

“Please Remember What We Have Done”

The World’s Leprosy/Hansen's Disease Heritage Sites

Reclaiming a Place in History

“After we have passed away, who will continue to fight for us against this stigma and discrimination? Please remember what we have done.”

-- Michihiro Koh, Japan, General Secretary, Zen Ryo Kyo, National Association of Residents of Hansen's Disease Sanatoria



The cemetery for individuals who had leprosy and lived in the hospital at Tracadie, New Brunswick, Canada. *Photo by Henry Law*



A 15th century Gothic chapel in Sighisoara, Romania, was used by people who had leprosy between 1647 and 1684. Not allowed inside, those with leprosy listened to the priest as he preached from a pulpit built on the outside of the church. *Photo by Henry Law*



S.K. Jung (right) and M.W. Park in front of the monument they helped build to list the names and commemorate the lives of the 84 people who were killed on Sorok Island, Republic of Korea. *IDEA Photo*



Wall separating the Kikuchi Keifu-en Sanatorium, Japan, from the rest of the world. Holes can still be seen that were scraped by residents so that they could have a glimpse of the outside world. Kikuchi Keifu-en was opened in 1909 as the Kyushu Hospital. *IDEA Photo*

Heritage Sites, Memorials and Museums

Prior to the advent of a cure for leprosy, people throughout the world were forcibly separated from their families and isolated in places far removed from society. This was done for the supposed protection of society at great cost to the lives of the individuals and their families. In some cases, whole family lines came to an end if an only child had leprosy. Over the years, many of the residents of these communities have become some of the world's greatest human rights activists. They challenged prevailing laws and traditions by simply insisting on justice.



Francisco A.V. Nunes, "Bacurau," Brazil, founder of MORHAN and IDEA's President for International Advocacy. Photo by Pamela Parlapiano

Stanley Stein, Carville, U.S.A., Editor of The STAR, which "radiated the light of truth about Hansen's Disease" around the world.

Mamoru Kunimoto, Japan, Poet, Author, photographed on Homecoming Hill at Tama Zensho-en Sanatorium Photo by Nobuyuki Yaegashi

Many countries throughout the world, some of which are included in this newsletter, have recognized the historical significance of these leprosy heritage sites. Others have dismissed the importance of these areas with the resulting destruction of important history. IDEA is working to build a strong international network to support the efforts of conserving leprosy heritage sites as an important part of the history of the world, while at the same time ensuring that the older generation can continue to live in these places they have come to regard as home.

Lo Sheng, Taiwan

"It's easy to destroy, but what about the plan for preservation?"

-- Lee Tien Pei, President, IDEA Taiwan



While the destruction of Lo Sheng proceeds, residents continue to try to preserve their history and their home. Photo by Pamela Parlapiano



Lu De Chang shows the fossils and plants he has rescued from the demolition site. Photo by Henry Law

St. Jørgen's Hospital, Bergen, Norway



St. Jørgen's Hospital. Photo Courtesy The Leprosy Museum, Bergen, Norway

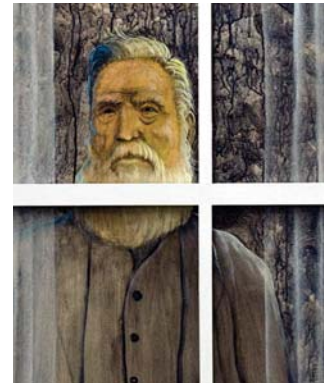
One of Scandinavia's oldest hospital institutions, St. Jørgen's Hospital was established in the early 1400's. In the 1870's, more than 170 people with leprosy were being treated there. The last two residents died in 1946. After over 50 years at St. Jørgen's, they both died within a few months of each other, at 82 and 78 years old.

St. Jørgen's is now the site of The Leprosy Museum, which remembers the residents of St. Jørgen's, including poet Peder Olsen Feidie. The Museum also focuses on Norwegian work and research, including the discovery of the leprosy bacillus in 1873 by Dr. G.H.A. Hansen.

Tracadie, New Brunswick, Canada

Ursule Landry was the first known person to have had leprosy in New Brunswick. She died in her home in 1828. Beginning in 1844, individuals with leprosy were sent to Sheldrake Island, including 8-year-old Bernard Savoie, better known as Barnabé. Conditions were harsh and he and his brothers, Stanislas and Marin escaped. Barnabé was apparently apprehended and returned to Sheldrake where he probably died since he was not among the 15 individuals transferred from Sheldrake to the new hospital in Tracadie in 1849.

In 1868, The Religious Hospitallers of Saint Joseph of Montreal arrived in Tracadie to care for those with leprosy. The last resident of the hospital died in 1964.



A painting in The Historical Museum of Tracadie, depicting Jean Louis, who was admitted to Tracadie in 1907 at age 76. Photo by Henry Law

Robben Island, South Africa

"Oh our beloved Queen listen to me and oh let us hope that we shall be made free . . . let us go to our families. We live as if we were dead on this Island . . . It is so hard to be here away from wife and children, for God says what He has joined together, let no man put asunder."

-- Frans Jacobs, who was sent to Robben Island in 1886 at the age of 35, in a letter to Queen Victoria, 10 August 1892 (*National Archives of the U.K.*)

Robben Island, a World Heritage Site, is, in the words of the Robben Island Museum, a symbol of "the indestructibility of the human spirit of resistance against colonialism, injustice and oppression." It is estimated that between 3,500 and 4,000 people with leprosy were sent to Robben Island between 1845 and 1931.



Esther Johns was 24 when she was sent to Robben Island on May 2, 1906. *Western Cape Provincial Archives*

Kalaupapa, Hawaii



The Makanalua peninsula, commonly known as Kalaupapa. Photo by Henry Law



Ben Pea (left) was sent to Kalaupapa in 1914. David Kupele arrived in 1915. They became life-long friends. IDEA Photo

“Some people who are trying to learn about their family history will come to find out they had relatives at Kalaupapa. If they feel at all the same way that we do, they will be proud that their family was part of the ‘āina, part of the soul of this land.”

-- Bernard K. Punikai'a (1930-2009) – IDEA's President for International Advocacy; Chairman of the Board, Ka 'Ohana O Kalaupapa; Member, Kalaupapa National Historical Park Advisory Commission

The first 12 individuals were sent to Kalaupapa in 1866. They would be followed by an estimated 8,000 more people, at least 90% of whom were Native Hawaiians. In 1982, the U.S. Congress designated Kalaupapa as a National Historical Park for the education and inspiration of present and future generations. This designation, which ensured the right of the last residents of Kalaupapa to live out their lives in this, their home, was an official recognition of the significance of Kalaupapa's history to Hawaii, the United States, and the world.

Agua de Dios, Colombia

Agua de Dios was officially founded in 1870 on the grounds of a hacienda called Agua de Dios (Water of God). It was founded by 77 people affected by leprosy who were expelled from a nearby city and who were forced to live on the lands of this hacienda, where they constructed their homes. These lands were later purchased by the Colombian government and designated for the construction of a leprosarium.



Photo courtesy of Agua de Dios and Patty Devia Angarita

Today the municipality of Agua de Dios has a population of 13,000, approximately 1,200 of whom were affected by leprosy and 250 of whom live in Sanitarium housing. In addition to the Medical Museum of Leprosy, all of Agua de Dios is considered to be a living museum.

Culion, Philippines

Modeled after Kalaupapa, Culion became the largest leprosy facility in the world. Culion Admission Records show that between 1906 and 1980, 31,803 individuals were admitted to Culion. The year 1935 saw the population of people with leprosy hit a peak of 6,928. On May 9, 1995, Hilarion Guia, who had been sent to Culion as a young boy, was elected its first mayor, three years after most of Culion’s 15,000 residents (including thousands of family members and others who had not had leprosy), voted to make Culion a municipality. Mr. Guia initiated this effort as a means of reducing stigma and ensuring that the residents of Culion were afforded their right to vote for local officials.



Hilarion Guia (center), a former teacher at Culion, with two of his students, who now work in the hospital. *IDEA Photo*



Cresciano Rosello points to 1947, the year he was admitted to Culion along with 534 other individuals. *IDEA Photo*

Fontilles, Spain

“This is my home. It used to be that this was our home that was forced on us; now it is our home by choice.”

-- Emilio Laurelio, Fontilles

“Every effort should be made to enable the elderly residents of residential facilities for people affected by Hansen’s disease to live out their lives in these places that have become their homes. No one should be forced to either stay in or leave these facilities . . .

“By recording complete histories of the lives of persons affected by Hansen’s disease, we can turn the negative legacy so often portrayed by the media into a universal message of hope and triumph.

“The history and experiences of people affected by Hansen’s disease should be recognized while they are still alive and can be acknowledged for their contributions to society . . .”

-- Excerpts from The Fontilles Resolution, adopted at IDEA’s International Workshop entitled “The Last Leprosy Hospitals and the People Who Call Them Home,” held April 14-18, 1997, at Fontilles



Sanatoria San Francisco de Borja, Fontilles. *Photo Courtesy Fontilles*

Thirteen National Hansen's Disease Sanatoria, Japan

"I can hear always the voices of the spirits who have passed away. Please keep remembering our voices and our agony. Each sanatorium should remain as a human rights museum. The young people will learn in that place what are human rights . . . Each country has its own situation. Each should not be ignored."

-- Michihiro Koh, speaking at a World Health Organization Meeting in the Philippines, 2010



Michihiro Koh (second from left) at the WHO meeting, where he focused on the urgent need to preserve the Hansen's disease sanatoria in Japan as well as the history of Hansen's disease worldwide. With him are (left to right) Zhishun Xu, Dr. P.K. Gopal, Shehu S/Fada, José Ramirez, Jr., and Sophea Leng. *IDEA Photo*



The ashes of fetuses that were forcibly aborted in Suruga Sanatorium as a result of the Leprosy Prevention Law, including the son of Koji Kaneda, whom he named "Takatsu." *IDEA Photo*

Quail Island, New Zealand

In 1906, Will Vallane was isolated on Quail Island because he had leprosy. He lived alone for 18 months until Jimmy Kokere was sent to the island in 1908. In 1925, the last eight residents of Quail Island were transferred to Makogai Island in Fiji. One of the most famous of these was Ernest Wolfgram. In 1939, Ernest wrote to what is now the Pacific Leprosy Foundation, returning half the money that had been raised for them:

"We feel that we should do all we can to help in the war effort, and we at Makogai can help by doing without some of the small luxuries which are not strictly necessary. We would be pleased if you will present to the New Zealand Red Cross £100 of the money collected for us."



A reconstructed hut on Quail Island. *IDEA Photo*

Antônio Aleixo, One of Many Hansen's Disease Heritage Sites in Brazil

"They took me in a covered canoe pulled by a boat. Three days of travel and I used to get food by cans that the boat would leave in the water for me to catch from behind. I arrived at the Antônio Aleixo colony, and did not yet understand what was really happening to me. I felt such pain, having to leave my family in order to be isolated . . .

"Today we have only the old structures, which with time have turned into ruins. I would like to preserve those buildings that were so important to us, and turn them into a historical site to commemorate the lives we had there . . . The government itself is destroying this history, since for them there is no interest in preserving these ruins. We have to preserve this ourselves."



Valdenora da Cruz Rodrigues
Photo by Pamela Parlapiano

-- Valdenora da Cruz Rodrigues, Founding member of MORHAN, from an interview at the First National Seminar of Former Colony Hospitals, Rio de Janeiro, November 2004. *Transcribed and translated from Portuguese by Gabriel de Mesquita Faccini and Lavinia Schüler-Faccini.*

Sorok Island, Republic of Korea

Sorok Island was established in 1934 during the occupation of Korea by Japan and was a result of the strict Japanese isolation policy.

"Their rights regarding forced sterilization, forced abortions, medical experimentation and forced labor were not protected . . . In 1945, after liberation from Japan, the patients on the island tried to resolve the issue of their cruel treatment. However, 84 patients were murdered by the staff in the middle of a struggle between the staff in the hospital . . .

"In Korea, the human rights violations against those affected by Hansen's disease will be written in the law as a lesson for future generations. A Memorial Hall will be built on Sorok Island so that it can become an educational center where future generations will cherish the memory of those affected by Hansen's disease."

-- S.K. Jung, President of IDEA, who went to Sorok Island as a teenager



Table upon which forced sterilizations were performed, Sorok Island. IDEA Photo

Sungai Buloh, Malaysia



Sungai Buloh and one of its residents, Loh Ah Tong, age 70. *Photos by Lim Yong Long*

Sungai Buloh was built in 1930 and became one of the largest leprosy settlements in the world. It was equipped with advanced facilities and planned as a self-sustaining agriculture settlement. Over the years, the settlement also became a research centre for leprosy. Portions of the site have already been demolished and used for other purposes. The residents of Sungai Buloh and many other Malaysians continue to urge the government to retain and preserve Sungai Buloh as a national heritage site, which has also been supported by the Heritage Commissioner.

Bungarun, Australia



Photos Courtesy of The Department of Indigenous Affairs

Bungarun (former Derby Leprosarium) is recognized as a significant Aboriginal heritage site and was placed in the Register of Historic Places in 2000. It was in operation as a leprosy hospital from 1936-1986. By June, 1940 the population was 178. The Bungarun Memorial was funded by the Aboriginal Lands Trust and lists the names of the 357 people buried in the Bungarun Cemetery, whose graves are marked with anonymous white crosses.

Publication of the IDEA newsletter is made possible through a grant from the Sasakawa Memorial Health Foundation

Addresses for Correspondence

Dr. P.K. Gopal
President, International Relations
58 Selvam Nagar, Collectorate P.O.
Erode 638 -011 INDIA
Phone: 91-424-226-7395
E-mail: ideaind@sancharnet.in

Ms. Mary O'Friel
Administrative Coordinator
699 Main Street
Ashby, MA 01431-2309 USA
Phone: 1-978-386-0048
E-mail: ideaofriel@verizon.net

Ms. Anwei Skinsnes Law
International Coordinator
32 Fall St., Suite A; P.O. Box 651
Seneca Falls, NY 13148 USA
Phone: 1-315-568-5838
E-mail: alaw@idealeprosydignity.org