
email: FLLee@uic.edu

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. Maria T. Ochoa
email: mochoa@mednet.ucla.edu
PH: (323) 226-3373

Public Health Nurse - Helen Mora, RN
email: hmora@dhs.lacounty.gov

Occupational Therapist - Rob Jerskey
email: robjerskey@yahoo.com

MARTINEZ HD CLINIC

Contra Costa Regional Medical Center
Outpatient Specialty Clinic
2500 Alhambra Avenue
Martinez, CA 94553
PH: (925) 370-5868 Fax: (925) 370-5529

Primary Physician - Drs. Sutherland/Saffier
email: ssutherland@hsd.co.contra-costa.ca.us
PH: (925) 370-5867
email: ksaffier@yahoo.com

PH: (925) 370-5200 Ext.:4743

Public Health Nurse – Barbara Hobson, RN
PH: (925) 313-6757

email: Barbara.Hobson@hsd.cccounty.us
Community Health Worker - Maria Soto
email: Maria.Soto@hsd.cccounty.us

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
email: Aburdick@med.miami.edu

Public Health Nurse - Gail Chepenik, RN
email: gchepenik@ihsmiami.org

NEW YORK HD CLINIC

Bellevue Hospital Center

Department of Dermatology
462 First Avenue, Room 17-N-7
New York, NY 10016
PH: (212) 562-5670 Fax: (212) 263-6423

Primary Physician - Dr. William Levis
email: william_levis@yahoo.com

Public Health Nurse - Lydia Macwan, RN
PH: (212) 562-6096
email: Lydia.Macwan@bellevue.nychhc.org

Physical Therapist - Louis Iannuzzi, P.T., C.Ped.
email: Lni1@nyu.edu

PHOENIX HD CLINIC

Maricopa County Health Department
1645 East Roosevelt Street
Phoenix, Arizona 85006
PH: (602) 372-2039 Fax: (602) 372-3862

Primary Physician - Dr. Ronald Pust
Tucson Office: (520) 626-5650

Cell: (520) 668-6441
email: rpust@email.arizona.edu

Public Health Nurse - Eileen Smith, RN
PH: (602) 372-2039
email: eileensmith@mail.maricopa.gov

Physical Therapist - Tracy Carroll, MPH
email: tc Carroll@email.arizona.edu

SAN DIEGO HD CLINIC

HHS, North Central Regional Center
5055 Ruffin Road, Mail Stop: N-513
San Diego, CA 92123
PH: (858) 573-7338 Fax: (858) 573-7325

Primary Physician - Dr. Erik O. Gilbertson
email: erik.gilbertson@sdcounty.ca.gov

Public Health Nurse – Gina Sandoval, RN, PHN
email: regina.sandoval@sdcounty.ca.gov

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 Almodo'var
email: dermatol.rcm@upr.edu

Public Health Nurse - Sonia Santos-Expo'sito, RN, BSN
PH: (787) 758-2525, Ext. 5503
email: sonia.santos@upr.edu

SEATTLE HD CLINIC

Harborview Medical Center
2 West Clinic – 359930, 325 Ninth Avenue
Seattle, WA 98104
PH: (206) 744-2128 Fax: (206) 744-5109

Primary Physician - Dr. James Harnisch
email: jpharnisch@comcast.net

Public Health Nurse – Marlene Skinnell, RN
email: mskinne1@u.washington.edu

Physical Therapist - Tom McClure, PT, CHT
email: tmcmpt@u.washington.edu

SPRINGDALE HD CLINIC

Outreach Clinic of Washington County
614 E. Emma Avenue, Suite 247
Springdale, AR 72764
PH: (479)-751-3630 Fax: (479)-973-8491

Primary Physician: Linda McGhee, MD
PH: (479)-521-0263 PH: (479) 973-8450 (office)
email: lmcghee@uams.edu

Public Health Nurse - Sandy Hainline Williams, RN
PH: (479)-751-3630 Cell: (479)-409-9134

email: sandra.hainline@arkansas.gov

TEXAS HD CLINICS

Department of State Health Services
Hansen's Disease Program
P. O. Box 149347, Mail Code 1939
Austin, TX 78714-9347
PH: (800) 252-8239 Fax: (512) 776-7787

Nurse Consultant: Linda Brown, MS, RN
PH: (512) 776-6331

email: lindaj.brown@dshs.state.tx.us

Officer Administrator: Kirbi Woods

PH: (888) 963-7111 Ext.: 6608

email: kirbi.woods@dshs.state.tx.us

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
email: jbcohendo@aol.com

PH: (817) 753-6633 (private practice)
email: sharon.nations@utsouthwestern.edu

PH: (214) 645-8800

Public Health Nurse - Nancy Bernstein, RN, BSN

email: nbernstein@dallascounty.org

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
email: Tmwill3502@aol.com

PH: (281) 332-8571
email: Steven.Mays@uth.tmc.edu

PH: (713) 500-8329

Public Health Nurse – Marion Matsu, RN, CCM
email: Marion.Matsu@houston.tx.gov

Main: (832) 393-4798 Cell: (832) 248-7150

Texas Center for Infectious Disease

2303 S. E. Military Drive
San Antonio, TX 78223

PH: (210) 531-4526 Fax: (210) 531-4508
Physician - Dr. Robert N. Longfield

PH: (210) 531-4959
email: robert.longfield@dshs.state.tx.us

Physician - Dr. Adriana Vasquez

PH: (210) 531-4565
email: adriana.vasquez@dshs.state.tx.us

Physician - Dr. Lynn Horvath

PH: (210) 531-4524
email: lynn.horvath@dshs.state.tx.us

Public Health Nurse - Debbie Mata, RN

PH: (210) 531-4576 PH: (210) 531-4295 Cell: (210) 389-3568

Appointment Secretary (210) 531-4526
email: debbie.mata@dshs.state.tx.us

Department of State Hlth Services Region (HSR) 11

601 W. Sesame Drive
Harlingen, TX 78550
PH: (956) 423-0130 Fax: (956) 444-3295

Physician - Dr. Richard Wing

email: richard.wing@dshs.state.tx.us
Public Health Nurse – Grace Flores, RN

PH: (956) 423-0130, Ext. 5573
email: grace.flores@dshs.state.tx.us

Other Clinics

HAWAII HD PROGRAM

Hawaii State Department of Health
Hansen's Disease Community Program
3650 Maunalei Avenue
Honolulu, HI 96816
PH: (808) 733-9831 Fax: (808) 733-9836

Program Manager: Lori Ching, RN
Direct Line/Voice Mail: (808) 733-4663

email: lori.ching@doh.hawaii.gov

Office Physical Address:
Diamond Head Health Center
3627 Kilauea Avenue Room 102
Honolulu, HI 96816

Rev. 10/2011

VOITURE NATIONALE
777 North Meridian St., Suite 300
Indianapolis, IN 46204-1421

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

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

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

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

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



FACTS ABOUT HANSEN'S DISEASE

What is HD?

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

HD affects the skin, peripheral nerves, and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, and the testes.

There are both localized and disseminated forms of HD. If left untreated, HD causes nerve damage, which can result in loss of muscle control and crippling of hands and feet. Eye involvement can result in blindness.

Where is HD Found?

In 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