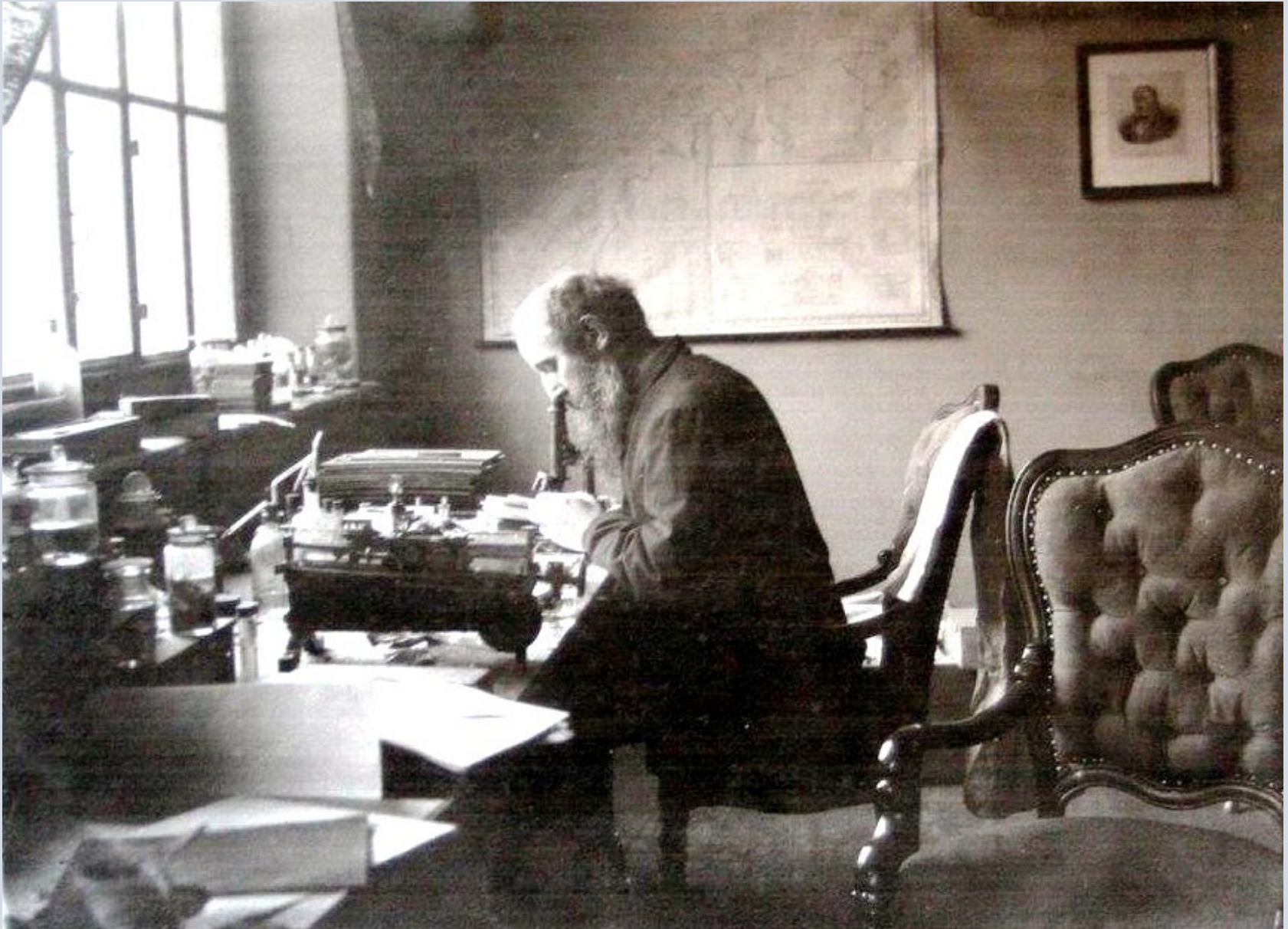


The Star

RADIATING THE LIGHT OF TRUTH
ON HANSEN'S DISEASE

JANUARY 2023 -
JUNE 2023
VOLUME 64 - 33



**150th Anniversary of the Discovery
of *Mycobacterium leprae* by
Dr. Gerhard Henrik Armauer Hansen**

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Founder - Editor, 1941 - 1967

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease. 2.) Serve as advocate for those who have experienced or been impacted by HD. 3) Foster self-empowerment of those who have experienced HD.

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

Editorial Policy On Terminology

The Star stands firm in its opposition to the use of the term "leprosy." We shall never abandon our campaign to secure general acceptance of "Hansen's disease." Nevertheless, the word "Leprosy" does appear in **The Star** under circumstances which we feel are unavoidable, namely: when signed articles are authored by someone who does not agree with us or when material discusses the disease prior to the introduction of the term "Hansen's disease," or when it is used as a medical term. We dislike the word "leprosy" intensely, but we dislike the practice of censorship even more. Furthermore "The Star endorses Section II, 13c of the United Nations Principals and Guidelines addressing discrimination of persons who have experienced Hansen's disease, that encourages the media to portray persons who have experienced the disease using 'dignified images and terminology.' "

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Bergen University Celebrates the 150th Anniversary of Armauer Hansen's 1873 Discovery of *Mycobacterium leprae*

by Claire Manes and Paul Mange Johansen

(Authors' note: when the terms Hansen's disease and Leprosy are used in this article we are following the practice of the Sasakawa Institute which recognizes the two terms as they are used by different countries. The Star continues its use of Hansen's disease as the acceptable term for the condition)

Hansen's 1873 discovery of *Mycobacterium leprae* in Bergen, Norway changed human history. As the very first bacterium shown to cause disease in humans, its discovery was a critical building block upon which the entire field of bacteriology rested. It provided the first small step toward discovering antibiotic treatments, decades later, for a wide range of afflictions. It also provided critical new understanding of a disease that had caused intense fear and panic for millennia. Hansen's insight slowly altered long-held assumptions about how this disease, as well as others, was transmitted. If a bacillus caused it, this was not a curse from God or a hereditary disease; maybe it could be treated, or even cured!

On February 28, 2023 the University of Bergen (Norway) and the Sasakawa Leprosy (Hansen's disease) Initiative teamed up to host an 80-minute webcast covering a wide range of topics relating to Hansen's discovery, including a social and cultural history of leprosy in Norway and testimonies from current patients [see program on next page]. The webcast included interviews with scholars, doctors, people now living with Hansen's disease, patients' rights advocates, archivists, and WHO goodwill ambassadors. It even included a moving song, "Feidie's Lamentation," written by a long-deceased patient, brought to life by Mr. Lars Foss Sørhus, an actor at the Bergen City Museum.

You can view "The 150th Anniversary of the Discovery of M. Leprae—A Look at the Past, Present, and Future of Leprosy (Hansen's Disease)" here -- <https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/3257> -- and can take this fascinating journey back in time over and over, anytime you want.

February 28, 1873 provides a convenient date on which to celebrate Hansen's discovery, but in reality, it took years for him to be convinced that the microscopic rod-shaped objects he saw were the cause of the disease. *Mycobacterium leprae* is a particularly difficult bacillus to stain and study. Hansen later confessed, "Indeed I am not sure myself when I first saw the bacillus of leprosy; it was in 1870 or 1871, not 1872. I sent my report to Christiania [Oslo], but the report was not published until 1874."¹

The webcast was just the appetizer: on June 21-22, the University of Bergen will host "The 2023 Hansen Anniversary," a two-day conference bringing together experts and advocates from across the globe. You can learn more about this important anniversary event here: www.Hansen2023.org.

Personal reactions:

CLAIRE MANES: On a personal level I was awed by the wealth of material archived at the University of Bergen and the reverence of those curating it. I was particularly touched by the words of Dr. Hansen's great grandson a French speaking gentleman who has only recently begun to discover the work his mother had done on her grandfather, a man whose name has become so familiar to us in the Hansen's disease community.

PAUL MANGE JOHANSEN: If you would like to learn more about Hansen's 1873 discovery, please read my 1992 article in *The Star*.² There are so many fascinating aspects of Hansen's discovery. The world's leading leprologist at the time, Daniel Cornelius Danielssen, was not only Hansen's boss, but his father-in-law. Danielssen believed the disease



1973 Postage stamps hailed the one hundredth anniversary of the discovery of *Mycobacterium leprae*

was hereditary, a belief he carried with him to the grave in 1894. What impresses me the most about Hansen's discovery is how humble he remained about it the rest of his life. He was primarily interested in eradicating the scourge from Norway, a passion that got him into serious legal trouble. He honestly believed that the discovery would have been made by anyone with "the eagerness, intelligence, and skill,"³ We are the heirs to his mission, and there is much work that remains to be done.

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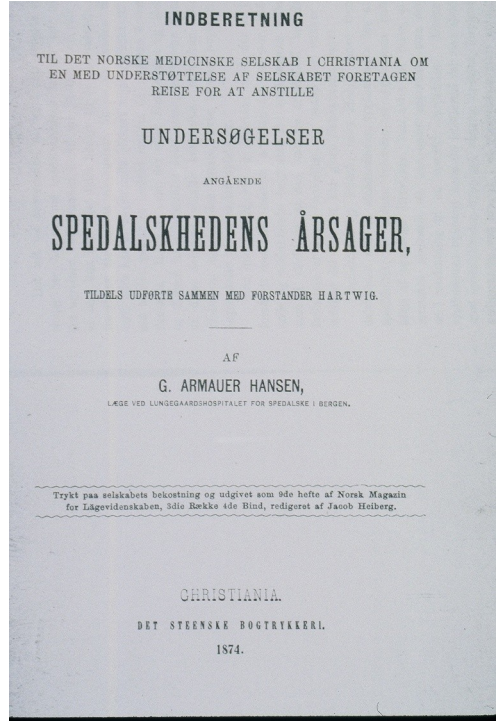
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Program for the University of Bergen Webcast

Host	Magnus Vollset, Associate Professor, history of medicine, history of science magnus.vollset@uib.no / www.uib.no/en/persons/Magnus.Vollset
Welcome remarks	Prof. Margareth Hagen, Rector, University of Bergen
Messages from special guests	Dr. Tedros Adhanom Ghebreyesus, Director-General, WHO Dr. Lia Tadesse, Minister of Health, Ethiopia
Deep history of leprosy in Norway - social and cultural history	Ms. Grete Eilertsen, Curator, Leprosy Museum, Bergen
Feidie's lamentation	Mr. Lars Foss Sørhus, Actor, Bergen City Museum
Discovery: Context and consequences	Prof. Lorentz Irgens, Emeritus professor, Department of Global Public Health and Primary Care, University of Bergen
Hansen's trial: legal perspectives	Prof. Henriette Sinding Aasen, Professor, Faculty of law, University of Bergen
Preservation of material history	Ms. Stine Dornfest, Conservator, Bergen Univeristy Museum
Bergen Leprosy Archives	Mr. Yngve Nedrebø, State Archivist, Bergen State Archives Ms. Gina Dahl, Librarian, Bergen University Libraray
Testimonies	Mr. Kofi Nyarko, President, IDEA Ghana Ms. Paula Brandão, Coordinator, Morhan Research Center
The decendants today	Mr. Abbi Patrix, Storyteller and Armauer Hansen's great grandson
Message from WHO Goodwill Ambassador	Mr. Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination/Charman, The Nippon Foundation
Armauer Hansen today & welcome to the June 21-22 conference	Prof. Gottfried Greve, Vice-Rector, University of Bergen Prof. Per Sigvald Bekke, Dean, Faculty of Medicine, University of Bergen



Lepramuseet in Bergen was part of St. Georges hospital that once housed Hansen's disease patients.



Hansen's 1874 Paper "Undersøgelser Angående Spedalskhedens Årsager (Investigations concerning the etiology of leprosy)". Norsk Mag. Laegervidenskaben

Because he only published in the Norwegian medical journal, which was not read by scientists outside Norway, he nearly lost credit for his discovery to young Albert Neisser.



Remembering All 36 Patients from the Penikese Island Leprosarium (1905-1921) by Paul Mange Johansen

Last fall I wrote in *The Star* about the “Penikese Island Leprosarium in Massachusetts: 1905-1921.”¹ Unlike many other places of care for people with Hansen’s Disease, Penikese was very small, caring for only 36 patients over 16 years: 30 (83%) men and 6 (17%) women. The vast majority were immigrants from around the globe, making communication a challenge: 6 each came from Cape Verde, China, and Russia; 3 each from Greece, Italy, and the United States; 2 each from the British West Indies and Turkey; and 1 each from the Azores, India, Japan, the Philippines, and Syria. Upon diagnosis, their ages ranged from 16 to 72, with half in their 20s (the median age was 27). For 15 of those 16 years, they were treated with dignity and respect by Dr. Frank Parker and his wife Marion, who tried valiantly to make Penikese as much of a home as possible.

The few facts we have about each patient are based primarily on a 1916 administrative report² and on Tom Buckley’s 1997 book, *Penikese: Island of Hope*.³ Since they are now over a century old, these original patient photos appear in print for the first time, courtesy of the Public Health Museum in Tewksbury, MA. Here are a few stories about each patient. While some of these stories continue through family members, many ended with a patient’s death.

When 38 year-old **Frank Pena** from Cape Verde became the first case of leprosy (Hansen’s Disease) identified in Massachusetts in the 20th century, the loud and immediate public outcry spurred the State Board of Charity to balance satisfying the needs of patients while minimizing the outsized fear of Massachusetts residents. After a few failed attempts – including the state hospital in Tewksbury, which refused to accept the first few patients – a leprosarium on remote Penikese Island became their solution. Separated from his wife and eight children, Mr. Pena helped build some of the needed structures for the community.

The efforts of the Parkers were recognized and appreciated by many of the patients. **Goon Lee Dip**, known as the Chinaman (23, China) was always cheerful even under the most trying conditions. He grew a moustache to emulate Dr. Parker and was paid to do laundry. As his disease progressed, **Joseph Needham** (23, Trinidad) wrote Dr. Parker expressing “my very best thanks and appreciation to you and your wife for all the kindness and good treatment I have received from you both.” **Nicholas Cacoulaches** (27, Greece) had been a dishwasher and requested to stay at Penikese, believing the “care and treatment are more humane” than in Greece. Dr. Parker and his wife showed the same compassion to another Greek immigrant, **John Marketakois** (24), a machinist’s helper, rubber worker and baker. His sister in Greece also needed medicine to treat her Hansen’s Disease, which Dr. Parker sent. **Julia Lowe** (60, FL) was another patient who appreciated the island care. She petitioned the State Board of Charity to remain at Penikese although she had no connection to Massachusetts and had a near blind husband and a daughter in Florida.



Henry Chin Yen—1912

When feasible, patients were deported as quickly as possible, sometimes rejoining family elsewhere. **Bertha Osis** (19, Russia), described as “beautiful,” spent only 6 months at Penikese before being deported to Russia. **Elias Applebaum**, a painter, (55, Russia) was discharged for treatment elsewhere through the efforts of his wife and 8 children. Similarly, **Henry Chin Yen** (30, China), a restaurant keeper, was allowed to rejoin his wife and 2 year-old son in China. **Chilin Chiang** (23), a chemistry student at the Massachusetts Institute of Technology, also returned to China. **Marion Braga** (34, Azores) spent a short period on Penikese Island before being deported. Mr. Braga worked briefly as a fireman at the New Bedford Almshouse.

Two patients were deported as a result of their behavior, while another desperately wanted to be deported. **Demetrias Phresa** (25, Greece) was short-tempered and injured another patient with a knife before being deported. **Nessem Mecholam** (28, Turkey) was a leather worker who spoke Turkish, Spanish, Greek, Hebrew, and some English. He was a “disturbing element” and it is assumed he was deported after a year. One patient escaped, hoping to be deported to Japan. **Iwa Umezakia** (26, Japan), a man of “considerable intelligence,” had worked on the estate that later became the Isabelle Stewart Gardner Museum in Boston. He rowed 4 miles from the island to New Bedford, MA but was returned to Penikese Island.

As in other isolated communities, some patients adjusted admirably to their unfortunate circumstances. **Yee Toy** (24, China) spent almost 12 years on the island. He was remembered as a spirited, courageous person who liked to keep

busy. **Lucy Peterson** (27, Russia) was “pretty”, friendly, and encouraging to others. She was paid \$2.00/week for cleaning cottages and serving as a nurse and interpreter. She is buried on Penikese next to her friend, **Isabelle Barros** (27, Cape Verde). Ms. Barros was pregnant when she arrived, but was only allowed to stay with her newborn son for 20 days before he and two other siblings were placed in foster care (see poem). Their story inspired the engaging 2017 young adult book Beyond the Bright Sea by Laura Wolk.⁴ Sadly her husband, a fisherman, drowned the following year. **Solomon Goodman** (64, Russia) was a man with a “rugged constitution” who was “rarely depressed.” He had been a popular Hebrew teacher in Boston’s North End. **Hamed Ali** (21, Syria) had been a pack peddler selling goods from town to town. He “adjusted easily to the isolated life and was a pleasant man.” **Archibald (“Archie”) James Thomas** (16, Barbados), the youngest patient, was a bright high school student from Upton, MA. His fascination with physics, electricity and the “wireless telegraph” motivated him to create a system allowing communication with the outside world, including updates during World War I. Archie reported news of a devastating fire on January 13, 1912 to the mainland⁵, although not in time to prevent total destruction of the Parkers’ home. According to Ed Lyons Archie used the handle “1ZP”; after his sudden death at 22 his obituary was published in the London Times.⁶



Isabelle Barros—1907

Isolation and the loss of family weighed heavily on some patients, leading to deep depression, despair, and breakdowns. **Morris Goldblatt** (41, Russia) was visited once by his wife and five children. He never heard from them again and “rocked back and forth in his corner of the hospital waiting for a letter.” **Mary Martin** (44, Cape Verde) separated from her husband and daughter gradually began to “lose her mind.” **Flavia Ballentino** (47, Italy) could never adjust to life on the island; her mind slowly deteriorated until she was considered “completely insane.” **Hassan Hallile** (30, Turkey) was a widower with three children in Turkey. He had worked in tanneries but spoke no English and was “frequently in tears.”



Charles Beals—1907

The remaining dozen patients also have compelling stories worth remembering. **Charles Beals** (54, New Orleans LA) had travelled in the southern US as an accountant. Widowed while on Penikese, he was the only person to die on the island but be buried elsewhere, in Boston. **Manueil Baptiste** (24, Cape Verde), a cranberry bog laborer, had plans to be married before his diagnosis. **Wong Quong** (38, China), a cook and waiter in Boston’s Chinatown, had an advanced case of the disease when he arrived on Penikese. **John Roderick** (34, Cape Verde), a sailor, was one of eight family members with Hansen’s Disease and the first patient to die and be buried on the island. **Walter Keene** (72, Bourne MA), the oldest patient at Penikese, had “lived an active life” and travelled extensively. He contracted malaria in Brazil but “never saw Hansen’s Disease.” He had noticed numbness in his feet for 10 years, but as a Christian Scientist did not consult a doctor until two weeks before his diagnosis. **Hyman Klein** (26, Russia) had been a brush maker for about four years. He appeared to have recovered, but the bacillus betrayed him. He was one of the patients transferred to Carville on March 10, 1921, where he was remembered as a tailor. He was the last of the Penikese patients to die there.

John Matthias (26, Cape Verde) was diagnosed only a few months after showing acute symptoms. **Fong (“Jimmy”) Wing** (23, China) was married and had been a waiter in Boston. **Frank Lena** (24, Italy) had worked in a candy factory. **Nicholas Bruno** (age unknown, Italy) had been a cement worker in Baltimore MD. **Getulio Avelino** (age unknown, the Philippines) had been in the Navy and served in World War I prior to being admitted to Penikese. **David Ernsberger** (22, India) completed college in Ohio, joined the Marines, and was diagnosed in France. He was the last person to be admitted to Penikese Island and one of the 13 Penikese patients sent to Carville, Louisiana. While there he served on the Sixty Six Star, Stanley Stein’s early incarnation of this newspaper.

To summarize:

7 patients were deported or discharged: Bertha Osis; Demetrias Phresa; Marion J. Braga; Chilin Chiang; Nessem Mecholam (assumed); Henry Chin Yen; and Elias Applebaum (treated elsewhere).

15 patients died, 14 of whom are buried on Penikese: Frank Pina; Goon Lee Dip; John Roderick; Yee Toy; Isabelle

Barros; Joseph Needham; Lucy Peterson; Morris Goldblatt; Soloman Goodman; Archie Thomas; Iwa Umezakia; Nicholas Cacoulaches; Walton Keene; Julia Lowe. Charles Beals died on Penikese but is buried in Boston.

13 patients were sent to Carville March 10, 1921: Mary Martin; Flavia Ballentino; Manueil Baptiste; Wong Quong; Hyman Klein; Hassan Hallile; John Matthias; Fong Wing; John Marketakois; Frank Lena; Nicholas Bruno; Getulio L. Avelino; and David Ernsberger.

It is unknown what happened to Hamed Ali.

The administrative notes from 1916 and Tom Buckley’s book gave identity to these men and women, who have also become the source of literary remembrance. In 2004 **Eve Rifkah** published a book of poems, *At the Leprosarium*, bringing many of these patients to life (www.eve-rifkah.com), including Isabelle (see poem below). Combining historical research with a vivid imagination, the poems won the 1st Annual Revelever Publications Chapbook Contest. Building upon her early success, she expanded this into “a docu-drama in verse”⁷ in 2010, including a Prologue, four Acts and an Epilogue. Eve’s poems later inspired director and playwright **Scott Barrow** of the Tectonic Theater Project (www.tectonictheaterproject.org) and the Moment Work Institute (www.momentwork.org) to bring some of these Penikese patients to life.⁸ On November 3-5, 2022, he helped produce, “Outcasts: The L... of Penikese Island”, a “devised project” at the American Academy of Dramatic Arts in New York City (www.aada.edu). A devised project is a non-traditional way of creating theater where the production is created in the studio through a democratized process focusing on theatrical elements as much as the text. Having researched these patients for decades, it was deeply moving to see them come to life right in front of me onstage.

Scenes from Scott Barrow’s Production bringing Penikese patients to life

Isabelle, by *Eve Rifkah*

The day my son was born, I breathed fear and joy
gazed at his perfect body, inspected each finger and toe.
My son, my son, held a fleeting twenty days
sent to join brother and sister.
Dear husband, where are your gentle hands,
your soft voice my comfort?

I dreamed of beginning.
In our new home we would live and prosper.
Napoleon, my husband, out to sea at daybreak
provided well.
The children came, first lovely Dorothy

then a son strong of limb and lung.
He howled so hard I thought he called
the devil to enter our home.

Perhaps he did.
Another woman holds my children
presses their clothes sends them to school
and Napoleon, who cares for you?

Doctor Edmonds whispered hope into my heart
said the word cured, oh, how happy
until the new doctors came and slammed my joy
down hard on the rocks. Husband, my arms are empty
I can’t hear my children’s cries,
my home one room and a narrow bed,
your letters laundered by my tears.
This is not the beginning I bargained for.



The Public Health Museum in Tewksbury, MA – located on the grounds of the same State Hospital which refused to accept the first patients with Hansen’s Disease – continues to commemorate the centennial of Penikese closing in 1921 with an exhibit. To watch a panel discussion from October 21, 2021 that accompanied the exhibit, please visit <https://www.youtube.com/watch?v=Np7UtcJBb7A&t=2044s>, or visit the museum website, www.publichealthmuseum.org.

To learn more about Penikese, please email Paul Johansen (iguanaphoto@gmail.com) or Eve Rifkah (erifkah48@gmail.com) or Scott Barrow (Barrow_212@yahoo.com) or look for these resources:

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- 7) Eve Rifkah (2010), *Outcasts: The Penikese Island L... Hospital, 1905-1921*, Little Pear Press. A previous version of this graceful book of poems was published by Reveler Publications in 2004 as *At the Leprosarium*. You may purchase this book by contacting Eve at erifkah48@gmail.com.
- 8) Scott Barrow (November 3-5, 2022), *Outcasts: The Penikese Island ... Hospital, 1905-1921* (a devised theater project based on the poetry of Eve Rifkah), American Academy of Dramatic Arts, New York, NY, <https://drive.google.com/file/d/1NkQnh95-pWDRc4ZvhK8fSLX2vQ3tQ8OA/view?usp=drivesdk>. You may contact Scott at Barrow_212@yahoo.com.

Leprosy: Ancient Disease Able to Regenerate Organs By James Gallagher

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Leprosy bacteria may hold the secret to safely repairing and regenerating the body, researchers at the University of Edinburgh say. Animal experiments have uncovered the bacteria's remarkable ability to almost double the size of livers by stimulating healthy growth. It is a sneakily selfish act that gives the bacteria more tissue to infect. But working out how they do it could lead to new age-defying therapies, the scientists say. Leprosy causes disability when it infects the nerves, skin and eyes.

Throughout history, those infected have been shunned. But the bacterium that causes it, *Mycobacterium leprae*, has other, unusual properties, including the ability to perform "biological alchemy", converting one type of bodily tissue into another, which are fascinating scientists. So the researchers turned to another animals that catches the disease - armadillos.

The armadillo is the only other known host for the leprosy bacterium. The experiments, which were performed in the US, showed the infection heads to the armoured animals' livers, where it performed a controlled hijacking of the organ to re-program it for its own purpose. "It was totally unexpected," Prof Anura Rambukkana, from the University of Edinburgh's centre for regenerative medicine, told me. The results, published in *Cell Reports Medicine*, showed the liver nearly doubled in size. You might expect such growth to be defective or even cancerous - but detailed analysis showed it was both healthy and functional, complete with the usual array of blood vessels and bile ducts. "It is kind of mind-blowing," Prof Rambukkana said. "How do they do that? There is no cell therapy that can do that."

It appears the leprosy bug is rewinding the developmental clock in the liver. Fully grown liver cells are metabolic powerhouses with hundreds of jobs in the body. But the bacteria are taking them back a stage - like becoming a teenager again - where they can rapidly increase in number before maturing back into adulthood. Interrogating the activity of different parts of the cells' DNA revealed a picture more akin to that of a much younger animal or even a fetus, when the liver is still forming.

But the precise details of how this is all happening remain elusive. Nobel Prize-winning research has shown it is possible to forcibly turn the clock all the way back to the point at which cells regain the ability to become any other type of cell in the body - but this runs the risk of turning them cancerous. "The [leprosy] bugs use alternative pathways," Prof Rambukkana told me. "It's a much safer way and they take a longer time to do that, so this is a natural process."

The hope is the approach can be harnessed for repairing the livers of people waiting for a transplant - or even to reverse some of the damage caused by ageing elsewhere in the body. "The dream is to use the same bacterial strategy, to use the ingenuity of bacteria to generate new medicines for regeneration and repair," Prof Rambukkana said. "If you can harness that, you should be able to turn that mechanism into a jab you have every three months or something" All these ideas remain untested, however. Dr Darius Widera, of the University of Reading, said: "Overall, the results could pave the way for new therapeutic approaches to the treatment of liver diseases such as cirrhosis. "However, as the research has been done using armadillos as model animals, it is unclear if and how these promising results can translate to the biology of the human liver. "Moreover, as the bacteria used in this study are disease-causing, substantial refinement of the methods would be required prior to clinical translation."

Report from Hyderabad: Summary of 2nd Global Forum of People's Organizations on Hansen's Disease

By Sasakawa Leprosy Initiative 2022/12/08

The 2nd Global Forum of People's Organizations on Hansen's Disease was held in Hyderabad, India, Nov. 6-8, 2022. As with the inaugural Global Forum held three years earlier in Manila, Philippines, the event preceded the International Leprosy Congress (ILC) and ensured that persons affected by leprosy would be able to speak up for themselves.

Leading up to the 1st Global Forum in 2019, three regional assemblies were held in Africa, Asia, and Latin America/Caribbean to help shape its agenda. For the 2nd Global Forum, an organizing committee consisting of people's organizations' representatives voted on by their peers¹ met a couple of months earlier in Bangkok, Thailand, to decide on the agenda. The organizing committee selected three topics for exploration in 2-hour sessions at the Forum: 1) capacity building; 2) inclusion; and 3) partnerships. The sessions included "sharing good practice" presentations, Q&A, group discussions, and presentations at the end to share results.

More than 70 persons affected by leprosy representing 21 people's organizations from 16 countries and one international organization took part in the three-day event, which was hosted by Sasakawa Leprosy (Hansen's Disease) Initiative as part of its "Don't Forget Leprosy" / "Don't Forget Hansen's Disease" campaign launched in August 2021 amid the coronavirus pandemic.

Including observers, interpreters, representatives of supporting organizations, and members of the International Federation of Anti-Leprosy Association (ILEP)'s advisory panel, more than 100 people attended the Forum each day.

Attendees included WHO Goodwill Ambassador Yohei Sasakawa as well as special guests Miss World Brazil 2022 and Miss Supranational India 2023, both of whom pledged their commitment to using their public profile to raise awareness of leprosy/Hansen's disease.

Also taking part was UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members Alice Cruz, for whom the event was a valuable opportunity to gather material for her final report as special rapporteur, which will be presented to the UN Human Rights Council in June 2023.



Participants in the 2nd Global Forum of People's Organizations on Hansen's Disease

The Forum ended with Conclusions and Recommendations drawn up by a drafting committee to be read by a representative at the ILC's inaugural function.

The Conclusions and Recommendations took into account that COVID-19 and measures against the disease, such as lockdowns and other restrictions, had a heavy impact on the lives of persons affected by leprosy/Hansen's disease living in marginalized communities. Attention was diverted from treatment and services for leprosy/Hansen's disease to other areas. In some countries, the support provided by people's organizations, which worked in partnership with NGOs and other organizations, was a lifeline.

Capacity building was highlighted in the Conclusions as being essential to ensuring the stability and realizing the potential of people's organizations. The Recommendations reflected points discussed in each of the three thematic sessions: 1) capacity building; 2) inclusion; and 3) partnerships. Additionally, it was noted that many of the issues raised in the Conclusions and Recommendations from the 1st Global Forum in Manila have yet to be adequately addressed. People's organizations urge governments, non-governmental organizations, and other stakeholders to take all necessary steps to implement the recommendations coming out from both Global Forums.

For many participants, the Forum was a special opportunity to meet in person for the first time in three years. "It brought us together. It was inspiring. Just to say hello is very important," said Tesfaye Tadesse Haile, the managing director of the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), who briefed the Forum on the recent opening of the organization's new headquarters building in Addis Ababa and stressed the importance of working ceaselessly for one's dream. "I felt comforted, energized, and valued to be here, interacting with people affected from different parts of the



Jayashree P. Kunju, a member of the drafting committee, explains the draft of the Conclusions and Recommendations to Forum participants to obtain their approval.

world. It has been an honor for me," said Mohamedi Ally Mtumbi, president of the Tanzania Leprosy Association. "We are still small. We started functioning properly four years ago. We aspire to be like ENAPAL one day."

"The smaller sessions involving presentations by the groups, where it was possible to ask questions and interact a little more — so much valuable work was being done," said Zoica Bakirtzief da Silva Pereira of ILEP's advisory panel. "I learned a lot and heard many different points of view," said Brima Kpeh of Sierra Leone's National Association of Persons Affected by Leprosy. "We need to strengthen people's organizations and put them at the forefront. They know their people, they know their situation, they know what they need better than any third party."

As well as the feel-good factor it generated and the sense of solidarity it created, the Forum also provided participants with practical ideas to take back to their respective countries.



Members of IDEA Nepal and ALO

"We run an organization of women and children affected by Hansen's disease and other NTDs," Lilibeth Nwakaego Evarestus of Purple Heart Initiative Nigeria, said. "I heard someone talk about an initiative called "goat bank" in terms of empowering women. Women are given a goat; they raise the goat and if it gives birth to two kids, they keep one for themselves and give one to the goat bank. "I also heard women in Bangladesh say they have a rice bank where they put aside rice for them and their children for use in times of need. I think my women in Nigeria will be very eager to put this into practice. We will look at the idea that best suits our own environment. We will see how it aids us in terms of social and economic empowerment of women."

¹Selected representatives were from the following six organizations: MORHAN (Brazil, Americas); IDEA Ghana (Ghana, Africa); ENAPAL (Ethiopia, Africa); IDEA Nepal (Nepal, Asia-Pacific); HANDA (China, Asia-Pacific); and APAL (India, Asia-Pacific).

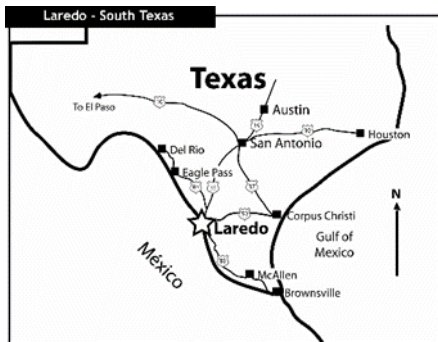


Representative of People's Organizations Share Results of Discussion Groups

Rescue From Societal and Medical Kidnappings

By José Ramirez, Jr.

I have experienced **two types of kidnappings in my lifetime**; both in the environs of my hometown of Laredo, Texas, i.e., societal and medical. Growing up in the border town of Laredo, Texas, I was witness to some unique cultural occurrences; many I did not appreciate as they seemed so routine until they were erased by the fear of being kidnapped. Along with the residents of Penikese Island (see article in this issue) and the millions of brothers and sisters worldwide, I too faced controlled kidnapping, a unique type medically orchestrated.

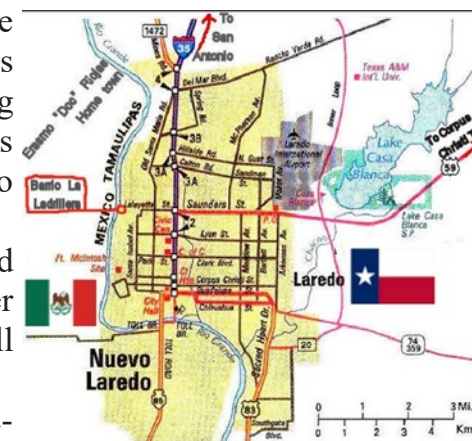


Laredo in the 1960's was, and continues to be, a community where everybody is fluent in two languages. It was a community full of memories and adventures. I grew up in a housing project with my parents, 12 siblings and maternal grandparents. I would wake up every day to the smell of coffee and tortillas being made by mom, Rosa. **From elementary to high school my days were filled with new adventures** shared with other kids from throughout the Guadalupe Housing Project. We would all walk home for lunch and returned to school for more adventures before afternoon classes.

Our family's adventures stretched beyond the neighborhood. We routinely went to Nuevo Laredo, Mexico. We did not need visas nor passports to travel to another country. The fare for walking across the border was five cents. All of us became familiar with the market where our parents would buy groceries, cheaper than on the U.S. side. Our monthly haircuts also happened next to the beautiful market filled with every imaginable item sold by merchants.

As I grew into my teens, I would drive to **Nuevo Laredo** to watch my dad (nicknamed Kinnin) umpire Mexican Major League baseball games between the Tecolotes (Owls) and other teams from throughout Mexico. I learned by watching him and thus umpired amateur baseball and softball games on both sides of the border for spending money.

We enjoyed going to seasonal events such as bullfights on Sunday afternoons and wrestling matches on Monday nights. **I would take my girlfriend, Magdalena to the movies and annual Fair.** We purchased handmade corn tortillas at the market so we could make tacos with cooked pork and beef sold by street vendors. It was a wonderful experience eating delicious tacos with fresh spicy salsa as we watched others walk by enjoying the scenes and scents of Mexico. Our children, in their teenage years, were able to enjoy going to the market with us and eating enchiladas and tacos while we savored some frozen margaritas.



Laredo, Texas too has had seasonal events which attracted visitors from both sides of the border. Two were the celebrations of the George Washington (GW) Celebration and Border Olympics. The GW was started in 1834 by settlers to signify that Laredo was part of the U.S. and not Mexico. Starting in the 1930's, the celebration allowed a "paso libre," or liberal issuance of tourist visas to Mexican citizens (stopped after 9/11). Month long events have included air shows, festival featuring a costumed Martha and George Washington, carnival, fireworks and a parade. Three of my sisters and Magdalena marched in the parade as members of their school dance group, while I made money selling peanuts to the crowd.

Another money making event for dates with Magdalena was to assist with events at Laredo's annual track meet, Border Olympics started in 1932. The event attracted participation from all the major universities and high schools in Texas. I saw many of the athletes who competed and went on to the Olympics or played in different professional sports. All looked forward to "walking over to Mexico" during their off days. Like the Laredo natives, they enjoyed the market, bars, and restaurants.

In the summer of 2001, we visited our favorite margarita bar in the market and were informed that it was closed. Merchants whispered that **the owner had been kidnapped for refusal to pay a "protection fee."** As we walked around the town we heard about other kidnappings. After returning to our residence in Houston, we heard on the news about American citizens being kidnapped for ransom, and many murdered. Such tragic and sad news put an end to our "walks" to Nuevo Laredo, Mexico.

Between 1968 and the kidnappings in 2001, I personally suffered another kidnapping in my home town of Laredo. In February of 1968 I was kidnapped by the State of Texas. I had been diagnosed with Hansen's disease and the policy of the Texas Health Department at the time was that anyone diagnosed with the condition could not stay in the state unless they were receiving treatment for the illness. I was in isolation at Laredo's Mercy Hospital, with increasing nerve damage, many open sores and an inability to walk. At the time the only place in the continental United States where someone could receive treatment for the disease was at the U.S. Public Health Hospital in Carville, Louisiana.

Like thousands before me, my family was expected to transport me to this place known simply as Carville. The state health department offered to transport me for free in a station wagon. Luckily my parents received assistance from the Sisters of Mercy and thus transport became available. The transport was in a hearse. After the funeral director who owned ambulances was informed of my destination, he told my parents, “Ambulances are for the living, hearses are for the dead.”

We arrived in Carville after a 700 mile, 17 hour trip at 55 mph on two lane highways with many stops for rest. I was assigned “patient number 2855.” The hospital was operated by the federal government and **admission was on a “voluntary basis,”** masking the fact that without special permission one was not allowed to leave the 350 acre facility partially encircled by the Mississippi River and surrounded by an 8 foot tall fence.

During a seven year stay at Carville, I underwent treatment, conditioned to follow a long established daily agenda, and expected to comply with unwritten rules and practices. **I was in a community like no other in the continental United States.** I was separated from my family and their respective milestones, from friends, and my girlfriend. However, I was fortunate to have received support from the hospital Social Worker and thus, unlike over 3,000 other patients, completed my college education at Louisiana State University while patient # 2855.

The practice of kidnappings, due to grossly misunderstood images, and fear, of the disease occurred for thousands who arrived at Carville before me. Most never left and are buried on the hospital grounds. **These kidnappings were never legally authorized, nor outlawed.** They occurred throughout the United States, as the account about Penikese Island is highlighted in another article.

Kidnappings have routinely occurred throughout the world as thousands of “hospitals” were built, typically far away from communities. These hospitals built to **segregate persons with Hansen’s disease,** greatly contributed to the stigma linked to the disease. Outside of the U.S., laws were enacted in endemic countries (China, India, and Japan) to arrest and segregate persons diagnosed with the disease.

In the year of my diagnosis, globally there were over 12 million new cases annually. In 2023, the number of new cases is approximately 300,000, with as many as **1.5 million family/friends impacted.** This dramatic decrease has occurred due to a mix of luck, ingenuity with medical research, and early diagnosis efforts. While newly diagnosed cases continue to decrease, stigma continues to climb.

Thousands with a medical kidnapped status in segregated facilities have initiated efforts for better treatment: medically, emotionally, and spiritually. Advocacy efforts have been primarily localized. However, these efforts have been oftentimes dismissed by the experts who are providers of services or involved in research for new medications. **Historically, this type of advocacy has not been recognized nor accepted,** as patients have been labeled as not formally educated and thus limited in communication and comprehension. This is a false premise.

Advocacy has produced change for many throughout history. For those with Hansen’s disease, international change began only 29 years ago, in 1994. A group of individuals diagnosed with Hansen’s disease representing 10 different countries met in Brazil **to form IDEA.** The acronym stands for Integration, Dignity and Economic Advancement. This patient founded organization seeks to recognize the life education possessed by its members as well as their capacity and courage to demand equal participation on boards and policy making bodies which for too long saw Hansen’s disease survivors as token members of the various organizations related to the disease.

IDEA slowly grew and received funding to address self-advocacy and capacity building. This was done by hosting the first gathering of persons with Hansen’s disease in Fontilles, Spain to address the last HD hospitals and the people that called them home. It also hosted the first and only international conference for women who have experienced HD; conducted oral histories around the globe; visited isolated HD communities in Africa, India, Japan, Philippines and Ukraine; hosted Hansen’s disease related exhibits in Austria, England, Italy, Hawaii, Morocco, and New York City; made keynote presentations at the International Leprosy Congress in China; and during the COVID pandemic commenced “The Gathering.”

“The Gathering” is a monthly meeting done virtually. Persons who have experienced Hansen’s disease and their families from 30 different countries with a multitude of interpreters participate in monthly sessions. The participants discuss a variety of topics designed to enhance capacity building. Together we lessen the stigma which surrounds us.

All of these efforts have contributed to the webbing of **rescuing individuals from societal and medical kidnappings** and allows them to walk with steps full of dignity. We are no longer just a label of “patient,” but now remind others that we have a name and an identity. We are sons and daughters, brothers and sisters, husbands and wives, uncles and aunts, grandparents and we possess a unique level of expertise.

Hansen's Disease Education Through Philately

By Tom Adams

Through my philatelic hobby I have found a way to help me “radiate the truth about Hansen’s disease.” As a philatelist since my youth, postage stamps introduced me to people, geography, and events that would have otherwise been unknown to me. Like most philatelists, I began by collecting stamps to fill an international album. Later (and continuing until today) I have collected stamps of the United States.

As is true for many philatelists today, the days of acquiring postage stamps to fill an album have given way to novel approaches of organizing and displaying stamps. It is now common practice among philatelists to collect stamps by topic, to include Hansen’s disease. (Among its many topical checklists, The American Topical Association publishes a checklist devoted to Hansen’s disease that includes hundreds of postage stamps. Such a checklist saves collectors from the arduous task of finding HD stamps from among the thousands of international stamp issues.)

I have organized my HD stamps and related philatelic material into a thematic display suitable for entry into philatelic exhibitions (stamp shows that support exhibits of topical and thematic material). At a recent show, I was privileged for my thematic exhibit on HD to receive prestigious awards from the American Philatelic Society, and the American Topical Society. An accolade from a show judge included “very interesting topic,” a comment echoed by several attendees of the show. For the remainder of this article, I have chosen some of the material from my exhibit to picture and discuss. My goal was for the material in the exhibit to be interesting enough to attract attention and enhance the viewers’ understanding and appreciation of HD.

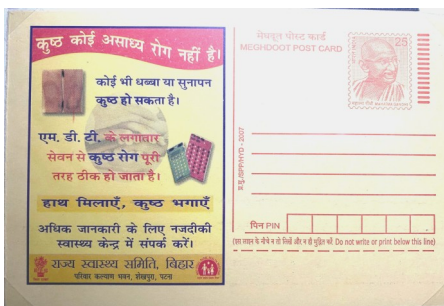


The author and his award-winning exhibit



A stamp from Laos (postmarked on the first day of stamp issue) is among those issued by many countries that recognized the 100th anniversary of the discovery of HD’s causative bacillus by Dr. Hansen. (See page 3 for two other stamps recognizing the anniversary.)

Multiple stamps of the exhibit are dedicated to Semisi Maya of Fiji. Cured of his Hansen’s disease after 14 years of suffering but with severe deformity of his hands, Semisi Maya left the leprosarium in Makogai for St. Elizabeth’s rehabilitation hospital in Suva. Seeking a way support himself, a nun suggested he learn to paint. He developed a unique form of painting using his deformed hands and became Fiji’s most acclaimed artist. His works were included on several Fiji postage stamps.



A Post Card (left) mailed to the populace of India reminds of the availability of free blister-packs of multi-drug HD therapy available at no cost.

A recently issued stamp (right) honors Pakistani physician Dr. Ruth Katherina Martha Pfau (9 September 1929 - 10 August 2017). She was born in Germany and became a nun of the Society of Daughters of the Heart. Dr. Pfau was 29 when she left Germany for Pakistan. She devoted over 50 years of her life to those affected by HD, earning her the title “Pakistan’s Mother Teresa.” She was instrumental in establishing 150 HD clinics throughout Pakistan. (Note the unusual circular design of this stamp.)



The exhibit pays homage to Raoul Follereau by including some of the many stamps (one at left) that have honored him for his philanthropic work and for the advent of the annual World Leprosy Day.

The above stamps and post card exemplify some the varied topics to make this a thematic exhibit. Hopefully viewers will always be drawn to it at exhibitions thus fulfilling my purpose to “radiate the truth about Hansen’s disease.”

Philately: No New Subject for The Star By Tom Adams



Eunice Weaver



Padre Bento

The following is reprinted from the March-April 1972 edition of The STAR. The stamps referenced in this article honor two Brazilians whose noteworthy contributions made a difference in the lives of those affected by HD.

A new stamp issued this year by the Brazilian Post Office honors Mrs. Eunice Weaver who founded 25 Preventorios in Brazil where children of HD patients could be raised away from their parents and thus avoid contracting the disease. These homes are now called Educandarios.

Mrs. Weaver, a Brazilian, was married to an American Methodist missionary. He was a widower with seven children at the time of their marriage; it was after the children were grown that Mrs. Weaver began her work to save the children of HD patients. Mrs. Weaver died in 1970.

Translation of the Portuguese on the stamp reads: "Preservation of the child against Hansen's disease."

In Brazil an annual campaign for support of the Educandarios is accomplished through various postage stamps. Beginning in 1952 with a stamp honoring Father Damien, another stamp issued first in 1954 honors Padre Bento, a catholic priest who became known as "the Brazilian Damien" for his lifetime of labor in the cause of HD patients.

Pending Photography Project Takes Carville Story on the Road By Claire Manes

The Friends of Carville Historic District (Facebook Friends of Carville Historic District) are creating a photography exhibit relating the story of the children and adults who called Carville home.

The exhibit will be an artful expression and design that will capture the attention of its viewers and stand alone as a means of taking the Carville story on the road. The exhibit's first stop will be the Tulane University School of Public Health and Tropical Medicine where it will be viewed by many healthcare disciplines. From there it will be exhibited at locations in Louisiana and then other locations throughout the country will likely vie to serve as hosts.

Visit the Facebook page of Friends of Carville Historic District to stay apprised of the exhibit.

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Public Health Nurse: Krista Langlois, R.N.,B.S.N.
email: krista.Langlois@lahey.org
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Public Health Nurse - Zina Jones, RN
email: Zina.jones@nychhc.org
Telephone: (212) 562-5671

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Tucson Office: (520) 668-6441
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Public Health Nurse - Lynn Moriarty, RN
PH: (602) 610-3169
email: lmoriarty@wesleychc.org

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Public Health Nurse – Soila Gomez, RN
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Fax: (713) 524-3432
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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 Armauer 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 2016 there were 216,108 new HD cases registered from 145 countries according to World Health Organization official figures. The countries with the highest number of new diagnoses are India, Brazil and Indonesia followed by some of the African nations. More than half of all new cases of leprosy are diagnosed in India.

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. 178 new cases were reported in the U.S. in 2015. Most of the new cases were reported in Arkansas, California, Florida, Hawaii, Louisiana, New York, and Texas.

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 dapsone, 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