MEETING OF THE TWO WORLDS, SAME PASSION:

Front: Hong-Sun Woo; Dr. David Scollard, Director of the NHDP.
Back Standing: Irma Guerra, Director of Outpatient Services; Captain John Figarola; Ms. Oh Eun-Jeoung; and Mr. Kim Jonggook
CONTENTS

The Pope is Coming, The Pope is Coming!
José Ramirez Jr.................................................................3

Forty & Eight Activities
Joseph Steil ...........................................................................5

WHO Goodwill Ambassador for Elimination of Leprosy
José Ramirez Jr.................................................................6

New Self-Guided Audio Tour for Carville’s Museum
Elizabeth Schexnyder ..........................................................7

My Journey to the National Hansen’s Disease Program
Hong-Sun Woo .................................................................8

An Inside View of Carville..................................................10

Middle Eastern Regional Symposium
José Ramirez Jr .................................................................11

WHO Issues Annual Leprosy Update..................................13

Forty and Eight Chef de Chemin de Fer and La Societe Leadership
José Ramirez Jr .................................................................14

Hansen’s Disease Clinics.....................................................15

All correspondence concerning The STAR should be addressed to:
Voir Sainte Nationale
250 E 38th Street
Indianapolis, IN 46205-2644

EDITORIAL BOARD
Simeon Peterson - Editor
José Ramirez, Jr. - Managing Editor

CONTRIBUTORS:
Joseph Steil
Irma Guerra
James Krahenbuhl, Ph.D.
Elizabeth Schexnyder, NHDP Museum Curator

Stanley Stein
Founder - Editor, 1941 - 1967

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

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

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

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

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

$2.00 Per Year Domestic
$5.00 Per Year Foreign

National Hansen’s Disease Program
1770 Physician Park Dr.
Baton Rouge, LA 70816
Phone: (800) 642-2477
Fax (225) 756-3806
Website: www.hrsa.gov/hansendisease
As news spread that Pope Francis was venturing on his first trip to the United States a burst of spiritual energy engulfed the community of Catholics. Almost immediately hotel rooms in the Philadelphia area became prized commodities for many of the faithful. Instantly hundreds of thousands were able to forget about the daily challenges of life and instead focused on the announcement that Pope Francis, a head of state and outspoken leader of the Catholic Church, would touch many souls in the United States.

The love for Pope Francis commenced as soon as he chose the name of Saint Francis, an advocate for the poor, hopeless, and the “lepers”. On the latter topic, there is a unique history on how this issue became such a special cause for Christians. The apostles were granted the power by Jesus to cure those with leprosy. Later, others canonized as saints routinely followed what is now known as non-discriminatory practices of those different than the majority, especially those with leprosy.

Pope Francis regrettably has used the word leprosy to refer to all that is bad in the world and has jeopardized the contributions made by some saints. He also has managed to resurrect the stigma closely linked to leprosy that began centuries ago. The Pope should be informed by his advisers in the U.S. that this stigma must stop, and one way to relay the message is via the written word. One of these messages should be on how many saints have positively reinforced the true Christian belief that all of us are God’s children. These saints have included Lazarus, Aegidius (Giles), Sylvester, George, Francis of Assisi, Vincent, Damien and Marianne Cope.

In 1987, Carville’s Hospital Chaplain, Rev. Raymond G. McPherson wrote an article for the December issue of The STAR titled “Biblical Leprosy vs. Present Day HD.” In the article he describes those newly diagnosed with leprosy arriving at Carville were psychologically impaired as there was “conflict in the mind and spirit of the patient.” He attributed this to the trust we generally have in physicians or authorities in medicine, and the strong religious faith common among most persons. In essence, the diagnosis of leprosy as confirmed by a physician means that biblical references to “lepers” or outcasts and sinners must mean verification of both, and God is now punishing them with leprosy.

Rev. McPhearson and many others have quoted Dr. Stanley G. Browne on his research titled “Leprosy in the Bible” to dispel the myths surrounding the word leprosy. According to Dr. Browne, the words “leper” and “leprous” are Hebrew translations of Tsara’ath, meaning any type of surface blemish caused by uncleanliness and thus stigmatized.

This scholarly explanation does not diminish the image that most people have of leprosy. The word “leper” is used throughout the bible and has such prominence that no other disease is thought of by the general populace.

For Christians, there are two Lazarus. One was resurrected by Jesus and the other was a “poor leper” adored only by dogs, licking his open wounds caused by leprosy. It is the latter who overcame his homelessness to build hospitals for those affected by leprosy. These facilities became known as Lazarettos.

Aegidius, better known as St. Giles, was accidentally wounded by the King of France. Aegidius lived as a hermit and was reportedly nourished back to health by milk from a mother’s breast. The king founded a monastery on his behalf as compensation for the accident, and Aegidius used the facility to house and care for those banished from their communities due to leprosy. He also became known as the protector of mothers who breastfed their babies. One of the leprosaria in England was called simply St. Giles and I had the opportunity to visit there in 2001 before it closed.
Emperor Constantine of Rome was persuaded by Bishop Sylvester to convert to Christianity. This reportedly occurred after St. Sylvester cured him of leprosy.

St. George is deemed the patron of several European countries and of various diseases such as herpes, skin diseases, syphilis, and leprosy. The patron of sexually transmitted diseases likely gave rise to the erroneous belief that leprosy is sexually transmitted. St. George is linked to the “Golden Legend” whereby he allegedly kills a dragon that ate young women.

Francis of Assisi was never ordained as a priest but he thoroughly followed the teachings of Christ. He was born into a very wealthy family but he devoted his adult life to helping the poor, nursing those affected by leprosy and caring for orphaned animals. He became known as the patron of animals and the environment.

St. Vincent de Paul was a man with little patience for protocol. He was probably influenced by his eccentric life which included living among the poor, and unaccepting of things deemed a luxury such as a comfortable bed. He also was a slave to a group of Turks, freed after converting to Christianity, became a priest and arrived in a town abandoned by its residents because they feared one of its citizens had leprosy, whom he cured and the townspeople returned. Additionally he helped the King of France overcome an infection from a sword wound, becoming the Chaplain of the Royal Court. He became the patron of the sick, prisoners, charitable workers, and “lepers”. He started the Order Daughters of Charity, focusing on nursing the sick. Ironically, the Daughters of Charity volunteered to work at the Louisiana Leper Colony in 1894 and the Order stayed until 2005 at the leprosarium known throughout the world simply as Carville.

St. Bernardino of Siena cured a person with leprosy by giving him his sandals and restoring the feeling lost by leprosy from nerve damage. Carville was one of the first places in the world to creatively design footwear to displace pressure on slowly healing ulcers common among many persons affected by leprosy.

St. Damien was the son of a farmer/carpenter from Belgium. He was attracted to the priesthood by his Catholic parents. He started his studies at an early age, as did his brother. His brother was assigned to take over as priest at a church in Hawaii but became ill and was unable to accept the assignment. Damien persuaded his superiors to go in place of his brother though he was not yet ordained. Once in Hawaii he completed his studies and was ordained a priest, becoming known as the priest on horseback as he traveled the island. He overcame bureaucracy challenges and became the priest at Kalau-papa (leprosarium) on Molokai Island. He helped the patients with emotional and food nourishment (farming) and shelter (homes and church). He became an international figure and used his written and verbal skills to change the culture of Hawaii whereby the state now is working on a memorial for the 8,000 who died at Kalau-papa. I have visited his church at Kalau-papa, was present for his canonization on October 11, 2009 and visited his birthplace and tomb in Belgium in 2013. When Damien was canonized I thought, “Who would have thought that one of us affected by leprosy would be welcomed in such a royal manner at the Vatican!”

Sister Marianne Cope was born and raised in Syracuse, New York, becoming the 11th American canonized a saint on October 21, 2012. Saint Marianne of Molokai was a nurse by training and an excellent administrator by necessity. She was able to decrease the number of infections associated with hospitals in the late 1800’s by demanding proper hygiene among its staff; started training medical students, and her efforts became part of the College of Medicine at Syracuse University; and accepted a challenge from Father Damien to use her skills at Kalau-papa. She arrived with six other sisters in Kalau-papa several months before Father Damien died and stayed for 35 years. I have been fortunate enough to have visited the church in Syracuse where she received her training and took her vows.

With The STAR being circulated to over 165,000 readers throughout all 50 states and 154 foreign countries, surely one of us can deliver our battle cry to Pope Francis. Dearest Pope, please stop comparing leprosy to all that is bad in the Vatican Court, with those who care more about their careers than the faith, and with sexual abusers of children. Those of us affected by leprosy have been symbolically declared “the living dead”. We do not wish to metaphorically be the “sinful dead”.

The Star * July - December 2014 — 4
The Promenade Nationale is the Forty & Eight's national convention. It is a time of renewed fellowship and election of new national officers. The 95th Promenade Nationale was held from 11–15 September 2014 in Virginia Beach, Virginia. Some of the activities include a Children's Party for disadvantaged children by our Boxcar Hobos, updates on our programs including Carville Star, Americanism, Nurses Training, Child Welfare, POW/MIA, VAVS, and Youth Sports, and presentation of Americanism Award, Hero of the Year Award, and Law Officer of the Year Award.

The finale of Promenade Nationale is the election of officers for the upcoming year. Our new Chef de Chemin de Fer (National Commander) is Mike Wood. He should be familiar to long-time readers of The Star as he was the Carville Star National Directeur from 2006-2008. Mike was and is a real Hansen’s Disease advocate. He was instrumental in the procurement of the monument for the Carville Cemetery that lists the names of patients buried at Carville from 1895 to 1922. This monument was dedicated in February 2009 with over 100 people in attendance and 8 distinguished speakers. Mike also arranged for individuals affected by Hansen’s Disease to visit and speak at local 40&8 chapter meetings in California and Texas. He has also served as National Directeur of Membership and of Child Welfare. Mike should be a great Chef de Chemin de Fer, and we look forward to the upcoming year.

Besides our continued support of The Star, the 40 & 8 will help fund the creation and installation of interpretive signs highlighting significant landmarks in the Carville Historic District. The 40 & 8 has pledged support for the purchase of these interpretive signs, and we will work diligently to make it happen this year.

The Voyageurs of The Forty & Eight, along with the outstanding support from the Dames of La Societe de Femme, are proud to have supported The Star from 1943 to the present. From the original presses and type setters, to the new modern full color format that is also available electronically, the Forty & Eight is ensuring that the research on Hansen's Disease is distributed around the world.
It is often said that children never forget their parents, and for boys it is their father. At age 75, Yohei Sasakawa is no longer a little boy, but a man who has grown wiser with age. He has followed in his father’s footsteps, attacking stigma, challenging the United Nations to end discrimination against persons affected by leprosy, building rapport with others to restore human dignity to all with disabilities.

Mr. Sasakawa’s father established the Nippon Foundation in 1962, a private non-profit foundation with a mission to carry out philanthropic activities. Mr. Sasakawa had a great teacher, becoming a trustee of the foundation in 1981 and Chair in 2005. In his role as Chair he travels the globe, monthly visiting former or current facilities used to treat persons with leprosy. He inspires others with his charisma and energy, motivates many to move forward with their lives by providing funding for education, training, medicine, and forges ahead in the on-going battle to end the struggle against stigma.

Mr. Sasakawa has numerous honors from many countries, but he reminds his loyal staff that the greatest honor has been the opportunity to serve those affected by leprosy. One of the many places he has visited was the National Leprosarium at Carville, Louisiana.

The Star wishes Mr. Sasakawa continued energy in our joint effort to restore the dignity and respect stolen from persons affected by leprosy, a grossly misunderstood disease. In 2015, Mr. Sasakawa will commence the 10th anniversary of the Global Appeal effort. This is comprised of a signed document committing to the Global Appeal to end stigma and discrimination against persons affected by leprosy. Some Signees have included President Jimmy Carter, Dalai Lama, Desmond Tutu, Rabbi Yona Metzger (Chief Rabbi of Israel), Cardinal Archbishop Rosales of the Philippines, Sir Richard Branson of Virgin Management, the International Bar Association, The World Medical Association, Chancellors of Universities throughout the world and persons affected by leprosy.
To give the Carville Museum visitor the best possible overview of our site history and Hansen’s disease, a new feature has been added to enhance their experience, the audio tour.

The self-guided audio tour was launched the first week of November. All visitors, from the young and tech-savvy to the seasoned seniors, have found the hand held wands easy to use.

At the moment, there are 47 audio stations offering visitors information about the artifacts on exhibit and background history of Carville’s leprosy hospital. The wands have the capacity to record, store, and playback up to 200 different audio clips. The tour can be played back in sequence or the numbers selected randomly, as the visitor prefers.

To activate the tour, a visitor simply pulls a wand from the base unit, and presses the audio station number on display into the wand keypad. This activates an audio recording. The audio descriptions are from 1 minute to 2 minutes in length. Some of the topics covered are an overview of Hansen’s disease, Louisiana Laws relating to Leprosy, Daughters of Charity, and Patients’ Stories. After completing the tour, the wand is reinserted into a base where it recharges before its next use.

There are 10 wands in the set, which gives up to 10 individual visitors access to a self-guided tour simultaneously. The audio is easy to hear with the wand held close to the ear, like a telephone, but does not interrupt other visitors as they view the exhibits.

The museum has recently hired a part-time assistant who is bilingual. Juliana Benitez, who began working at the museum in September, speaks Spanish as a second language. Julie also currently aids the National Hansen’s Disease Programs Social Services Department with Spanish translation.

The museum tour translation process will begin shortly. After translation, Julie will record the Spanish language tour. Then the Spanish tour will be loaded into the audio wands so that each station offers Spanish, as well as English, audio interpretation.
I went to the United States on my third trip, and my first to the National Hansen’s Disease Program (NHDP), December 7-11, 2014. Accompanying me on the trip were Mr. Kim Jonggook, Deputy Director of AIDS, HIV, and HD and Ms. Oh Eunjeong, Director of HD, Korea Center of Disease Control (CDC).

Since my discharge from the South Korean Navy as an officer, I have travelled around the world and had opportunities to meet many people of diverse backgrounds and learned very much from them. The journey to the NHDP was of special significance as two of my fellow travelers represented a highly regarded government agency in South Korea, and they were specialists in the field of Hansen’s disease.

My initial reluctance on making the trip to the NHDP was based on the length of the journey. The long flight of 14 hours to New York’s JFK airport, plus an additional 2 ½ hours to New Orleans and a one hour drive to Baton Rouge, Louisiana reminded me of my previous promise to my body not to take another long trip again. However, I put my fatigue aside and instead focused on the journeys taken by those affected by HIV and HD. I realized that with the help of my Lord, and Savior Jesus Christ, this trip was possible.

We arrived in Baton Rouge on the day that the United States celebrates Veteran’s Day, and everything was closed so we tried to recover from jet lag. On our first day of the tour we were introduced to Navy Captain John Figarola who is always with a smile on his face. His rank and service was similar to mine so this was a pleasant surprise. Captain Figarola escorted us to the laboratory research branch at Louisiana State University. With a greeting to Dr. Richard W. Truman, chief of lab, we were introduced to the armadillo (not seen in Korea), the only living mammal sharing the same genetic strain of HD as human beings and thus a good animal for experiments in preparing future mutation viruses that evolve from the bacteria of HD.

One of the sites we looked forward to touring was the national leprosarium which operated from 1894-1999 and is now named Gillis W. Long HD Center located in Carville, Louisiana. José Ramirez, Jr., former patient and now HD advocate arranged for the visit but was unable to travel from Houston, Texas. Today only 2 persons affected by HD live at the facility and are cared for by medical staff. Some in Korea view the care of so few by the government as a waste of money, but the persons were admitted at a young age and now call the facility “home”. The former leprosarium, a self-contained community, is now operated by the Louisiana National Guard for training of adolescents experiencing challenges in school. The Guard takes care of the infrastructure, including the cemetery embraced by large pecan trees and a decorative wrought iron fence.
We were very impressed with the HD Museum on the grounds of the former leprosarium. The museum was filled with artifacts and stories of those who endured life-long separation from society. My desire is to build a similar museum on the HD experience in Korea.

In 2005 the Korean Federation of Hansen’s Association, an organization of persons affected by HD, lobbied for legislation to closely exam the truth of HD-related incidents. Since its proposal in September, 2005, the legislation was introduced to the Korean National Assembly Full session and passed on October 17, 2007. The reason for this enactment is that in the past those affected by HD have been discriminated against due to extreme stigma. Many were forcefully hospitalized at accommodations such as the National Sorok Island Hospital. Segregated and denied of their basic human rights, they were imprisoned, abused, forced to do harsh labor, and sterilized. In addition, severe stigma against HD patients gave rise to a horrible massacre on Sorok Island, followed by incidents of bloodshed on Bitori Island. The slaughter of 84 patients in 1948 was carried out by staff and security officers over a management dispute.

Over 50 years have passed since these incidents took place but the Korean Government agreed to a very special mandate in the legislation of 2007…the building of a memorial hall in tribute to the victims of HD. Now the government claims a lack of funding for not following up on this mandate. This is an example of both discrimination and disregard for those affected by HD in Korea, and not respecting the rule of law.

After the tour of the museum we met with the NHDP management staff. The group realized that we have a common theme in advocating for a productive use of former facilities used as leprosariums, such as nursing homes. I suggested that we start an international discussion on the issue. Dr. David Scollard, the director of NHDP recommended that Korea could be the country to host such an international workshop for attacking this problem in 2016 after the 16th International Leprosy Congress in China. Such a meeting would help in providing a meaningful start for discussing other options for the effective use of former leprosariums as they become empty. I agreed to initiate an effort, in consultation with Korean government officials, to host, discuss and hopefully resolve these issues. I also learned that all the staff at NHDP are humble, devoted and integrated to work for those affected by HD, and making a world without HD a manifest reality. The three of us from Korea learned very much from this visit, felt pleasantly overwhelmed with the agenda organized by the NHDP staff, and greatly enjoyed their welcome meal called gumbo with white rice -- a mix of vegetables, sausage, sea food and plenty of spices.

My journey in helping those affected by HD in Korea has not yet peaked. I have much more to learn from others around the world. This trip was one that will help to close my gap of knowledge about HD. This journey and others to come will give me the insight to think creatively and propose new ideas to assist persons affected by HD.
Dr. Barbara Michiels Hernandez, a professor and graduate coordinator at Lamar University in Beaumont, TX, visited the Carville museum and The Gillis Long Medical Center in Baton Rouge on a research grant from the university three times in September and October, 2014. Dr. Hernandez is a native of Alexandria, Louisiana and knew of Carville as a child. Her interest was piqued when reading about the 1999 events and decided to pursue a grant to do historical research on a famous worldwide facility in Louisiana that changed the way that Hansen’s disease was treated and viewed. Previously, in 2009, Barbara and 3 graduate students received a grant to access archival materials at the Carville museum and published a journal article that was entitled: The Legacy of Carville: A History of the Last Leprosarium in the U.S. in November, 2009 in the Journal of Health Studies, edition 24 (2), pages 314-325. Dr. Hernandez also supervised a published Master’s degree thesis by Gincy Thomas in 2010 on: The Rehabilitation of Hansen’s disease: historical review of medical & psychosocial treatment interventions of adult patients at Carville, Louisiana from 1894-2009. This new research, currently in progress, will be 3rd project the by Dr. Hernandez on Hansen’s disease at Carville.

The purpose of this recent research, entitled: An Inside View of Carville: Oral Histories of Patients and Staff from the Last United States Leprosarium was to transcribe, verify, summarize, and publish a research article from patient/staff digital video/audio oral and transcribed histories. The subject of Hansen’s disease stigma, human rights discriminations, experimental medical trials, and other classifications determined by the investigator occurring at Carville, La., the last leprosarium in the U.S. will be the focus of this research. Dr. Hernandez is assisted by Ms. Carrie Burns, a graduate student at Lamar University. Seventeen oral histories were reviewed from those archived and only available on site at the National Hansen’s Disease Museum at Carville and the National Library of Medicine in Washington DC. The authors interviewed 7 additional patients and staff, creating oral histories for future transcriptions and use in the published article. The transcripts and newly recorded oral histories will be donated to the Carville museum. In the study of historical research, when recorded oral histories are subject to historical scrutiny, a secondary source becomes a primary source. The oral histories and transcriptions will be validated using historical methods research analyses of the eye witness transcribed print and oral history interviews. The story of the patient and staff views of medical treatments and societal issues within the national leprosarium needs documenting for historic preservation. The investigators will now analyze the transcripts and determine the selection of these for a research article that will be submitted for publication. The written summaries will chronicle eye-witness accounts transcribed into print medium. This will be a manuscript that documents and disseminates the unique personal histories of Hansen’s disease patients and staff at Carville.
On October 20, 2014, individuals affected by leprosy from Middle Eastern countries, and others met in Rabat, Morocco. Over 100 persons came together to address issues related to the violation of human rights of persons affected by leprosy.

This event was jointly hosted by the Kingdom of Morocco, Ministry of Health, and Yohei Sasakawa, Chair of the Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination. The symposium was one of four (Brazil, India, Ethiopia), held in conjunction with meetings by the International Working Group (IWG) on Leprosy and Human Rights chaired by Dr. Yozo Yokota, President of the Center for Human Rights Education and Training based in Tokyo, Japan.

The symposium in Morocco included three major components. The first was on “Medical and Social Aspects of Leprosy”. One of the presenters was Dr. Barbara Frey, describing the “Implementation of the Principles and Guidelines to Eliminate Discrimination against Persons Affected by Leprosy”. Dr. Frey is a member of the IWG and Director of the Human Rights Program at the University of Minnesota.

The second was on “Leprosy and Women: The Need for Empowerment Through a Human Rights Approach”. The distinguished panel of women was expertly moderated by Támara Biole Soares, Director of Human Rights and Justice in Brazil. The panel included Alem Galeta, President of the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL); Shahira Amin, correspondent from Cairo, Egypt; Azzouzi Naima, President of the Morocco Association of People Affected by Leprosy (APAL); and Magdalena Santos Ramirez, clinical social worker from Houston, Texas. The presenters enlightened the audience with unique perspectives and strategies on the empowerment of women.

It is commonly known in the world of leprosy that even though the disease affects twice as many men than women, it is the women who experience the greater degree of stigma. A combination of myths have merged to create the impression that a woman affected by leprosy is undesirable: alleged carrier of a sexually transmitted disease and thus promiscuous; and giving birth to a child ill with leprosy. A way to overcome such prejudice is to teach women affected by leprosy about the techniques of self-empowerment, and to educate businesses, organizations, foundations and society in general to participate in empowerment opportunities for these beautiful and talented women who have learned to overcome huge challenges.

The session was particularly moving as it was attended by up to 20 persons affected by leprosy, mostly women, who were citizens of Morocco. These individuals were interviewed by the media and most acknowledged that they had never publicly spoken about their diagnosis, much less attended a meeting where other women were the speakers. King Mohammed VI of Morocco is a strong advocate for services to persons with disabilities, but HD is one of those diseases still swelling with stigma and discrimination.

The third session was on “Preservation of History- Tangible and Intangible”. Moderating the panel was José Ramirez, Jr., clinical social worker, managing editor of The Star and USA Coordinator for IDEA (International Organization for Dignity and Economic Development). Serving on the panel were Professor Abdalhak Sakkat of the Instruction Military Hospital Mohammed V; Dr. P.K. Gopal of India; Artur Custudio Moreira of MORHAN in Brazil and Fumihiko Takayama, non-
fiction writer. The audience was reminded that the preservation of history has a two-fold effect. One, is to serve as a reminder that injustices, such as those experienced by persons affected by leprosy, should not be duplicated in the future. Two, is to preserve the culturally iconic places such as the thousands of prison-like facilities throughout the world used to isolate those deemed “outcasts”. Both can become a reality via efforts to engage in the United Nations World Heritage Sites Program. This program stops the threat of demolition and forgetting, and opens the door for funding to renovate and maintain these sites as museums.

It was the general consensus of the presenters that the history of leprosy is a very important part of the world: negative consequences of stigma, the cruel separation of families geographically, and the forced loss of identity. These conclusions were not unique to a gathering such as this one, but it represents one more battalion fighting the war on stigma.

Stigma, an act of labeling, rejection or unexplained fear of a person, has not lessened in intensity throughout the centuries. This is a phenomenon that is counter to the decrease in new HD cases throughout the world. A minus (-/ of new cases) should not equal a plus (+/ of stigma). This is a profound example of an oxymoron.

An example of preserving history occurred when speakers at the symposium and other guests traveled to Casablanca to meet with staff operating the National Leprosy Programme, and visit one of the remaining leprosy hospitals in Morocco, Ain-Chock Hospital.

Based on written manuscript, it is known that the word “leprosy” did not exist in Berber, the origins of Morocco. It was not until 722 when the Arabs founded the town of Sijilmassa is the word mentioned in manuscripts, describing persons affected by leprosy working in emptying cesspits. Obviously, our brothers and sisters of ancient time were stereotyped and not deemed worthy of a more distinguished form of work.

Manuscripts linked to El Ouazzani (Léon the African) refer to leprosariums in Marrakech (South) and Fez (middle of country), in the sixteenth century. These leprosariums were considered some of the “best run” in the Middle Eastern countries. Treatment at the time consisted of proper hygiene, sulfur baths and the application of residue from the Smilax aspera plant.

Not until the 1920’s-1950’s were efforts undertaken to identify and isolate persons affected by leprosy, locating them in hospitals in Fez, Casablanca and Marrakech. Fez is like a unicorn of communities. It has the high walls of ancient cities, narrow and meandering passages filled with people selling their crafts, and donkeys resting in a stall at the travel inn or hauling merchandise and wool to market. This old city is embraced by a 15 foot wall originally built for protection and now allows visitors to envision a walk into ancient times. The other part of the unicorn is the modern city with high rise apartments, beautiful boulevards and multiple universities that render free education to Moroccans.

In the 1960’s there were 360 beds available at leprosy hospitals for persons diagnosed with the disease, with Ain-Chock having 216 beds. Currently, Morocco has less than 20 new cases diagnosed annually. However, the level of disability is considered grade two, or with loss of sensation, disability of the hands and feet, and foot ulcers. This level of disability, according to the Morocco National Leprosy Programme is due in large part to the stigma associated with the disease and thus avoidance of health officials and treatment.
WHO Issues Annual Leprosy Update

Fourteen countries accounted for 96% of new leprosy cases in 2013.

In its annual round up of the global leprosy situation, the WHO’s Weekly epidemiological record for September 5, 2014, revealed that 215,656 new cases of leprosy were reported in 2013, down from 232,857 in 2012.

Of the total, India contributed 126,913 cases, Brazil 31,044 cases and Indonesia 16,856 cases. Between them, these three countries made up 81% of all new cases of leprosy.

A further 11 countries reported a thousand or more new cases. They were: Ethiopia (4,347), DR Congo (3,744), Nigeria (3,385), Nepal (3,225), Bangladesh (3,141), Myanmar (2,950), Tanzania (2,005), Sri Lanka (1,990), Philippines (1,729), Madagascar (1,569) and Ivory Coast (1,169).

The top 14 reporting countries together accounted for 96% of total leprosy cases in 2013.

In an editorial note, the WER noted that new cases have plateaued in the range of 245,000 to 215,000 between 2009 and 2013, and that “greater and more focused attention to the problem by all stakeholders is warranted.”

It also stated that of new cases, 13,289 had Grade 2 disabilities, “which reflects low awareness about leprosy in the community and sub-optimal capacity of health systems to detect the disease early.” Furthermore, 9.2% of new cases were in children, indicating continuing transmission of the disease. The target envisaged by the current global strategy for leprosy 2011-2015, that of reducing the rate of Grade 2 disabilities in new cases to 35% of that in 2010, “does not yet seem to be within sight,” it said.

Reprinted from the WHO Goodwill Ambassador Newsletter.

The tour of Ain-Chock was jointly provided by staff from the National Leprosy Programme and members of the Morocco Association of People Affected by Leprosy (APAL).

Ain-Chock Hospital is located on a busy boulevard in Casablanca surrounded by small businesses and a residential area. The facility is embraced by a ten foot fence with broken glass on the top, and has a heavy iron gate with a width sufficient to accommodate only one vehicle to enter at a time. The site is no longer used to forcefully isolate persons affected by leprosy, but instead used as a temporary home for persons free from the bacilli and in need of foot care and other rehabilitative services.

The facility is made of cinder block covered with stucco and painted white, as most buildings are in Casablanca (White House). The windows have sky blue panels that are in disrepair and with peeling paint. Many of the buildings previously used for X-rays, surgery, and recovery are now non-functional due to a combination of decreasing number of new cases and lack of funds. The narrow road meandering around the premises has pot holes with tall weeds on its borders. Abandoned among the uncut grass and tall weeds was a wheelchair, symbolic of how society throughout the world, and leprosy, can physically, emotionally, and spiritually disable a person affected by a tiny but cruel bacillus. Members of APAL shared a dream of turning this large facility into a combination museum and treatment center for both the community at large and persons affected by leprosy.

Hope was not lost among the ten patients at the facility with clean and comfortable beds recovering from open ulcers or awaiting a new prosthesis, receiving services from caring staff. Hope was also not lost among the four members of the APAL who helped to conduct the tour of a facility once brimming with many fellow Moroccans. Hope was not lost among the guests who were glad to have partially contributed to the lessening of stigma related to leprosy by speaking at the Symposium and engaging the media in attacking myths associated with leprosy.

All who traveled to Morocco during October of 2014 were very grateful for the warm welcome and hospitality offered by the Kingdom of Morocco, Ministry of Health, National Leprosy Programme and members of APAL.
In 2005 my wife and I met Mike Wood for the first time. He was accompanying the Carville Star National Directeur and basically learning the unique duties of this position, which he held from 2006-2008.

My wife, Magdalena, and I had gone to the Gillis W. Long HD Center at Carville, La. to pay our respects to our friends at the cemetery. So many souls close to our hearts remained forever in the home chosen by the laws of stigma.

During one beautiful spring day, we joined Mike and his colleague from the Forty and Eight for lunch. The place we chose was located on a narrow road parallel to the Mississippi River and several miles from the HD Center. This place, nestled amongst giant pecan trees and known by many for its Cajun cuisine, seemed like an ideal place to introduce Mike to the wonders of South Louisiana.

As we settled into our uneven chair and a well-worn dining table, Magdalena encouraged the two from the Forty and Eight to choose something they had never eaten before. As our wait person took the orders, Mike appeared perplexed. The orders we placed included crawfish, seafood gumbo, red beans and rice, catfish, etc. Mike calmly scanned the menu and ordered a hamburger with fries. After a few moments of silence, we all started laughing at the irony of eating a hamburger at a restaurant known for Cajun food.

Mike has learned a great deal about regional food since that day in 2005. As he travels throughout the United States as Chef de Chemin de Fer we are confident that he will not order hamburgers at every stop, but that he will certainly talk about and spread the word about his theme for 2015, “What can I do?” We at The Star salute this wonderful man and wish him great success on his journey as Chef de Chemin de Fer, and invite him to try the spicy crawfish on his next visit to Louisiana.

Mike’s colleagues on La Societe Leadership will be Diane Carignan, Grande de Michigan and La Presidente Nationale; Bernie Sampson as Correspondent Nationale; Rene Vanmulem as L’Editeur Nationale; and Joe Steil, Carville Star Nationale Directeur.

The Forty and Eight and its members have been financially and spiritually supporting The STAR since the 1940’s. Without their support and generosity, The Star would not have BFF’S (Best Friends Forever) like Mike, Diane, Bernie, Rene and Joe. From a one page mimeographed sheet called 66 STAR, to a monthly journal called The STAR distributed throughout the world, to a biannual publication still mailed globally, the Forty and Eight has made a major contribution in the education of the misinformed about Hansen’s Disease. A big MERCI to all its members. Have a great new year in 2015.
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 for 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.

FACETS ABOUT HANSEN’S DISEASE

HANSEN’S DISEASE

or leprosy, is a chronic disease that affects the skin, nerves, and other parts of the body. It is caused by a bacterium called Mycobacterium leprae. The disease is usually spread through close contact with an infected person. Symptoms can include skin changes, nerve damage, and sometimes other issues. The diagnosis is usually made through skin biopsy and laboratory tests. The disease can be treated with medications such as dapsone. The disease can be prevented by avoiding close contact with infected people. The Forty & Eight is an honor society of veterans created in 1920.