

The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

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Dr. P. K. Gopal Receiving Padma Shri Award from the President of India for His Contributions in Education about Hansen's Disease -Story on page 3

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Editorial Policy On Terminology

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

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Dr. P. K. Gopal – International Self Advocate

By Anwei Law

On March 22, 2012, Dr. P. K. Gopal, an international self advocate on Hansen's disease was awarded the Padma Shri Award. This award annually goes to a citizen of India for distinguished contributions in various spheres of activity. Dr. Gopal received the award from India's President Pratibha Patel for his contributions in Education about Hansen's disease. The award is a geometrical pattern of a lotus flower with burnished bronze on the sides and embossed in white gold.

In 2005, Dr. P.K. Gopal visited the site of the home of Mahatma Gandhi in Johannesburg, South Africa, something he would never have dreamed possible when he first developed signs of leprosy some 48 years earlier while studying in high school. Following the African Regional Leprosy Congress in Johannesburg that year, he participated in an international conference, co-sponsored by IDEA, (Integration, Dignity and Economic Advancement) on Robben Island, where the prison that Nelson Mandela was housed in was built on top of the graves of people who had leprosy.

The world of leprosy has changed significantly since the days of Gandhi and the days when the history of those who had this disease was virtually erased from the memory of Robben Island and other places. It is not only the sulfones and MDT that have changed the world of leprosy, but the determination and wisdom of those individuals who have turned a diagnosis of leprosy into a personal challenge, and ultimately a personal victory.

One of those individuals is Dr. P.K. Gopal who has lived his life with grace, wisdom and dignity. He has turned his personal challenges into a vehicle through which he has worked to improve the lives of people who have had leprosy both in India and throughout the world. Although Dr. Gopal has represented individuals affected by leprosy around the world since 1994 as IDEA's President for International Relations, he has also refused to let himself be defined by the disease. First and foremost, he is a social worker.

Dr. Gopal received his Master's Degree in Social work in 1972. That same year he started the first Department of Social Welfare and Rehabilitation in a leprosy hospital in India (Kumbakonam) and became the first professionally qualified social worker to work in the field of leprosy in India. In 1984, he presented a paper on rehabilitation at the XII International Leprosy Congress in New Delhi.

In 1986 he received a National Award from the President of India for outstanding work in the rehabilitation of persons affected by leprosy. In 1988 he presented a paper on rehabilitation at the XIII International Leprosy Congress in the Netherlands.

In 1993, Dr. Gopal received his Ph.D. in rehabilitation from Ranchi University in India. That same year, he presented a paper on rehabilitation at the XIV International Leprosy Congress in Orlando, USA. It is interesting to note that when Dr. Gopal was invited to be a participant in the Pre-Congress Workshop in Orlando where half of the participants were individuals affected by leprosy, it was not initially known that he had had leprosy himself. He was recommended to participate in the workshop because of his experience in social work. The organizers were very happy to learn that he also had the expertise of having had leprosy himself.

It was at the Congress in Orlando that the seeds were laid for the establishment of IDEA, which was officially founded at a meeting in Brazil in 1994. Dr. Gopal was a founding member and elected IDEA's President for International Relations. In this capacity, he has represented IDEA in countless international meetings. In 1996, he was elected a member of ILEP's Medical-Social Commission. In 1997, Dr. Gopal established IDEA India.

In 1997, Dr. Gopal stood alongside UN Secretary-General Kofi Annan, along with other dignitaries, to launch the *Quest for Dignity* Exhibit, a joint partnership between IDEA, WHO and The Nippon Foundation. This Exhibit went on to travel to many countries and portions were translated into several languages including French, Italian, German, Portuguese, Chinese and Hindi. In 1998, Dr. Gopal was elected a Council member of the International Leprosy Association, a position he still holds. That same year, he presented two papers on rehabilitation at the XV International Leprosy Congress held in Beijing, P.R. China. In 2000 he was invited to chair the WHO-AIFO Workshop on Rehabilitation at WHO Headquarters in Geneva. That same year, he accepted AIFO's Award Raoul Follereau on behalf of IDEA for the organization's role as an agent of social change, together with Jose' Ramirez, Jr.,

also a social worker in the U.S., a self advocate and Managing Editor of The Star.

In 2001, Dr. Gopal received the Wellesley Bailey Award from The Leprosy Mission International in London.

In 2001-2002, Dr. Gopal worked hard to identify and assist two women from India in getting visas to participate in the First International Conference on Issues Facing Women Affected by Leprosy, held in Seneca Falls, New York. He supported these two women as they faced humiliation and discrimination in the visa application process. They were not granted visas. However, Dr. Gopal worked with them to organize the first Women's Empowerment Workshop in India which, for the first time, provided a platform for women affected by leprosy in India to meet and discuss the discrimination that they faced.

In 2004, Dr. Gopal received the FESCO (Foundation for the Encouragement of Social Contribution) Award from The Nippon Foundation, which was presented by Their Royal Highnesses, the Prince and Princess Hitachinomiya. He was selected because of "the brilliant way he has taken his life's difficulties and crafted them into a successful movement that is having strong, concrete effects on those around the world who have been affected by leprosy."

In 2005, Dr. Gopal initiated a nationwide survey to identify the leprosy colonies in India. Through this survey about 850 self-settled leprosy colonies in 23 States were identified. Data concerning the living conditions of the residents have been collected.

In 2005, Dr. Gopal organized the first National Conference on Integration and Empowerment of People Affected by Leprosy and created the National Forum, of which he was elected Chairman, a position he continues to hold. In 2006, he organized the Second National Conference on Integration and Empowerment of people affected by leprosy at Vigyan Bhavan, New Delhi, with the Vice President of India, Hon. Shri. Bhairon Singh Shekhawat as the Chief Guest at the inauguration.

Between 2005 and 2010, Dr. Gopal was integrally involved in the successful effort that resulted in the UN Human Rights Commission adopting guidelines to end the discrimination against persons affected by leprosy and their family members.

In 2007-2008, IDEA was responsible for organizing 25% of the plenary sessions for the International Leprosy Congress in Hyderabad, as well as a training session on eliminating stigma. Dr. Gopal was integrally involved in this process as well as the planning of other aspects of the Congress, including the participation of 100 individuals affected by leprosy from India.

In 2008, Dr. Gopal worked to make the Parliament of India aware of the needs of people affected by leprosy and a Petition was submitted to the Parliament.

In 2010, Dr. Gopal worked closely with WHO to identify participants and organize a meeting in Manila to develop guidelines to strengthen the participation of persons affected by leprosy in leprosy services. That year he also participated in the WHO South East Asia Region National Programme Managers Meeting in Colombo. In 2011, he participated in the WHO South East Asia Region National Programme Managers Meeting in Myanmar.

These are only some of Dr. Gopal's professional accomplishments. Over his career, Dr. Gopal has directly influenced the lives of thousands of individuals affected by leprosy in India and worldwide through his efforts to promote social and economic justice. Children of persons affected by leprosy, supported by the IDEA India Scholarship Fund, have become useful citizens of India by qualifying themselves as doctors, nurses, engineers, and information technology professionals.

Not only has Dr. Gopal insisted on the basic rights of individuals affected by leprosy and their families at the highest levels of government, he has implemented programs that serve to break the cycle of poverty and social exclusion so often associated with leprosy.

The inclusion of individuals affected by leprosy in leprosy programs and services is something that is now almost taken for granted. It is easy to forget how much courage it took 15 years ago for a person to stand up in front of the media and acknowledge that he had leprosy well knowing that he and his family could face severe discrimination. By facing the public with confidence and the wisdom of his experience, Dr. Gopal continues to develop platforms that encourage countless others to do the same. In this way, the world of leprosy continues to change as individual after individual assumes their rightful place as part of the process.

Veteran's Day Ceremony, St. Claire Manor, Baton Rouge

by Vickie Joseph

Every year Tara High School Drill Team visits St. Claire Manor to honor the veterans. Although I had attended in years past, this year was special to me. My husband is MSG Johnell Joseph (RET), coach of the Tara High School Drill Team. He and I would see some old friends.



Tara High School's Unarmed Drill Team practicing in the parking lot. MSG Johnell Joseph (RET) inspects uniforms and grooming before entrance for the ceremony.

From 2003 until 2010, I volunteered and worked at the National Hansen's Disease Museum in Carville. There I made many friends, some who are now living at St. Claire Manor.

The program to honor our veterans included a welcoming statement by St. Claire staff, and then a prayer and a poem were said by 4th graders from a local Catholic school. After everyone recited the Pledge of Allegiance and sang the Star Spangled Banner, the drill team performed their routine.



State champions performing drill routine for the residents of St. Claire Manor.

MSG Johnell Joseph (RET) then said a few words honoring the veterans and thanking them for their service. Following his speech, the cadets presented the veterans with American flags and certificates.



Cadet salutes veteran

During the course of the events, I was able to visit with five former Carville patients whom I had not seen in 2 years. Even though they are not at Carville any longer, they are still together, like a family, which is nice to know.

As enthused as the older folks were to have the cadets come in and perform their exhibition drill, I overheard the cadets talking about how they also got

a lot from the meeting. Before the performance a cadet said "I'm not going to cry, I'm not going to cry." Well, she did cry and she might not have been the only one. Perhaps it was because one of the old vets teared up when he received his recognition and award.



MSG Johnell Joseph (RET) honors and thanks the veterans.

And that's what JROTC is all about, making meaningful connections and giving young kids a chance to become better citizens.

Forty and Eight Activities

by Joseph Steil, Nationale Director, Carville Star

The Carville Star Program of the Forty & Eight is focused on spreading the word on Hansen's Disease around the world and preserving the Carville legacy. La Societe de Femmes is a fraternal organization of women founded in 1963 for the sole purpose of supporting the programs and principles of the Forty & Eight. La Presidente Nationale for 2011-2012 was Sandy Wood, and she named the Carville Museum as her Presidente's Project.



Sandy Wood traveled to the Carville Museum on 6 October and made her presentation of \$5,669 to Elizabeth Schexnyder, Museum Curator, and Simeon Peterson (Mr. Pete), *The Star* Editor. The donation will be used for the purchase of preservation supplies to protect *The Star* archives, preservation papers and plastic products for storing documents and museum collection photographs and artifacts. These are all costly items, and the museum can certainly put this donation to good use.

Mr. Pete has been a resident at Carville for over 60 years; he arrived here from the Virgin Islands in 1951. Mr. Pete chose to stay at Carville in 1999 when the NHDP relocated its hospital and administration offices to Baton Rouge. He is the 7th *Star* Editor and is the NHDP Museum Ambassador. When you visit the NHDP Museum, Mr. Pete will be there to lead you on your tour, tell jokes, and relate his experiences as a resident.

Current Carville historic district restoration projects include beautification of the “Tea Garden” located between the original hospital Infirmary and Patients Cafeteria. It is an area with wheelchair height concrete tables and a large in-ground fountain where the residents would relax and enjoy fresh air and fellowship after meals. It had fallen into a state of disrepair. This area is being cleaned up, and the plan is to restore the fountain and gardens. The second restoration is a much bigger project. The area is the original Carville Patients Cemetery that was used from 1895 to 1922. The fact that there was a “first” cemetery had been unknown to most Carville residents, even though a monument with the 130 names of those buried has been standing at the location since 1922. The boundaries of the cemetery have been determined using the museum’s archival records; lamp posts have been installed at the four corners and light-up at sundown. In the coming months, a fence will be installed around the graveyard and a historic marker will give those buried here a fully recognized final resting place. After these improvements, the cemetery can be incorporated into the museum walking tours of the Carville Historic District. In addition, benches, walkways, and a reproduction of a coke bottle decorated garden will be installed. In the early days of quarantine, patients created the “bottle-gardens” because Coca-Cola would not accept bottles back for refund. When that changed in the 1940s because of the successful drug trials to treat Hansen’s disease, the bottles were dug up for cash.



Another project in the works is the creation and installation of interpretive signs highlighting significant landmarks in the Carville Historic District. The Forty & Eight has pledged support for the purchase of these interpretive signs. The museum is also expanding its outreach by developing a *Carville Historic District Welcome Center* in a tiny free standing building (12’x12’) built in 1922 and historically known as the “Tea House”. The tiny building was used by the Daughters of Charity for many different activities including greenhouse, catechism classroom, and arts and crafts. Now it will hold exhibits on Carville history that will be accessible to after-hours visitors.

The Carville Star Program had a very successful year. With your continued support, 2013 will be an even better 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 available on the Web, the Forty & Eight is ensuring that research on Hansen's disease continues to be distributed around the world.

The Link to Heritage

By Magdalena S. Ramirez

In May 2012 my husband and I travelled to Skaneateles, New York (Stella Maris Retreat Center) to attend a meeting hosted by IDEA (International Hansen's disease Advocacy Organization for Integration, Dignity and Economic Advancement). The purpose of the meeting was to explore the designation of sites of conscience or Leprosy Heritage sites. These historic sites are dedicated to remembering past struggles for justice, dignity and respect. Considering that injustices occurred in so many leprosy settlements, IDEA wants to connect the past with the present so that these acts are not repeated in the future.

The meeting was attended by persons affected or impacted by HD from Brazil, Canada, Colombia, Japan, Taiwan, South Africa and of course the United States.

One of the unique things that occurred during the trip to Skaneateles was a visit to Syracuse, New York to view the Church of Assumption and its museum in honor of Sister Marianne Cope. Sister Cope followed Father Damien at Kalaupapa Settlement on Molokai Island. Both were canonized Saints. She was canonized on October 12, 2012 for her work with leprosy patients in Molokai.

Barbara Koob was born on January 23, 1838 in the town of Hessen, West Germany to Barbara and Peter Koob. The Koobs migrated to the United States in 1840 due to the constant threat of poverty seeking a new start in the land of promise and changed their name to Cope. They chose Utica, a small town in the central part of New York where a considerable number of immigrants from Germany had settled. The family became fluent in English and German. Her father was naturalized in 1855 and the children became U.S. citizens. Five other children were born to the Copes.

Barbara contemplated the religious life at age 15. Her desire to turn from the secular world to the religious was very strong but felt that God had not willed it until nine years later. Two events impacted her decision about religious life. In 1859 the administration of St. Joseph Parish in Utica was given to the Franciscan Friars, Minor Conventuals. In 1860 four Sisters of the Third Order of St. Francis came from Philadelphia to teach the young boys and girls in St. Joseph parish under the leadership of Mother M. Bernardina Dorn. Her contact with the Friars and Sisters greatly impacted her life.

She entered the religious life on August 26, 1862 at age 24 after caring for her ailing father until his death. With her mother's blessings, she applied for admission to the Sisters of the Third Order of St. Francis and at a chapter held in St. Clare's Convent in Utica.

On November 19, 1862 Barbara was invested in the habit of the Order of the Sisters of St. Francis of the Newmann Communities and became known as Sister Mary Anna Cope. Through the years her name would be spelled different ways, Mary, Marianna, Marianne and by 1871 she kept Marianne exclusively.

In 1865 she was elected as vicaria of St. Anthony's Convent while keeping the same duties at St. Francis Convent. She would work many hours in the classroom at the parish school, mornings and evenings in prayer, and chores of housekeeping. In 1866 a second phase began in her religious career that would last 17 years as an administrator due to her skills of efficiency, good judgment, devotion to work and ability to direct people without arousing their resentment. During a five year period she held various positions as Supervisor, Principal and hospital administrator of St. Joseph's Hospital in Syracuse.

The Franciscan concern for the sick led them naturally to establishing the first hospitals for the care of patients from the general population of central New York State. Mother Marianne Cope participated in the establishment of the first two hospitals in the New York area – St. Elizabeth Hospital in Utica (1866) and St. Joseph's hospital in Utica (1869). These hospitals carried a charter for caring for the sick without distinction as to a person's nationality, religion or color, an admission criteria not honored by other hospitals during this era. She was the administrator for the St. Joseph Hospital for six years.

In June 1883 Mother Marianne received a letter from a priest, Father Leonor Fouesnel, assigned to the Catholic Mission in the Kingdom of Hawaii. He ask Mother Marianne to assist in "procuring the salvation of souls of leprosy patients and take charge of the Hospitals and schools". Her interest was awakened and felt an irresistible force drawing her to follow this call. Of the more than fifty Catholic institutions in the United States & Europe Father Fouesnel wrote to, Mother Marianne Cope was the only one who offered him hope.

On October 22, 1883 Mother Marianne, at age 45, and six brave Sister soldiers set sail from San Francisco arriving in the Hawaiian Islands on November 6, 1883. She made a promise to her Sisters that none would contract leprosy and none ever did. The Franciscan Sisters treated the patients as human beings, dressing their wounds, hearing their pleas and sorrows and never judging them for their illness.

King Kalakaua and Queen Kapiolani of Hawaii thanked the Sisters of St. Francis for taking up a burden that no one else would assume. Within a year she established the first general hospital in Maui. With the King and Queen's support, Mother Marianne pushed for and founded in 1885 the Kapiolani Home to care for healthy female children born to parents affected by HD. She then worked at Oahu Hospital caring for adults with HD.

"Working for God" seemed to be Mother Marianne Cope's central theme in all that she did and she did it happily. She was not afraid to ask for what she needed. She was a good planner and administrator and knew what was needed for appropriate patient care.

In 1887 a new Hawaiian government took charge and the officials closed the Oahu Hospital and reinforced the old banishment policy. Father Damian De-Vuester, canonized as a saint in 2009, had established the "Apostle of the Lepers Medical Facility" in Molokai. He asked her to take over the care of his patients after he was diagnosed with HD and became very ill. Mother Marianne followed the Oahu patients to Molokai and became the settlement's primary care provider and religious leader after Father Damien died. Mother Marianne Cope died on August 9, 1918 at the age of 80 in Kalaupapa. She was buried on the island.

Mother Marianne Cope was clearly far ahead of her times. She instituted hand-washing between patients to prevent the spread of diseases. She set up patient's rights. She welcomed all people regardless of race, creed or economic standing to the medical facilities. She was a shrewd administrator, an inspiration to others, an advocate for those who had no voice, a politician in the era of male dominance, and a very humble person who wanted none of the limelight.

I went to Skaneateles to contribute my time and effort to a very personal and worthwhile cause. I returned to Houston in awe of not only IDEA's efforts, but also inspired by the wonderful and unselfish contributions of such a gentle, caring and compassionate woman, Saint Marianne Cope. She and her colleagues were innovators at the time when women were not perceived as creative or leaders. She helped to create a link to the heritage of all affected by and impacted by Hansen's disease.

My Visit to Carville

by Carole Prietto, Archivist, Daughters of Charity

I first became acquainted with the Carville story through my work in the Daughters of Charity's archives in St. Louis. Sisters Hilary Ross, Laura Stricker, and Dorothy Bachelot, along with many others, compiled an extraordinary record of the Sisters' 109 years of ministry to Hansen's disease patients. I cataloged the collection in 2005. Ever since then I've looked forward to visiting Carville and seeing the site for myself. On May 29, 2012 I got the chance to do that, thanks to an invitation from Elizabeth Schexnyder, curator at the National Hansen's Disease Museum.

Among the many highlights of the Museum were: the Stanley Stein display, with its statue of Tallulah Bankhead and photo of a young Stanley taken during World War I, some of the machinery used in producing *The Star*, Johnny Harmon's bicycle, and the wheelchair used by Zella Berry Brown which I had read about in Neil White's book, *In the Sanctuary of Outcasts*. A large and especially interesting exhibit was devoted to numismatics and HD. In earlier times, because of stigma attached to HD, some governments printed special coins and bills for use exclusively at leprosy hospitals. The Museum holds a large and comprehensive collection of these coins and many were on display. I was not familiar with this side of the history of HD, as the practice of making special money did not happen at Carville and so it is not represented in the Sisters' collection.



In addition to the main exhibit room there is a smaller room devoted to the Daughters of Charity. It was a special treat to see Sr. Hilary Ross' microscope and camera and artifacts from the Sisters' Residence. Throughout the exhibitions there were panels describing HD, the treatment of HD, and the work of the National Hansen's Disease Programs – part of the Museum's mission to educate the public about the disease.

Elizabeth gave me tour of the site as well, pointing out the Plantation building, the Sisters' Residence, the houses built for the Medical Officers in Charge, and other buildings, giving me much history about changes in the physical plant over the years. We stopped at the cemetery, and I saw the grave sites for a number of patients I had read about in the Daughters of Charity's collection: Humberto (Buddy) Negron, Emmanuel Faria, Louis Boudreaux, and Wasey and Mary Ruth Daigle. It was also a chance to see the graves for the Daughters of Charity buried at Carville. A highlight of the campus tour was Sacred Heart Catholic Chapel, with its beautiful altar, tabernacle and stained glass windows.

Following the tour of the grounds we went to the cafeteria for lunch. On the way to the cafeteria Elizabeth pointed out the Canteen. As she did so I remembered reading about all the patient activities that took place there over the years. Oh, if those walls

could talk! When we reached the cafeteria we met up with Pete Peterson, who joined us for lunch – meeting “Mr. Pete” was a special treat, and I would meet with him again later in the day.

After lunch, Elizabeth continued the building tour, pointing out the Ballroom and Theatre. Then we returned to the Museum. Mr. Pete and I had a long talk about his experiences as an HD patient: his early years in the Virgin Islands, being diagnosed with HD at the age of 6, coming to Carville in 1951, his memories of patient activities such as the Easter and Christmas shows and Mardi Gras, and his memories of Sr. Laura Stricker. Pete's memory is amazing and I'm grateful that he's so willing to share his memories with Museum visitors.

My visit to Carville was a special day and one I'll always treasure.

A Quest for Dignity

by José Ramirez, Jr.

On October 30, 1977, Bernard Punikai'a made the following comments at the United Nations-

It is appropriate that we begin our united campaign against fear and ignorance (of leprosy) at the United Nations..... we want to be part of the process, to be in a position to help others, as well as ourselves..... A Quest for Dignity.

Punikai'a, an international self advocate knew about the lack of respect for persons affected by Hensen's disease. At age of 6, he was diagnosed with the disease and at 12, in 1948, he was sent to Kalaupapa Settlement on Molokai Island. He was separated from his family and forced to live in isolation for many decades.

Punikai'a, like millions of others who have been denied their basic human rights, learned to survive after being deemed a part of "the living dead." His challenges and ultimate success are chronicled in the recently released book titled Kalaupapa by Anwai Law.

Another soon to be published book is about the Landry Family of Louisiana written by Claire Manes. The Landrys were institutionalized at the leprosarium at Carville, Louisiana. The book chronicles their 50+ years journey and is titled Out of the Shadow of Leprosy: the Carville letters and stories of the Landry Family.

Other books that describe the unique and painful consequences of being diagnosed with leprosy include Alone no Longer by Stanley Stein, Miracle at Carville by Betty Martin, King of the Microbes by Johnny Harmon and Squint: My Journey with Leprosy by José Ramirez, Jr.

Regrettably, books and presentations by persons affected by leprosy and their families are not enough to STOP the negative labeling, perpetuation of horrible images, on-going spreading of stigma, and denial of dignity. Some of the examples include social and printed media, entertainment, and sports.

Some examples whereby our Quest for Dignity continues to be challenged include, but not limited to:

In June, 2012 health and criminal justice officials in Minnesota shared much ignorance about HD, pejorative labeling and human rights when an inmate was diagnosed with HD and placed in isolation. State media portrayed a very negative situation.

In July, 2012, Former Arizona State Senator Russell Pearce equated the fear of leprosy with the topic of immigrants by describing undocumented individuals as being "imported leper colonies."

In August, 2012, Rusty Hardin, attorney who represented Roger Clemens against federal perjury charges described Clemens' legal ordeal as "being treated like a leper...." Unlike those of us affected by leprosy Mr. Clemens always had legal representation to ensure that his rights were not violated.

In October, 2012, Sister Marianne Cope was canonized as a Saint at the Vatican in Rome and described world wide as the "nun of lepers." She followed in the footsteps of Father Damien (also canonized and also labeled) by rendering services to those isolated at Kalaupapa Settlement.

Each of the responsible parties associated with misinformation and unfounded fears received a letter from the STAR's Managing Editor. While Education on HD was emphasized, a correction was demanded (usually done by publishing our letters).

All of these negative labels must be challenged by the same medium that continues to deflate our Quest for Dignity. It is time to tap into our next generation- children, grandchildren, nephews, nieces- teenagers in educating their peers and others about the bullying associated with leprosy.

The readers of this publication should participate in this Quest for Dignity by sharing with others the "Ten Rules for Overcoming Stigma." All should be encouraged to post the following in their respective social media accounts.

Avoid any type of labeling of individuals.

Avoid rejecting anyone with different abilities.

Embrace the United Nations Article I, Declaration of Human Rights.

Do not exhibit fear of others simply because they are different.

Consistently refer to persons with different abilities using person first language.

Remind self of the negative effects of stigma on others.

Educate others about Stigma.

Serve as an advocate on behalf of others.

Do not endorse the "Law of Silence" i.e., remain silent when stigma or bullying occurs.

Always strive for community inclusion.

Bernard coined the phrase "Quest for Dignity." Now all of us must ensure that his dream becomes a reality.

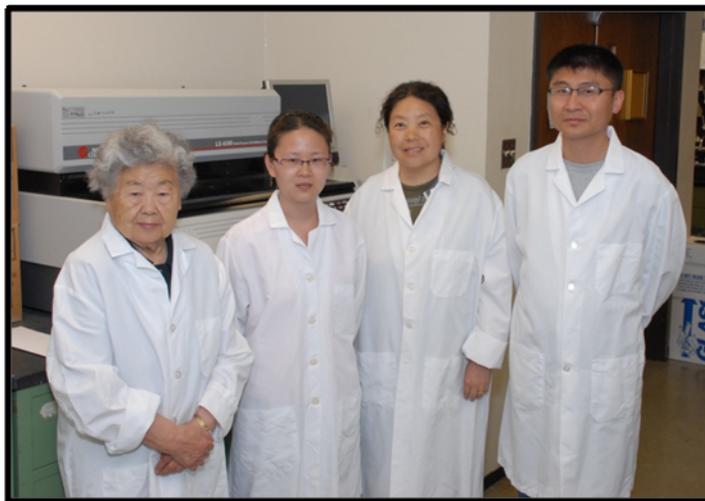
Dr. Li Huang-Ying's visit to the National Hansen's Disease Program

by James L. Krahenbuhl, Ph.D.

In May 2012 the National Hansen's Disease Programs (NHDP) hosted a visit by a distinguished Chinese leprologist and researcher, Dr. Li Huang-Ying. At age 92 Dr. Li's work ethic, dedication and daily schedule at the Beijing Tropical Research Institute surpasses that of any outstanding worker half her age. Dr. Li was visiting the U.S. as a distinguished *alumna* of Johns Hopkins School of Hygiene and Public Health in Baltimore where she earned her M.P.H. in 1952.

Dr. Li was accompanied to the U.S. by 3 younger colleagues, Drs. Liu Jian, Wen Yan and Xing Yan. A visit to the NHDP was a major stop in their itinerary where they spent 7 days training and interacting with all aspects of our comprehensive program. In the Laboratory Research Branch the Chinese doctors spent four days observing ongoing experiments and gaining hands on experience in classic animal model techniques. Dr. Li is in the process of installing a modern diagnostic / research lab in Beijing. She and her group were supplied with detailed protocols for the various procedures and learned state-of-the-art molecular techniques used for studying leprosy pathogenesis, drug resistance and diagnostics.

In the NHDP Clinical Branch, several referral outpatients were presented and discussions were held on "The Need for Leprosy Awareness in the U.S" and "The U.S. Model for Managing Leprosy in a Low Endemic Country." Our Rehabilitation Branch also presented several outpatients referred to the NHDP for leprosy complications and discussed the methods and resources available to fight the stigma of leprosy. The visitors received hands-on experience with the use of monofilaments for hand and foot screens and observed several techniques for wound management, callous removal and nail care. Demonstrations in the NHDP shoe shop gave the visitors lessons in foot wear selection, fabrication of an insole and how to build the famous Carville rocker shoe.



L to R, NHDP visitors from the Beijing Tropical Research Institute; Drs. Li, Xing, Wen and Liu.



Dr. Li, Huang-Ying during her 1980 visit to Carville.

Dr. Li especially enjoyed her visit to the NHDP Museum and Carville historical site where she reminisced about her first visit in 1980 when she spent several weeks as part of a WHO training tour. As China is faced with the same problems Carville faced in 1999, an aging resident population of patients reluctant to leave their "home," Dr Li showed great interest in the program and patient relocation plan implemented by the NHDP and recognized the enormous educational potential of the NHDP museum for addressing the stigma associated with leprosy.

Dr. Li began her career in leprosy at an age, 58, when most physicians are thinking about retiring. She became the voice and leader of China's leprosy-control program in 1978, and has worked tirelessly in rural areas to foster early detection of leprosy and use of multidrug therapy to reduce the prevalence and incidence of new cases of the disease. A key component of her program is elimination of the stigma and fear of leprosy because, "Fear comes from superstition, lack of education and lack of sympathy." Dr. Li leads a simple life style but vigorous daily routine. In her seminar at the NHDP her plans for her own future were clear. "Never give up," she said, "I'm still very enduring. I'm experimenting to see how long I can live, and how long I can work with leprosy."

Faria took The Star from Print to Internet

By Julia R. Elwood

**Note: Some information was taken from The Star, Jan – Dec. 2004, Article by Martha Corson*

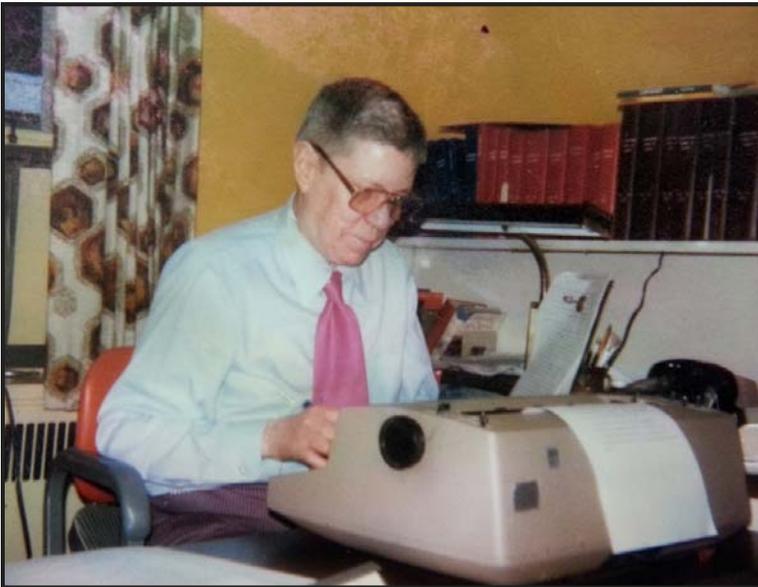
This is a continuing series on editors of The Star

I met Emanuel Faria when I started working at Carville in January 1970. He stood a good 5'9", a little stocky, with good posture, and a lovely British accent. This well dressed man always wore a white shirt, tie, and a sport coat. He was admitted in 1968 and was still sort of new to the hospital. Emanuel worked at The Star at the same time as Ray Elwood, my future husband to be. Before that time, I knew neither one of them.

After I met Emanuel, I found he was a complete gentleman and generous with his compliments. When we happened to pass each other in the long hallways, I would greet him with, "Hi, Emanuel, how are you?" Immediately he answered, "Not as lovely as you." Being a self-educated man, Emanuel kept up with current events and loved hearing all about world politics. He also enjoyed his wine with his dinner.

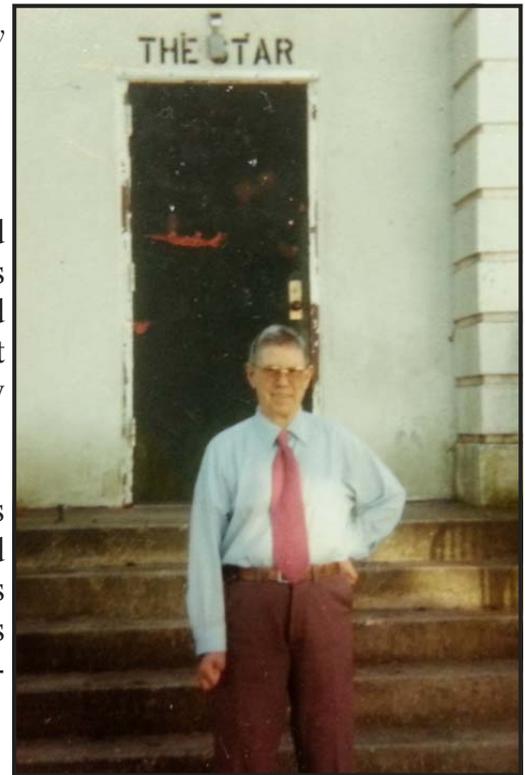
He came to the hospital directly from Mahaica Hospital in Guyana, South America. Hansen's disease had taken a toll on him. His fingers were paralyzed and his eyes and feet were also affected. Even with all these disadvantages, he was active and walked to the dining room daily. Eventually he was forced to use a wheelchair. He worked at The Star until his death in 2004 at the age of 92.

Emanuel started as a proofreader of The Star and later was assigned to write articles. An activity started while he was there was to interview Hansen's disease specialists from other countries, as well as a solicit articles for publication from other foreign HD experts. He obtained an article for publication from a doctor in Russia when it was not deemed proper to communicate with citizens from this country. This led to the request for many Star subscriptions from Russia.



When he went to work at The Star, Emanuel did not know how to type. He practiced this skill by using an old manual typewriter which had been collecting dust in his office. Emanuel found a way to learn in spite of his HD related disability in his fingers. He tied a pencil on each hand and pecked randomly with the eraser part of the pencil at the keys, becoming progressively better as he practiced. He had found his niche and was happy working at The Star.

After Emanuel became editor, a letter from Mahaica Hospital arrived at The Star warning the staff about him. "You should be warned about your new co-worker, Emanuel Faria, he is a treacherous and deceitful man." When he heard this, Emanuel lost his temper saying, "All those years ... of helping and serving my fellow patients! Do you know what they did to me? Be-



cause I believed in democracy and they didn't, they dragged me across the courtyard and beat me up! They beat me quite severely! And when I finally recovered, I knew I was finished in Guyana. It was no longer my country because they would try again. They would kill me if they could!"

He was a man who was no stranger to difficulties and problems in his life and survived both physical and political obstacles. Working at The Star was a real challenge and he was up to it. He did his best to introduce new goals for the betterment of the publication.

Eventually, this intelligent man of many talents could not keep The Star going without assistance from others. Many residents were being discharged from Carville and only a few remaining had the skills needed to continue working at The Star. With the help of the Forty and Eight Veterans Organization, The Star was converted into an internet entity, and Emanuel became part of the electronic era so familiar to the world in 2013. Emanuel was able to continue the work started by the previous three editors of The Star as his commitment to educating others about HD never wavered.



Symposium on Human Rights

by Patricia Devia Angarita, Agua de Dios Leprosarium Colombia, South America

On February 1, 2012, I had the privilege of being invited to the first of a series of international symposiums on "Leprosy and Human Rights" in Rio de Janeiro, Brazil. The meeting was hosted by MORHAN, the national organization of persons affected by leprosy in Brazil and led by Artur Custodio de Souza. The symposium was attended by representatives from Brazil, Colombia and Argentina, as well as the Nippon Foundation, United Nations (UN), Pan American Health Organization and the World Health Organization (WHO). Two special guests were Mr. Sasakawa, UN Ambassador for the Elimination of Leprosy, and activist Estella Barnes de Carl otto from Argentina, recipient of the UN Advocate for Human Rights award.

The program was comprised of forums and round table discussions on social injustices and discrimination directed at persons affected by leprosy throughout the world but particularly in Latin-America. The participants also heard an update on the UN Committee on Human Rights' efforts to end stigma and discrimination towards this population. A special event at this symposium was the launching of the 2012 Global Appeal to end stigma and discrimination against persons affected by leprosy. This appeal, signed by The World Medical Association and over 50 of its members from all over the world, is similar to past resolutions endorsed by world leaders, religious leaders and persons affected by leprosy.

The participants adopted a proposal that will eventually be presented to the UN. This effort is to have the UN accept a resolution for the acceptance of a pledge from elected officials and the scientific community to protect the rights of persons affected by leprosy. Additionally, the resolution would include restitution to this population for the injustices of forced isolation and discrimination directed at persons diagnosed with an illness misunderstood and feared by society in general. These acts have regrettably resulted in emotional misery and unemployment and poverty for those affected as well as their families.

Four symposiums will be held in Europe, Asia, Africa and Australia. A final one will be held in New York, City, home of the UN. I returned to Colombia hopeful that these efforts will succeed. This extraordinary experience made me feel very proud that those who have experienced isolation and injustices will finally be heard throughout the world.

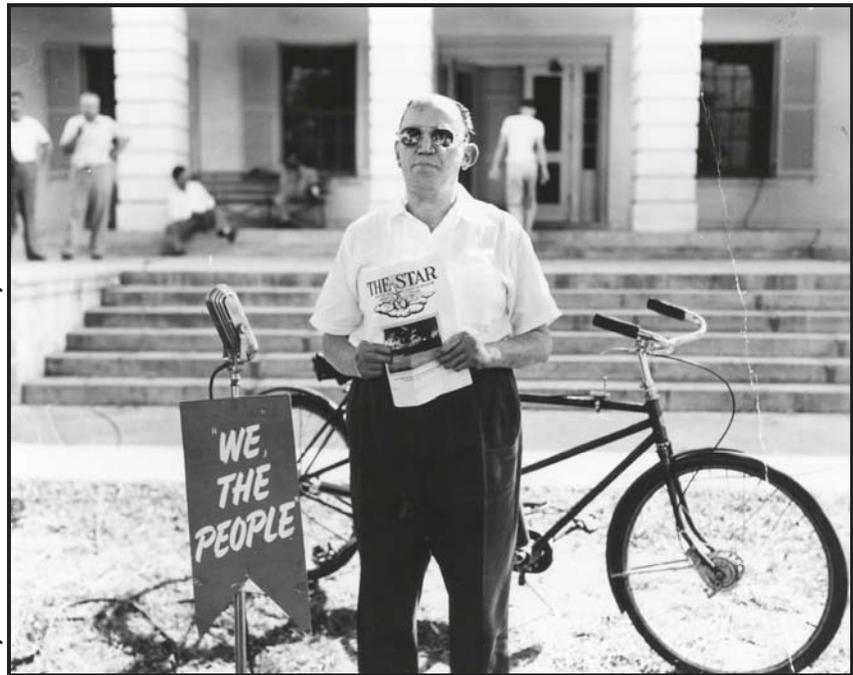
Changing the Bible: Stanley Stein's Battles with "That Odious Word"

By: Heather Varughese John

PART 1

Stanley Stein, founding editor of *The Star*, arrived at Carville in 1931 and spent the rest of his life fighting the stigma that had brought him there. For three decades, Stein sought to correct misunderstandings about Hansen's disease. He lobbied for changes in public portrayals of the disease – in Hollywood scripts, radio programs, newspapers, encyclopedias, sermons, and even the Bible. But he started with the name of the disease itself.

We use the term Hansen's disease today because of the efforts of Stanley Stein and like-minded advocates. They felt that "leprosy" conveyed inaccurate notions, of a highly contagious, incurable, and uniformly disfiguring disease. "Leper" (which Stein referred to as "that odious word") was used in common parlance as a synonym for a social outcast. These words were associated with a sense of fear – of the disease and people with it – which undergirded the confinement of people with leprosy in the name of public health. The hope was that changing the name would combat that fear.



A number of possibilities were under consideration. Physicians who were experts in the disease had suggested terms emphasizing biomedical features, such as "globinosis" and "myco-bacterial reticulosis." Others preferred a name commemorating the physician Gerhard Hansen, who in the 1870s had helped establish the bacterial origin of the disease. "Hansenitis" was occasionally used in the 1930s, but, in the 1940s, Stein and *The Star* settled on "Hansen's disease."

Stein devoted himself to increasing the use of "Hansen's disease" and distancing it from "leprosy." Stein was heartened when in 1952 the American Medical Association recognized "Hansen's disease" as an "official synonym" for leprosy, but he remained cautious about using the two terms interchangeably out of concern that the negative associations of the older word would transfer to the newer one. Throughout his years as head of the paper, *Star* articles repeatedly bore the message that "leprosy" and "leper" should be avoided. *The Star* itself strove to set a good example. In one instance, the Carville chaplain submitted an article titled "Hansen's disease" (leprosy)." In preparing it for publication, an editor inked out the parenthetical phrase.

Stein maintained a friendly but insistent disagreement with International Leprosy Association official Dr. Robert Cochrane about the advisability of using the term leprosy. Cochrane believed that the word could be "disinfected" – that is, that it could be stripped of stigmatizing connotations through the dissemination of accurate information. One aspect of this was reorienting public understanding about the true nature of the disease in the present day – that is, that it was curable and not particularly contagious. Another was distancing the modern disease from leprosy as it was described in the Bible.

PART 2

[*Star* editor Stanley] Stein and [International Leprosy Association physician Robert] Cochrane were united in the belief that "biblical leprosy" had played a key role in the stigmatization of those with Hansen's Disease. The book of Leviticus described leprosy as "unclean," and decreed that those with it must be separated from others. Some biblical scholars and physicians, however, doubted that the leprosy of the Bible was the same condition as modern leprosy. They pointed out that key features of the modern disease, such as anesthesia of the skin, were absent in the biblical description. Moreover, the word

that came to be translated as “leprosy” had been a non-specific term for “defilement” in the original Hebrew – it did not specify a particular skin condition.

In the 1950s, Stein, Cochrane, and a Library of Congress reference librarian named Raphael Brown began lobbying various Bible translation committees – who then happened to be working on new translations for Jewish, Protestant, and Catholic audiences – to take these considerations into account when rendering the term.

The 1953 Confraternity-Douay Version of the Catholic Bible was the first English-language Bible to indicate issues with the word “leprosy.” Textual references to “leprosy” were accompanied by footnotes stating, “the Hebrew term used does not refer to Hansen’s disease, currently called leprosy.” The Jewish Publication Society of America chose to use “leprosy affliction” in Leviticus, with a note declaring that the original language encompassed many diseases. *The New English Bible*, a Protestant Bible, eliminated “leprosy” from Leviticus altogether – it substituted the non-specific term “malignant skin-disease.” Bibles today either avoid using “leprosy” in the text, or include footnotes which distance the biblical condition from a specific modern disease.

Stanley Stein was not satisfied with these changes alone, however. In thinking through the sources which shaped public opinion, Stein also targeted encyclopedias and the mass media.

Stein had found that numerous encyclopedias contained wildly inaccurate information about “so-called leprosy,” including suggestions that appendages fell off and that quarantine was an effective way to combat the disease. Stein wrote to over thirty American encyclopedia publishers, urging them to update their entries with accurate information. Less than half responded, but Stein publicly commended those that did in the pages of *The Star*.

Many years of efforts to combat stigmatizing portrayals in radio, newspapers, television, and movies had mixed results. In the days when radio was a major news and entertainment source, the American Legion Auxiliary, a key supporter of *The Star*, sponsored nationwide radio broadcasts on Hansen’s disease. *The Star* also scored favorable representations in *Reader’s Digest*, *True Confessions*, and the *Rex Morgan, M.D.* comic strip. Insiders on the Spencer Tracy-Frank Sinatra film *The Devil at Four O’clock* and the Audrey Hepburn vehicle *The Nun’s Story* also responded well to suggestions that “leprosy” be portrayed responsibly. Stein had less suc-

cess with efforts to influence the television show *Ben Casey* and the film *Ben Hur*.

Stein saw dramatic changes in the medical and social treatment of Carville patients during his lifetime. When he was admitted, there was no clearly effective treatment for the disease, and a patient might remain institutionalized for the duration of their lives. By the time of Stein’s death in 1967, curative treatment was available, and newly-admitted patients could expect to return to life outside Carville after a short-term stay. The efforts of Stein and *The Star* to educate the public about the reality of Hansen’s disease thus became all the more important. Stigma had no place in that reality.

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PH: (404) 686-5885

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

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

CHICAGO HD CLINIC

University of Illinois
College of Medicine at Chicago
Department of Dermatology, (MC 624)
808 S. Wood, RM 376 CME
Chicago, IL 60612
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email: robjerskey@yahoo.com

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PH: (925) 370-5867

email: ksaffier@yahoo.com
PH: (925) 370-5200 Ext.:4743

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email: Barbara.Hobson@hscd.cccounty.us

Community Health Worker - Maria Soto
email: Maria.Soto@hscd.cccounty.us

MIAMI HD CLINIC

Jackson Memorial Hospital
1611 N.W. 12th Avenue
ACC East – 2nd Floor
Department of Dermatology
Miami, FL 33136-1096
PH: (305) 585-7348 Fax: (305) 585-6397

Primary Physician - Dr. Anne Burdick
email: Aburdick@med.miami.edu

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

NEW YORK HD CLINIC

Bellevue Hospital Center

Department of Dermatology
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New York, NY 10016
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Public Health Nurse - Lydia Macwan, RN
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email: Lydia.Macwan@bellevue.nvchhc.org

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

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Phoenix, Arizona 85006
PH: (602) 372-2039 Fax: (602) 372-3862

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Tucson Office: (520) 626-5650

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

Public Health Nurse - Eileen Smith, RN
PH: (602) 372-2039

email: eileensmith@mail.maricopa.gov
Physical Therapist - Tracy Carroll, MPH

email: tc Carroll@email.arizona.edu

SAN DIEGO HD CLINIC

HHS, North Central Regional Center
5055 Ruffin Road, Mail Stop: N-513
San Diego, CA 92123
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email: erik.gilbertson@sdcounty.ca.gov

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

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University of Puerto Rico
Medical Sciences Campus
School of Medicine - Dept. of Dermatology
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San Juan, PR 00936-5067
PH: (787) 765-7950 Fax: (787) 767-0467

Primary Physician - Dr. Pablo Almodovar
email: dermatol.rcm@upr.edu

Public Health Nurse - Sonia Santos-Exposito, RN, BSN
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email: sonia.santos@upr.edu

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email: jbcendo@aol.com
PH: (817) 753-6633 (private practice)

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PH: (214) 645-8800

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email: grace.flores@dshs.state.tx.us

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Hansen's Disease Community Program
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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 Amaner Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without difficulty and counteract most of the fears generated by the folklore surrounding this disease.

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

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

Where is HD Found?

In 2008 the World Health Organization reported that there were 212,802 new cases of HD worldwide. In 1993, there were 591,000 new cases reported, and in 1992, 690,000 new cases. The largest numbers of Hansen's disease patients continue to be in Southeast Asia and Central Africa with smaller numbers in South and Central America. The largest number of patients in the Western Hemisphere are in Brazil.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began who are still living. This includes approximately 3,300 cases currently receiving medical treatment for HD by the NHDP Ambulatory Care Program Clinics or private physicians with assistance from the NHDP. There were 150 new cases reported to the registry in 2008. California, Hawaii, Louisiana, Florida, Massachusetts, and New York contributed the largest number of cases in 2008.

How Does HD Spread?

While this aspect of the disease remains a medical mystery, the most commonly accepted theory is that it is transmitted by way of the respiratory tract, and abraded skin. The degree of susceptibility of the person, the extent of exposure, and environmental conditions are among factors probably of great importance in transmission. Most specialists agree that 95% or more of the world's population have a natural immunity to the disease. Persons working with HD contract the disease only rarely. Cases of HD which respond satisfactorily to treatment become noninfectious within a short time.

How is HD Treated?

Although the sulfone drugs, introduced at Carville in 1941, continue to be an important weapon against the Hansen bacillus, Multidrug Therapy (MDT), which includes dapson, rifampin, and clofazimine, is the recommended treatment for HD in the U.S. The rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Treatment rapidly renders the disease noncommunicable by killing nearly all the bacilli within a few days, although it takes a number of years for the bacilli to be cleared from the body. This slow process is what can cause a condition known as "reaction," which can cause inflammation of the peripheral nerves, leading to nerve injury, pain, loss of sensation, and muscle atrophy. If not treated promptly, this process can cause deformity and disability.

NHDP SERVICES Website: www.hrsa.gov/hansens