

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

**JULY - DECEMBER
2013
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WORLD LEPROSY DAY, JANUARY 26, 2014



One of Kind Visit —Saint Damien of Molokai

Photo by Henry Law, Story on Page 3

Photo at Crypt: L-R, Tse-Chun (IDEA Taiwan), Alain Schlim (Damien Foundation), Yun-Ming Lee Chang (IDEA Taiwan), Rigo Peeters (Damien Foundation), Magdalena S. Ramirez (IDEA USA), José Ramirez, Jr. (IDEA USA), Parwati Oli (IDEA Nepal), Lieve Hoogewys (Damien Museum), Kofi Nyarko (IDEA Ghana), Zilda Borges (IDEA Brazil), Jean-Pierre Wellens (Damien Foundation), Michael Chen (IDEA China), Hiro Nakayama (Japanese interpreter), Mieko Morimoto (IDEA Japan), Miyoji Morimoto (IDEA Japan), Ruben Boon (Project Damiaan Vandaag).

CONTENTS

July-December 2013 Vol. 64-15

One of a Kind Visit with a Saint <i>José Ramirez Jr.</i>	3
Patients' Library Closes its Doors <i>Elizabeth Schexnyder</i>	4
Programs of La Societe <i>Joseph Steil</i>	6
18th International Leprosy Congress <i>Claire Manes</i>	9
Carville and Dr. Paul Brand Remembered <i>W.C. Lowrey, M.D.</i>	10
My Tryst with Leprosy <i>Jayashree PK</i>	11
Pope Francis and Leprosy-Continued <i>José Ramirez Jr.</i>	13
Trips on Advocacy <i>José Ramirez Jr.</i>	14
Hansen's Disease Clinics.....	15

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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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ONE OF A KIND VISIT WITH A SAINT

By José Ramirez, Jr.

On September 20, 2013, others and I from different countries representing IDEA (International Organization of Self Advocates for Dignity and Economic Advancement) and, affected or impacted by Hansen's disease, were inches away from the relics of Saint Damien of Molokai. This unforgettable experience was made possible by generous planning from members of the Damien Foundation of Belgium, in particular its long time director, Rigo Peeters, who served as our travel hosts and guides.

The bus trip to Damien's home town of Tremelo and Leuven (where he received his education for priesthood and the location of his tomb), Belgium occurred on the day after the end of the 18th International Leprosy Congress in Brussels, Belgium. Saint Damien, who was beatified by Pope John Paul II on June 4, 1995 and then canonized by Pope Benedict XVI on October 11, 2009, has long been considered "the Patron of Leprosy and Outcasts." To those of us affected by this deeply misunderstood disease, he has represented the opposite of sin, the reversal of labels, and a role model for dignity and respect.

Some of us in the group had been present at Vatican City in 2009 when Saint Damien was canonized. I was especially moved when granted permission to be inside the Basilica as the formal process of canonization was initiated by the Pope. Feelings of joy for finally having one of our own arrive at this beautiful home of the masses, and extreme sadness in realizing that my mother, who bore the burden of punishment attributed to my diagnosis, was not able to witness this miracle. Tears engulfed my face with the conflicting emotions. The happiness of this occasion started around the world in 1995 when Pope John Paul II formally authorized the process of sainthood to commence. Pope John Paul II was the first Pope to call those of us affected by leprosy as his "brothers and sisters," so a connection to both Popes became a long-awaited and much welcomed sign of acceptance.

Jozef De Veuster, the birth name of Father Damien, was born in Tremelo, Belgium. The members of the group were able to visit the home built by his father. His father, a farmer and carpenter, ensured that the house would survive the elements for a long time by using brick instead of wood. We visited the room where Jozef was born and sat in the kitchen where he ate his meals and likely prayed with his parents and siblings. Jozef was known to ride the family horse to run errands for the family and swam daily in the river nearby during the summer months. Who would have known that his skills with swimming, horseback riding, farming and carpentry would one day be used to help others and build a one of a kind altar for use on Molokai Island. The simple home also contained the wooden casket originally used in Hawaii for his burial. So, his first and last resonating cries were embedded deep inside the walls of his first home. Before leaving the beautiful town of Tremelo, the group met with the city Mayor and other officials. Their pride in having one of their sons become a Saint was very obvious to all.

Jozef moved to Leuven, Belgium as a teenager to start his education to become a priest. He became a member of the Sacred Hearts of Jesus and Mary. The Catholic Chapel at Carville, deemed holy by many, is named Sacred Heart Chapel. In 1864, before reaching the level of training needed to be ordained as a priest, he volunteered to become a missionary in Hawaii. He did this as a replacement for his brother who had become ill and unable to make the months-long journey. He was ordained a priest in Hawaii and adopted the name of Damien, Father Damien. Nine years later he was to serve as the Catholic priest on Molokai Island. For sixteen years he provided the physical, spiritual and emotional needs of those forcibly isolated and quarantined for life on the island. This government policy existed from 1846 until 1969.

Father Damien died at age 49 in 1889 after contracting leprosy. At the time, those who died were usually buried within a 24-hour period in a simple grave dug into the volcanic rock which formed the peninsula that became a prison for

thousands diagnosed with leprosy. With Father Damien, the members of Kalaupapa Settlement prepared for his death. He was buried in a simple casket but entombed in decorative stone next to St. Philomena, the church he helped to build. This manner of burial preserved his body in a way that surprised those who removed his remains in 1937 for transport to the Sacred Heart Church in Leuven. President Roosevelt agreed to the request from the Belgium monarchy to “return Damien home.” His right hand, the one that guided the building of his church at Kalaupapa settlement, and which provided guidance on where to plant much needed trees for shelter and seeds for food, was left in the original grave.

In 1969, the state of Hawaii decided to ensure that Father Damien’s work at the Kalaupapa Settlement would never be forgotten. The state commissioned a sculpture of Father Damien and donated it to the National Statuary Hall Collection at the U.S. Capitol. The black stone of the statue matches the black stone of his tomb.

Upon entering the basement of Sacred Heart Church in Leuven, the group grew quiet and silently admired Saint Damien’s crypt. The ceiling was specially designed to resemble waves and wonderment. The crypt is made of volcanic stone smoothed to a shiny finish and placed at a slight angle as if to give the impression that he was ready to wake up and walk again. The blues in the background embracing his black and white portrait, and the earth tone walls radiated a serene calming effect to Saint Damien’s room. The earth tone colors were also linked to his work with the soil (food) and wood (carpentry). All of us were immediately awe-stricken by the realization that we were so close to one of our own who earned the label of SAINT.

This journey to visit one of our “brothers”, as described by Pope John Paul II, will forever be in our minds. Pope John Paul II, who also had the birth name of Jozef, like Father Damien, will be greeted by Saint Damien in the Hall of Saints in Heaven when Pope John Paul II is canonized a Saint in April. We hope to see them as our guides when visiting the Hall as tourists after we ourselves arrive in Heaven.

Patients’ Library, US Public Health Service Hospital, Carville, LA—Closes its Doors

By Elizabeth Schexnyder

A lending library for the patient population of Carville has existed from about 1900 until July 30, 2013.

When the patient employment program ended this summer, the hospital library officially closed its doors in the Carville Historic District. The collection, which contained 10,000 books in its heyday of the 1940’s, now consists of 3000 monographs, encyclopedias, reference books and magazines. It circulated library materials to the over 5000 patients who were at one time in residence for leprosy treatment and rehabilitation at the National Leprosarium. In the earliest days, the Daughters of Charity of St. Vincent de Paul managed the library, but patient librarians took over



Reading Room. Patients in the library reading books and newspapers. There were approximately 10,000 books in this library.

the responsibilities of day-in, day-out operation when the hospital was still funded by the State and called The Louisiana Leper Home (1894-1921). The library has been in its current location –a 25 sq. ft. room in the Patients' Recreation Building--since 1940.

The last full time patient librarian retired shortly after turning 100 years old in 2008. Mr. Perry took over as librarian when his wife, also a patient, died 10 years earlier. Enrique was born and raised in the Philippines. He immigrated to the USA's California coast by tramp steamer in the 1920's. Mr. Perry's favorite area of collection development was anything patriotic. He told me that his most prized possession was his US Citizenship papers and which he had framed.

This Summer I began the process of reducing the collection to a manageable selection of 300 or so books. I found 1st editions authored by Ernest Hemingway, John Steinbeck and Pearl Buck. I also discovered a well developed collection of books, and a portrait bust of Sweitzer on the shelves, along a portrait bust by artist Leo Cherne, dated 1955. Some books contain dedication inscriptions by the outside organizations who donated books to the Patients' library over the years –the American Legion Auxiliary and several LSU Sororities, for example. Donations of books by individuals were quite common. One donor in particular, William Richard Verber, must have willed his entire personal collection. I wonder what his association with Carville was. I also discovered that several New Orleans institutional libraries made sizable transfers of inventory—St. Joseph's Infirmary and the New Orleans Veterans Hospital were the best represented.

In the early decades of the hospital patients' checked out books using their names—real or alias—and their patient ID numbers. This changed after the successful drug treatment of the 1940s reduced hospital stays from quarantine for life to a few voluntary months. In the 1960's, staff at the hospital began to check out books from the Patients' Library as well. I surprised a co-worker with his signature on the check out slip of a book dated to 1983!

The library card catalog will also become part of the museum's archives collection, along with the 300+books that will ultimately make the selection. I feel somehow honored, and a bit nostalgic, that I will be the last librarian to close the doors and turn out the lights at the Patients' Library at the National Leprosarium.

P.S. As patient #2855 I checked out many books while a resident at "Carville" for seven years. I loved the quiet time to transport myself to other parts of the world via the words in the many books at the library. There were also newspapers from Baton Rouge, New Orleans and other parts of the state. Occasionally my parents would send me our hometown newspaper, The Laredo Times, and I would read it only at the library. Others enjoyed reading this as the paper also had a section written in Spanish. My visits to the library also gave me an opportunity to share experiences with other residents in a whispery voice so as to avoid the "be quiet" stare of Willen, Mary Ruth, Tom, Emmanuel and the others who served as librarians while I was at Carville. I also learned quite a bit about the history of Hansen's disease, treatment and on-going research by visiting the Medical Library restricted to staff only. This privilege came with my job as Tour Guide and having access to one of the side rooms to show an 8 mm film on the disease to persons who came for one of three daily tours. The many hours I spent at both libraries gave me the knowledge and confidence to speak out against the stigma glued to this disease and to become an advocate for dignity, respect and empowerment.....José Ramirez, Jr.

PROGRAMS OF LA SOCIETE

Joseph Steil, Nationale Directeur Carville Star

“Laugh and the world laughs with you; weep, and you weep alone... If one can keep his sense of humor, and if one can make light of misfortune or hardship, he is better prepared to handle disaster when it strikes”. These were the thoughts of a group of Legionnaires, led by the late Joseph W. Breen, who met in Philadelphia, in 1920 to organize 'La Societe des Quarante Hommes et Huit Chevaux,' the fun and honor society of servicemen and women. We are a fun outfit, but our greatest fun is service. Service to mankind and to children - especially to children.

Most issues of The STAR include an article focusing on the long-term support of the 40&8 to Carville and The STAR. For this issue, I wanted to discuss the other programs of La Societe. Besides Carville Star, our programs are:

CHILD WELFARE: This was our first program established in 1923 to ease the pain and suffering of those children whose fathers never returned or who were unable to care for their needs after the "Big War." Today, this program has grown to include all children with emergent needs, and our efforts touch over 1,300,000 children annually, with an annual investment of over 8 million dollars.



CHARLES W. ARDERY MEMORIAL CHILD WELFARE TRUST FUND: The primary function of the Charles W. Arderly Trust Fund is to provide reimbursements of funds expended by a Voiture Locale or a Grande Voiture in meeting the emergent needs of children 17 years of age or younger. Emergent is defined as: "A situation which has developed of a serious nature demanding prompt attention." This situation may arise out of natural disasters, i.e., floods, tornadoes, hurricane, fire, etc. Emergent cases are given prime consideration and are undertaken by the Local Voiture where established agencies, (Red Cross, churches, welfare, etc.), are unable to move rapidly or cannot act at all. However, this aid is not intended to replace or supplement that assistance which may be available through established agencies.

YOUTH SPORTS: The Youth Sports Program was established in 1994. Through this program, the 40/8 provides financial assistance in the form of grants to individual athletes or teams who lack the funds required to attend and participate in amateur sports programs. This program encompasses all amateur sports programs for all youths from 7 to 20 years of age. The motto of the Youth Sports program is: 'No athlete shall stay home for lack of funds.'



NURSES TRAINING: In 1941 we began issuing Nurses Scholarships to deserving individuals willing to undergo formal training and make a career of that very noble profession. In 1946 an acute shortage of nurses came to the attention of our Voyageurs and a Nurses Training Program was initiated at the Voiture Locale level. In 1955 Voiture Nationale formally established our current Nurses Training Program.

The Nurses training Program is primarily administered by Voiture Locales. There are no fixed guidelines for either the number of scholarships or the dollar value of the scholarships

awarded. Many Locales have established their own guidelines specifying the quantity and value of each scholarship. Every Voyageur is expected to support the Nurses Training Program through the contribution of time, talent, treasure, and/or prayers. Our lives depend on it.

In many cases our scholarships are the critical difference that allows recipients to pursue their studies and go on to receive a nursing degree. We have the satisfaction of knowing that La Société has done a great deal to curb the shortage of nurses in this country. Since our National Program's inception in 1955, La Société as of September, 2013, has expended over \$31,290,000 and assisted 51,900 nurses in obtaining their nursing degrees. In 2013, \$427,304 was donated with 745 nurses in training and 303 nurses graduating. The scholarships not only represent monetary support but also our emotional support and best wishes for success in their noble endeavor to serve us. Knowledge of that helps sustain students during inevitable difficult periods in their curriculum.

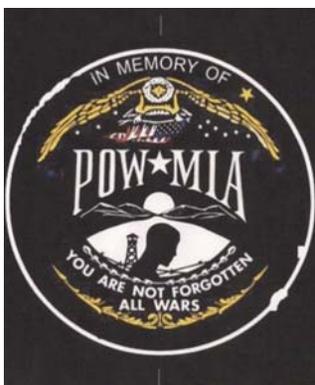
GEORGE B. BOLAND NURSES TRAINING SCHOLARSHIP TRUST FUND: The Boland Nurses Scholarship Trust was founded to provide additional scholarship support to those Voitures Locale who have exhausted their scholarship funds but who still have qualified individuals applying for scholarships. The trust is administered by Voiture Nationale.

AMERICANISM: Voyageurs sponsor various Americanism projects including 'Flags for First Graders,' respect for the flag, and annual Law Officer of the Year and Hero of the Year Awards. Americanism projects, respect for the flag, Constitution, Law and Order and the proven willingness to defend these principles is evident in the day-to-day activities of members of our society.



VAVS (Veterans Affairs Voluntary Service): The Forty & Eight, as are most Veterans Organizations, is an active member and participant in the VAVS program. As part of this program, Voyageurs (called Representatives or Deputy Representatives) represent the Forty and Eight by regularly attending the VAVS Committee meetings at their Local Veteran Administration Medical Centers (VAMC's). They as well as other Voyageur Volunteers visit the VAMC's on a regular basis, where they give comfort and assistance to, or just visit with, the hospitalized veterans. VAVS Volunteers are a priceless asset to the Nation's Veterans and to the Department of Veterans Affairs.

The Forty & Eight has adopted an additional program for these veterans, called "Keep Those Wheelchairs Rolling." Under this program, the VAVS Representative (or Deputy Representative) writes a brief letter outlining a "need" of the patients. These "needs" may cover a project, equipment or comfort and convenience items needed by the hospitalized veterans. The entries are then judged on the need and benefit to the patients, and those selected receive the item(s) requested, courtesy of the National Box Car Association.



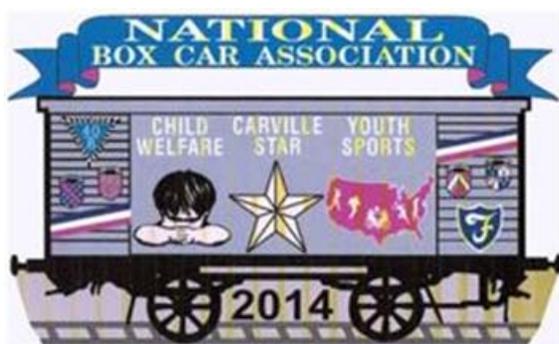
POW/MIA: The purpose of the National POW/MIA Program is to raise funds in Honor of the Servicemen & Women who were Prisoners of War, or are considered Missing in Action while serving in the defense of the United States of America, or its allies during times of armed conflict. The funds are raised to facilitate the formation and continuance of a Scholarship Trust Fund for the direct descendants of verifiable POW/MIA Servicemen and Women. Scholarships are limited to the Veteran, the Spouse of the veterans, children, grandchildren and great grandchildren of the veteran.

NATIONAL BOX CAR ASSOCIATION: In 1947, American newspaper columnist Drew Pearson was so moved by the conditions in war torn Europe that he called on Americans for donations of food, clothing, medical and other supplies to aid the plights of France and Italy. He proposed a plan for a train to cross America collecting car loads of donated supplies as it went.

The “Friendship Train”, as it was called, left Los Angeles on November 7, 1947 with eight empty boxcars. The response from across America was overwhelming and eleven days later on November 18, 1947 the “Friendship Train” arrived in New York with some 700 Box Cars loaded with donated goods worth \$40 million. The supplies were then shipped to the region.

As the aid began to pour in, a French veteran of WW I and railroad worker named Andre’ Picard was so grateful for America’s outpouring of generosity that he formulated a response and joined with the French Veterans Association to reply with a 49 car “Merci Train” of WWI era boxcars, each filled with mementos from the French people and sent to America.

The boxcars arrived in New York Harbor February 3, 1949 and as the “Gratitude Train”, as it came to be called in America, crossed the Nation one boxcar with its contents was donated to each of the 48 States with one shared by the District of Columbia and the territory of Hawaii. Today these “Box Cars” stand in their respective States as a testament to these two incredible displays of goodwill and have evolved through the efforts of “La Societe de 40 and 8” and the National Boxcar Association to annually raise funding to support the many charitable programs of the 40/8 in support of our communities across this great Nation.



The National Box Car Association was founded in 1965 as an affiliate of “La Societe’ de Forty & Eight” with the primary purpose of preserving the Box Car as the symbol of the Forty & Eight. Over time Locomotives were added to the symbolic rolling stock of the NBCA since they were connected and needed to haul the Box Cars.

The National Box Car Association set goals of making contributions to Hospitals, Children’s Homes and Orphanages. Expanding its efforts the NBCA supports special projects at the annual Promenade Nationale (National Convention). A party for special children is held in the host city where the children and their escorts are treated to lunch, train rides on visiting Locomotives, and entertainment by the NBCA HOBBO Clowns and bands, etc. Also a monetary donation is made to the host city’s local VAVS Hospital or Clinic. Other donations go to the National Boland Nurses Training Trust Fund, the Charles Ardery Child Welfare Trust Fund and other programs requiring assistance, such as the National 40&8 Membership Committee, 40&8 Magazine, Law Officer of the Year program, and many others. All funding raised by the NBCA is distributed in the same year it is raised. The NBCA raises funds by selling Crew and Associate Membership Cards. These funds are used at Promenade Nationale to fund the party for special children described above. An additional donation is made to the VAVS Office at the local VA Hospital or Clinic. Any excess funds are distributed to other Programs. All funds collected are completely expended in the year they were raised."

As you can see with these programs and Carville Star, the Voyageurs of the 40&8 are very active in their communities, nation, and the world. Truly we are ‘still serving.’

Reflections on the 18th International Leprosy Congress

By Claire Manes

Pride and passion are operative words for my personal experience at the 18th International Leprosy Congress in Brussels, Belgium, September 16-19, 2013. The congress, held every five years, is open to the interested public and scientists, physicians, researchers, patients, and others dealing with any aspect of Hansen's Disease. Anwei Law, IDEA, knew of my book *Out of the Shadow of Leprosy: The Carville Letters and Stories of the Landry Family* (University Press of Mississippi 2013), the story of my grandfather Edmond Landry aka Gabe Michael and his siblings, patients in Carville between 1919 and 1977. At her suggestion I participated in the Congress. Had she not informed me of it, I would not have known of its existence. Today I stand grateful for her invitation and filled with a sense of pride and passion for my connection with this movement.

I witnessed this same pride and passion in the over 750 delegates from all continents except Antarctica who convened around the congress theme: "Hidden Challenges." There was nothing hidden about the work, passion, and activism of delegates: a cross section of men and women who are part of the Hansen's disease community. Those who live with the

condition united with others representing multiple disciplines in the sciences and social sciences to uncover, face, and alleviate the hidden challenges of HD.

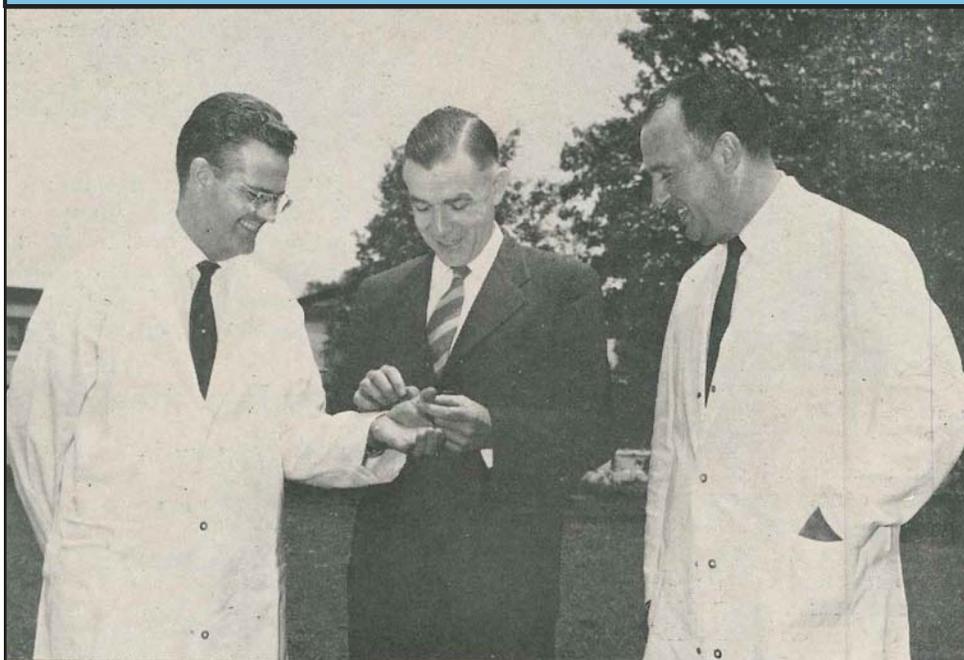
Key note speakers, seminar and workshop participants, and more than 500 E-Poster presenters highlighted the medical research into HD, the social impact of the condition and the efforts of activists to shed light on the truth about HD. There were accounts of people and places where social stigma still exists, but there were also the stories of individual and communal efforts to seek full dignity and opportunity for all. It was these actions that inspired me most: the accounts of those doing research and outreach today and the efforts of those uncovering the errors of past treatment of persons affected by leprosy. I am a latecomer to this Congress, but I have found a place in a powerful community.

The next two Congress' will be held in China in 2016 and the Philippines in 2019. Considering the fast pace changes in the world of leprosy, these international meetings will be held every three, instead of every five years, *At the conference Claire Manes presented her E-Poster "Edmond Landry (USPHSH 1924-1932): An Analysis of One Man's Advocacy as Told Through His Letters."* She also authors the website www.leprosychronicles.com



Carville and Dr. Paul Brand Remembered

By W.C. Lowrey, M.D.



Dr. Daniel C. Riordan, Consultant in Orthopedic Surgery to Carville; Dr. Paul Brand world renowned pioneer surgeon in Hansen's disease; and Dr. Carl Enna, Carville surgeon, display good humor in discussing surgical procedure.

My first visit to Carville was as a senior medical student in the 1950's. I was impressed by the white cottages and multi storied white buildings over a huge area of manicured grass. The buildings were connected by screened and covered hallways. Some patients even rode bicycles in the halls. Later as a hospital surgical resident in the late 1950's I accompanied Dr. Riordan (a world renowned surgeon) on visits to Carville. We would have a clinic and operate on patients. Dr. Brand visited Dr. Riordan in 1960 as he traveled on a full Rockefeller grant. This represented his first visit to Carville. I knew about a patient being seen at New Orleans Charity Hospital Clinic with a partial hand paralysis. I notified Dr. Riordan of this case and he requested Dr. Brand demonstrate his operation on a paralyzed hand. Brand accepted this request and I was fortunate to assist at the surgery.

I had no contact again until the mid-1960's when Dr. Brand was appointed by the US Public Health Service as Chief of Rehabilitation at Carville. We renewed acquaintances and I asked him to speak at our Church. He accepted. On arrival to my home in Alexandria he stated that he had forgotten his white shirt and I was pleased to buy him one. He was most humble as a house guest. I asked him if it was true that he appeared without proper formal wear when Queen Elizabeth of the United Kingdom bestowed an honor upon him. He answered that yes, it was true, and that they immediately clothe him in formal attire for the ceremony.

Dr. Brand was magnificent in the pulpit. He discussed the four hands of Christ: (1) the innocent hand of the child, (2) the working hand as an adult, (3) the praying hand in worship, (4) and the crucified hand. Years later when Dr. Brand retired, I presented him with a four-paneled petit point embroidery illustrating each of these actions.

Dr. Brand was the son of an English missionary to India. Later he was educated in England. He trained for surgery in London during the German bombardment of WWII. After becoming a physician, he returned to India as a missionary and revolutionized the treatment of Hansen's disease. He was the first to recognize the loss of protective pain as the cause of disability in leprosy patients.

Tulane surgical residents accompanied me to Carville for many of Dr. Brand's rather remarkable teaching sessions. On one trip the residents and I were stopped by a truck accident. The vehicle had run into a muddy field in a rainstorm. The medical residents continued on to Carville while I remained until a helicopter landed for the injured driver. He was taken to a Baton Rouge hospital. I was more than an hour late when I arrived for Dr. Brand's session and muddy all over. Dr. Brand clothed me in surgical scrubs. He then did his two hour lecture without notes or slides—very impressive. I returned to Alexandria in scrubs and carried my muddy clothes. Later Dr. Brand sent me a package with a freshly cleaned and pressed tie.

Over the years, I supplied the Carville Rehabilitation Department with amputated limbs for research and training. My wife was most uncomfortable with my transporting amputated frozen limbs to Carville for scientific dissection. She especially worried how we would explain this if ever stopped by a Louisiana State Trooper.

One forearm and hand specimen I delivered to Dr. Brand was from a patient who had lost the extremity after walking into a taxiing airplane. The operation I performed on her saved her life, but could not save her limb.

The last specimen I took to Carville was an extremity of a farm worker. The man lost his arm while separating a stallion from his potential mate. Dr. Brand noted that this was only the second case he had heard of where a stallion bit off a human arm.

I cherished my time from Dr. Brand in the operating room, the pulpit, and especially as a guest in my home. His medical skill, understanding and desire to teach were unforgettable.

I cherished my time from Dr. Brand in the operating room, the pulpit, and especially as a guest in my home. His medical skill, understanding and desire to teach were unforgettable.

My Tryst with Leprosy

By Jayashree PK

The year was 1983. I was 21 years old. I had enrolled for a professional course in accountancy, after having completed my graduation. For a few months I had experienced a peculiar ‘tug’ on the little finger of my right hand. I also noticed a huge glistening pinkish patch on my right arm, around my elbows. My parents took me to meet a skin specialist, who took a biopsy of my skin.

Before the results of the biopsy were known, some intuition, premonition of a doom, forced me to review some medical books at the central library of our city, Coimbatore, India. So prior to having been informed by my family, I already knew that I had contracted leprosy.

I immediately changed from being a confident young woman to one whose world slipped away in a brief moment. From being someone who wanted to speak up, I turned into someone who became voiceless, opinionless and future-less.

My family was devastated too – however they handled the problem in a very compassionate manner. My older sister Shri took charge of my emotional, physical and psychological life by being around me constantly, playing funny tricks, including doing her best to eat out of my plate. She did everything to make me understand that my family was not going to abandon me, and they were not going to allow me to take my own life should such thoughts have crossed my mind.

1983 also happened to be a special year. It was the year that Multi Drug Therapy (MDT) was introduced in our city. Dapsone, prescribed by my doctor was becoming ineffective - my right hand began to develop a claw-like appearance. The patch grew bigger, but my sister again took charge and persuaded my parents to seek a second opinion, therefore we met Dr. David Rajan, an Orthopedic surgeon who put me on the wonder-drugs called MDT.

We did not speak about my situation at home. There was always a silence around all of us. I felt I had lost the right to speak and felt guilty that I was subjecting my parents to so much torture. Soon I was a wreck - with the fear of the disease leaving me anxious and worried all the time. Apart from MDT I was put on anti-depressants and few other medications for a heart-related problem I had developed. I needed valium to go to sleep. The future looked bleak.

In 1987 I wanted to move to Bangalore and I convinced my parents to let me go. Here I had the advantage



Dr. Manimozhi, Mrs. Lusy B, Jayashree P K

of anonymity. No one walked up to me on the road and asked me, ‘Jayashree, what happened to you? Why have you lost weight? Why are you looking so sick?’ I could also avoid looking at the saddened eyes of my parents. I learnt to take care of myself including buying my own medicines whenever I felt there was some ‘germ attack’.

My biggest fear was that of being discovered by my then best friend Chita – when I held her little babies in my arms I felt like an imposter. I was sure that if Chita were to know that I was being treated for leprosy she might have screamed at me and asked me to leave her house, never to return. I felt I needed to keep the secret of what I ‘really’ was, close to my chest. I felt like a liar and an outsider who did not belong anywhere. I lived in a make-believe world where my only hope was to find love with someone also affected by leprosy and start a family.

In 1989 I met Dr. Paul Neelamkavil, who helped me overcome a fear I had of whether I am cured at all. I had been self-medicating myself for years! Dr Paul told me about Sister Mary Masceranhas who was involved in providing rehabilitation services for persons affected by leprosy in a suburb close to Bangalore. His letter addressed to Sister Masceranhas referring to me as “someone who was keen to work with,” left me with a long-lasting impression. Instead I felt happy that I was asked by a man I had met, to whom I had shared about my past illness, to marry him. The marriage, based on gratitude, did not last long.

In 1993 my sister Shri died in a road accident, leaving behind her husband and a four year old daughter, and us, her family devastated. My sister’s death brought one drastic change in me. My sister believed in fighting back. I felt I owed it to her, to be like her. I brought in changes to others’ lives – volunteering for an agency for over 15 years in Life Sciences. Time had moved on - my siblings were married and had families. At last, I too found love. My husband, Jayant Gandhi and I operate a business of training executives of multinational companies. This business success has allowed me the time and financial resources to do leprosy work- this time for real. I am involved in volunteer work for LEPRO and AIFO. I am very grateful to Dr. Mani and Dr. Jose Manikkathan of AIFO for educating me about the great deal of work that still needs to be done. This work includes early diagnosis, education, treatment and the on-going practice of dignity and respect. I believe I was born to work for this cause.

Of course, even during the years that I was being a ‘passive observer’ I kept following up with the stories on leprosy, including studying the statistics on the disease. A few years ago, it seemed to me that without me being involved everything was going well – that the world in general and India in particular has been successful in eliminating this disease. Sadly, the reality is far removed from my earlier assumptions. I would truly like to see the day when Leprosy is cured, eradicated and eliminated from the collective conscience of humanity itself.

A memory from the year 2001 flashes before my eyes. I was reading some stories on leprosy, secretly patting myself that I was being true to what Mahatma Gandhi said, that ‘An ounce of practice is worth more than tons of preaching’, that I am indeed being ‘involved’. When I woke up the next morning and discovered that I had left the materials on leprosy near my bed, I felt I had ‘dirtied’ my bedside by having these documents next to it! Instantly I was shaken up by the irony of it all. The irony that I, a carrier of the disease, was reacting so negatively!

My physical leprosy got cured long ago. However, I was mentally affected by the illness for many decades. Now, I am available to help others like me so that their physical and emotional recovery does not take so long as it did for me.

Pope Francis and Leprosy-Continued

By José Ramirez, Jr.

On March 13, 2013, the papal conclave elected Cardinal Jorge Mario Bergoglio from Argentina as the 266th Pope of the Catholic Church.

As reported in the summer issue of The Star, Pope Francis quickly became popular among the people for his devotion to the poor and rejecting the excesses of Vatican City. However, his preference for using the “L” word, or “leper” as a metaphor to describe things that he deemed as inappropriate or evil (“The court [leaders of the church] are the leprosy of the papacy.”), led to disfavor among anti-leprosy organizations and those affected by leprosy.

On September 22, 2013, he appeared to be diminishing his frequent use of the “L” word when he met with Antonio Este of Cagliari, Sardinia Iglesia Italy. Mr. Este was admitted to the Santissima Trinita Leprosy Hospital in 1950 after having experienced ostracism from society, and loss of sight from the disease. Similar to Saint Francis of Assisi, the name Pope Francis adopted, he hugged and kissed a person affected by leprosy.

The honeymoon did not last long though as Pope Francis once again utilized the “L” word to metaphorically describe something negative and evil, i.e. “careerism is a leprosy.”

Letters were mailed to Pope Francis and his public relations person, Monsignor Federico Lombardi, urging him to cease perpetuating the stigma of leprosy. Letters written included:

“ There is a widespread habit of using the word ‘leprosy’ metaphorically (that leads to) a violation and marginalization (of those affected by Hansen’s Disease).”

*Douglas Souter, Ph.D.
General Secretary
ILEP
London, England*

“.... It is most regrettable that Your Holiness has used the word leprosy as a metaphor for something negative or corrupt. Doing so risks exacerbating all of the old stereotypes about the disease and those (affected) by it”

*Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination
Tokyo, Japan*

“ I believe that you have portrayed those of us affected by leprosyas greedy, selfish and unclean..... you’ve wounded our families.....priests, having been granted permission through your example, are taking liberties to further label us...”

*José Ramirez, Jr.
IDEA and The Star
Houston, Texas*

“... Hansen’s disease is completely curable today...but the disease is disabling because of the cruel stigma... old perceptions of the disease die hard and are reinforced by stigmatizing language.”

Letter signed by persons affected by leprosy from Brazil, Columbia, Ethiopia, Ghana, India, Indonesia, Japan, South Korea, and the USA

All of the letters ended cordially, inviting Pope Francis to celebrate World Leprosy Day on January 25, 2014. Regrettably, Pope Francis never responded to the many letters. However, there is still hope that someday he will. For those interested in sending a letter you can write to:

His Holiness Pope Francis
Apostolic Palace
00120 Vatican City
Rome, Italy

Trips on Advocacy

By José Ramirez, Jr.

In March, 2013, the International Working Group on Leprosy met in Tokyo, Japan. The members, invited by The Center for Human Rights Education and Training, were from Brazil, Egypt, Ethiopia, India, Japan, Sri Lanka and the USA. The purpose of the meeting was to address strategies for the lessening of stigma by distributing correct medical and scientific information with a focus on human interest scenarios. A follow-up meeting was held in Guuma, Japan in August, 2013.

In May, 2013 Vagavathat Narsappa and Guntreddy Venugopal from India and I co-presented with Mr. Yoshi Sasakawa of the Nippon Foundation in Geneva, Switzerland. The presentation was to the UN's International Coordinating Committee for National Human Rights on the global appeal to end stigma and discrimination against people affected by leprosy. The 200 members of the committee voted unanimously to endorse the appeal. The resolution will be presented to the U.N. members in New York City in 2014.

In September, 2013, my wife and I attended the 18th International Leprosy Congress in Brussels, Belgium, courtesy of the 40&8. I presented on "The Star: A Voice for the Unseen" with a focus on the history of Hansen's disease and the 40&8, and how these two organizations partnered to initiate changes. Some of these changes, which influenced global change, included: removal of barbed wire from the fence that shrouded Carville; establishment of a post office; installation of phones for public use; the right to vote; repeal of laws related to quarantine, public transportation, incarceration without due process and marriage.

A second presentation was titled "Love and Leprosy: Images of Pain and/or Comfort" and made jointly with Magdalena as part of a larger panel that dealt with challenges that are thrust unexpectedly upon persons newly diagnosed with leprosy. The general consensus among the presenters and audience was that, while there are some unique ways that persons affected by leprosy can learn to overcome unforeseen burdens, the stigma that continues to live in the community will create roadblocks that can be more difficult to bypass.

A pre-conference seminar titled "Community-based Approaches to Patient Detection and Improving Leprosy Services" was hosted by the German Leprosy and TB Relief Association (GLRA) and the Novartis Foundation for Sustainable Development. The meeting was by invitation only for "leading experts from several organizations and academics." Considering that persons affected by leprosy were not viewed as "experts" or "academics", I challenged this interpretation and received an invitation just days before the session convened. The data presented by researchers from four different countries was interesting but not new to those of us who are self advocates. Kay

Yamaguchi of the Sagakawa Memorial Health Foundation made a statement in reference to how people affected by leprosy, rather than being valued for their practical skills, are instead treated with a type of "tokenism" attitude. I also challenged the group and reminded them that the work with individuals---human beings, did not contain any "hidden challenges" as was the theme of the Congress. Self-improvement has been practiced throughout the ages by persons affected by leprosy, but it is the "challenges" created by others that have prevented the creation of a true and viable collaboration for "community-based approaches."

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HANSEN'S DISEASE CLINICS

ATLANTA HD CLINIC

Emory MidTown Hospital
550 Peachtree Street NE
7th Floor MOT

Atlanta, GA 30308

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PH: (404) 686-5885

Public Health Nurse: Roberta Dismukes, RN

email: roberta.dismukes@emoryhealthcare.org

PH: (404)-320-7668 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. Danielle Miller

email: daniellemiller@lahey.org Public Health Nurse -

Ms. Stephanie Burns, RN, D.N.C. email:

stephanie.a.burns@lahey.org

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

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LAC+USC Medical Center

1200 N. State St.

Clinic Tower A5B123

Los Angeles, CA 90033

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PH: (323) 226-3373

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email: hmora@dhs.lacounty.gov

Occupational Therapist - Rob Jerskey

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MARTINEZ HD CLINIC

Contra Costa Regional Medical Center

Outpatient Specialty Clinic

2500 Alhambra Avenue

Martinez, CA 94553

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email: ssutherland@hsd.co.contra-costa.ca.us

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MIAMI HD CLINIC

Jackson Memorial Hospital

1611 N.W. 12th Avenue

ACC East – 2nd Floor

Department of Dermatology

Miami, FL 33136-1096

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email: Aburdick@med.miami.edu

Public Health Nurse - Gail Chepenik, RN

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NEW YORK HD CLINIC

Bellevue Hospital Center

Department of Dermatology

462 First Avenue, Room 17-N-7

New York, NY 10016

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email: william.levis@yahoo.com

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PH: (212) 562-6096

email: Lydia.Macwan@bellevue.nvchhc.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 - 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@sdcouny.ca.gov

Public Health Nurse – Krisanto Equipado, RN

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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

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614 E. Emma Avenue, Suite 247

Springdale, AR 72764

PH: (479)-751-3630 Fax: (479) 751-4838

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email: lmcghee@uams.edu

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PH: (817) 753-6633 (private practice)

email: sharon.nations@utsouthwestern.edu

PH: (214) 819-2010

Public Health Nurse - Claire Keels, RN

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Houston Hansen's Disease Clinic

Northside Health Center

8504 Schuller Street

Houston, TX 77093

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Other Clinics

HAWAII HD PROGRAM

Hawaii State Department of Health

Hansen's Disease Community Program

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Honolulu, HI 96816

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RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

GET TO KNOW THE FORTY & EIGHT

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

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

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



FACTS ABOUT HANSEN'S DISEASE

What is HD?

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