

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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Dr. Yo Yuasa (1926-2016)

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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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Remembering Dr. Yo Yuasa (1926-2016)

By Kay Yamaguchi

Dr. Yuasa, who had served as executive and medical director of Sasakawa Memorial Health foundation (SMHF) from 1975 to 2005 and as advisor till 2012, passed away on September 7 in Kyoto, Japan at the age of 90. He spent more than forty years of his professional career for leprosy in order to free humanity from suffering of leprosy.

Dr. Yuasa first encountered with leprosy in 1946 when he visited Aisei-en leprosy sanatorium located in Nagashima island in the Inland Sea region of Japan. He was 20, had returned from US, and was recovering from Tuberculosis. As he had spent some time in TB sanatorium both in US and Japan, wanted to find out about the life in leprosy sanatoria. At Aisei-en he met a leader of patients' association, Mr. Shigeo Suzuki (alias Fumio Tanaka). Later in 1956 Dr. Yuasa was asked by Mr. Suzuki to come to his sanatoria, where the only high school in Japan for young patients had been opened. Accepting invitation he stayed in the sanatorium for several months and helped students with English for college entrance exam. One of them was Mr. Miyoji Morimoto, who later established IDEA Japan and continues to be active in fighting injustices. Soon after, Dr. Yuasa was asked to help organize the 7th International Leprosy Congress held in Japan in 1958. He worked as a liaison between the Japanese Leprosy Association and its International counterpart, ILA. This brought him into close contact with prominent leprologists and scientists of those days from around the world, including Drs. Wade, Muir, Ross Innes, Jagadisan, Follereau and many more. After the congress, he single-handedly edited its proceedings, which equipped him with a comprehensive knowledge of leprosy and its up-to-date topics and challenges. Thus it was natural for him to gear his intended medical career towards leprosy.



Dr. Yo Yuasa in 2001



May 1996 Dr. Yuasa with Mr. & Mrs. Morimoto and Kay Yamaguchi—formerly Board Member of Sasakawa Memorial Health Foundation (retired in March 2016)

a new regimen for leprosy, known as multidrug therapy or MDT, in order to overcome the resistance to dapsone which was threatening future of anti-leprosy efforts.

After qualifying as medical doctor from Edinburgh University and Liverpool University Tropical Medicine, Dr. Yuasa joined The Leprosy Mission (UK) and spent several years as medical doctor and superintendent of Anandaban Leprosy Mission hospital in Nepal. In 1975 he received a calling that destined his life thereafter, an invitation from a newly established Sasakawa Memorial Health Foundation (SMHF) of Japan to join the global fight against leprosy. SMHF was a brainchild of Prof. Morizo Ishidate and Mr. Ryoichi Sasakawa; the former was a pharmacological scientist and a professor, known as Father of chemotherapy of leprosy in Japan, and the latter was an eminent philanthropist committed to work for relief of the people affected by leprosy. He joined SMHF as a medical director and with full support from the Japan Shipbuilding Industry Foundation (later named The Nippon Foundation) he lost no time to put SMHF in alliance with all the key stakeholders in leprosy from international agencies and the governments of endemic countries in order to deliver the cure to the world. He was also fully committed to strengthening the capacity of WHO and other technical agencies in order to develop

He believed that a key to success for combating leprosy was to bring the service through the general health services, rather than creating leprosy specific, vertical services. This required ensuring political commitment, innovative approaches by

the specialists, capacity building of the general health workers, and even designing drug packaging as blister packs of MDT. The blister packaging was first tried out in the Philippines where he was involved in MDT implementation pilot program through the general health service of the provinces. Blister packaging soon became the norm drug delivery as it was easy to be handled by grass-roots level health workers and was also patient-friendly.

Throughout 1980s and 1990s a number of technical meetings, professional exchanges, training sessions and public advocacy gatherings were organized in many parts of the world under the banner of ‘MDT for every patient in every village’. Clearly it was the time of unprecedented focus on fight against leprosy, ‘a window of opportunity’ was open to spotlight leprosy among other health issue. But Dr. Yuasa was aware, perhaps more than anyone else, that the window could not stay open indefinitely. He was, therefore, adamant to prioritize public health ownership of leprosy to ensure early diagnosis and cure by MDT in order to reach every corner of the world. He called himself one of the “most radical protagonists” of MDT and even stated provokingly that “care of insensitive hands and feet or treatment of eye complications will probably have to wait even longer.” But in sharing his enthusiasm, he was always humble and kind with whoever he came into contact. Thus, from the top government health authority to grass roots village health volunteers, people found him easy to work with and were motivated to push their leprosy agenda further.

There was another Dr. Yuasa who looked most at ease being with and among those affected by leprosy, especially those from the days before the effective cure became available. People found him at ease standing closely and holding their hands which very often showed the delay of diagnosis or failure of treatment. He genuinely admired the resilience of those survivors demonstrated in overcoming the disease physically, mentally and socially. He had a number of opportunities to interact with these survivors of leprosy and willingly participated, especially after mid 1990s when SMHF acknowledged and started supporting people’s organizations throughout the world. Very naturally, he found his place among them as he was not wrapped in a ‘doctor’s air’ nor a ‘philanthropist’s posture’. He was among them simply as an admirer of their strength sharing some common bond with them, although deep in his heart I am sure he was intensely aware of the words of his esteemed friend, Prof. Michel Lechat, “*Neglected patients of yesterday are the disabled today; neglected patients of today will be the disabled tomorrow.*” He was acutely aware of the pain of those who had no opportunity to prevent the damages on their bodies. After all this was where his vow for leprosy began, as he had once planned to be as an orthopedic surgeon to serve for leprosy but later chose to take up public health path.

One sunny afternoon in August, 2016, I visited Dr. Yuasa at his bedside in a hospital in Kyoto, his hometown. I brought with me an enlarged copy of the editorial by Prof. P. Fine from the latest issue of Leprosy Review as I know he had wanted to read it. We talked about the International Leprosy Congress in Beijing, scheduled less than a month away and he was willing to send a message to the Congress. He recalled 15th ILA Congress also held in Beijing in 1998 which he presided as the president. We also talked a little about possible future paths of leprosy. He did not talk much but it was clear he understood them all. Then after a few fax exchanges the text of his message to ILC, Beijing was finalized. On September 6th I emailed the text to ILA president, Dr. Marcos Virmond, and the chair of the Chinese organizing committee, Prof. Zhang Guocheng. The next day, 7th September, in the morning he left us forever at the age of 90. He was survived by his wife and a daughter both living in Kyoto.

He lived and served the cause of leprosy “*Quietly, firmly, faithfully, brilliantly*” as described in the certificate of appreciation given to him by American Leprosy Missions. His memory will remain in the heart of everyone who has come to know him personally or through his works and papers.

Recalling the thirty years I worked with Dr. Yo Yuasa, I am deeply grateful to have had him as my immediate superior. I was introduced to and exposed to leprosy through the right person and at the right time, and was able to closely observe the evolution of leprosy and its related challenges. Encounter with leprosy has humbled me to realize that there are so much more to learn. In leprosy I have come to find an inexhaustible source of inspiration for the world of today and tomorrow. Thank you Dr. Yuasa for your guidance.

Our Journey to Carville

by Caitlyn Diamond

My name is Caitlyn Diamond, and I recently had the honor to portray the role of Sister Catherine in Bend in the River- Louisiana's Secret people, a play written by Tonya Hays and Dustin Ballard. The play focused on several residents, doctors, and nuns at the former National Leprosarium of Carville, LA, and was performed by the high school students at WINGS Performing arts on the Mississippi Gulf Coast. It traveled to many schools along the coast, and had several weekend performances as well as special performance at Carville for students in the Youth Challenge Program. The two casts were entirely made up of students from ages fourteen to eighteen. Being given the opportunity to radiate a light of truth on the stories of Carville and properly inform others of Hansen's disease (previously known as leprosy), we first had to educate ourselves...

At the beginning of our rehearsal process, we were each assigned a research project to complete and present to the rest of the cast. Some of the projects included "Stories of Carville", "Cajun Music", "1940s New Orleans", "Louisiana Secrets", and "Daughters of Charity". Each project was presented in its own creative way. "...I wrote a rap because I wanted a unique way to present something ...Through this, I engaged a crowd and gave info." said senior Metri Lyons about his project on "Unlawful Incarceration".

Amanda Overmyer, a homeschooled junior, wrote about her group's project "Stories of Carville" saying, "... We presented it like as talk show. We each researched our people and came up with several questions and answers." Senior Madison Gillam was the costumer for our play. She traveled to Carville to gather information for costume ideas and even hand made rosaries for nun costumes to look as close as possible to images she saw of the Daughter's of Charity rosaries.

To further learn about the people and place that inspired our play, many students had the opportunity to visit Carville. Several cast members commented on their experience there, "Being at Carville was such an incomprehensible feeling. I could not get over the fact that I was in the same building and grounds as the characters in the show", said Christina Larson, a junior in high school who played the role of Sister Benedicta, a nun who fought for the rights of the patients. Jeb Vonderbrugge, who portrayed Stanley Stein, after reading Stein's memoir and visiting Carville says, "...it was the place I had read about and it felt like the world came to life off the page!" Some of the cast even says that through visiting, they were able to get a better understanding of their characters, "...every one of us played a real person", says senior Elain Morrow.

It was spectacular to have told these people's stories, and it was an honor to have educated so many on an important part of history. I think one lesson we can all take away from this is one of acceptance, and to not stigmatize others.



Members of the Cast

ILEP Advisory Panel of Persons Affected by Leprosy



Panel members: Mathias Duck, Rachna Kumari, Jose Ramirez, Kofu Nyarko

The Panel was formally introduced in October 2015 in Paris. In that meeting we proposed working on a communications policy, which was taken up by the ILEP Office and ILEP Members. The new policy was recently approved by the ILEP member's assembly.

In March we met in Geneva. We agreed to take up research on the experience of stigma of people affected by leprosy. The ILEP Office and ILEP Members supported us in this endeavor and we managed to obtain the 265 responses from 20 countries. The findings were presented at the International Leprosy Congress in Beijing in September:

- Discriminatory practices and language are still largely part of the experience of persons affected by leprosy.
- There is little or no evidence as to the state's involvement in the elimination of discrimination against persons affected by leprosy.
- The participation of affected People is still limited.

The findings of our research will be included in the UNHRC report on the implementation of the Principles and Guidelines.

We were also able to establish and expand relationship with many organizations of persons affected by leprosy.

For the final meeting in October 2016 in Bern, we presented a number of recommendations for the future of the Panel. We believe that these recommendations will contribute towards full inclusion, full participation and full empowerment for all people affected by leprosy.

Leprosy in the US: Out of Sight, Out of Mind

By Judith Justice

In general, people are always surprised to learn that there is leprosy in the U.S. and that the Federal Government funds a treatment-care program. The Hansen's Disease (H.D.) Program has a long history, beginning in 1894 when Carville, formerly a large plantation with a hospital run by the Catholic Sisters of Charity, was officially opened and remained the focus of the U.S. program until 1999, when the National Hansen's Disease Program was relocated to Baton Rouge, Louisiana. The U.S. Federal Government continues to operate a museum in Carville, which is open to the public. The second well-known residential facility in Hawaii, Kalaupapa on Molokai, is no longer the location for current clinical treatment, but former patients have the option to maintain a residence until death.

Government-funded care and services for leprosy were authorized by Congressional legislation, resulting in a Federal program in 1921. Currently, there are 15 Regional Hansen's Disease clinics around the country supported by the U.S. Government, in addition to a State-supported Hansen's Disease Community Program in Hawaii. As noted earlier, the headquarters of the National Hansen's Disease Program is located in Baton Rouge, LA, and includes clinical and research staff. In fact, leprosy is one of the few diseases for which the U.S. Government provides free support for comprehensive care, including the 15 clinics, each having a network of public health nurses and physicians, plus referral for dermatology, eye care, foot and hand specialists, physical and occupational therapists, medications, and special equipment designed for insensitive hands/feet, foot wear, etc. For most surgery and treatment requiring intensive specialty care, patients are sent to the National H. D. Program in Baton Rouge.

Although the ambulatory (outpatient) Hansen's Disease Clinics are limited to treatment of leprosy and directly related conditions, in my observation the clinic staff do their best to refer and coordinate with medical staff providing other services. Because the Hansen's Disease Clinics are dealing with specialized needs, in addition to the associated fears and stigma of patients and family, staff try to provide a reassuring and accepting environment—in many ways, it is an example of how medicine should be provided in the U.S., but often is not. Because the clinics are regional, many patients travel long distances, some up to 3 to 4 hours each way—and yet they still come. I often ask the patients why they are willing to travel so far to the clinic, especially those who are no longer on treatment and have no on-going complications, but come only for yearly follow-up—and the responses are that they are treated as family and it is reassuring.

The figures vary by year, with approximately 200 new patients diagnosed each year. Although the majority of patients are born in other countries, approximately one-third are white and born in the U.S. Twenty years ago when I first visited all of the Hansen's Disease clinics in the U.S., I was impressed with the differences, not only in the physical settings, but how each clinic reflected the local immigration pattern. For example, in Boston there were many Brazilians and people from the Azores, in addition to patients from an older Portugese population living in near-by states (e.g., Rhode Island and Connecticut), Miami reflected the Cuban and Caribbean communities in Florida, and the three clinics in California (San Diego, Los Angeles and San Francisco) had more patients from Mexico, the Philippines and South East Asia (Vietnam, Laos and Cambodia) and several older former patients from China—reflecting the long-term history and immigration patterns of each region. With the increased migration of foreign-born technology workers to Silicon Valley, the Northern California clinic has six recently diagnosed patients from India. A few years ago, a new clinic was opened in Arkansas to provide services to the increasing migration of Marshallese (30,000), who come to work primarily in the chicken-packing factories.

Thus, one of the many challenge of working in a low endemic country such as the U.S., is the diversity of the patient population. Each immigrant group has its beliefs related to leprosy, with varying degrees of fear and stigma among family and the

community. Given that leprosy is almost unknown in the U.S., it is not surprising that there is much misinformation and misunderstanding about the disease, but it is surprising that there is still intense fear and stigma. For example, recently in Southern California, two children were diagnosed with “suspected leprosy”—and sent home from school—and parents were sent a letter about these children, with assurances that the school was being “decontaminated.” There were several articles in the local and national press, leading to much fear and withdrawal of other children from the school. I thought of how hard the H. D. Clinic staff work to dispel the stigma and how such irrational and inappropriate media coverage will affect patients and their families.

However, the greatest challenge in a low-endemic country such as the U.S. is in being diagnosed. Not only is leprosy unknown to the general population, it is largely unknown to the medical community—most doctors, nurses and other health workers are unfamiliar with the symptoms and don’t recognize leprosy. Thus, the title of this article—Out of Sight, Out of Mind, although in this case it would be more accurate to reverse the cliché to Out of Mind, Out of Sight, (that is, if one doesn’t think of leprosy, it is not seen or diagnosed). It is the exception when local doctors, especially in private practice, even think of leprosy as an option. As a result, patients seeking a diagnosis see many doctors, and often there is a delay for up to several years, before medical personnel think of leprosy or do a biopsy. Almost all patients I’ve met and interviewed at the Northern California Regional H.D. Clinic have experienced difficulty in being diagnosed, going from doctor to doctor and being referred to specialists. It is especially difficult for patients who don’t have easy access to health insurance and medical care, which is often the case for many immigrants. There is even an example of one patient who was familiar with leprosy symptoms from another family member and told the doctor, who was still unwilling to accept the patient’s request and to make the diagnosis. This patient, from Mexico (although a long-term resident in California), went to three doctors, before the fourth doctor agreed to do the requested biopsy. Another example is provided by an Indian engineer, who had access to a university medical system, but his increasing hand and foot weakness was misdiagnosed and mistreated for several years. Limited awareness of the disease and reluctance to make a diagnosis have a profound impact on case finding and timely treatment.

Therefore, a major challenge is reaching out and educating the medical community, including educational institutions—as limited or no training about leprosy is being provided as part of nursing and medical education. The Regional H.D. Clinic in Northern California does invite medical students and residents to attend and participate in the weekly Clinic sessions. Also the staff have conducted a few educational sessions in the community, but most of the attendees are from public health and not doctors who are more likely to be the first-line contact for patients. In addition, finding doctors who can treat members of immigrant populations can be challenging—and as noted, many immigrants do not have access to regular medical care. For example, despite intense efforts to reach out to the Marshallese population in Northern California (estimated to be about 1000), the H.D. Clinic has met with resistance from the community, who are very private and have been reluctant to have Clinic staff visit to give educational sessions. The National Hansen’s Disease Program in Baton Rouge holds an annual seminar on comprehensive management of Hansen’s disease and also has an on-line course on Hansen’s disease. In addition, the staff in Baton Rouge provide consultation to private doctors who request advice on how to treat and deal with complications. At present, it is estimated that approximately 504 private-sector doctors are caring for usually only one patient, although there may be more as not all report to the National Program. In addition, it is time-consuming for private doctors to learn how to care for one patient who is viewed as having a “rare” disease. In the case of the current patients from Silicon Valley, the H.D. Clinic doctor has established working relationships with the Infectious Disease and Dermatologists treating the patients from this region, although the patients have selected to continue coming to the H.D. Clinic for follow-up on treatment and related complications. Therefore, the availability of the Regional Clinics is an asset for the local physician and the patient.

Despite these efforts to reach out to the immigrant communities and to inform the medical community, most remain uninformed about leprosy, thus contributing to miss diagnosis and late diagnosis. Therefore, educating the medical community and public remains a major challenge in low endemic settings.

Making a Difference to Policy and Practice

At the recent 19th International Leprosy Congress held in Beijing I was asked to give a presentation on “Making a difference to Policy and Practice.”

The Principles & Guidelines behind the UN Resolution “Elimination of discrimination against persons affected by leprosy and their family members” have been established for over five years and we conducted research to find out if they have, in reality, been put into practice.

Earlier this year, we disseminated a questionnaire among organizations of people affected by leprosy, leprosy hospitals and ILEP Members worldwide. We received responses from 265 people affected by leprosy from 20 countries about their experience of stigma.

We explored different areas where stigma can be found:

Residence

Only half of the respondents said that they were free to choose where they wished to live.

Work

More than a third of respondents thought that people affected by leprosy were not treated equally at work in terms of hiring and promotion. Two thirds had experienced discrimination.

Marriage

More than half of the respondents thought that leprosy was often or frequently used as a reason for a denial of marriage or grounds for a divorce. In some countries, (China, Liberia, Guinea Bissau and Afghanistan) this figure was much higher.

Access to transport

Less than half of those surveyed said that people affected by leprosy enjoyed equal access to public spaces and that included transportation.

Discriminatory language

More than a third experienced discriminatory language being used against them. One in five respondents heard discriminatory language used against other people.

Participation in Policy-making

Respondents were asked, if people affected by leprosy were involved in decision-making for policies that impact on their lives and a third responded that they were not involved. However, one fifth had been involved.

State involvement

12% or one in eight respondents were aware of action taken by a state to abolish existing discriminatory laws. 15% confirmed the state’s involvement in family reunification, many people (46%) were not aware of the state’s involvement. A quarter of respondents said that the state did not provide information about leprosy to community leaders

In conclusion, we could summarize:

Discriminatory practices and language are still largely part of the experience of persons affected by leprosy.

There is little or no evidence of the state’s involvement in the elimination of discrimination against persons affected by leprosy.

The participation of people affected by leprosy is still limited.

It is important to emphasize that the latest report of the Human Rights Advisory Committee of the United Nations insisted on the participation of persons affected by leprosy and the involvement of the state in order to implement the Principles & Guidelines.

I concluded the presentation, by saying “It’s great to have the Principles & Guidelines. It’s great to have inclusion as part of the WHO GLP strategy, as well as the ILEP strategy. We now need very concrete steps to be taken both at the international and the national level. We know that the Principles & Guidelines represent an ideal that seems very far away in the case of many countries.”

I quoted a Spanish proverb “Del dicho al hecho hay un largo trecho” (“from saying to action there is a long way”) and I urged policy makers to “keep moving in that direction so that every year, every month, every week and every day, the Principles & Guidelines become more and more real in the lives of people affected by leprosy so every person affected can experience inclusion in their everyday life.”

i Acknowledgments to Vera Lacey and Anna van’t Noordende, who carried out the quantitative and qualitative analysis, to the ILEP Office, ILEP Members, partner organizations in the field, affected people organizations and other helpful people for translation and data gathering. Last but not least, we would like to thank the affected people for trusting us with their story.

HANSEN'S DISEASE ON POSTAGE STAMPS

By Thomas R. Adams (Carville STAR Directeur, 40&8 Voiture 1411)

As a long-time postage stamp enthusiast, I have been afforded the opportunity to combine areas of personal interest like history, geography, and medicine with stamp collecting. Of late, I have begun to acquire worldwide stamps related to Hansen's Disease (HD) and in the process have expanded or reinforced my knowledge of the disease.

Stamps honor Dr. Gerhard Hansen, discoverer of *Mycobacterium leprae*, including many that were issued in 1973 in honor of the 100th anniversary of the discovery. One such stamp from Senegal (Scott C-125, pictured) is collected as an oddity because it also includes the causative bacteria growing on a Petri dish, which is not possible!



It is fitting that many stamps honor Raoul Follereau, French philanthropist and journalist who among countless contributions to combat HD, in 1954 promoted World Leprosy Day as a way to raise global awareness of HD. In 1964 Belgium was the first to honor this Day with a stamp (Scott 604). A distinctive and colorful stamp from Spain (Scott 3199) recognizes the 50th anniversary of the Day.

Though far less than half the size of average postage stamps, postal tax stamps from Brazil (Scott RA3-RA30) honor giants among Brazilians and others who provided succor to HD patients. Included are Father Bento Dias, Eunice Weaver, Father Santiago Uchoa, Father Vincente Borgard, Father Nicodemos and Father Joseph Damien. Use of these stamps as supplements to regular postage was mandated for the expressed purpose of generating revenue for the care and treatment of patients affected with HD.

A 1948 stamp (Scott 414) from Cuba marks the occasion of the International Leprosy Congress in Havana in 1948, where the basis of the modern classification of HD was first proposed. Since then, several countries have issued stamps to commemorate some of these quinquennial Congresses that first met in 1897 in Berlin.

In 1970 the closing of Leprosy Hospital, Makogai was observed by Fuji by the issuance of four stamps, one of which depicts the gathering of the yield of a "chaulmugra tree". (The seeds of the *Hydnocarpus* tree are a source of chaulmoogra oil, at one time the mainstay of HD treatment.)



The Republic of Djibouti honored Follereau and Hansen in 1987 with a wooden stamp sheet (Scott C-231A, pictured) that includes the two on a perforated stamp. The inscription lutte contre la lèpre ("fight against leprosy") is included on the wood below the stamp as are the emblems of Lions Club International and Rotary International. (These two organizations are honored on stamps from other countries for their sustained assistance to those affected by HD.)

Conspicuously absent are any United States Postage Stamps related to HD. This despite the many contributions of physicians, staff, and residents at the United States Public Health Hospital at Carville, Louisiana.

There is much to learn about HD and its history from postage stamps of the world. HD related stamps continue to be issued by many countries of the world and can serve as an effective medium to educate the world's population and consequently reduce the stigma associated with the disease.

2016 World Forum on Hansen's Disease

“Shaping A Better Future: Historic Significance of Hansen's Disease Cultural Heritage”



World Forum Presenters (from left): Patricia Devia Kuhnlenz, Agua de Dios/IDEA Colombia; Deirdre Prins-Solani, Education, Culture and Heritage Specialist; Valerie Monson, Ka 'Ohana O Kalaupapa; Shu-yi Pearl Wang, Chinese Cultural University.

Delegates from 16 countries gathered in Seoul, Korea, to participate in the World Forum held November 1-3. The logo of the Forum, a bluebird, represented the poem of the same name, written by Han Ha-un, a widely renowned poet in Korea in the 1940s and 1950s, who contracted Hansen's disease.

The focus of the forum was to “form a social consensus on the preservation of tangible and intangible Hansen's disease cultural heritage, foster international cooperation for alternative use of former Hansen's disease facilities, and promote endeavors to list Hansen's disease heritage sites as UNESCO World Heritage sites,” according to Lee Kil Yong, President of the Korean Federation of Hansen's Disease Associations (KFHA), the organizer of the Forum. Notably, KFHA was founded and is led and managed by people who have experienced Hansen's disease.

Information about the shared as well as unique heritage of several sites around the world including China, Columbia, Japan, Korea, Norway, the Philippines, South Africa, and Taiwan was presented. Programs related to reconnecting families, from families who had ancestors who lived at Kalaupapa, Hawai'i, to a program today managed by IDEA Ghana where people living in leprosy communities—some for many decades-- are returning to their homes. Other presentations made by delegates from South Africa and Brazil, focused on memory and healing, activism and resistance. For the first time, a representative from the Fortress of Spinalonga in Greece, participated in an international forum on Hansen's disease heritage, discussing the Island's Tentative Listing for World Heritage. Participants also heard about the issues people with Hansen's disease still face today, from representatives from India, Indonesia, Nigeria and Thailand.

Chung Sy-kyun, Chairman of the National Assembly of the Republic of Korea, one of the highest ranking officials of the Korean federal government, gave a congratulatory address at the opening ceremony. This was followed by a reading of the Seoul Declaration by representatives from 16 countries, each reading a point in their mother language.

Additional sessions included the status of legal appeals by attorneys in Korea related to the human rights violations experienced by persons who had Hansen's disease in Korea; and a special session of researchers from various historical and cultural institutions and disciplines in Korea, brought together to discuss the unique and sensitive heritage of Sorok do.

The Forum provided an excellent opportunity to bring together experts including researchers, people who had experienced Hansen's disease, government and NGO representatives, and heritage specialists to continue discussions on the heritage movement, inform new individuals and organizations about this process, and continue to identify ways to work together to highlight this important history.

The Story of Carville

by Howard Hoover National Directeur Carville Star

The story of pure human endurance begins and hopefully ends in Carville, Louisiana; where in 1894, the area was transformed from an abandoned plantation into more than just a refuge for persons diagnosed with Hansen's disease, more commonly known as Leprosy, and described in pejorative terms in the Bible. Men, women and children alike were forcibly removed and isolated from families, friends and society. They were placed under strict quarantine inside the confines of an old, mysterious and misunderstood place behind a twelve foot barbed wire fence. Like at the zoo, a fence was meant to keep them in. Having been diagnosed with leprosy, Hansen's Disease, they were seen as a blight on society and their very own family.

Leprosy was distorted by the biblical imagery of disfigurement and uncleanness. But here at this place there was triumph not only against the disease but the stigma that had caused their life to be altered. The Louisiana Leper Home, a former operating plantation, over 300 acres forsaken, forgotten and neglected for many years, was now their home. United States law required those with leprosy to be quarantined at Carville. Unlike the workers, who could come and go, their view of everything was through that fence. Those living at the home were forbidden from leaving the area. In the beginning they were called "inmates" with numbers not names, not residents. As many were to become reluctant residents of Carville, it was here they were to stay. The isolation of the home and it's effect on the residents was one of despair as "they were required to stay within the enclosure until the merciful hand of death would liberate them."

These good, innocent people were stripped of their rights, their dignity and often even their own identity. Living at Carville meant the loss of the right to marry, vote and even use a telephone. One was to lose everything deemed important to them by being society's dreaded outcasts. Once the measures were taken to enter, a new life, a new world began. For everything that was before was to be forever outside, to stay. Moreover that's the way society and the world wanted it. Young or old they faced a whirlwind of emotions more than any one should ever have to endure.

Indian Plantation turned out to be more than a place where the residents were kept out of sight and out of mind. Carville, as it would be known, was truly a place where hope began. This forgotten and abandoned place was transformed just as it's residents were. The compound was transformed into a place of beauty, serenity, self reliance and self efficiency; soon becoming independent not just because they had to, but more over because they wanted to. The residents, like supplies, were dropped off at a safe distance from the plantation gates. Those diagnosed with Leprosy were forbidden from riding in public transportation. Later, those compelled to call the "Home" home arrived via rail-car separated from others, handcuffed in a police car or in a hearse. Yes, a hearse because it was said "that ambulances are for the living, hearses for the dead." Once they entered inside, their life began to change, as the caterpillar becomes the beautiful butterfly. Not knowing what awaited them, Carville was there with hope. Reaching out with open arms like a mother, welcoming them all. This forsaken place was ready once again to flourish and bring nourishment for the body and soul, as it had before. It brought life and salvation to those in need, not caring who or why. With it's fertile fields and room to be at peace with what is happening to them. Carville did exactly that.

The increasing number only made her show more love and who she was to become. Along with the lack of outside support the plantation had to depend on the wide skills and trades of the residents. That old plantation soon became a place of joy, happiness and love. Not a dark forgotten old southern plantation or hospice. Soon the rust and dust began to disappear and Carville smiled. Once again she was able to give life to those who thought they had none.

On April 6, 1896 the original four "The Daughters of Charity" who heeded the call when no one else would. They began the journey as one reporter described the scene: "It was something of the tribute that a hero receives when he goes forth with deathless courage to battle to the end and wrest victory in a cause that is all but lost." The long abandoned mansion reserved for the sisters required eviction of tenants. Rats, snakes, bats and spiders had long claimed the once grand plantation house as their own.

With the arrival of Sisters, hope indeed had come to stay. As their tenure turned years to decades, the daughters advanced the physical condition of the home from run-down slave cabins to a full-fledged research hospital. They played a huge role in humanizing conditions for the patients. As they sought to transformed the prison-like "Leper Home" into a true medical research facility. The sisters were the glue that bound everything and what made this truly become Carville, not a place to be encamped like inmates waiting to die. The Sisters were the voice for those who had none.

The grounds were overgrown with weeds and the work ahead of the sisters seemed monumental. However, they rolled up their sleeves and began the work of cleaning up the mansion and it's grounds. Soon the place was habitable and the sisters could get down to the work, the real work of helping the residents.

The fields and gardens were planted, cattle and chicken were raised, and Carville was giving back. From tiny seeds, hope grew and grew. As a gentle breeze made the flowers dance, the morning sun kissed the dew, the plantation greeted residents, staff and others alike. She would say "Today is a new day and it's ours". You could feel it's heart, a big strong heart beat, there was still life. Those who had been ripped out of society and deposited here, soon began to, as did Carville itself, feel useful again.

Indian Camp, Pest Home, Louisianan Leper Home, Marine Hospital #66, Carville or just that place; no matter what it had been called, it stood fast. Slowly as things changed, so did Carville. Like any of us with a haircut and some new cloths, she began to feel better.

When the miracle came in the early 40's. It was from a very unlikely source, sulfone. YES, sulfone, a sulfone by-product, the new medical treatment discovered there was began to work. Now once again hope grow, the effects of Hansen's were slowed down, almost stopped. Only this time every patient, every staff member and everyone who touched her ground could feel it. A place of truly remarkable resurgence. A sense of normality, the spirit of hope grow and grow.

The years of endless hard work and persistence was paying off, like a brake in the clouds after a hurricane. The sun, shined through as a sign from above, shining down on Carville and everyone there. Those dark clouds that had hung over them, over this place so long, almost forever were lifting. Doctors, Nurses and the residents could feel it, the pain and stigma was starting to vanish. Carville, here she was after all these years, giving once again. Like the tree of life she gave nutriment, spiritual and passion back to those who thought there was none.

As you drive by and look, one may think she is a plantation estate again or maybe a country club. Even today you can feel it, her warmth and heart beats. If you have a bucket list put Carville on it, she will be here, smiling.

ILEP 50th Anniversary 1966 - 2016

Prior to 1966 there were several organisations around the world focussed on leprosy. The oldest Member dates its foundation back to 1874, others to the first half of the twentieth century, whilst the majority of them were created after the Second World War. Most owed their birth to the inspiration of exceptional persons such as Father Damien and Wellesley Bailey. Several were inspired by charismatic individuals like Raoul Follereau, founder of World Leprosy Day and Abbé Pierre, creator of the Emmaüs movement.

Pierre Van den Wijngaert was the catalyst who accelerated the creation of the ILEP Federation in 1966. Inspired, too, by the recent development of the Common Market in Europe and with the support of Raoul Follereau, he rallied support of various anti-leprosy organisations and organised a series of meetings to discuss ways to work together using a federal model. These moves culminated in this series of landmark events:

- The 2nd October 1965 meeting in Brussels of the first working group of the European Anti-Leprosy Associations.
- The formation in Bern on 25 September 1966 of the European Co-ordinating Committee of Anti-Leprosy Associations.
- The constitution in Paris on 19 April 1969 of ELEP under the name The European Federation of Anti-Leprosy Associations.
- The legal recognition of ELEP in France on 25 October 1971.
- Pierre Van den Wijngaert became the first General Secretary of ELEP and remained in this position until the end of 1989. He was responsible for establishing the co-ordination structure, which today remains the hallmark of the Federation.
- The adoption of internationalism in 1975 becoming the International Federation of Anti-Leprosy Associations (ILEP).
- Move of the ILEP Secretariat to London in September 1979.
- The adoption of a new Constitution and Bye-Laws on 31 March 2006, favouring more effective and efficient governance.
- Move of the ILEP Secretariat to Geneva in 2015.

Marcel Farine depicted the foundation of what later became ILEP in his book «Encounters of Hope», a book about Abbé Pierre and the Emmaüs Movement. Farine was the Host and Chairman of the founding meeting in Bern.

The founding meeting in September 1966 took place in Bern in the *House of Sports* in the *Olympia Hall* with the five olympic rings on the wall, symbolising the union of the five continents. Marcel Farine took this as a good omen.

In this photo you see the President of the German Leprosy Relief Association, Hubert Graf von Ballestrem, signing the statutes.

ILEP's story is one of success. Over the last 50 years the number of people affected by leprosy has been massively reduced. Millions of people have been cured of leprosy. The development of multi-drug therapy (MDT) the production of MDT by Novartis, the integration of leprosy treatment into the public health system, the efforts made to prevent disability and inclusion, are further milestones.

But the fight against leprosy is not yet over. Leprosy elimination has not been as straightforward as it seemed. Leprosy is a unique and enigmatic disease and one of the few diseases to have been known in ancient and medieval times and



This photo shows the founding fathers of ILEP. Raoul Follereau is standing in the centre of the photo, holding a cane. To his left is Marcel Farine the first President of ALES, *Aide aux Lépreux Emmaus Suisse*, now called FAIRMED. To his right is Pierre Van den Wijngaert, General Secretary of *Les Amis du Père Damien* (Damien Foundation).

one of the first diseases to be linked to a specific infection agent *Mycobacterium leprae* in 1873. Even today, the organism cannot be cultured *in vitro* and important gaps persist in our understanding of its biology and epidemiology. In particular, although contact with a known case of leprosy is a major risk factor in contracting the disease, scientists are not certain how the organism is transmitted from one individual to another, nor do they know when, throughout the period of incubation and clinical disease, an individual is particularly infectious. These limitations have prevented the development of highly effective leprosy control measures and there is little evidence that the transmission of the disease has been significantly reduced in recent years, despite efforts made towards that goal.

While the elimination target has been reached in most countries and substantial benefits to people affected by leprosy (including the universal availability of MDT without charge) to the patient, it is only when every last person affected by leprosy has been successfully diagnosed and treated, when everyone with impairments has been supported and everyone subject to stigma is fully included, will the fight against leprosy be over.

ILEP members and guests reconvened in Bern Switzerland October 11-14, 2016 to celebrate half a century of helping individuals affected by Hansen's disease. I attended as a member of the panel of persons affected and was accompanied by my wife. Besides listening to ideas in attaining the "elimination target," I also had an opportunity to meet up with long time friends I first met in 1996. During one of the evening events, all of the participants were treated to a dinner at the Sanctuary of Burgdorf or "Home of the Sick" opened in 1508 to segregate persons deemed to have Leprosy. The "home" is now a large building supported only by two story walls made of stone.

A local anthropologist explained that the parish Bishop, following rules established in the Book of Leviticus, would examine each person suspected of having leprosy and upon "confirming" the diagnosis, banished them to the sanctuary for life. The "home" could accommodate up to 20 individuals, including spouses who did not have the illness. All were forced to give up their property and history of having been born, working the land to survive and also "granted the right to beg." Upon death, they were buried next to a chapel build specifically for the "home." This practice was common throughout Europe during this time. The facility was closed in 1798 and in

1905 the local residents destroyed all of the interior walls believing that the populace might some day be "contaminated" by the remaining germs.

I personally felt a unique sense of love being in a building that likely housed hundreds if not thousands of my brothers and sisters with the disease. Enjoying my meal inside a cold building allowed me to resurrect the warm spirits of those who had been branded so harshly, and who likely were self advocates as well. The walls were free of graffiti so it appears that the sanctuary residents indeed made the "home" a Home.

Jose Ramirez, Jr.

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HANSEN'S DISEASE CLINICS

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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 Arander 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