

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JULY - DECEMBER
2015
VOLUME 64 - 20**



WORLD LEPROSY DAY, JANUARY 31, 2016

Valdenora Rodrigues of Brazil asked Pope Francis to stop referring to all of us affected by leprosy as “lepers” and to stop describing that all things that are bad as “a leprosy,” and he responded, “No más. No más. No más.” (No more.....).

— Photo by Artur Custodio Moreira de Sousa, National Coordinator for MORHAN, Brazil

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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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Empowerment Awakened

By José Ramirez, Jr.

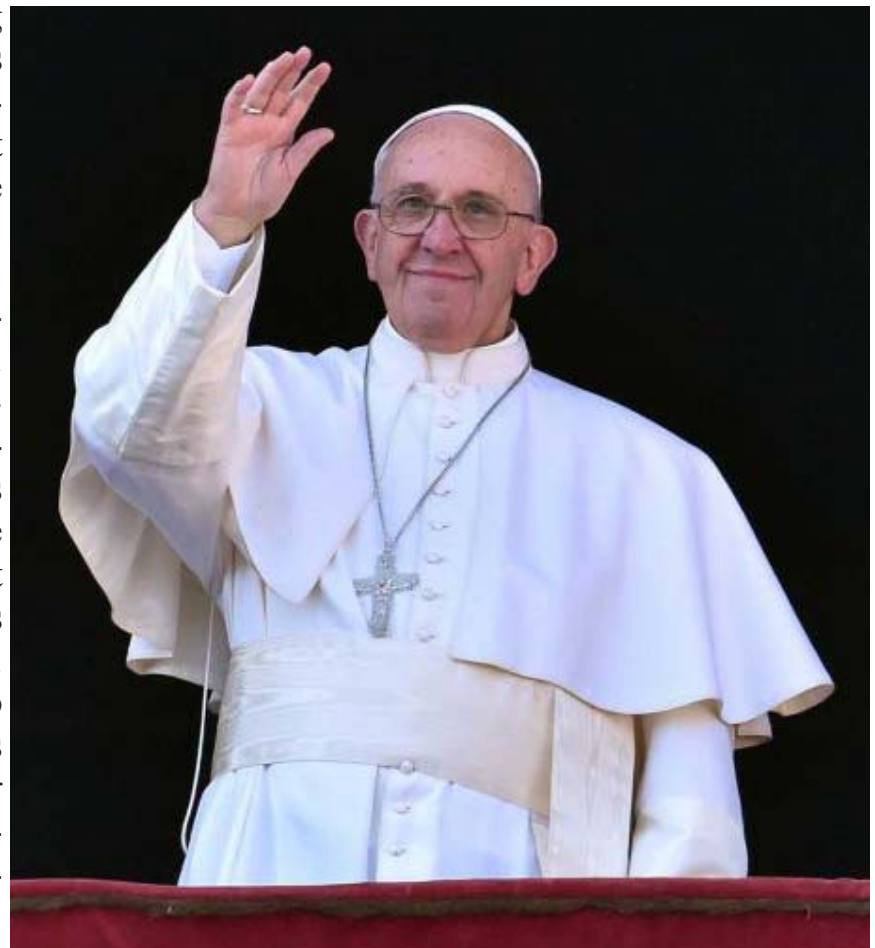
The word “empowerment” has two basic meanings. One refers to being granted power by an authority (figure or organization). Another definition refers to controlling and claiming power. Those of us affected by leprosy have always sought empowerment as defined in the second example, controlling our own destiny and not having someone else do this on our behalf.

Empowerment in the world of leprosy has existed via writings in publications, poems, books and letters. Empowerment has existed via the voices of those unafraid to demand equality in life. Empowerment has existed through participation or change agents, especially via patient organizations that create a picture of unity, of solidarity, of a family fighting against injustice. Empowerment continues to exist as we demand an end to being described as “equals” but “walking separately.”

An example of four individuals walking together as members of ILEP’s (International Anti-leprosy Federations) Panel of People Affected include: Kofi Nyarko, Mathias Duck, Rachua Kumari and José Ramirez, Jr. This panel is designed to assist ILEP in working collaboratively with persons affected, such as creating a guide on how to use non-offensive language and the appropriate use of photography that includes written consent.

Ms. Kumari from India has participated in a workshop addressing community changes in perception, communications and behaviors. Mr. Duck attended a national forum in Morrou, Columbia and discussed issues related to combating stigma, strategies for inclusion, networking and the great need for psychosocial services to address trauma, fear and depression. Mr. Nyarko made a passionate presentation at a conference in Geneva about collaboration. I made a presentation in Geneva to the UN Human Rights Committee on self-empowerment.

Likely one of the most powerful examples of empowerment occurred on June 15, 2015 on the steps of St. Peter’s Basilica in Rome, Italy. On that day, 4’10” Valdenova Rodrigues of Brazil, a person affected by leprosy met 5’9” Pope Francis. She gently squeezed his hands while staring up at his face and pleaded, “Please stop using the word “leprosy” to refer to all things that are bad or to refer to us as “lepers.” Pope Francis raised his hands up to the heavens and said, “No more. No more. No more.” With that simple response of “No more,” Pope Francis acknowledged that leprosy is NOT a punishment from God, validated our search for empowerment, and gave us the power to continue waking up to the global community about self-empowerment.



Retiring a Passport

By Jim Krahenbuhl, Ph.D.



Dr. Col. Robert R. Jacobson, USPHS, Retired, age 83, of Woodstock, GA died peacefully on December 1, 2015. Dr. Jacobson was a physician and international authority on clinical Hansen's disease. He practiced at the Gillis W. Long Hansen's Disease Center for 34 years where he rose to the position of Director for the center. During his career he pioneered work on drug resistance in Hansen's disease by introducing Rifampin to the multi-drug therapy for the disease. He published extensively and traveled to places such as the South Pacific, the Philippines, Japan, China, India, Switzerland, Malta and Venezuela as a researcher and consultant for the World Health Organization, governments and other organizations to help treat the disease worldwide. Dr. Jacobson loved his work and received numerous commendations from the United States Public Health Service (USPHS) including the Commendation, Meritorious Service, and Distinguished Service Medals. He also oversaw the relocation of the hospital from Carville to Baton Rouge, Louisiana before his retirement in 2000.

Dr. Jacobson was a graduate of the University of Wisconsin with a PhD in Organic Chemistry and of the Medical School- University of Minnesota with a MD. His undergraduate degree was in Chemistry from the University of Minnesota.

Dr. Jacobson is survived by his wife of 58 years, Alice Tyykila Jacobson; three children : Michael and his wife Jan, Mark and his wife Tammi, and Eric; three grandchildren: Sabrina, Anna, and Peter; brother Bill and his wife Carol, sisters Mary Wasik and her husband Hank, and Janet Wilson and her husband Laird; and many beloved nieces and nephews, friends and co-workers.

Editor's Note: Dr. Jacobson was the first physician I saw the morning after my midnight arrival at Carville. The fear I felt while staring at spider webs on the ceiling of a cold hallway while being transported to the infirmary on a stretcher was transformed to a comforting feeling in a warm and clean room when a tall bespectacled man in an elegant dark uniform entered my hospital room. The doctor-patient relationship with Dr. Jacobson gradually changed so that by his retirement in 2000 we were friends. This beautiful man not only had the hands to heal, but also the heart to lessen one's fear of leprosy. He accomplished both for me.

I Am Naima Azzouzi

Symposium on Leprosy & Human Rights, Geneva Switzerland

As a little girl, I never would have imagined making a presentation at a symposium in Geneva. This thought did not cross my mind because I recall being ill since very young, and at age seven I was diagnosed with leprosy. My father took me to see many doctors, but they did not know what I had and treated my pain and loss of sensation with penicillin, which did not help my condition. The lack of proper treatment resulted in my hands becoming insensitive to pain and then deformed due to nerve damage.



Luckily, a general practitioner finally sent me to the national leprosy hospital in Casablanca. I was there for one year, following treatment and had many operations on my hands in an effort to repair the nerve damage often caused by leprosy. Unfortunately both of my parents died during the year I was in the hospital.

After the death of my parents, I was alone and experienced a very difficult life forced to live in a hospital with primarily older patients. I ended up staying in the hospital for 10 years. While I was there a Moroccan association dedicated to helping persons affected by leprosy provided me and others affected by leprosy with sewing classes. I eventually received a certificate as a seamstress. When I left the hospital at age 17, I was unable to find work making clothes. I was often turned away when potential employers realized I had leprosy, even though I had become an excellent seamstress.

Eventually, I found employment as a cook for a lady from France living in Casablanca. Besides finding employment, I also found a husband who loved me as Naima and not as a disabled person with leprosy. I am happily married with two children and the pain of my past has been replaced with love. I still make my own clothes, cook for the family, drive a car and have started the Association Accompanying People Affected by Leprosy in Morocco, becoming an advocate for human rights.

Morocco now has some good doctors familiar with leprosy, but there is still insufficient education of the community. Most who know of persons affected by leprosy will not touch them, refuse to employ them and openly discriminate against them. The government has not done enough to dispel myths about leprosy, and then the cycle of discrimination continues.

My wish is for the human rights of people affected by leprosy to be respected in Morocco, and for discrimination to be eliminated in my country too. Regretfully our small association for people affected by leprosy in Morocco is unable to operate properly because it receives no financial or other support. The community is too scared due to the misguided assumption that they too will contract leprosy. Hopefully, my involvement with other international events related to human rights will open the door for our association's members to secure additional support.

My thanks to all of the people who work for people affected by leprosy, and especially Dr. Sasakawa, Chair of the Nippon Foundation and United Nations Goodwill Ambassador for the Elimination of Leprosy for inviting me to be a presenter at the symposium in Geneva, Switzerland on June 18, 2015. I loved meeting my new family affected by leprosy that travelled from all over the world to this unique event.

Mardi Gras at Carville, 1950

By Elizabeth Schexnyder

At Carville, Mardi Gras Kings and Queens were selected by the patient body.

According to the local school weekly called the “Question Mark” (QM) dated Friday, January 27, 1950, Their Royal Majesties, the King and Queen of Mardi Gras, were selected in the theatre just prior to the regular movie by a young patient called “Little Jimmy” from a hat containing the names of the various candidates nominated by all the patient organizations. Little Jimmy drew out the names of the lucky couple who would reign over all the gala Mardi Gras festivities on February 21st.

Darrell Broussard and Maria Lucio were selected to reign as King and Queen. However, since Maria declined the honor, it was the unanimous opinion of representatives from each of the patient organizations that Darrell then be allowed to choose his own Queen. This he did in the personage of none other than his charming wife, Mary Ruth.

Plans for the big Mardi Gras celebration included decorations for the ball room and assembly of floats by the various patient organizations like, the American Legion and The Boy Scouts. The Entertainment Committee was in charge of the big event, encouraging all the participants to prepare their costumes or float in a timely manner. The Committee also provided the refreshments and prizes for the ball.

On February 21st, 1950, the Mardi Gras parade began promptly at 7:00 pm at House 15 (upstairs). All floats and maskers paraded around the walks, proceeding to the Ball Room where the “Lord Mayor” presented the key to the city to his Royal Highness King Rex. Following a toast to the King and Queen, all guests danced to the music of Jimmy Fisher and his New Yorkers.

According to QM researchers, the earliest Carnival at Carville was in 1915, when the hospital was under the aegis of the State of Louisiana. A patient called “Little Oscar” Bishop had to be Queen because at that time the “gals were on the other side of the fence and were not allowed to mingle with the male patients”. Oscar admitted to being a charming queen.

Editor’s Note: Darryl and Mary Broussard were designated my surrogate parents upon my admission to Carville. I became an international advocate in large part due to Darryl’s influence as he was a game changer in his role as Postmaster, President of the Patient’s Foundation, President of the Carville Lions Club and Precinct Chair. Mary referred to everyone as “sweetie” and received permission from my mother, Rosa Ramirez, to call me “son” while I was an in-patient.



**19th International Leprosy Congress
Beijing, China: September 18th-21st**



International Leprosy Association

The International Leprosy Congress has been held throughout the world for over a century, with some exemptions during times of military conflict. This unique meeting was originally designed to introduce innovative treatment protocols and discoveries of medications, and attendance was restricted to leprologists and other scientists.

Gradually, the discussions at the Congress shifted to the human factor, e.g., issues of stigma, denial of basic human rights and terminology. On the latter, the Congress meeting in Cuba in 1948 adopted a resolution to delete the word “leper” from ILA’s (International Leprosy Association) vocabulary. This unique action did not permeate throughout the world so negative labels continues into 2016.

Labels however are not enough to keep persons affected by leprosy from attending this important meeting as a large delegation is expected in Beijing.

The organization of the Congress welcomes all to visit the ILA website at <http://cicst.org.cn/ILC2016/index.html> and register for the conference.

The organizers include Marcos Virmond from Brazil (President, ILA), Zhang Guocheng from China (Chair, China Organizing Committee), and Cairns Smith from Scotland (Chair, Congress Scientific Committee).

The War Effort at Carville

By Claire Manes

Seventy years after the end of World War II we still celebrate the deeds of those who fought, but we pay less attention to those whose volunteer efforts supported the war. On the home front, civilians sacrificed loved ones, planted victory gardens, bought war stamps and bonds, endured rationing and volunteered with the USO or the Red Cross. In Carville the patients and hospital staff were a significant subset of those stateside warriors.

Even before the United States entered the war, patients followed world politics on the radio and in print. They felt the pull between patriotism and their inability to be directly involved in the fighting. In the August 1941 *Star* readers of the newspaper were reminded of the power that they did wield. An article counseled the power of attitude in the success of any effort. Patients were encouraged to participate in the V (Victory) campaign: concentrate on victory, talk victory and pray for victory. The suggestion was a familiar truism that patients lived daily in their war against HD.

Maintaining a victorious attitude was insufficient for some who longed for action. At least a few patients escaped through the hole in the fence, lied about their home address, passed the physicals, and for a brief time served in the war before HD resurfaced and thwarted their exploits.

Equally important if less dramatic were the fundraising efforts at the hospital. In January 1942, Dr. Bernard Prejean headed the Red Cross war relief efforts at the hospital, in Carville, St. Gabriel and environs. Patients rose to the challenge to contribute and a booth was set up in the cafeteria to accept donations. Soon patients organized Red Cross fairs that included dancing, raffles, games and the sale of handmade and baked goods to raise funds. Weeks were spent planning the events for the bi-annual fairs.

The fairs were communal celebrations, but patients also supported the war efforts with the purchase of defense stamps, books and war bonds. Exhibits in the cafeteria and patriotic cartoons in *The Star* encouraged these individual efforts.

The Star reported on the endeavors among patients and staff and became a source of patriotism beyond the hospital. In January 1943 a soldier in the South Pacific thanked the staff for copies of *The Star* which added to the meager reading material for those serving abroad. V letters were also encouraged and *The Star*, April, 1944 touted the value and simplicity of these letters. It was even suggested that “typists among us” would be more than happy to type letters.

Less was said about the personal sacrifice of residents who may have had family or loved ones in the service, but at least one such story was noted. Mr. Oubre, the proud father of George was recognized in the July 1944 *Star*. His son had received a Purple Heart for actions on Anzio Beachhead Italy.

No doubt jubilation rang out in Carville when freedom was achieved. At that point patients returned to their own war fighting the bacteria that was still undefeated, but for a few brief years attention had turned to achieving freedom for a world torn by war. It is worth remembering too that the efforts in Carville were made by some who were not citizens of the United States, and by citizens who were denied the right to vote due to their illness.

Did St. Peter have Leprosy?

By José Ramirez, Jr.

Prior to the visit by Pope Francis to the United States, Dr. Bennett Futterman of New York State published an interesting article in the journal Clinical Anatomy. Dr. Futterman, a former orthopedic surgeon and current anatomy professor at the NYIT College of Osteopathic Medicine, wrote that contrary to common belief, “St. Peter had ulnar nerve damage to his right hand, and not median nerve damage.”

Damage to the median and ulnar nerves can be caused by “severe pressure, trauma or illness.” The median nerve is located in the middle of the palm and a repetitive motion can result in severe discomfort of the hand, from the ring finger to the thumb. This is similar to what is referred to as Carpal Tunnel Syndrome, or a numbness and weakness of the hand.

The ulnar nerve extends from the elbow to the tips of all of the fingers. Damage to the ulnar nerve typically results in a “hand of benediction... a half-open hand, with pinky finger, ring finger and middle finger remaining curled or flexed to the palm.”

Dr. Futterman completed a scientific anatomy analysis of St. Peter’s hand by studying art, history, icons, tomb paintings and religious practices. He concluded that St. Peter, the first pope, “...had an ulnar injury... Out of respect for St. Peter, the other popes followed with the same (hand) pattern.” Pope Francis and other popes have used an opposing form of blessing with an open hand.

Dr. Futterman describes damage to St. Peter’s ulnar nerve as an “injury.” However, what if the inflammation to the ulnar nerve and “curled fingers” were due to an illness? What if this illness was aggravated by pressure from the inflammation of the ulnar nerve and trauma from a repetitive motion?

Before he became a disciple and later an Apostle, Peter was a fisherman. Peter led a life known as “thunder,” a word used to describe the rough, brutal and manly world of fishermen, ignoring all types of pain. Peter and the other fishermen used their hands to constantly repair fishing nets and used the oars of their small boats. It was also common during this era for fishermen to donate some of the fish to those excluded from the community, e.g., individuals deemed to be affected by leprosy and banished.

Peter’s possible contact with persons affected by leprosy during a time of poor hygiene, and potentially similar genes among the 231 million living in an area now known as Southern Europe, Middle East and Northern Africa, could have allowed for the introduction of the leprosy bacillus into his body. This description of a potential



St. Peter with “hand of benediction” at St. Peters Square in Rome

transference is what might have occurred to Father Damien of Molokai, now Saint Damien. Current research has shown how hygiene and genes can be important factors in determining how someone might end up with leprosy.

Other factors to consider besides hygiene, genes and living in close quarters include incubation period, level of disability, the sensation of pain and disfigurement. The leprosy bacilli might be in the body for many years without any obvious signs of the illness because the incubation period for leprosy can be as long as 20 years. Art depicting Peter as a young man does not show the “curled fingers” so the onset of leprosy could have occurred later in his life.

The level of disability probably would fall under Grade 2 as currently defined by the World Health Organization, with accompanying sensory loss. Damage to the median nerve results in a “weakened hand,” which is not shown in art depicting St. Peter. However, “sensory nerves directly connected to the ulnar nerve are the first affected by leprosy” and a “claw-like” (curled) hand is a potential outcome. Finally, leprosy has a unique element in that it can cause blindness, sensory loss, nerve damage, disfigurement, loss of eyebrows, and secondary infections all at once, or it might unfold as only one of these six characteristics. In essence, not all who have leprosy experience facial nodules and disfigurement, and images of St. Peter never show facial disfigurement.

It appears that artists who would draw St. Peter with nerve damage to the right hand were recording accurate his-

tory. In essence, even with the potential that St. Peter did have leprosy, his facial features did not have to mimic disabilities seen 1,949 years after Peter's death in 67 A.D.

In 1968 when I was first diagnosed with leprosy, I was quickly sent to the national leprosarium in Carville, Louisiana. At the time there were 12 million new cases diagnosed annually in a global population of 3.5 billion. Besides the treatment with multiple drugs such as dapsone, chlofazimine, thalidomide and steroids at the national leprosarium, the medical teams focused on lowering the inflammation of the ulnar nerve which typically leads to sensory loss and deformities of the hand. Now, there is a global population of 7.2 billion with 230,000 new cases annually and a continued focus on lessening the inflammation of the ulnar nerve that runs from above the elbow to the tips of the fingers in persons affected by leprosy.

The recovery I experienced during my seven years at Carville was due to the introduction of experimental medications that were a forefront to the phrase multiple-drug therapy (MDT). I also underwent an emotional healing after having been administered the last rites on the first day of my diagnosis. I could never forget the trauma and pain my mother felt believing that leprosy was a punishment from God.

St. Peter's "hand of benediction" has a very special significance for me as my mother never gave up on her faith in spite of the negative references to leprosy in the Bible. She believed that my illness of leprosy was her punishment for sins committed. She would daily bless me, my father, and my siblings as we would leave the house, and used the same hand gesture as St. Peter when I started on my journey with leprosy, blessing my path which she thought would end up in slow death, as in crucifixion.

St. Peter was upside down when crucified, having lived twice as long as his mentor. Those of us who have experienced the trauma of leprosy have at times lived in a world turned upside down by stigma so often associated with leprosy.

So, did St. Peter have leprosy? If the answer is "no," then what is the explanation for the damage to his ulnar nerve. If "yes" he would become one of our millions and millions of lost brothers with leprosy who experienced ulnar nerve damage.

Regardless of the answer, my mother died peacefully 36 years after my diagnosis following my share with her of some comforting news. When I informed her that Pope John Paul II had described all persons affected by leprosy as his "brothers and sisters", my mother calmly responded by saying, "Now I can die with a clean soul." Now living in Heaven she is probably receiving daily blessings from St. Peter.

My Trip to Carville

By Howard L. Hoover

Recently I was given the pleasure of visiting Carville, Louisiana home of the National Hansen's Disease Museum. It was a totally eye opening, mind boggling and life changing day. While taking the drive to Carville, the camaraderie and jokes grew rapidly. No one gave me any idea what was in store for me. Approaching our destination, it wasn't the beautiful, elegant, southern plantation house or magnificent grounds I noticed. It was the ten foot high, barbed-wired topped chain link fence that caught my attention. My first thought was because the National Guard now runs the compound.

Sometimes in one's life an occasion or event happens that is so totally mind jolting, eye opening, your life changes forever. Not like the birth of your first child. More like when a new discovery rewrites history. Altering not only your life, but your parent's life, your grandparent's life, and the lives of everyone for generations to come. Years of thinking one way is proven false. Your mind tries resisting the new found truth, but to no avail. The truth is the earth is NOT flat; the earth DOES revolve around the sun, and everything you know about Hansen's Disease is wrong.

Once inside the museum, I started to sense what had been happening at Carville for years and years; about its long, dark, mysterious and misunderstood history. The walls were lined with pictures showing the daily lives of its residents in "simpler" times. When people were forcefully removed from their homes, in the darkness of night, riding in a hearse or towed with frail rope in a small boat more than hundred feet behind a barge or ship. About the devoted care and compassion of those who rose above superstition to help and comfort. About the archaic medical equipment to modern advances. From the heart warming pictures of the residents doing things we take for granted such as sports, dances and just compassion; to the bone chilling realization of the sinful way they have been treated so wrongfully for years.



But not here, not at this secure, safe place. Protected from the outside world of unknowing, bigoted people to something all of us want; home. This sanctuary was that, a place where they fit, where they were not “evil”, not outcast. A place where good, innocent people could call home, Carville, La.

Stepping toward the showcase that housed years of 40/8 memorabilia, my heart began to swell with pride. Realizing that for decades La Societe very quietly has stood tall with the residents. La Societe reached out its hand and showed that we care plus they are not forgotten. Later during the tour, we were told about the fence. It's has been there for years and years. It's sole purpose to keep the residents “in” not others out. Just because they are safe here, they were still quarantined.

As that chill ran down my spine, I realized that like so many others my own ignorance had created prejudice and misunderstandings. Felting the merit about being part of La Societe, a family of very dedicated and committed individuals. Who has showed those that societies had ostracized; one; you are not forgotten. Two; there is hope and together we can overcome. Three; La Societe will not stop until there is no need.

Later that day as we climbed back into the van, the jokes soon started again. Back on the road heading for Ochsner Hospital in Baton Rouge, the home of National Hansen's Disease Program. But truly very uncharacteristic of myself, for the most part I just sat there looking out the window. As the trees whipped by, my mind and heart were trying to take in what I just had seen, heard and more curiously what truly laid ahead.

Upon arrival we were greeted warmly. Continuing to study and analyze the area, this looked like any old hospital anywhere. Once inside we had a few meet and greets. During that time we learned that Ochsner Hospital is the only place devoted to diagnosis, treatment and research for Hansen's. Also in 1999 the 130 residents at Carville were given three choices. One; they could receive a monthly stipend and go home or two; relocate here to the hospital. Last and the one many took, stay at Carville and live out their lives. My opinions of those three choices would soon change.

Starting our tour the elevator doors opened before us to what again looked like any typical hospital. Nothing could have been farther from the truth. Our first stop was at the physical therapy room. Like any other, it had tables and machines. Our guide pointed to a gentleman doing leg-lifts in the far corner. She said he has diabetes. Through the work being done here, he now has a fighting chance. As I looked over there, it was then that I saw he had no feet.

The next stop was the famous “Shoe Factory”. Inside was an enormous selection of materials to work with plus some home-made custom machines. Coming from a long line of artist and craftsmen, I was extremely impressed. Our guide began by saying that the man who ran that room was off today. Here he has made very special, one of a kind and unique shoes. Allowing those with tender, painful or misaligned feet a fighting chance of

normality. As I listened, my eyes scanned the room, taking in the hundreds and hundreds pieces of different materials just to create these unquestionable special shoes. She then said the man we saw in the other room has a pair from here, which has enabled him to walk without assistance. Still trying to adsorb everything, someone said that a member of our group has a pair from here too. After hearing that I was totally floored, for I think of him as a friend, a mentor, someone I look up to. Now the reality of the great work and progress done here, the thousand of lives touched, finding out this place has helped more than just Hansen patients. Oh My God, my eyes were truly opened.

As we continued our tour, it was here that I soon made two enormous mistakes. Walking down the hallway, we were being shown some of the resident's rooms. Half way down the hall we stopped and were shown a room where many were playing bingo. While standing in the back, I asked "Are there other activities?". That was the first time I met Mr. Pete and last time I would ever interrupt his bingo. Mistake number one, don't talk too loud and mess with the man's bingo, bad move on my part. Continuing on our journey, we got to the end of the hall. After meeting some more residents playing checkers, we started our return. By this time Mr. Pete had finished his bingo game and was there to meet us. After some small talk I asked which room was his. Mistake two, Mr. Pete told us with great pride that he still lived at Carville and without any hesitation said that he would die there. For it has been the only home he has ever known. Mr. Pete arrived at Carville as a child, at a time when the world ignored, shunned and cast them out. He found what countless others had; the simple things, the cherished things, existence, and life without judgment.

Now this day was truly the day that I saw the light.

Realizing that we, the 40 & 8, were a lot more than just hospitality room attendees. We are truly an honor society, going above what is needed. Doing for others without a second thought, doing what it takes to get it done. Knowing that this misunderstood disease and mistreated people, along with thousands and thousands around the world, have been helped through the dedicated hard work of my fellow Voyageurs.

Howard L. Hoover,
40&8 Directeur Carville Star Nationale

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Clinic Tower A5B123
Los Angeles, CA 90033
PH: (323) 409-5240 Fax: (323) 441-8152
Primary Physician - Dr. Maria T. Ochoa
email: mariatoc@usc.edu
PH: (323) 226-3373
Public Health Nurse - Helen Mora, RN
email: hmora@dhs.lacounty.gov

Occupational Therapist - Rob Jerskey

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: (501) 590-2536
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

MARTINEZ HD CLINIC

Community Health Worker - Sebastian Basalic
email: Sebastian.Basalic@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@jhsiami.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 - Tina Rendini, RN
PH: (212) 562-6096
email: tinaarendini43@gmail.com
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 - Brenda Cabrales, RN
PH: (602) 372-1407
email: brendacabrales@mail.maricopa.gov
Physical Therapist - Tracy Carroll, MPH
email: tc Carroll@email.arizona.edu PH: (520) 312-5750

SAN DIEGO HD CLINIC

HHSA, 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 – Krisanto Equipado, RN
email: krisanto.equipado@sdcounty.ca.gov (858) 573-7320

SAN JUAN HD CLINIC

University of Puerto Rico
Medical Sciences Campus
School of Medicine - Dept. of Dermatology
P. O. Box 365067
San Juan, PR 00936-5067
PH: (787) 765-7950 Fax: (787) 767-0467
Primary Physician - Dr. Pablo Almodovar
email: dermatol.rcm@upr.edu
Public Health Nurse - Sonia Santos-Exposito, 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) 520-5000 or (206) 744-5113
Toll Free: (877) 520-5000
Fax: (206) 744-5109

Primary Physician - Dr. James Harnisch

email: jpharnisch@comcast.net

Public Health Nurse – Chinh Tran, RN

email: tranc@u.washington.edu

SPRINGDALE HD CLINIC

Joseph H. Bates Outreach Clinic of Washington County
614 E. Emma Avenue, Suite 247
Springdale, AR 72764
PH: (479)-751-3630 Fax: (479) 751-4838
Medical Director: Naveen Patil, MD, MHSA, MA
PH: (501) 661-2415 (Office) (501) 772-4809 (Office Cell)
Fax: (501) 661-2226
email: naveen.patil@arkansas.gov
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)-422-0190
email: sandra.hainline@arkansas.gov

TEXAS HD CLINICS

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) 819-2010

Public Health Nurse - Claire Keels, RN

email: Claire.keels@dallascounty.org

Houston Department of Health and Human Services

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 – Barbara Martinez

email: Barbarah.Martinez@houstontx.gov

Main: (832) 393-4771 Cell: (713) 582-2517

Fax: (832) 393-5245

Texas Center for Infectious Disease

2303 S. E. Military Drive
San Antonio, TX 78223
PH: (210) 531-4526 Fax: (210) 531-4508

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

Physician - Quatulain F. “Annie” Kizilbash, MD, MPH

PH: (210) 531-4959

email: quratulain.kizilbash@dshs.state.tx.us

Public Health Nurse - Debbie Mata, RN

PH: (210) 531-4576 PH: (210) 531-4295

Cell: (210) 834-9002

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 – Melissa Davis, RN

PH: (956) 423-0130, Ext. 5574

email: Melissa.davis@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

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The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

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

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

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



FACTS ABOUT HANSEN'S DISEASE

What is HD?

Hansen's disease, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr. Gerhard Amanuel 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 non-communicable by killing nearly all the bacilli within a few days, although it takes a number of years for the bacilli to be cleared from the body. This slow process is what can cause a condition known as "reaction," which can cause inflammation of the peripheral nerves, leading to nerve injury, pain, loss of sensation, and muscle atrophy. If not treated promptly, this process can cause deformity and disability.

NHDP SERVICES Website: www.hrsa.gov/hansens