

International Symposium on Hansen's Disease/Leprosy History as Heritage of Humanity

22nd – 25th April 2017, Okayama, Japan



Organised by Sasakawa Memorial Health Foundation, Japan
In corporation with Setouchi City, Okayama, Japan



Day 2@Yume Topia Osafune

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1. Wind Dance monument, National Sanatorium Oshima Seisho-en, Kagawa, Japan
2. Spinalonga, Greece
3. History Museum, National Sanatorium Nagashima Aisei-en, Okayama, Japan
4. The building that housed the former elementary and junior high school, National Sanatorium Oku Komyo-en, Okayama, Japan
5. Old photo of Bergen, Norway, showing St. George's Hospital
6. Culion Island, Philippines

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Hansen's Disease/Leprosy History as Heritage of Humanity**

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Note:

While the word leprosy is widely used internationally, Hansen's disease is the officially designated term in some countries including Brazil and Japan. It was agreed that the speakers may use either terms according to their choices. However the word 'leper' will only be used in the historical background in the context.

Foreword

Definitely, this symposium served as an excellent opportunity for us to think about and learn so many things. Mainly, I have two thoughts about the talks of the participants. It was 43 years ago when Sasakawa Memorial Health Foundation was established by Mr. Ryoichi Sasakawa and Dr. Morizo Ishidate, who believed that to work for leprosy in the world was an honorable duty of Japan. I presume that, in those days, what they had in mind was so-called biomedical, or medical treatment of leprosy. Although it has been said that the number of newly detected cases was more than 15 million at that time, the precise number was unknown. The number has been gradually going down since then, and it is about 200,000 today. Certainly, this is largely caused by medical contributions. On the other hand, what has been revealed is this disease causes human rights-related or humanitarian issues including stigma and discrimination. These issues cannot be addressed only by biomedical and medical approaches.

Looking back on the history of leprosy, in the 8th century, during the era called the Tenpyo period, Empress Komyo, a wife of Emperor Shomu, made up her mind to make a sort of dry sauna to cure 1,000 patients. After the bodies of 999 patients had been cleaned up, there was one last patient, whose body was all covered with dirt and pus. This patient asked Empress Komyo. “May I ask you to suck up the pus on my body? If you could do it for me, my disease would be cured.” Empress Komyo did as she was asked. Just then, the patient turned into Ashoka Tathagata with Buddhahood, and then his body shined brightly and he disappeared.

I think we can learn two things from this story. One is that the disease can be cured by cleaning our body, in other words, by proper treatments. The other is that “mind treatments” to meet the request made by patients, in other words, humanity or social treatment, are also essential to cure this disease.

In his lecture, Dr. Nakamura said, “We can see not only leprosy but also many other diseases in Afghanistan.” This means that we still need to work on leprosy as a biomedical or infectious disease in some countries. At the same time, even though we have not found yet how to do it, we should not forget about social approaches for stigma caused by leprosy, for human rights, and humanity.

In fact, we live in a time when culture has been fully developed and our life is full of convenience. Nevertheless, if deep-rooted stigma still exists and human rights have not been protected in this world, I wonder for what purpose the human race has studied so far? Sasakawa Memorial Health Foundation aims to carefully study all aspects of the history of leprosy and to share what we learn from it so that the Foundation will contribute to the promotion of human rights issues and humanity all over the world.

I thank Okayama Prefecture, especially people from Setouchi municipality, for their support and help with holding this 5th International Conference. We will continue to seek for future opportunities to hold conferences like this.

Thank you all for coming to this symposium.

Prof. Etsuko Kita, MD, PhD
Chair
Sasakawa Memorial Health Foundation



Greetings I

To begin with, I would like to thank you all for coming to the International Symposium on Hansen's Disease / Leprosy History as Heritage of Humanity today. Sasakawa Memorial Health Foundation was established 43 years ago in 1974 when Dr. Morizo Ishidate, a father of chemotherapy of Hansen's disease, met Mr. Ryoichi Sasakawa, the founder of The Nippon Foundation for the first time. Dr. Ishidate was successful in synthesizing Promin for the first time in Japan after he had come to know about Dr. Faget, who first started a clinical trial of Promin in the United States during World War 2. In those days, Promin was the first medicine which was able to cure leprosy. Today leprosy is treated with MDT (multidrug therapy).



One day, Dr. Shigeaki Hinohara, Dr. Morizo Ishidate, Mr. Ryoichi Sasakawa, Mr. Yohei Sasakawa, the current chairman of The Nippon Foundation and I got together. Dr. Ishidate said, "In Japan, the fight against leprosy first started with the help of foreigners. Koyama Fukusei Hospital in Gotenba city is one of the first modern sanatoriums established by Father Germain Léger Testevuide. Besides, Ms. Hannah Riddell also founded a hospital for leprosy patients in Kumamoto city, which was called a hospital for "resurrection of hope".

However, he went on to say, the leprosy-related problems have not been solved yet in other countries such as Korea, Thailand, the Philippines and Vietnam. Considering this fact, Dr. Ishidate said, "Japan needs to work against leprosy together with all those countries, which would be the honorable duty of Japan." Mr. Ryoichi Sasakawa then slapped his knee and said, "I am very fascinated by leprosy, too! If you lead us, I will work on leprosy throughout my life." Mr. Ryoichi Sasakawa was 75 years old and Dr. Ishidate 73 years old at that time. Can you imagine, there are people who start new business even at 75 years old?

At that time, I worked for Ministry of Health, Labour and Welfare and thus asked the ministry for permission to establish a new foundation. Dr. Fujio Otani was a manager of the section in charge of national sanatoriums. He focused especially on leprosy among many medical issues and made a lot of efforts to repeal Japan's leprosy prevention law. This is how our foundation was established. Dr. Otani was the one whom we should owe a lot.

Although the number of patients has been decreasing, human beings can learn so many things from the history of leprosy. In all countries, there are still cases of patients being abandoned by their families. Leprosy is one of the most difficult diseases among human rights-related issues. We thus believe that our foundation needs to preserve the history and to hand it down to future generations. This is the reason why we are holding this fifth meeting today. With the great help of the mayor, this symposium is taking place in the beautiful city of Setouchi. Leprosy-related issues must be addressed worldwide. I do wish this symposium will be very productive and mean a lot to you. Thank you very much for listening.

Prof. Kenzo Kiikuni
President
Sasakawa Memorial Health Foundation

Greetings II

Good morning, everyone. I am Mayor Takehisa of Setouchi City.

Allow me to express my gratitude to SMHF and to City Council Members.

Setouchi City is the only municipality in Japan that has two National Hansen's Disease Sanatoriums within its district. We have been seriously attending to the issues of Hansen's disease. In order that we may study these issues even further, I felt that it would be meaningful to become co-sponsor of this event.



Currently, Setouchi City is making endeavors to have the two Sanatoriums— 'Nagashima' and 'Oku'— registered as a World Heritage Site. It is done in cooperation with the staffs, residents and the residents' associations of the sanatoriums. Our aim is to preserve and continue the legacy regarding the history as well as the various institutions, for posterity. Through this effort, we seek to deepen the understanding of the public even further, and also be recognized nationally as the city committed to human rights.

It is a historical fact that the Hansen's disease patients were not the only ones stigmatized, but the staffs and the area around the sanatorium were also discriminated against and stigmatized. When we discover how the issue germinated in the local society, learn from it and understand it properly, I believe we can turn this so called 'negative legacy' into an asset to pass onto future generations. That is the reason we are striving for this project.

Today, I believe we will learn from examples of other countries, the various ways the history and preservation are handled. Also, there will be a lecture by Dr. Tetsu Nakamura, who has been working successfully around the world.

I pray from the bottom of my heart that this event offers a good opportunity for the city of Setouchi to think of the future of Hansen's disease. As the co-sponsor of this event, let us cordially welcome you all.

Mr. Akinari Takehisa
Mayor
Setouchi City

Greetings III

I am so pleased to see you all here today. I am the President of Resident committee at Oshima Seisho-en and also the president of Zenryokyo (national network of residents of national Hansen's disease sanatoriums). Oshima Seisho-en was established in 1909 as a public leprosarium and became a state sanatorium in 1941. In other words, it has an 87-year history. The history of segregation finally ended in 1996 when the leprosy prevention law was repealed 21 years ago. In 2001, a court finally ruled that the policy of segregating Hansen's disease patients was unconstitutional and should have been discontinued after the leprosy prevention law had been brought to the court by our sanatorium members in 1998. Since then, the situation of the sanatoriums has dramatically changed. In 2008, an Act to Accelerate the Resolution of the Hansen's Disease Problems was promulgated at last.



Zenryokyo now has to seek the future of the state sanatoriums and so far, we have discussed it. How would it be possible for us to preserve the historical buildings, museums and ossuaries located within the sanatoriums? Currently, we are reaching the agreement that the government should have responsibility for preservation of all those historical buildings as the dark heritage of humanity.

Today, the sanatoriums have less than 1,500 residents. They are now requesting the government to preserve the sanatoriums as state facilities. We, the representatives of the sanatoriums, will soon meet and discuss this matter on April 26.

Our average age is now over 85 years old. We have no time to lose. We strongly hope that the government will solve this problem not in the distant future. We wish to discuss how and what we need to do. Surely, we will face many obstacles. There are some issues which have not been addressed under the new law. In the end, we may need to ask the government to change the present law.

Each sanatorium has a different history. We thus wish to preserve the sanatoriums as the place for human rights education and study. Today, participants from many countries are gathering here. I believe that each county has been trying hard to find out how the history of leprosy sanatoriums could be handed down to the present and future generations. I am very much looking forward to knowing about the sanatoriums with old history in other countries, such as the one in Hawaii, which has an even longer history than the sanatoriums in Japan. I thank Setouchi city and Sasakawa Memorial Health Foundation for organising this symposium. I wish this symposium success.

Mr. Kazuo Mori
President of resident committee
National Sanatorium Oshima Seisho-en

Greetings IV

Today, I am so delighted to be here to join the 5th International Symposium on Hansen's Disease / Leprosy History as Heritage of Humanity which is organised by Sasakawa Memorial Health Foundation and co-hosted by Setouchi municipality in Okayama Prefecture. Thank you very much for coming to this place.



In Japan, the 2nd and 3rd generations of the people affected by the disease cannot be found at state sanatoriums in Japan. Therefore, the sanatoriums will be closed after the 1st generation is gone in the near future. There is a residents' association called Zenryokyo (national network of residents of national Hansen's disease sanatoriums). Today, the average age of the Zenryokyo members and the presidents of the residents' associations at 13 sanatoriums is very high. I am not really sure till when Zenryokyo will exist, for another five years or maybe even less than that. Some presidents are 90 or 91 years old and still fine enough to work for their associations. However, they have neither children nor grandchildren. In the next 20 years or so, the number of the residents will drop fast. Reflecting this situation, Zenryokyo has decided to make all efforts to preserve 13 state sanatoriums as the heritage of humanity within a few years. Our preservation efforts will facilitate an ongoing project implemented by the sanatoriums on Setouchi Islands for UNESCO World Heritage nomination. There is no time to waste. To achieve our aim, we must strongly commit to the intended preservation work.

This symposium will be going on until April 25.

I trust that this symposium will stimulate the participants and mean a lot to them.

Thank you very much for listening.

Last but not least, I am very pleased to introduce to you an official sanatorium mascot of Oku Komyo-en, "Komyo-tan". This is our beloved mascot character and popular in Japan.

I hope you too will like him.

Mr. Takeshi Oku

President of resident committee

National Sanatorium Oku Komyo-en

Keynote Lecture



Keynote Lecture

From Leprosy to Water for Life

Dr. Tetsu Nakamura

Representative
Peshawar-kai in Pakistan and Afghanistan

Hansen's disease is not bound by the issue of 'Hansen's disease' alone, but is suggesting many problems for us. I would like to illustrate to you how Hansen's disease triggered changes in Afghanistan.

Let me briefly introduce the area where I reside, in the eastern part of Afghanistan, to the west of Pakistan. Afghanistan is in Middle East/Central Asia. If one was to travel westward along the Himalayas, Afghanistan is at the very end. It is a mountainous country, with the Hindu Kush Range containing mountains that are 6000m in height, occupying most of the country. And that has great significances to the people that live there.



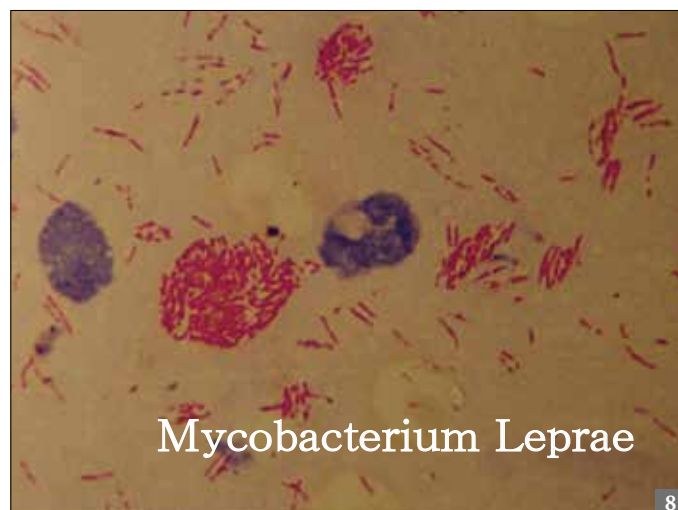
There is an Afghan saying; *'You can live without money but you can't live without snow.'* The snows of Hindu Kush have supported the livelihood of 20 million people. The glacier that developed over tens of thousands of years, snow of winter melting in summer, promising abundance of harvest along the river. The snow of mountains worked as giant water reservoirs.

Afghanistan is a multi-racial nation. Its society consists of at least 20 ethnic groups and tribes that are known to coexist, and it is unlike the modern, centralized nations. It is a nation where nearly 100% of the people are Muslims that are considered to be the 'most conservative Muslims in the world.' It is the religion that is holding the country with such diverse peoples together.

The gap between the rich and the poor is immense here, and this gap brings forth the feeling of helplessness for the medical staff upon arrival. Over 99% of the persons that become ill, die because he/she did not have little money, less than one US\$. It is a society where special considerations must be made by the medical personnel, to benefit as many people as possible, with as little money as possible.

Under such circumstances, our 'Peshawar-kai' participated in the Hansen's disease elimination 5-year-plan. The places with the most concentration of patients were in areas that were quite difficult to access, and also hotspots for all diseases one can imagine. Unlike Japan, there was relatively little stigma attached to Hansen's disease, and so special considerations were needed NOT to overly treat Hansen's disease as something extraordinary, to make it stand out and amplify stigma.

Also, we have made it our iron rule NOT to judge a local culture as good or bad. Many issues are solvable within the culture. For example, in a culture where women are banned from exposing their skin, we have



accommodated female staffs or asked the family member to sit-in for the treatment. We continuously searched for a solution that would not violate the local custom. It is very likely for a foreigner, when faced with things not familiar, to make judgements whether it is good or bad; superior or inferior. We often talk about and emphasize the discriminations against Hansen's disease, but I feel that we must also point out the discriminations of Westerners or Japanese toward the local people. Hansen's disease made me review my own values and judgments; an experience that was tremendously meaningful for me.

Patients with the worst symptoms were coming from Afghanistan, which at that time was invaded by the former Soviet Union army, resulting in 30 million refugees and 20 million deaths. We were inevitably drawn into the Afghan situation by the Hansen's program and medical support we were providing. Airstrikes by the US military began, and the situation was worsening.

Many of the Hansen's disease patients could not afford the transportation fare to the clinic. So, we decided to make a clinic in an accessible location. We aimed to tackle together the troublesome infectious disease as well as paralysis caused by other ailments, gradually, getting nearer and nearer to the area with the most Hansen's disease patients. Even during the conflict, we walked around barefooted and tried to deepen our relationships with the villagers.

By this time, various organizations were participating in Hansen's disease elimination programs and making some progress. The numbers seemed to say that the patients were decreasing. However, in reality, the number of new patients was rapidly growing. It was not that the disease was eliminated, but rather, the facilities that treat Hansen's disease were diminishing. This is true for other programs as well; when the topic is newsworthy, money, goods and people gather around it, but as soon as it is no longer talked about, they disappear as if the tide had left. I felt it to my bones.

"How can I say 'so long and good-bye,' just because statistically the 'number' became zero?" I thought. Around April, 1998, seizing the opportunity of the 15th anniversary of the on-site Peshawar-kai, we created an organization structure that would allow us to remain active in the on-site location, at least as long as supplies from Japan were coming in.

Then, the drought of the century affected eastern Afghanistan. Sadly, due to political reasons, no international help arrived. Villages disappeared one by one around our clinic. In the self-sustaining life style of Afghanistan, when there is no water, farming becomes impossible and food cannot be secured. People were malnourished, and with low resistance to disease, drinking unclean water caused infectious diseases.

Then, after the terror attack on Sep. 11, 2001 in New York, there were whispers of sanctions and air strikes of Afghanistan. Images of Afghanistan being the hotbed of terror were fixed. Eventually, the picture of "Evil and heinous Taliban" vs. "Guardian of absolute liberty and justice, USA" spread throughout the world.

For a person on the spot, what followed were unbearable events that began to occur around the world indiscriminant bombings. The first to perish were the feeble and helpless, meaning women and children. And most likely, the Hansen's disease patients, as many of them had limited physical capacities. It was totally unbearable for us.

In this despicable situation, I realized that if we were really serious about the true recovery of



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アフガン東部・パキスタン北西部のハンセン病

- ・境界型が圧倒的→神経麻痺例多数
- ・山間部の寒村（貧困層）に多い
- ・多発地帯へのアクセスが困難
- ・多発地帯は他の感染症も多発
- ・偏見は比較的少ない

10



再建外科の発足

11



女性患者へのアプローチ

12



足底潰瘍の対策

13



戦乱の国

ソ連軍侵攻 (1979-1989)
欧米軍侵略 (2001-2014)

14



15



ヌーリストン山村

16

Afghanistan, we need to secure clean water to live, and then, to stabilize the self-sustaining life, furnish water for farming. We made plans to draw water from nearby Indus River, and in 2003, launched the "Green Ground Plan," which is still an on-going effort. In Japan, we have excellent technology and equipment for water-intake. However, this would never work in Afghanistan and, as with Hansen's disease, we needed the localized approach. What we noted was the technology from the Edo period (1603~1868), before modernization. In an area without electricity or equipment, where we could only use local material, the methods of Edo were adaptable.

Since 2008, we have been doing engineering work at an outrageous place called Gamberi Desert. During the summer, the temperature went up to 52 degrees Celsius. Each day, around a dozen men collapsed, but they did not stop working. They were former refugees. If they succeed, they could return to their villages, but if they failed, they would have to remain as refugees. Even though that was a life or death situation, they were truly dedicated to the project, with the hope of returning home to their families one day.

Reclamation of Gamberi Desert is steadily continuing to this day. In the past, cultivated lands were covered overnight with a sand storm, so we decided to plant trees simultaneously. Now, these trees are forming forests and temperature is decreasing. It is unprecedented around this area to plant rice in the desert, and when we began to harvest rice, wheat and fruits, the nomadic people began to appear. They need grazing land, but without water there were no grass, and they had to go elsewhere. With one irrigation ditch, not only humans but thirsty animals were quenched. Firewood became available, fertilizers could be made by themselves: When water is available, anything is possible, we learned.

Twenty seven kilometers of the irrigation canal was completed; lands for 150,000 people to live have been restored. When people returned and food became available, many trades were born and the population expanded dramatically. Even thereafter, we are trying to spread the water-intake system throughout the country, aiming for a grand expansion. It is expected that the Green Ground Plan will be completed by 2020. This is one model, which shows: "There are ways to survive, without hate and fighting."

We often say 'we need to settle our hatred' or 'human rights are invaded,' on specific topics regarding prejudices such as Hansen's disease, hate speech or racial discrimination. The discrimination against Hansen's disease may disappear superficially, but deep down, hate never goes away. If the theme of Hansen's disease vanishes, discrimination would move to another topic. It indicates that prejudice and discrimination inhabit somewhere deep down in each of our hearts. Unless we come in terms with these feelings, discrimination will only be repeated. Hansen's disease, physical handicap, mental fragility, etc., there may be differences in the level, but we all have issues. Basic human right lie with the concept of treating each other with care and respect.

Would discrimination disappear if we say 'Hansen's disease' instead of 'leprosy'? If people act not only with a play of words, but when they become aware from the bottom of their hearts that a human being is a human being, discrimination can be totally dissolved. Hating discrimination and prejudice is not the solution. That is what I mean by settling differences. I strongly feel that there lies the answer in making peace with one another, and making peace with nature. Hansen's disease was a humongous topic for us. We have dealt with many local issues through it. But all in all, I believe the solution is for each person to acknowledge each other's differences and live wholesome lives.

Thank you very much for your attention.



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P M S 基地病院建設 1998



19

大干ばつの襲来と対策 (2000～)



20

腸管感染症と餓死



21

水を求めて



22

空爆下の食糧配給 (2001)



23

無政府状態・麻薬



24



25



26



27

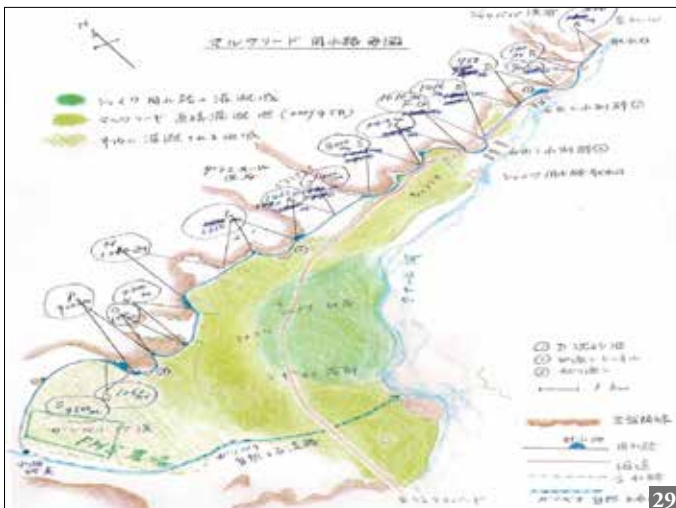
緑の大地計画

マルワリード用水路の建設

2003~2010

沙漠化で無人化した村々の復興
百の診療所より一本の用水路

28



29



30



31



32

日本の治水技術とアフガン

- ・ 急流河川と激しい水位差
- ・ 山間部や小平野の耕作地
- ・ 取水技術の類似性
- ・ 維持可能な適正技術
- ・ 天の時 地の利 人の和
(地域自然条件と文化の重視)

33



34



35



36



37



38



39



40



5 years after planting

14 May 2014



49

ガンベリ沙漠

2008年3月9日 工事前



50

ガンベリ沙漠横断(2008~2009)



51

沙漠横断水路通水(2009年8月)



52

ガンベリ沙漠開拓

新たな開墾地の拡大

2008年3月9日 工事前



53

2009.8.10



54

2012.4.15

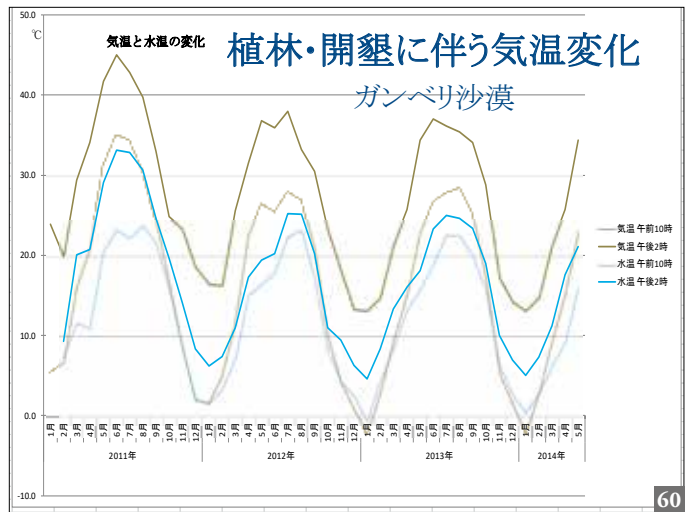
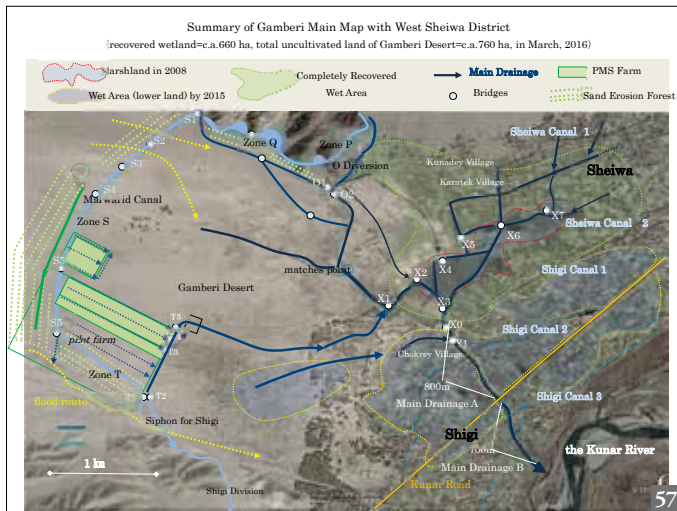


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2014.6.23



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遊牧民の楽園



67

伐採した木材の活用

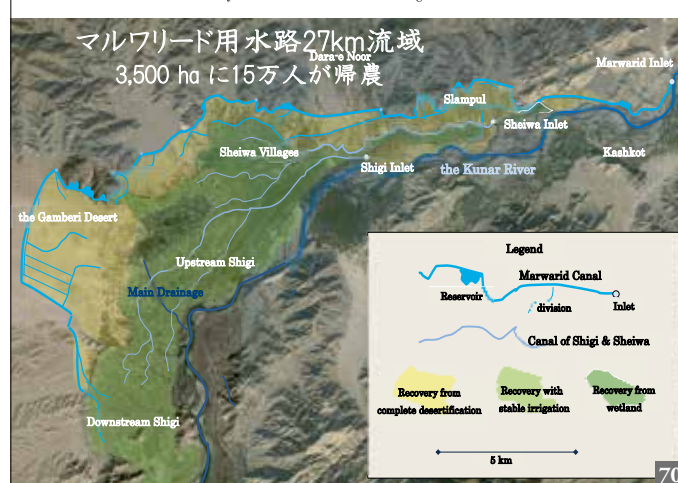


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堆肥の生産
無駄のない自然

69

Patterns of Recovery at the Main Sheiwa District (right bank of the Kunar River)



70

バサールの復活
2014.9.28

71

温暖化！

戦よりも食糧自給

遅れる気候変動への対処

進行する干ばつ

72



73



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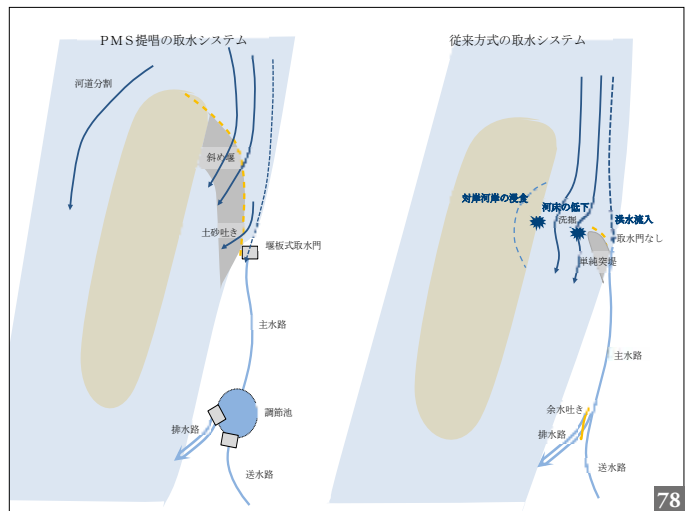
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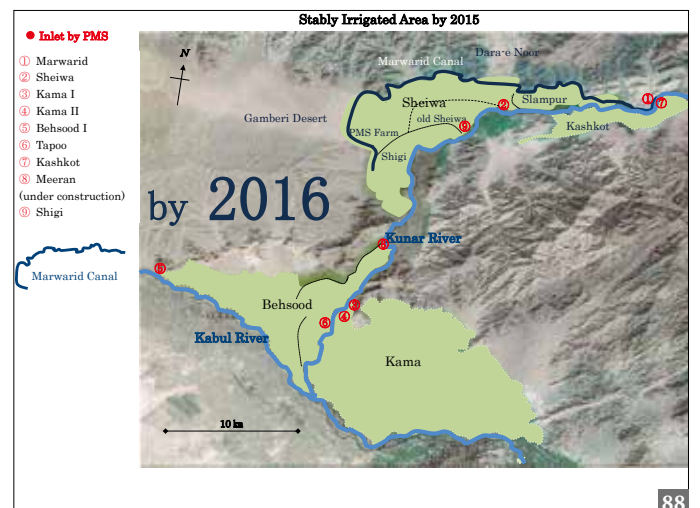
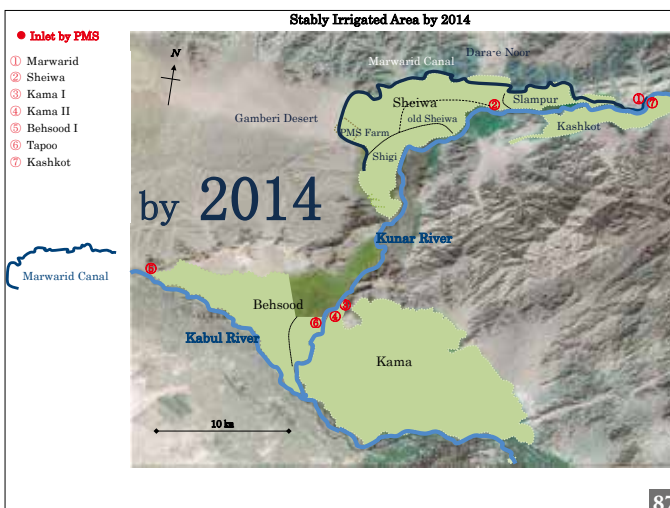
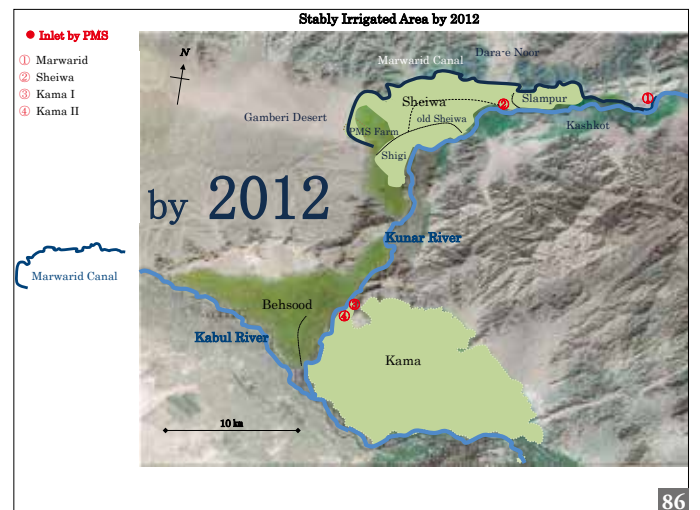
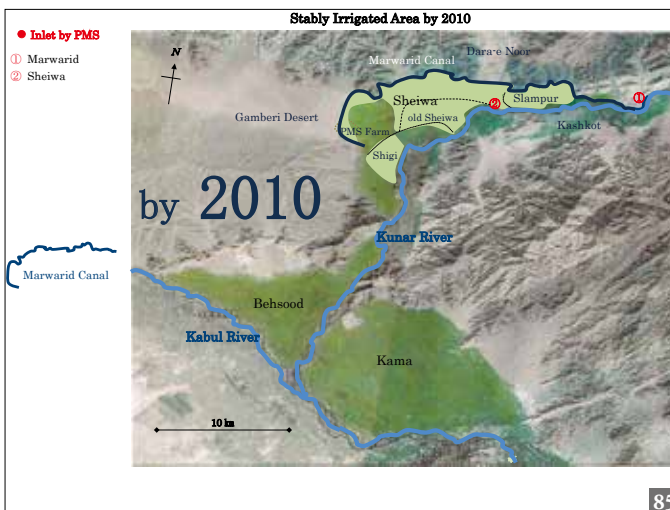
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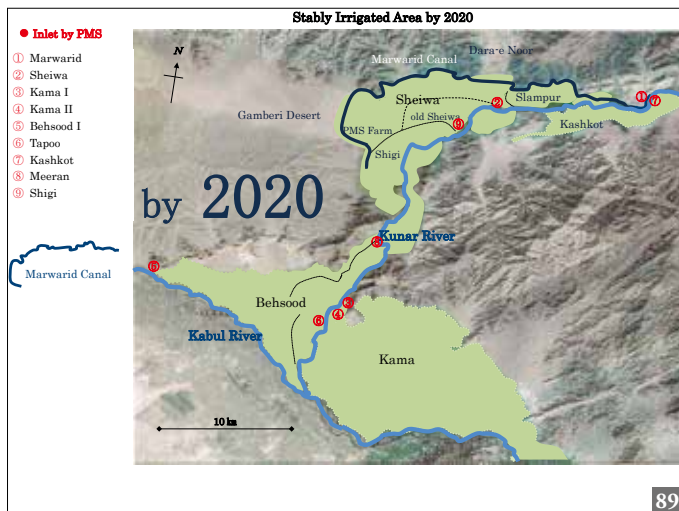


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*Session A****“Preserving Materials & Testimonies”***

Session A: "Preserving Materials & Testimonies" – Lectures

Preserving the Hansen's Disease History

Mr. Tomohisa Tamura

Curator
Nagashima Aisei-en History Museum

Why should we preserve the history of Hansen's disease? There are two reasons. First of all, by saving the history of sanatoriums, the residents and patients of Hansen's disease may be exonerated. Secondly, this history can work as the platform for learning, to avoid similar mistakes in the future—mistakes not limited to Hansen's disease. Unfortunately, the problem of prejudice and discrimination exists throughout the world, against matters such as disease, race and religion. By studying the history of Hansen's disease, one would know the importance of learning with humbleness and concern.

Next, in preserving the history of Hansen's disease, what can we regard as 'historical items?' There are: 'paper-based items,' 'objects,' 'architectures,' 'surrounding scenery,' and 'testimonies.' The objective of a museum is to Collect, Preserve and Educate. A significant mission lies with preservation, as a museum is the keeper to pass the items over to the later generations, to people 100 years or 200 years into the future.

It would be preferable to deoxidize the original text of the paper-based items, but if budget is limited, avoid direct sunlight and try to change the environment as little as possible. It is important to promote digitalization. Objects should be photographed, then the photographs should be attached to the catalogue. Architectures contain memories of the people who lived there. Many Japanese buildings are made of wood, and many are quickly becoming dilapidated. We listen to experts' opinions and, with the help of volunteers, work to conserve them. Preservation of surrounding scenery (landscape) cannot be undertaken by the sanatorium alone. It is better to involve local or national government and let it become part of urban planning. Make the case an issue of the whole regional area.

Above all, it is important to preserve how the residents lived and what their emotions were. Currently, we have a project to interview all the residents at Nagashima Aisei-en. We intend to save the interviews as transcripts and video recordings. When interviewing, we must remember not to ask questions with Yes or No answers, but to ask open-ended questions. Imagine that you are delivering the message to people at the other end of the camera. Also, the interviewer should never ask inducing questions that lead to a conclusion.

The work of a museum is not only to collect and display the items. In order to have an uninterrupted flow of visitors, it is necessary to create an 'Exhibition Plan,' and specify what the museum seeks to preserve, and for whose sake. Then, we build a story around that objective. Most visitors would tour the



Preserving the Hansen's Disease History

TOMOHISA TAMURA
CUARTOR, NAGASHIMA AISEI-EN HISTORY MUSEUM



1

Why Pass on the Memories?

- Restoring the dignity of the residents
- Never to repeat similar mistakes

2

Methods of Dissemination

- Internet
- Travelling Exhibitions
- Museums
- Visits to Facilities

3

How to Create Museums: Collecting/Preserving Historical Materials

Collection of historical materials

- Paper: medical records, administrative records, personal notes
- Objects: medical instruments, protective device, artworks of residents
- Testimonies: testimonies of residents or concerned persons
- Architectures: accommodation of residents, hospital ward, grave
- Landscape: surrounding scenery etc.

4

How to Create Museums: Collecting/Preserving Historical Materials

Preservation of historical materials

- Paper: ultraviolet screening, temperature and humidity control, deacidification treatment
- Objects: ultraviolet screening, temperature and humidity control, appropriate preservation method
- Testimonies: Protection of privacy
- Architecture: renovation of aged deterioration
- Landscape: developing urban plan

5

How to Create Museums: Collecting/Preserving Historical Materials



Extermination by medical freezer

Place the documents in acid-free boxes, and preserve in a room with no direct sunshine

6

How to Create Museums: Collecting/Preserving Historical Materials



7

How to Create Museums: Research and Creation of Inventory Lists

Survey of Background of Items in Collections

- Paper: when • who • for whom • objective • condition
- Objects: when • who • for whom • objective • material • condition
- Testimony: when • who • contents
- Architectures: when • who • objective

Make inventory in each.

8

site according to the Route plan, therefore, we should first think what route would facilitate the visitors' understanding, when we are creating the story.

One of the purposes of Aisei-en Museum is to exonerate the residents. Often, the residents are looked upon with pity. However, let me remind you that they are strong people who have overcome the cruel circumstances they faced. Let's think for a moment how we can best present these facts for the visitors' understanding.

To present them as 'people that lived with strength' we need to show how they lived strongly: Their 'Cultural Activities' or 'Actions for Petition to improve Treatment' are some examples. Visitors need to learn about the harsh living conditions in the sanatorium that forced the patients to resort to such actions. And, what caused the cruel living conditions? In Japan, erroneous governmental policies of enforced and life-long isolations were the cause. To reveal the errors of the government, one needs to correctly understand Hansen's disease itself.

Therefore, in thinking of the story for the exhibition, one must first have correct basic knowledge of Hansen's disease and what its after effects are: Next, know the errors of the national policy: Then, the cruel living conditions of isolation, and finally, examples of how people strongly survived through it all. Introducing the story in this order would allow the visitors better understanding. After creation of the story, display panels and items are collected to support it.

In the museums I have been to, there were many that merely displayed the items that they had collected. If you just line them up in a display, there is no story. What is important is to select items that are most appropriate to portray the story. Please note that what one sees in a museum are only the selected items from a large collection. It is said that ordinarily, a storage warehouse twice the size of an exhibition space is necessary to keep all the artifacts.

What is most important is how to administer a museum. In administration, crucial points are: marketing, public relations, scheduled exhibitions and special events. PR is important, but not very many would only see a pamphlet, and decide to go to the sanatorium. Events could draw visitors, but unless you can provide satisfaction, it would be difficult to have them repeat the visit. At Nagashima Aisei-en, where 90% are group visitors, we put strong emphasis on explanation of the display. How to make the visitors interested and have them leave with proper understanding are very important. Raising the satisfaction level of visitors would lead to a proliferation of information to other groups, friends and family, and could induce increase in visitors. By giving them a thorough explanation, many people would have a good learning experience in the sanatoriums. And, as a result, the residents could be exonerated.

In conclusion, I would present to you this phrase: "Hansen's disease could change the world." The discrimination and stigma of Hansen's disease have existed since ancient times. To seek solutions, many people (the majority of them young) are going to the sanatoriums to learn. They learn the history with the potential to utilize this knowledge later in life. In other words, here may be a clue to how to solve various types of discrimination. Through Hansen's disease, perhaps we can forever change the issue of discrimination around the world. I believe there is a tremendous potential in studying Hansen's disease.

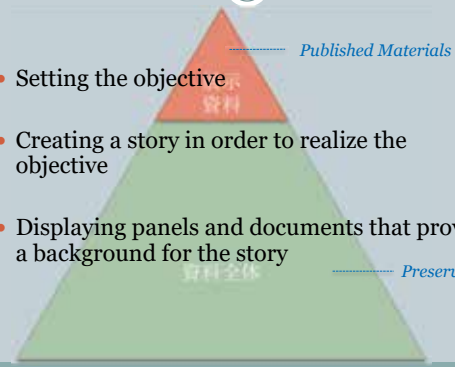
How to Create Museums: Research and Creation of Inventory Lists

Number	Name	Inscription	Size	Material	Age	Remarks
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How to Create Museums: Creation of Exhibition Plans

- Setting the objective
- Creating a story in order to realize the objective
- Displaying panels and documents that provide a background for the story



10

Running the Museum

- Marketing
- Public Relations
- Exhibition
- Events
- Explanations for Displays

11

Enhancement of visitors satisfaction

$$Y = aX$$

Y=Understanding level
X=Amount of information
a=Interest

12

Session A: "Preserving Materials & Testimonies" – Lectures

Preservation of Leprosy History and Heritage for Humanity: Philippine Experience

Dr. Arturo C. Cunanan Jr.

Medical Center Chief
Culion Sanitarium & General Hospital

The regional sanitarium were established after Culion Leper Colony to fully implement the Segregation and Isolation Law of "lepers" in the Philippine Islands and to bring about the eradication of leprosy in the country. They have volumes of documents, books, memorabilia and other records of individuals affected by leprosy and their families.

National Workshop on the Preservation of Leprosy History in 2013

The First National Workshop on the Preservation of Leprosy History in the Philippines was organized and spearheaded by the Culion Sanitarium & General Hospital on August 20-21, 2013.



Participating Agencies:

- a.) National Historical Commission of the Philippines (NHCP)
- b.) National Archives of the Philippines (NAP)
- c.) National Leprosy Control Program – DOH (NLCP)
- d.) Sanitarium of the Philippines
- e.) Coalition of Leprosy Advocates of the Philippines (CLAP)
- f.) DOH-Special Cluster

The workshop impressed upon participants the sense of urgency to take action toward the preservation of leprosy history in the sanitarium, as there is rapid physical infrastructure change or facelift of the sanitarium/hospital in consonant with the sanitarium expansion plan and there is sense of urgency as the residents in the sanitarium are becoming older and fewer with the success of MDT. The residents of the sanitarium are a rich source of history and materials so that when they are gone this valuable history is lost.

The preservation of leprosy history in the sanitarium in the Philippines and eventual museum display and archives preservation provides a good venue for advocacy and health education about leprosy as a curable disease and for the elimination of stigma and discrimination against people affected by leprosy and their families.

PRESERVATION OF LEPROSY HISTORY AS HERITAGE TO HUMANITY

Philippine Experience

Arturo C. Cunanan Jr., MD, MPH, PhD
Culion Sanitarium & General Hospital
Culion Palawan, Philippines

1

Background

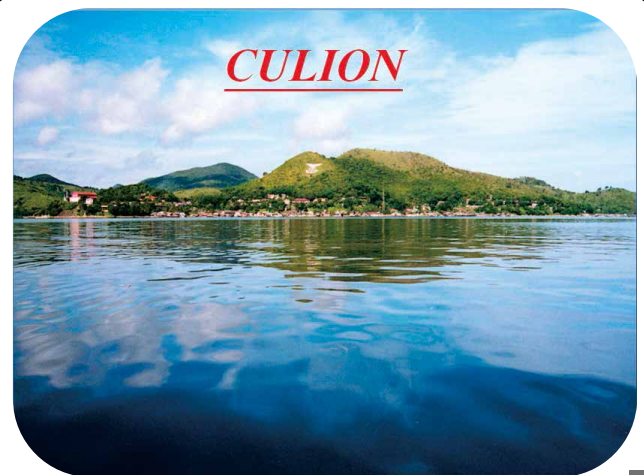
- ❑ The public health concern for leprosy has been limited to only few countries, although endemic pockets still persist needing a strategic and innovative response.
- ❑ there is now a realization of the need to look into how to preserve leprosy history and heritage globally, regionally and at country level.
- ❑ There is much to learn from the lessons of leprosy due to limitations of science have affected people's lives and their families,
 - ❑ Pain and suffering more than the medical aspects
 - Social stigma and discrimination not only to the affected person but to his families that runs to generations.

2

Background

- ❑ Many countries now are embarking on this journey of preservation of leprosy history and heritage
- ❑ Culion is one of the pioneers in the Philippines with the support of the SMHF, the Culion Sanitarium and General Hospital has established the Culion Museum and Archives in 2006
 - Became the repository of Culion history and heritage
 - the struggle of the country and the health institutions and the people affected in the fight and response to leprosy as a disease following interventions of isolation, treatment care, and research.

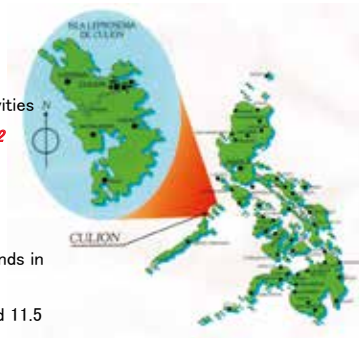
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In 1901 Culion was selected as Segregation Colony for people with leprosy

- Well isolated, sparsely inhabited
- Good anchorage
- Abundant water supply
- Opportunities for livelihood activities
- Culion Leper Colony- founded in 1902**
- Total land area of 150 sq. miles
- Located 200 miles southwest of Manila
- Part of Calamianes group of islands in the province of Palawan
- 19 miles from north to south and 11.5 miles across its widest part



5

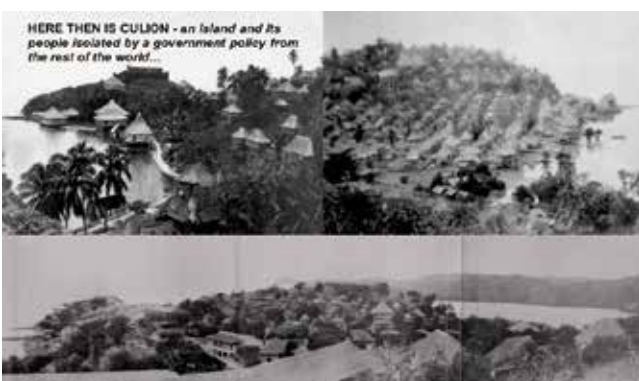
Segregation Law Act 1117 of 1907



6

CULION

Becoming The Largest Organized Leper Colony In The World – 1937



7

Culion Centennial Marker 1906-2006



National Historical Commission of the Philippines Historical Marker



8

This workshop was provided to sensitize the other seven sanitarium in the Philippines on the preservation of leprosy history in their respective sanitarium using the experience of Culion Museum and Archives and to re-echo the October 2012 meeting held in Tokyo regarding preservation of leprosy history. The workshop established a collaborative network among different sanitarium in the Philippines and the National Historical Commission of the Philippines and National Archives of the Philippines, and developed a plan of action for each sanitarium for the start of preservation of leprosy history and heritage.

As part of the recommendations of the first workshop on improving capacity of the sanitarium staff to perform records management and preservation and other essential activities, training on Basic Record Management and Preservation and Oral History Processes was held in July 2014. Conducted by National Archives of the Philippines (NAP) and University of the Philippines Department of History, it was participated in by Record Officers and Medical Social Workers of eight sanitarium of the Philippines. The participants were provided with the needed knowledge, awareness and skills to move forward the objectives of preservation of leprosy history. Each sanitarium prepared a plan of action for the preservation of leprosy history.

Monitoring of the Preservation activities in 2014-2015

In 2014, the Sasakawa Memorial Health Foundation (SMHF) gave a grant to seven sanitarium in the country in order for them to start their respective preservation of leprosy history. The sanitarium personnel also received several trainings and workshops in the preservation of leprosy history from the staff of the National Archives of the Philippines, the National Historical Commission and from University of the Philippines Department of History. In August 2015, a monitoring team conducted a visit to observe how the sanitarium have progressed in their preservation efforts. Six sanitarium were visited: 1. Dr. Jose N. Rodriguez Memorial Hospital, 2. Eversley Childs Sanitarium, 3. Western Visayas Sanitarium, 4. Bicol Sanitarium, 5. Mindanao Central Sanitarium, and 6. Cotabato Sanitarium.

Objectives:

- To monitor the implementation of the action plan in each sanitarium and the utilization of the “seed capital” from SMHF.
- To provide feedback and recommendations from technical experts of the monitoring team by sharing experiences of other sanitarium and countries engaged in leprosy preservation
- To strengthen the collaborative network between NAP, NHCP and CLAP-affiliated associations in the sanitarium.
- To determine future activities for the preservation of leprosy history and heritage in the eight sanitarium of the Philippines.

CULION THROUGH THE YEARS 1906 - 2017

- ❑ The museum opened last 6 May 2006, as one of the main activities of the Culion Centennial Celebration.
- ❑ The exhibition presented 100 years of Culion, featuring important aspects of its history and various chapters highlighting :
 - the segregation and isolation,
 - the resulting community life,
 - care of children
 - achievements and contributions in national and international leprosy research and treatment.
- ❑ The museum was damaged by super typhoon Yolanda last November 08, 2013 and re – open in July 26, 2014.

9

OBJECTIVES

- To preserve old manuscripts / documents, records, letters, research findings, clinical records and books of Culion Leper Colony.
- To collect / preserve old medical and laboratory equipment, which were early used for the treatment, research and care of leprosy patients.
- To collect / preserve old pictures of early Culion settlement, patients treatment and community life to include old coins, musical instruments, badges / uniforms of early local police, nursing aides, firemen, etc in collaboration and support of PAL / residents of Culion.
- To provide information regarding the role of Culion in the control of leprosy in the Philippines and the resultant community that evolves thereafter.
- To make all preserve documents and other materials, literatures available to interested researchers, students and individuals worldwide.
- To include Culion Museum in the Global Project on preservation of Leprosy History, providing linkages with international and national organization interested in this field.
- To be a venue to provide public health education on leprosy and to advocate in eliminating leprosy stigma and discrimination against people affected by leprosy

10

Culion Museum and Archives

PEOPLE AFFECTED BY
LEPROSY AS TOUR
GUIDES



11

Culion Museum and Archives Leprosy Social History & Memories Gallery

- ❑ The most important collection for the preservation efforts is to preserve the life stories of the people affected themselves
 - ❑ their struggle, how they survive amidst the indifference of the community and people around them,
 - ❑ the life in isolation, how they persevere and overcome, how they maintain and preserve their humanity and identity and t
 - ❑ their struggle for others to respect their human rights and dignity.
- ❑ These life experiences can't be seen in the buildings although the memories lingers, what is behind those walls, what is the story behind those instruments and apparatus use for and by patients.

12

The Social Gallery

- ❑ Show case the life stories and struggle of leprosy affected people segregated to Culion and in other sanitarium and featured how they live , survived and maintain their dignity and humanity.
- ❑ Offers a venue or a catharsis for residents or people affected by leprosy to ventilate their inner thoughts, feelings and ideas long suppressed through their oral history.
- ❑ Provided venue for display of many art works , music , poems , letters and literatures of the people affected by leprosy.
- ❑ Contributes to the elimination of social stigma and discrimination against people affected by leprosy and their families brought by the lack of knowledge negative awareness and stereo typing about the disease and the patients.
- ❑ Provided a venue for the current Culion youth or the 3rd and 4th generations, descendants of the segregated and isolated patients to know and understand Culion history better, identify and appreciate their roots and forefathers, and know the key people in the Culion community who patients as maybe yet contributed to what Culion is today
- ❑ Is a venue to honor and pay tribute and recognize the thousands segregated and isolated patients in Culion and for the religious missionaries and medical and non medical hospital staff who served Culion with utmost love, compassion and dedication.

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Culion Museum and Archives Leprosy Social History & Memories Gallery



14

PRESERVATION OF LEPROSY HISTORY IN 8 SANITARIA IN THE PHILIPPINES

15

8 DOH Sanitaria



16

International Workshop on the Preservation of Leprosy History and Heritage in 2016

To further highlight the importance of preservation of leprosy history and memories, and to further sustain the interest in the Philippines, the Culion Sanitarium & General Hospital teamed up with the University of the Philippines Department of History to hold a conference that served as a venue for social scientists, students and other researchers to present their work about social issues and the history of leprosy in the Philippines.

The International Workshop on the Preservation of Leprosy History and Heritage was organized last February 15-16, 2016 to provide a proper venue to present the monitoring findings and the recommendations by the monitoring team, and to share the best practices and experiences of the eight sanatoria as well as from China, Malaysia, Thailand, and Japan, which are also engaged in the preservation of leprosy history.

The workshop aimed not only to help sustain the momentum of the preservation of leprosy history, but also to pave the way in building networks and links among the sanatoria in the country and the Southeast Asia and Asia region.

Objective:

- The conference, "Leprosy: History, Memories, Stigma, and Public Health," aimed to put on center stage the social science dimension of leprosy. Harnessing the different social sciences (history, anthropology, sociology, etc.), leprosy was studied from different perspectives making richer the understanding of the disease.
- To enrich the production of knowledge about leprosy in the Philippines through the papers presented during the conference.

- ❑ The regional sanitaria, are established after Culion Leper Colony to fully implement the Segregation and Isolation Law of "lepers" in the Philippine Islands and will bring about eradication of leprosy in the country.
- ❑ They also have volume of documents, books, memorabilia and other records of individual person affected by leprosy, their families
- ❑ The First National Workshop on the Preservation of Leprosy History in the Philippines was organized and spearheaded by the Culion Sanitarium and Hospital last **Aug 20-21, 2013**

❑ **PARTICIPATING AGENCY:**

- a.) National Historical Commission of the Philippines (NHCP)
- b.) National Archives of the Philippines (NAP)
- c.) National Leprosy Control Program – DOH (NLCP)
- d.) Sanitaria of the Philippines
- e) Coalition of Leprosy Advocates of the Philippines (CLAP)
- f) DOH-Special Cluster

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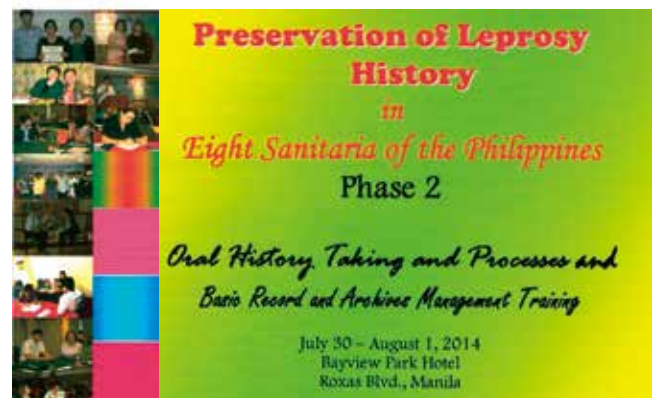
- ❑ The workshop has impacted to the participants the sense of urgency to take action toward the preservation of leprosy history in the sanitaria,
 - ❑ as there is rapid physical infrastructure change or facelift of the sanitarium/hospital in consonant with the sanitarium expansion plan.
 - ❑ There is sense of urgency as the number of residents in the sanitaria is becoming older and fewer with the success of MDT. The residents of the sanitaria are rich source of history and materials that when they are gone such valuable history is lost.
- ❑ The preservation of leprosy history in the sanitaria in the Philippines and eventual museum display and archives preservation
 - ❑ provide a good venue in the advocacy campaign and health education about leprosy as a curable disease and in the elimination of leprosy related stigma and discrimination against people affected by leprosy and their families.

18

The Workshop

- ❑ Sensitized the other 7 sanitaria in the Philippines in the preservation of leprosy history in their perspective sanitarium using the experience of Culion Museum and Archives and to re echo the October 2012 meeting held in Tokyo regarding preservation leprosy history
- ❑ Established a collaborative network among different sanitarium in the Philippines and the National Historical Commission of the Philippines and National Archive of the Philippines
- ❑ Developed a plan of action for each sanitarium for the start of preservation of leprosy history and heritage

19



20

- ❑ As part of the recommendations of the first workshop
 - ❑ of improving capacity of the sanitarium staff to perform records management and preservation and other essential activities, a training on Basic Record Management and Preservation and Oral History Processes was held last July 2014
 - ❑ conducted by National Archives of the Philippines (NAP) and University of the Philippines - Department of History, participated by Record Officers and Medical Social Workers of 8 sanitarium of the Philippines.
- The participants were provided the needed knowledge, awareness and skills to move forward the objectives of preservation of leprosy history
- Each sanitarium prepared Plan of Action for the Preservation of Leprosy History

21

WORKSHOP ON BASIC RECORDS AND ARCHIVES MANAGEMENT

July 28– August 1, 2014



22

FILES MANAGEMENT



Mr. Ricardo Eugenio, Supervising Records Management Analyst of NAP lectured on Files Management. Unfortunately suffered a massive heart attack three days later and died last August 1, 2014.



Mr. Antonio General of Sula Sanitarium presenting his group's output.

RECORDS DISPOSITION ADMINISTRATION



Mr. Larry O. Parilla, Senior Records Management Analyst of NAP gave a lecture about Records Disposition Administration.

RECORDS CENTER ADMINISTRATION



Mr. John E. Alvarez, Administrative Officer V of NAP lectured on Records Center Administration.

23

PRESERVATION AND CONSERVATION OF RECORDS



Ms. Leoncia A. Marquina, Supervising Records Management Analyst of NAP discussed about Preservation and Conservation of Records.

Workshop on Oral History Taking and Processes



Professor Camagay starts the workshop with an overview of Oral History. "It is a laborious process..."

24



25

DISASTER PREVENTION PREPAREDNESS IN RECORD MANAGEMENT



Ms. Merlie P. Magdamit, Training Specialist III of NAP, giving lecture about Records and Archives Disaster Preparedness



The group dramatizing the steps in response and recovery as part of disaster prevention preparedness

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28

Monitoring of the Preservation of Leprosy History and Heritage in the Sanitarium of the Philippines



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- ❑ in 2014, the Sasakawa Memorial Health Foundation gave a grant to seven(7) sanitarium in the country in order for them to start their respective preservation of leprosy history.
- ❑ The sanitarium personnel also received several trainings and workshops in the reservation of leprosy history from the staff of the National Archives of the Philippines and the National Historical Commission and from University of the Philippines Dept of History.
- ❑ in August of 2015, a monitoring team conducted a visit to observe how the sanitarium have progressed in their preservation efforts. 6(six) sanitarium were visited: 1. Dr. Jose N. Rodriguez Memorial Hospital 2. Eversley Childs Sanitarium 3. Western Visayas Sanitarium 4. Bicol Sanitarium 5. Mindanao Central Sanitarium 6. Cotabato Sanitarium

31

Objectives

- ❑ To monitor the implementation of the action plan in each sanitarium and the utilization of the "seed capital" from SMHF.
- ❑ To provide feedback and recommendation from technical experts of the monitoring team by sharing experiences of other sanitarium and countries engaged in leprosy preservation
- ❑ To strengthen collaborative network between NAP, NHCP and CLAP affiliated association in the sanitarium.
- ❑ To determine future activities in the preservation of leprosy history and heritage in the 8 sanitarium of the Philippines.

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TALA SANITARIUM

Dr. Jose Reyes Memorial Hospital



33

BICOL SANITARIUM



34

WESTERN VISAYAS SANITARIUM

Santa Barbara Iloilo



35

EVERSLEY CHILDS SANITARIUM

Cebu City



36

MINDANAO CENTRAL SANITARIUM

Zamboanga



37

COTABATO SANITARIUM



38

INTERNATIONAL CONFERENCE ON
LEPROSY HISTORY, MEMORIES,
HUMAN RIGHTS AND STIGMA

39

AN INTERNATIONAL CONFERENCE ON

LEPROSY

HISTORY, MEMORIES,
STIGMA & HUMAN RIGHTS

18-19 February 2016
Microtel Inn and Suites, UP Technohub Diliman
Quezon City, Philippines

A

PROJECT OF

CULION SANITARIUM & GENERAL HOSPITAL
and
UNIVERSITY OF THE PHILIPPINES
Department Of History

40

- To further highlight the importance of preservation of leprosy history and memories and to further sustain the interest in the Philippines, **the Culion Sanitarium & General Hospital as the proponent, join heads with the Department of History of the University of the Philippines** to hold a conference as venue for social scientist, students and other researchers to present their work about social issues and history of leprosy in the Philippines.

41

- The International Workshop on the Preservation of Leprosy History and Heritage was organized last February 15-16 2016
- to provide a proper venue to present the monitoring findings and the recommendations by the monitoring team, where the best practices and experiences of the 8 sanitarium
- sharing of experiences and best practices from China, Malaysia, Thailand, and Japan, who are also engaged in the preservation of leprosy history .
- The workshop aimed not only to help sustain the momentum of the preservation of leprosy history, but also to pave the way in building networks and links among the sanitarium in the country, the region of Southeast Asia and Asia.

42

Objective

- The conference, "Leprosy: History, Memories, Stigma, and Public Health," aimed to put on center stage the social science dimension of leprosy. Harnessing the different social sciences (history, anthropology, sociology etc.), leprosy was studied from different perspectives making richer the understanding of the disease.
- Enrich the production of knowledge about leprosy in the Philippines through the papers presented during the conference.

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The Plenary Presenters



The Participants



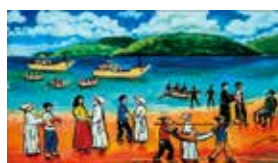
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History of Leprosy in the Philippines Book Launching thru the National Historical Commission of the Philippines



45

The Launching of Culion Commemorative Stamp



To celebrate the 110th founding anniversary of Culion as a Leprosy Colony in 1906 is the launching of the commemorative stamp showing the mural painting at the Culion Museum & Archives about the arrival of the first contingent of leprosy patients in the shores of Culion on May 27, 1906.



46

THE WAY FORWARD

47

UNESCO – MEMORIES OF THE WORLD REGISTER

United Nations Educational, Scientific and Cultural Organization

Memory of the World

Application for Regional and International Memories of the World Registry

Registration Form
International Memory of the World Registry
Cultural Memory of the World

1. Name of the Memory of the World
2. Description of the Memory of the World
3. Justification of the Memory of the World
4. Management of the Memory of the World
5. Conservation of the Memory of the World
6. Dissemination of the Memory of the World
7. Other relevant information

48

NATIONAL HISTORICAL COMMISSION RESTORATION PROJECT

**BASA AVELLANA HALL
/CULION TOWN HALL**



COLONY THEATER



49

NATIONAL HISTORICAL COMMISSION RESTORATION PROJECT

Glorieta



Grand Stairway



50

Culion Radiotelegraph Tower Restored



Dedicated on May 27, 2016 on the occasion of the Culion 110th Anniversary celebration

51

Thank you!

52

*Session A: "Preserving Materials & Testimonies" – Making them Available to the Public***SoNaMu—Sorokdo National Museum****Ms. Baek Mi Young**

Curator

Sorokdo National Hospital Hansen's Disease Museum

We have built a new building for SoNaMu to celebrate the 100th anniversary of Sorokdo National Hospital in 2016. As we pondered on what to show and how to design the museum, it was reasonable to listen to the opinions of internal and external voices, and of those who lived in Sorokdo for long years. The team was launched to prepare for the opening of the museum, internally collecting and making a catalogue of artifacts. We extracted the main themes from relics with vivid histories. These selected subjects composed the museum's regular exhibition.

When we say SoNaMu, it has two meanings. It is not simply an acronym for Sorokdo National Museum; it also means pine tree in Korean. A pine tree lives well on deserted slopes and infertile lands; its crooked appearance reminds us of a person affected by Hansen's disease.



The regular exhibition of SoNaMu is divided into six zones: Hansen's Disease, Human Rights, Transition Space,

Life, Sorokdo National Hospital, and Friends. The six zones have their own main motto in front of the entrance to the zone.

The main motto is expressed as a phrase that sums up each theme. If you visit SoNaMu, I recommend that you read the main motto before you step into the zone.

The first part of the exhibit is about Hansen's disease. The main motto is: "The history of mankind is a history of overcoming diseases, including Hansen's disease at last." This zone introduces the history of Hansen's disease and medicine. It is a space to clear up the misconceptions that Hansen's disease is hereditary or that it is highly infectious and incurable. There is a convincing story: A woman who lived 500 years ago cared for and nursed her husband who had Hansen's disease and eye complications. Although she lived with her husband for 19 years, she was not infected by Hansen's disease.

"Everyone has their own name and rights." This is the main motto of the second zone, on human rights. The people of Sorokdo were abandoned by family, friends and society. They give up their name for their families' sake or for a new, hidden life. But they are human beings who have the right to be respected. Early Sorokdo was not a space for treatment, but a space of isolation. Their lives were very miserable. Compulsory labor, sterilization, abortion, and unjust imprisonment kept Sorokdo far away from human rights.

SONAMU

2017. 04. 22.

BAEK MI YOUNG

1

Sorokdo National Hospital Hansen's Disease Museum



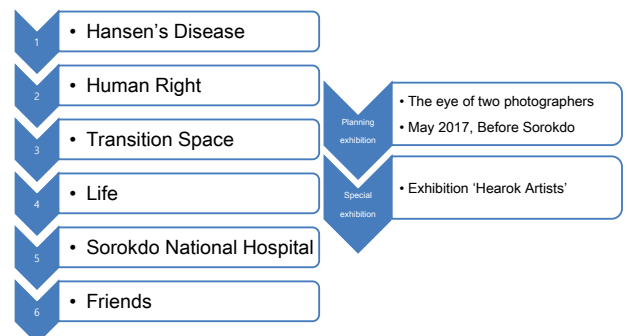
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SoNaMu is Pinetree

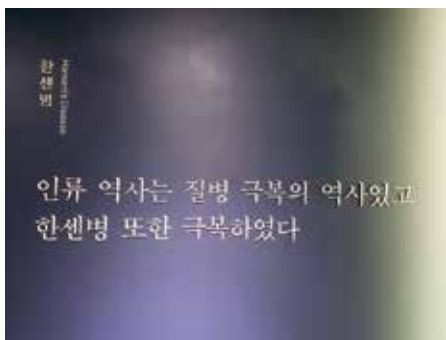


3

Contents



4



The history of mankind was a history of overcoming diseases, and also overcame Hansen's disease at last



5

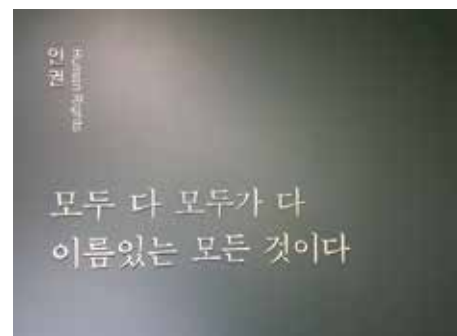
1. Hansen's Disease



6



7



Everyone, whoever has own name and right



8

Artifacts are displayed in the human rights zone. There are bricks made by patients and mokdo for carrying heavy stones. And you can hear testimony of the people who have suffered from sterilization, abortion and detention.

Also, visitors can experience the detention room. Despite liberation from Japanese rule in 1945, people who suffered from Hansen's disease did not experience freedom. Because of the prejudice of Korean society they could not be free, out of Sorokdo. We call it 'social death'. There is a saying that Sorokdo people experienced death three times: first with the onset of the disease; second with their biological death; and third at the autopsy table. We have made an image introducing the fourth death: social death. We wonder who can dare to break the wall of prejudice and discrimination that remains in the heart.

"Everyone is as beautiful as flowers, and sad as flowers—sounds of Sorokdo, toward rehabilitation." This is the main motto of the third zone, Transition. Special sounds can be heard here: church bells; the sound of waves of Sorokdo's sea; the sound of the walking sticks of the blind. Transition means moving. We saw an abyss and sad topics in the Hansen's Disease and Human Rights zones. Now we move to the stories of people who have never lost hope in a miserable environment.

"Alas! Sky and earth during the last 100 years." This is the motto of the fourth zone, the Life Zone. We want to show you their breath, and life. A large quantity of relics are displayed here and you can look at artifacts related to education, religion, and culture. The people of Sorokdo had to make things by themselves. It was crude and clumsy, but it was useful for their everyday life, so we registered some of these items as cultural assets.

"The breath of a century, the kiss of a new millennium." This is the motto of the fifth zone, Sorokdo National Hospital. We want to keep it permanently. You can see the history of the hospital here. From 1916 to 2016, it has been organized according to period and policy. The name of the hospital started as Jahyeuiwon. Since then, it has been known as Sorodo Gaengsaengwon, Central Leprosy Sanitarium, National Leprosy Hospital and, since 1982, as Sorokdo National Hospital. The artifacts representing each period are displayed.

"We walk together on the path of rainy mud." This is the motto of the sixth and last zone, Friends and Supporters.

It is a room that remembers people who have served and helped in Sorokdo. Here you can see names of the volunteers. If you write your name on the touch monitor, it will add your name to the list of supporters. We tried to portray the story of Sorokdo objectively. And we want to change the prejudice of ordinary people about Hansen's disease and people affected by the disease.

2. Human Right



9



Everyone is as beautiful as flowers and sad as flowers - sound of sorokdo, toward rehabilitation

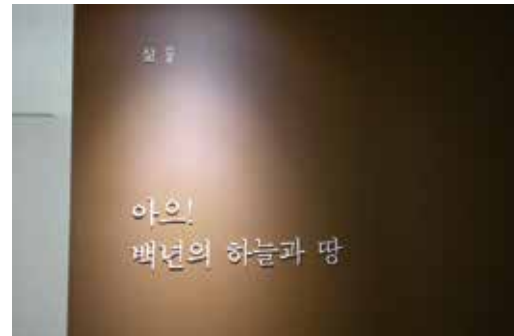


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2. Space of Transition



11



Alas! Sky and earth during the last 100 years

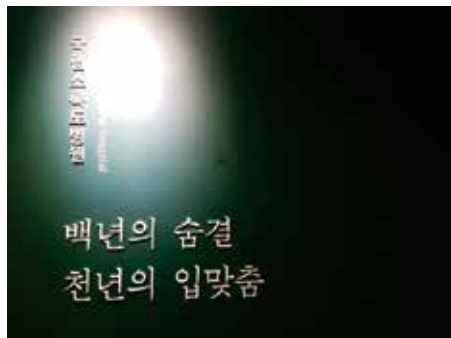


12

4. Life



13



The breath of a century, The kiss of a millennium

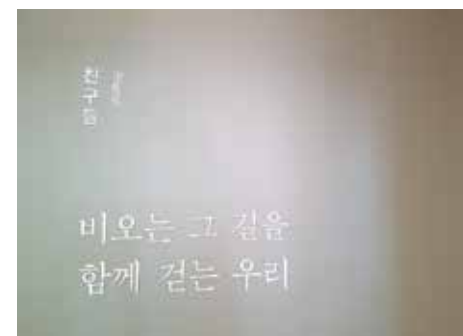


14

5. Sorokdo National Hospital



15



We walk together on the path of rainy mud



16

6. Friends



17

Museum education



Oral history



Planning exhibition,
Special exhibition



18

Thank you.



19

Session A: “Preserving Materials & Testimonies” – Making them Available to the Public**National and Regional Museums in Thailand****Dr. Arjin Cholapand**Director
Raj Pracha Samasai Institute

Slide 2: First of all, RPSI and RPSF would like to thank SMHF for providing funds to produce the book ‘The History of Leprosy in Thailand’ in English. We distributed copies of the book to many countries represented at the WHO-SEARO program managers meeting in Kathmandu, Nepal in October 2016.

Slide 3: The contents of this presentation will cover the topic of settlement overview, the progress of regional and national museums, lessons learned and challenges

Slide 4: This slide shows you where the five museums are located in Thailand: two in the north, one in the northeast, one in the south—these four sites are regarded as regional museums—while the fifth and last is located in a suburb [of Bangkok] and is regarded as the national museum. Dr.Amnaj and I presented on two of these museums—McKean and Phrapradaeng—at this meeting last year in Tokyo.



Slide 5: This slide shows you the progress overview of each regional museum. This overview includes the concept or categories of museum, who engages in funding and participation and the current situation of each. Most of them are history museums but the one at Nonsomboon is a specific theme about leprosy victory. All of them are mainly funded by NGOs, and involve the participation of PALs. Two of them have opened and two of them are still at the blueprint and collection of materials stage.

Slide 6: More details of McKean Chiangmai. Coordinated with the university’s experts to visit and study the possibility of museum arrangement in a professional way, and facilitated a workshop to formulate a proposal for historic building preservation.

Slide 7: More details of Bankrang. Facilitating the process of historic building preservation and facilitating the workshop. This site opened in 2016 and has been successful from the aspect of a strong contribution from PALs.

Slide 8: More details of Nonsomboon. This site is still at the blueprint phase. Highlights are strong commitment from the top level of the local administration and PALs. The latter have a specific theme to preserve history using inspiration from the victory over leprosy to create the concept of the museum. But there are still some problems about the budget to run this project, thus it is still at the blueprint phase.

Slide 9: This perspective was drafted from the leprosy victory theme and living museum. It tells the story from the suffering of the people to the helping hand they were given and empowerment made possible by the late King Bhumipol. So, in the present, all the people who suffered are more happy and have more dignity.

Slide 10: Theme monument

Slide 11: This slide shows you more details of Put-Hong.

Discussion with related organizations at different levels seeking the possibility of establishing a leprosy museum at Nonsomboon colony.

Slide 12: And the next is Phrapradaeng national museum. The significant changes compared to what was presented last year are the funding and the participation of people affected by leprosy, especially in decision-making regarding the blueprint.

Slide 13: The plan for the national museum: Phrapradaeng 1

Slide 14: The plan for the national museum: Phrapradaeng 2

Slide 15: The plan for the national museum: Phrapradaeng 3

Slide 16: The plan for the national museum: Phrapradaeng 4

Slide 17: The plan for national museum: Phrapradaeng 5

Slide 18: Lessons Learned

Slide 19: Challenges



Preservation of Leprosy History in Journals and Books

- Books in commemoration of 15th year and 40th year anniversary of Department of Disease Control, MOPH.
- Proceeding book of Annual National Conference on Disease Control in 2014.
- Annual report, Raj Pracha Samasai Institute
- Leprosy history in Thailand 2016
- [Electronic file](#)



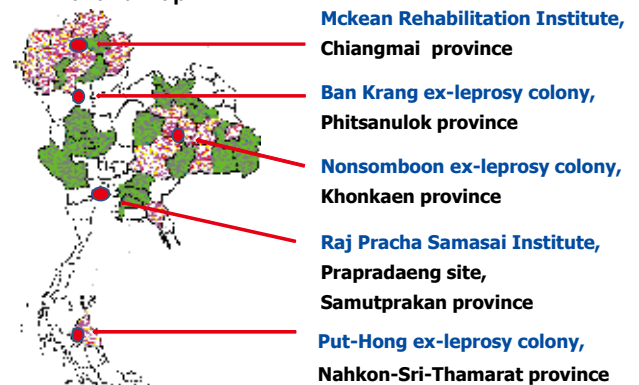
Making the materials and testimonies available to a public

1. Settlement overview
2. Progression
 - Regional museum
 - National museum
3. Lesson Learns
4. Challenges

1. Settlement overview :

National and Regional specific museums

Thailand Map



2. Progression : Regional museums

	Concept	Main Funding	participation	Current situation
McKean	History	NGO(McKean)	McKean People affected	<ul style="list-style-type: none"> • Open >10yrs • add old building to be preserved
Ban Krang	History	NGO(RPSF)	GO NGO(RPSF) People affected Local admin	<ul style="list-style-type: none"> • Open 2016
Nonsomboon	Leprosy victory	NGO(RPSF) Local Network Gov.	GO NGO(RPSF) People affected Local admin	<ul style="list-style-type: none"> • Blueprint • Collect materials and testimonies
Put-Hong	History	NGO(RPSF)	GO NGO(RPSF) People affected	<ul style="list-style-type: none"> • Collect materials and testimonies

Regional museums : McKean

- Coordinated with the university's experts to visit McKean Rehabilitation Institute, survey and study the possibility of historic building preservation in professional way
- Facilitated the workshop to formulate the proposal for leprosy historic building preservation



Regional museums :Ban-Krang

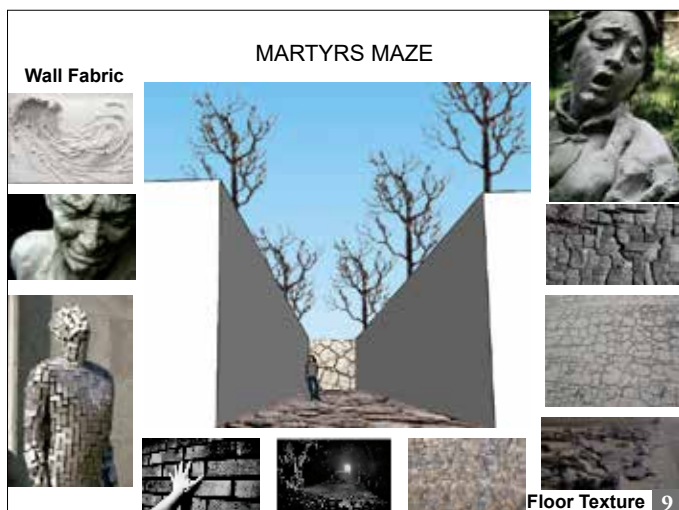
- Facilitating the process of historic building preservation
- Facilitating the workshop to formulate the proposal for leprosy historic building preservation



Regional museums : Nonsomboon

- Facilitating the process of local/NGO's museum establishment at Nonsomboon ex-leprosy colony





2. Progression : National museum

	Concept	Funding	participation	Current situation
Phrapradaeng	History +Hall of frame	NGO(RPSF)	GO + NGO + People affected	A blueprint changed by people affected



The plan for national museum : Phrapradaeng

- Preserving documents, materials and pictures



17

The plan for national museum : Phrapradaeng

- Preserving life-history of people affected by leprosy through interviewing.



18

3. Lesson learns :

- 1) Participation of people affected is needed to turn them from 'a receiver' to be 'a giver'
- 2) Participation of related stakeholders i.e NGO, local administrative organization and community is important to create a sense of ownership.
- 3) Collecting materials, pictures, life-history of people affected from ex-leprosy network

19

4. Challenges:

1. To keep directions
2. To keep empowering , facilitating , and monitoring the progress of museum establishment at regional and national levels.

20

Thanks for :

- SMHF
- RPSF
- Every participants in this and previous symposiums



21



History walk of the National Sanatoriums "Oku Komyo-en" & "Nagashima Aisei-en"

*Session B**“Reports from Countries”*

Session B: "Reports from Countries" - Malaysia

History of Rajah Charles Brooke Memorial Hospital

Ms. Angelina Jong Siew Phing

President

Heritage Society of Rajah Charles Brooke Memorial Hospital

Prior to 1962, it was called the Rajah Charles Brooke Memorial (RCBM) Settlement. Back in 1901, the first settlement was located at 5th Mile, Jalan Kuching-Serian. Due to its proximity to town, it was relocated to Satang Island in May 1924. However, this did not last long due to logistics issues and a malarial outbreak at that time. So on 17th October 1925, the residents were shifted one final time to the 13th Mile, Jalan Kuching-Serian.



This marked the inception of RCBM Settlement, and the residents started to build their homes from scratch, without their loved ones beside them. They all lived together, a family built on common grounds where this cruel disease had separated them from all that they own in this world. There were places of worship built on these grounds that still stand to this very day—the Roman Catholic chapel, Anglican chapel, Taoist temple, Surau, and a Rumah Kenyalang—and each had their own burial plots.

Even though families were separated by law, there were some who braved it all and secretly built houses deep into the jungles, just to be as close as they could to their loved ones. Evidence of their secret lives and stumps from old houses can now be seen, scattered within the forests that lie beyond the RCBM grounds.

In 1953, Mr Hamish McGregor, who was then the Superintendent of this settlement, decided to re-establish the whole place into something more systematic and organised. Eight-door and four-door dormitories were built and some of the residents were trained as patient workers. Some others were taught crafts and woodwork, and farming, in order to gain some financial independence. In 1962, the British left the RCBM Settlement. Mr Generawi Mok was the first local man to be in-charge of the RCBM Hospital.

Eventually, those who were cured started leaving the settlement and built their own homes outside. Those who did not have anywhere to go were given plots of land, adjacent to the hospital, and were aided by the leprosy association, MALRA.

Today, there are still a handful of in-house residents left in the RCBM Hospital.

RAJAH CHARLES BROOKE MEMORIAL SETTLEMENT

10th October 1925



1

THE PAST

2



3



4



5



6



7



8

Heritage Society of Rajah Charles Brooke Memorial Hospital (HSoRCBMH)

HSoRCBMH was founded by Angelina Jong and Dr. Goh Yi Xiong on 11th November 2015. We are registered under The Registry of Societies Malaysia, and currently we have 30 active members. Our patron is YB Lo Kheng Chiang, the Municipal Chairman of Padawan Municipal Council and Batu Kitang assemblyman.

The society's focus is mainly on the humanitarian welfare of the Hansenites and those directly related to this disease, as well as the preservation and conservation efforts for the old buildings and historical artefacts that date back to 1925 when Rajah Charles Brooke Memorial Hospital was a leprosarium. Apart from Hospital Sg Buloh, it remains as the only other leprosarium in Malaysia, and the only one in Borneo.

Stigma and ostracism are synonymous with those afflicted with Hansen's disease, also commonly known as leprosy. It is still very strongly instilled within the community and we feel that public education should be enhanced in creating awareness for this disease. Our aspirations are that one day Hansenites will no longer be discriminated against, and will be welcomed by society once more.

Historic preservation is about saving and sustaining historic places—preserving them for future use and protecting them for our future generations. Not only does it aid us in the process of understanding who we are, it also shapes the relationships built within our communities. Respect and celebration of these historic places is vital in ensuring that their history lives on, and the public understands the significance of sustaining communities today, and for our future generations.

We wish to ensure that historical structures and the cemeteries are kept to their original forms, adapted and preserved. The artefacts will be protected from damaging changes and preserved in the best possible condition. On-going examinations, research, cleaning and repairs, as well as activities to prevent further deterioration will be conducted on-site.

We are also concerned about the preservation of our stories: the oral history of those with Hansen's disease who embarked on this journey. It is essential to document their oral histories before they part from this life, and take their stories to their graves.

To date, we are working with various agencies in realising our efforts, namely UNIMAS, Sasakawa Memorial Health Foundation, Sarawak Biodiversity Centre, Sarawak Museum Department, and Sarawak Native Customs Council.

We have a vision to re-establish our grounds as a local heritage site, transforming it into an Open - Air Museum Concept, where we would be included as part of the Padawan Heritage Trail under the tourism industry. This would ensure a self-sustaining society on our part, as well as creating job opportunities for the Hansenite community.

In short, the HSoRCBMH has **FOUR** goals to achieve:

1. Creating public awareness on Hansen's disease through education and history.
2. Eradicate stigma and social segregation on Hansen's disease within the community.
3. Preserve and conserve our heritage for future generations.
4. To be part of the tourism industry in promoting our heritage and native culture.



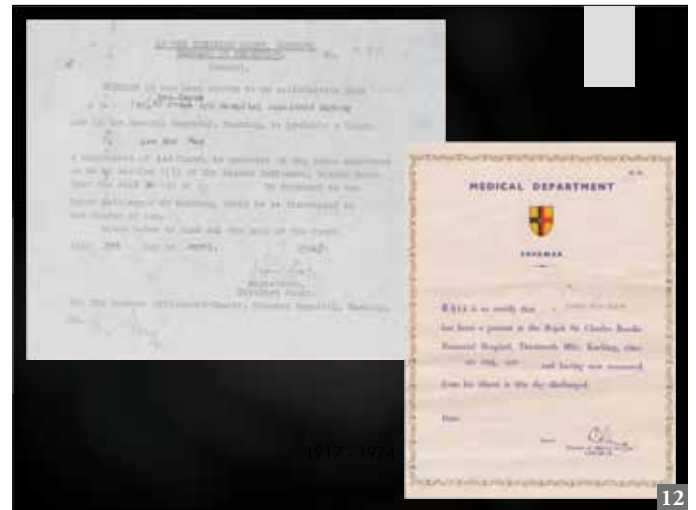
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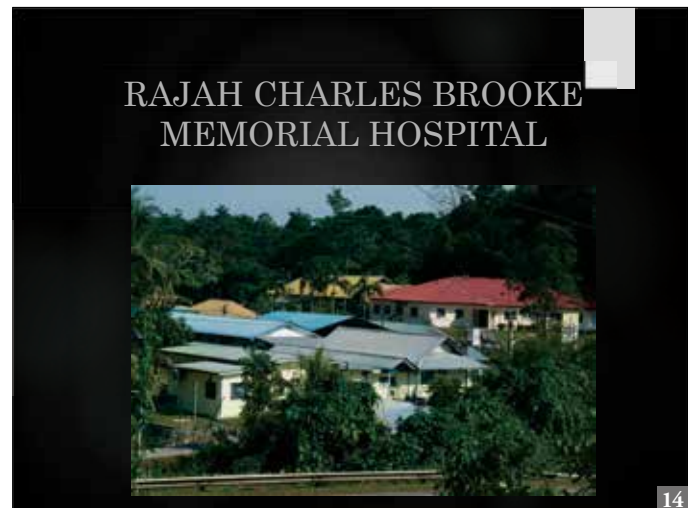
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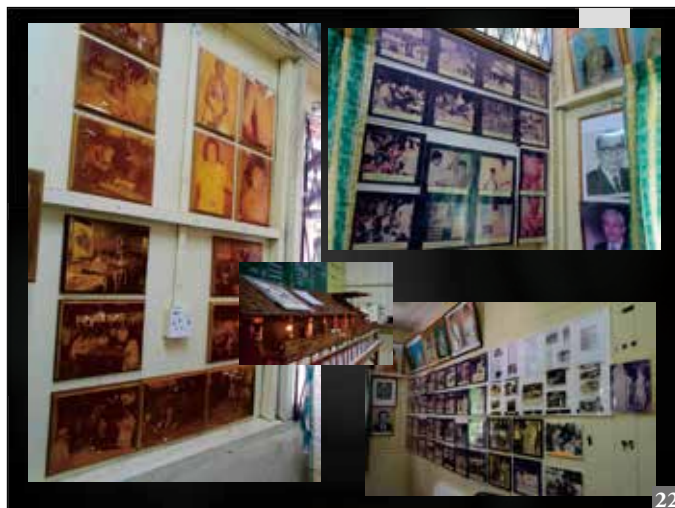
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22

A CALL FOR SOCIAL CHANGE AND HERITAGE PRESERVATION

23

2015

- * 17.10.2015 - Launching of Historical Book & 90th Anniversary of RCBM Hospital. A book entitled *In The Sanctuary of The Outcasts : Life Within the Rajah Charles Brooke Memorial Leprosarium* was written.



24

- * **22.10.2015** - Supporting letter received from our late Sarawak Chief Minister for local heritage gazettelement.

- * **11.11.2015** - Formation of Heritage Society of RCBM Hospital (HSoRCBMH).

25

HSoRCBMH



26

GOALS OF HSoRCBMH

- ▶ Creating public awareness on HD through education and history.
- ▶ Eradicate stigma, taboo & social segregation in HD within the community.
- ▶ Preserve & conserve our heritage for future generations.
- ▶ To be part of the tourism industry in promoting our heritage & culture.

27

2016

- * **05.03.2016** - HSoRCBMH organised a trek into the jungles within the RCBM Hospital grounds to retrieve historical artefacts and locate old dwellings of the Hansenites' families.
- * **01.04.2016** - Inventory listing started for the RCBM Mini Museum by the HSoRCBMH. Physical asset listing was completed on 27.04.2015.

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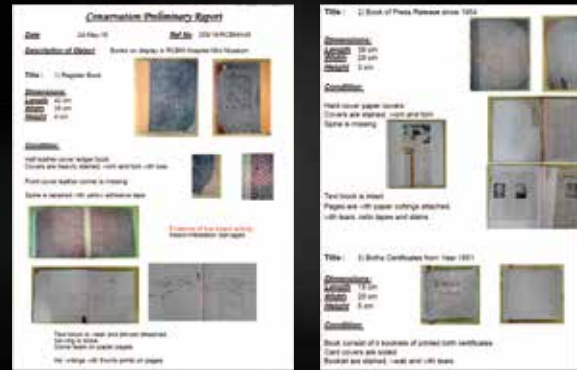
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- * Application for Local Heritage gazettement.
- 12.05.2016 - Meeting and site visit with Sarawak Museum Department.



33

- * 24.05.2016 – Visit by Mr Alex Teoh (Book & Paper Conservator) with FOSM to the Mini Museum HRCBM.



34

Title: 4) Visitor's Book since 1957

Dimensions:
Length: 28 cm
Width: 34 cm
Height: 5 cm

Condition:

Hard cover visitor's book.
 Cloth covers are worn and with lots of scratches.
 (new) sticker on front cover

Spine is torn and detached

Text block is weak
 Loose pages and sections
 Tears on paper pages
 Cello tape stains



35



16th June 2016 : Courtesy Call to the Permanent Secretary of Ministry of Tourism, Arts and Culture Sarawak

36

2017

- Embark on the Open-Air Museum Concept project for the areas gazetted under Sarawak Heritage status. To apply for local / international fundings to materialize this.
- Collaboration with the Faculty of Social Sciences, UNIMAS for a research project on History of Leprosy in Borneo, as well as Museum Documentation.

37



A talk and discussion entitled "Leprosy: The Silent Tears" to the academicians in UNIMAS on 20th January 2017.



38

06th February 2017



Partnership with Sarawak Biodiversity Centre to cultivate more baby Chaulmoogras.

39

07th February 2017



Discussion with Sarawak Native Customs Council on re-instating the age-old, dying tradition - miring ceremony in RCBM Hospital.



40

11th February 2017



Presentation on History of Leprosy in Borneo and Introduction to HSoRCBMH to Rotary Club Kuching Central.



41

- ▶ **28th February 2017** : Patron-ship of local State Assemblyman.
- ▶ **01st March 2017** : Partnership with Arkitek JFN for conservation efforts.
- ▶ **13th March 2017** : Courtesy Call to Superintendent of Sarawak Land & Survey Department.
- ▶ **20th March 2017** : Courtesy Call to Director of Sarawak Museum Department.
- ▶ **26th March 2017** : WE ARE ON FB!
▶ <https://www.facebook.com/pg/HSoRCBMH>
- ▶ **30th & 31st March 2017** : Chief Minister's office to make ourselves known and heard.

42

02nd April 2017

WE GOT IN THE PAPERS!!!

- calls for public talks started streaming in....



43

2018 -
2019

- **Upgrading of RCBM Hospital Mini Museum.** To incorporate modern displays as well as in-depth explanations on historical features and values.
- Systematical approach on the Open-Air Museum Concept on the arrangements of **displays and signages**.
- To develop Berek Igan as the **showhouse** for our Open-Air Museum Concept. Detailed floor plans would be done in order to emulate the dwellings of the past, where visitors would be wafted back into history.
- To create a **Chaulmoogra Park** in order to **conserve the existence of this tree** in RCBM Hospital as well as to **promote the awareness** of the Chaulmoogra oil in the early treatment of Hansen's Disease.

44

2020

- Partnership with the Sarawak Tourism Board for the **self-sustenance** of our Open-Air Museum Concept. This is also to **create awareness / understanding** amongst the public and the community towards Hansen's Disease, and to **erase the stigma and isolation** that came with it.
- **In-house sales** would be a beneficial project for the people from Kampung Sinar Baru to promote their crafts and goods. This would also create **job opportunities** for them, and at the same time, will serve as a constant and **stable income** for both the residents as well as HSoRCBMH.

45

2021-2024

- **Launching of the 2nd Edition of RCBM Hospital's historical book.** The book would cover mostly on the oral history and personal experiences of the Hansenites, taken from the outcome of the research project that was done in 2016-2017.
- Work plans for **National Heritage / Trans-Pacific UNESCO Status** to be in progress.

46

2025

- Celebrating RCBM Hospital's **100th Year Anniversary** on 10th October 2025.

47

THANK YOU



48

Session B: "Reports from Countries" - Brazil

The fight to regain social and human rights in Brazil

Mr. Artur Custódio Moreira de Sousa

Vice National Coordinator
MORHAN

MORHAN, the Movement for the Reintegration of People Affected by Hansen's Disease, is a social movement that emerged in Brazil in 1981, during the re-democratization period, after 20 years of a military dictatorship in the country. MORHAN's focus is the fight to regain social and human rights in the country, especially for those affected by Hansen's disease.

In Brazil, just like all over the world, there are many ways of being affected by Hansen's disease: it affects the body, but also affects family structures, interpersonal relationships, infringes people's right to come and go. Stigma also affects people's subjectivity and opportunities, withdraws people's professional perspectives, and so on.



MORHAN's historical goal was to pressure the Brazilian government, aiming to make the tough reality of this population visible and urgent, so that public policies should be planned and implemented in order to improve their quality of life and ensure their social rights to health, housing, social inclusion, and memory.

The right to remember is a struggle in Brazil, especially regarding memories related to human rights. There are few initiatives in Brazil that approach the past and future of, for example, our indigenous population, Quilombolas, and the violent memory of the military dictatorship itself. This systematic social refusal regarding the memory of topics related to human rights in Brazil is also present in the case of Hansen's disease.

There were 38 colonies in Brazil (27 still exist, and 11 are gone) and inside them a big population (patients and their families), architectural projects, social organizations (religion, economy, discipline, governance, medical practices), social practices (recreation, culture, arts, sports), among other social phenomena. And there is a lot to remember.

Registers related to the compensation law processes indicate that in 2007 there were 10,000 former patients who were isolated in these colonies still alive in Brazil. We estimate that today, in 2017, there are 8,000.

The preservation of colonies is a topic that relates to the past, present and future. Some colonies don't exist anymore, and there are few registers of their existence and of those who lived there. As state properties, all decisions about these spaces are made by the Brazilian government. So, in order to avoid their destruction, it's fundamental to influence state attitudes, driven by the pressure of the civil society through social movements like MORHAN.



MORHAN, the Movement for the Reintegration of People Affected by Hansen's Disease, is a social movement that emerged in Brazil in 1981

1



In Brazil, just like all over the world, there are many ways of being affected by Hansen's Disease:

it affects the body
family structures
interpersonal relationships
infringes people's right to come and go
stigma affects people's subjectivity and opportunities
withdraw people's professional perspectives

2



Systematic social refusal to the memory of topics related to human rights in Brazil – Indigenous population

3



Quilombolas - descendants of Afro Brazilian slaves who escaped from slave plantation that existed in Brazil

4



Military Dictatorship in Brazil – 1964 to 1985

5



27 colonies still exist
11 are gone
2007 – 10.000 former patients alive
2017 – 7.500 / 8.000 former patients alive

There were 38 colonies in Brazil, and inside them:

a big population
(patients and their families)

architectural projects

social organizations
(religion, economy, discipline, governance, medical practices)

social practices
(recreation, culture, arts, sports)

6



Some colonies don't exist any more, and there are few registers of their existence and of those who lived there.



7



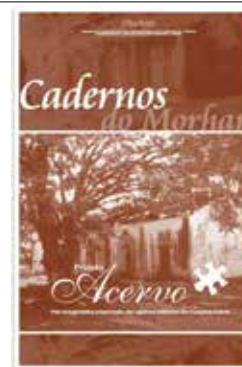
To preserve these Colonies is urgent regarding the memory of Hansen's Disease in Brazil but also the right of those who are still affected by this history considering their lack of housing spaces.

8



In 2005, Morhan organized a meeting of Colonies' residents from all the country. In this meeting a document was organized with proposals for the colonies, among them the preservation of memory.

9



In 2007, Volunteer historians held a conference on this topic and developed the PROJECT ACERVO, a survey of the material heritage of the Colonies in Brazil, which resulted in a book.

10

To preserve these colonies is an urgent need regarding the memory of Hansen's disease but also the right of those who are still affected by this history by their lack of housing spaces.

Patients who were targeted by the policy of forced isolation were, after its end, still segregated from all basic social rights including mainly the right to housing in the city.

In 2005, MORHAN organized a meeting of residents of colonies from all the country. In this meeting, a document was organized with proposals for the colonies, among them the preservation of memory. Volunteer historians, in 2007, held a conference on this topic and developed the project ACERVO, a survey of the material heritage of the colonies in Brazil, which resulted in a book.

Therefore, MORHAN acts continuously in this double movement—keeping alive the historical problem of housing for those affected by Hansen's disease, and also supporting initiatives of memory spaces, encouraging the creation of small museums and memorial rooms in the colonies. As state initiatives of preservation, we can list two:

1. National initiative—the preservation of one colony in Rio that belong to the Catholic Church
2. Regional initiatives—the provinces of Ceará and São Paulo both approved local laws on the protection of their colonies, but the law doesn't provide the financial support for all necessary actions that should come together with it.

MORHAN also continuously reinforces the importance of a close look at the historical cemeteries present in the area of these colonies. These cemeteries, nowadays, usually occupy a political space “in between” the hospital and the city and, by the end, keeping them is a challenge.

There's still a central issue to MORHAN that's not related to the material culture. It's the memory of the people who lived the history of Hansen's disease in Brazil. It's important to remember that “People leave us before the walls” and we have to register and tell their stories. MORHAN is always stimulating and standing for projects related to the memory of people through books, photographic projects, films, and also academic works about them and their stories. We are now trying to start a more systematic action on this topic, especially after the last years when we lost Bacurau, Pirelli and, last year, Cristiano among many others.

It is fundamental to tell their stories that are at the same time particular amazing trajectories but also relevant social experiences of the fight of those affected by Hansen's disease in Brazil and in the world. To remember them is to remember this fight.

In this same direction of the intangible memory of people, MORHAN has developed a strong action regarding the families' memories. Brazilian state policy of segregation produced families that were completely separated by Hansen's disease. Some knew that, and suffered by knowing.

Others didn't know why they were separated from their parents, and suffered by this ignorance and the imagination of rejection.

MORHAN has developed in the last five years a Reunion Project connecting the genetic memory of these families, with also their affective memory. DNA tests are rebuilding family ties, and these reunited families are facing the challenge of building new family memories different of the memory of separation.



Therefore Morhan acts continuously in this double movement: keeping alive the historical problem of housing for those affected by Hansen's disease, and also supporting initiatives of memory spaces, encouraging the creation of small museums and memorial rooms in the colonies.

11



The invented village

12

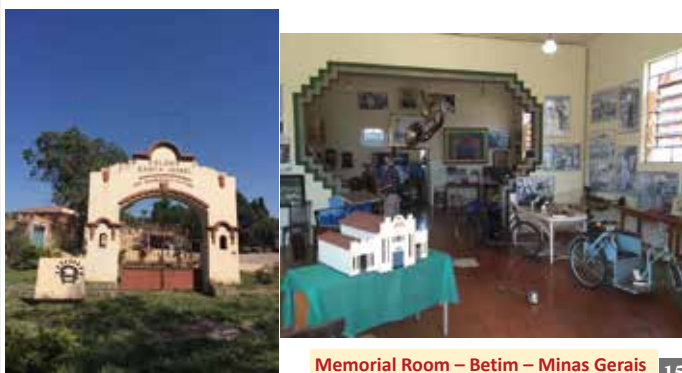


House of Bacurau

13

Memorial Room of Bacurau
Acre – Amazon region

14



Memorial Room – Betim – Minas Gerais

15



Memorial Room – Betim – Minas Gerais

16



Morhan also continually reinforces the importance of a close look at the historical cemeteries present in the area of these colonies.

17



The memory of the people who lived the history of Hansen's Disease in Brazil.

"People leave us before the walls"

18



Morhan is always stimulating and standing for projects related to the memory of people affected by Hansen's Disease through books, films, and also academical works about them and their story

19



José de Arimatéa - Pirelli

20

These pictures are of a family reunion that just happened in Brazil last week. Leon and Janine were born in the north of Brazil, separated from their parents, adopted by a Surinamese doctor who was also working on the control of Hansen's disease in Suriname, and in their youth they moved to Holland. Now in their 50's, they went to Brazil to know their biological families; Leon's father is still alive, but has Alzheimer's. He had the opportunity to meet him and also a brother and a sister. Janine's biological parents had 16 children. They have already died. She met five sisters and one brother on this trip, and when we go back to Brazil we are still trying to arrange her meeting with one more sister.

In order to finish this presentation, we would like to say that the memory of the colonies (buildings, documents, objects) is a difficult issue in Brazil. It belongs to a field that depends fundamentally on attitudes of the Brazilian government. A social movement like MORHAN can mainly put some pressure and keep going with the fight.

But the memory of people belongs to us. It belongs to each person affected by Hansen's disease. It belongs to each Brazilian. It belongs to all of us present here. So, we think it's our responsibility to keep this memory alive, and together with it, to keep alive among us all those who gave their lives for this fight.



Cristiano Claudio Torres 21

REUNION Project
Projeto REENCONTRO

Memories of families:
GENETIC Memory
AFFECTIVE Memory



15.000 – second generation in Brazil

22



GENETIC Memory 23



AFFECTIVE Memory

24



AFFECTIVE Memory 25



AFFECTIVE Memory

26

Session B: "Reports from Countries" - Spain

Challenges and opportunities for preservation of Fontilles legacy as a part of leprosy history

Mr. Eduardo Miguel Selma

Head of International Projects
Fontilles

The main goals of our presentation in the symposium were related with the preservation of history of Fontilles, being useful for society fighting against leprosy and all kind of social exclusions and promoting projects to generate new resources to become sustainable.

Fontilles was founded by the Jesuit Father Carlos Ferris and the lawyer Joaquin Ballester in 1902. Both joined together in a common dream to care for those with leprosy suffering alone without any comfort or help, isolated by a fearful society. In 1909 the "San Francisco de Borja" Sanatorium was opened and soon Fontilles played a main role in the elimination of leprosy in Spain, becoming a village on its own. Fontilles responded to the new concept that the founders had in treating the disease of leprosy, which is clearly seen in calling the place a "sanatorium colony" as opposed to a *Lazaretto*, indicating confinement and isolation, rather than healing and comprehensive treatment of patients.



Furthermore, the group was established as an agricultural colony in order to provide certain self-sufficiency while completing a sick occupational function (farmhouse, farmland, dairy, poultry farm, gardens, etc.). In 1923, a wall surrounding the colony was built because of the fears of the population of the villages near Fontilles. This fear, with time, became a deep friendship and solidarity between villages and Fontilles.

In 1947, leprosy courses for doctors and health workers from Spain and other countries began in the sanatorium. These courses have continued each year to our days as a support to all those fighting against leprosy throughout the world. At present, training activities in Fontilles are one of our milestones and hundreds of trainees and students from Spanish universities participate in these courses.

In 1968, an out-patients system was initiated. The patients being treated lived in their homes and attended the sanatorium for check-ups. This system is still working as Fontilles is the National Reference Centre for Leprosy in coordination with the National Health System.

In 1969, Fontilles joined ILEP, the International Federation of Anti-Leprosy Associations and in 1989, Fontilles began work abroad. The first dispensaries were set up and help given in zones chronically affected by leprosy in India. At present, Fontilles supports projects focused in the fight against leprosy in Asia, Latin America and Africa, helping more than 200,000 people affected by leprosy. Our international work is focused on:



10. Vista general de Fontilles con la montaña al fondo (1925)

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1



Challenges and opportunities for preservation of Fontilles legacy as a part of leprosy history 1902-2017



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Historic Highlights

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1902: The Jesuit Father Carlos Ferris and the lawyer Joaquín Ballester joined together in a common dream to care of those with leprosy suffering alone without any comfort or help, isolated by a fearful society.

1909: the "San Francisco de Borja" Sanatorium was opened and soon Fontilles played a main role in the elimination of leprosy in Spain, becoming a village on its own. Fontilles responded to the new concept that the founders had in treating the disease of leprosy, which is clearly seen to call the place "sanatorium colony" as opposed to the appointment of Lazaretto, indicating confinement and isolation, rather than healing and comprehensive treatment of patients.

Furthermore, the group was established as an agricultural colony in order to provide a certain self-sufficiency while completing a sick occupational function: Farmhouse, farmland, dairy, poultry farm, gardens, etc.

1923: a wall, surrounding the colony was built because of the fear of population of the villages near of Fontilles. This fear, with the time, became in a deep friendship and solidarity between villages and Fontilles.

1947: Leprosy courses for doctors and health workers from Spain and other countries began in the Sanatorium. These courses have continued each year to our days as a support to all those fighting against the leprosy throughout the world.

1968: An out-patients system was initiated. The patients being treated lived in their homes and attended the Sanatorium for checkups.

1969: Fontilles joins ILEP, the International Federation of Anti-Leprosy Associations.

1989: Fontilles begins work abroad. The first dispensaries were set up and help given in zones chronically affected by leprosy in India.

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Bookbinding

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5



Shoes repair shop

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6



Sewing workshop

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8

- Detection of new cases, treatment and control of leprosy disease
- Training of local health workers
- Struggling against exclusion
- Prevention of disabilities and physical rehabilitation
- Social and economic rehabilitation of those affected

The main activities implemented by Fontilles to become sustainable and to issue and release our important historic legacy are related with the support of universities. In this sense it is important to mention the collaboration of Universidad Politécnica de Valencia (UPV) in the promotion of a European Heritage Coalition of former leprosy sites. Thanks to this initiative, an informal coalition among former leprosy hospitals from Portugal, Greece, Italy, Norway and Spain became real and the basis of future collaborations has been developed. In the meantime, a very interesting study on the analytical model of the sanitary complex has been implemented and an integral recovery in terms of the heritage value of Fontilles has been planned. The idea and the challenge of a museum provided with the latest advances in new technologies are in our mind as a part of a future collaboration.

With the University of Alicante the collaboration has gone through three different paths:

1. Seminar in Global Health and International Cooperation. 5th Edition
2. Project: Life Stories: a compilation of Fontilles voices
3. Impact of food security in health in rural areas from Nicaragua
4. Digitalization of Fontilles archives. It is in this last point where we have concentrated our priorities because of the urgent need to act to avoid irreparable damages. In this point is important to mention the important collaboration of Sasakawa Memorial Health Foundation to make this dream real.

Finally, with the support of the Universidad Miguel Hernández we are working deeply in research projects related with the genotyping of *Mycobacterium leprae* of leprosy patients from the sanatorium at Fontilles; and the molecular biology used for developing diagnostic techniques.

Networking is the key word to become useful and sustainable. It is impossible for us to think about preservation of our legacy without the help of all those who estimate and appreciate our work after so many years.

As a proof of this, two examples:

- (i) The collaboration with the schools from the villages around Fontilles that brings to Fontilles more than 3,000 young students wishing to know about our history and our work against the leprosy
- (ii) The collaboration with local NGOs, implementing a global rural development project with students in various professional agricultural families from: forestry, agriculture, and gardening to services to the person and the rural territory and tourism. Through this project to be developed in Fontilles we will promote and rescue our former fields, gardens and forest to give again the use they had in the past when Fontilles' inhabitants depended on it to recover their dignity.

Finally, it is important to mention the *Revista de Leprología*, the only scientific publication about leprosy in Spanish. Published after 1944, this review becomes a window to connect with our partners in Latin America and share knowledge and experiences.



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Main Goals of our present work

1. Preservation of history of Fontilles
2. Being useful for society fighting against leprosy and all kind of social exclusion
3. Promoting Projects to generate new resources to become sustainable

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fontilles

Regional networking:
Digital Model for Dissemination and Highlighting European
Heritage
The Leprosy Heritage Sites

THE SAN FRANCISCO DE BORJA SANATORIUM OF FONTILLES.
ANALYTICAL MODEL TO THE SANITARY COMPLEX. INTEGRAL
RECOVERY IN TERMS OF HERITAGE VALUE

THE CHALLENGE OF THE MUSEUM

14

Arquitectura y
paisaje en el
Sanatorio de
Fontilles
Architecture and
Landscape in the
Sanatorium of
Fontilles



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LAS ARQUITECTURAS DEL AISLAMIENTO
Arquitectura y paisaje en el Sanatorio de Fontilles

THE ARCHITECTURES OF ISOLATION
Architecture and Landscape in the the Sanatorium of Fontilles

Jorge Ugoña Verdú (Dir.)

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THE CHALLENGE OF THE MUSEUM



<https://pcabezos.webs.upv.es/fontilles/p1/p1.html>
<https://pcabezos.webs.upv.es/fontilles/p2/p2.html>
<https://pcabezos.webs.upv.es/fontilles/p3/p3.html>
<https://pcabezos.webs.upv.es/fontilles/p4/p4.html>
<https://pcabezos.webs.upv.es/fontilles/p5/p5.html>



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1. Seminar in Global Health and International Cooperation. 5th Edition
2. Project: Life Stories: a compilation of Fontilles voices
3. Impact of Food security in health in rural areas from Nicaragua
4. Digitalization of Fontilles archives

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Research in Leprosy

Molecular biology useful for
developing diagnostic
techniques.

Genotyping (SNPs) of *Mycobacterium leprae*
of leprosy patients from Sanatorium
Fontilles, Spain.



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ECVET for Living Innovation Fontilles Experience , 2017



Implementing a global rural development project with
students in various professional agricultural families from:
forestry, agriculture, gardening to services to the person and
the rural territory and tourism



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- 1) Organic agricultural production and arboriculture
- 2) Impact of pollution on ecosystems
- 3) Marketing of agricultural products
- 4) Food, health and culture according to the seasons
- 5) Service to the person and the rural territory
- 6) Sustainable and equitable development, rural tourism, heritage: vocational High School for Tourism and Catering
- 7) Global and sustainable management of a Mediterranean forest



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- 1) International projects
- 2) Training
- 3) Research
- 4) Revista de Leprologia
- 5) Leprosy Reference Center
- 6) Sensibilisation and Education

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1. International projects



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1. International projects

Fontilles supports and implements health cooperation projects in countries from Latin America, Asia and Africa, always working together with local NGOs or the local government.

The work in the projects is focused on:

- detection of new cases, treatment and control of leprosy disease
- training of local health workers
- struggle against exclusion
- prevention of disabilities and physical rehabilitation
- social and economical rehabilitation of those affected

Nowadays Fontilles has extended his work to other diseases linked with the poverty: Buruli ulcer, Chagas, leishmaniasis, malaria...

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2. Training

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Library

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Since 1947, Fontilles has organized International Leprosy Courses for medical professionals in the Sanatorium. Each year more than 70 doctors, health workers, missionaries and social workers, involved in fighting against leprosy throughout the world, are trained in the Sanatorium.

2. Training

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3. Research

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1930: Former
quarantine building
2001: laboratory
2003: pharmacy



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Fontilles, with a specialized laboratory, is also a research center, working together with universities and institutions all over the world. This analytical research focuses on molecular biology useful for developing diagnostic techniques.

3. Research

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4. Revista de leprología



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4. Revista de leprología

Since 1944, Fontilles has published the "Revista de Leprología", the only scientific publication about Leprosy in Spanish. This review is published every four months and includes collaborations from Leprosy Review (LEPRA-England) and Spanish and foreign universities



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5. Leprosy Reference Center

Grupos de edad	Hombres	Mujeres	Total
0 - 14	0	0	0
15 - 24	0	0	0
25 - 44	5	3	8
45 - 64	0	1	1
65 y más	0	2	2
Total Estatal	5	6	11

5. Leprosy Reference Center

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6. IEC activities



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6. IEC activities



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Thank you !!!

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*Session C**“Various Initiatives to Preserve the HD History”*

*Session C: "Various Initiatives to Preserve the HD History"***Culion: Preserving a Cultural and Historical Heritage****Dr. Rene Ramajo Escalante**

Commissioner and Acting Chair
National Historical Commission of the Philippines

If one will visit Culion these days, one will see that the old colonial structures built during the American period and the presence of people with deformities were no longer that numerous. In fact, the structures that people affected by leprosy used before are now part of a general hospital that serves patients with all kinds of illnesses. Others were demolished to give way to new structures and the rest are already dilapidated. If no intervention will happen in the coming years, there is a big possibility that the history of Culion as a former leprosy colony will be totally forgotten by the next generations. As regards the present inhabitants of the island, many of them belong to the third or fourth generation of the original segregated patients. The rest are newcomers who have no relation with its former occupants. As time goes on, less and less inhabitants of Culion have a vivid memory of what the island was during the American period.

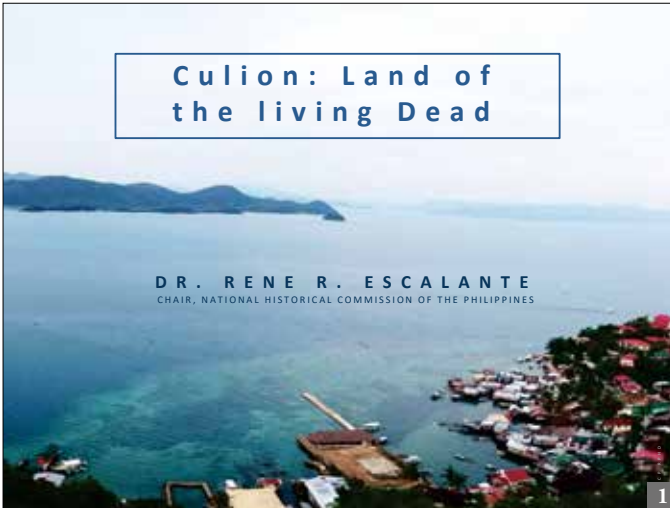


For the past decade, there was a conscious attempt on the part of the Culion General Hospital under the leadership of Dr. Arturo Cunanan to preserve the memories of Culion. Originally, it was part of the preparation for the celebration of the centennial of the institution. With the help of Sasakawa Memorial Health Foundation, they put up a library, archives and a museum. These new facilities contain various historical documents and artifacts that give visitors a glimpse of the life of the patients when it was still a leprosy colony. Their collection is rich enough that it attracts a lot of scholars and researchers who are dealing with the history of leprosy. The move to preserve the memories of Culion is still a work in progress and there are still a lot of things that need to be done.

The National Historical Commission of the Philippines (NHCP) recognizes the historic value of Culion as a former leprosy colony. As part of NHCP's mandate to promote the preservation of historical, cultural and social sites, the present leadership of NHCP has decided to restore some original structures of the old Colony Town Complex. Priority was given to those structures that are still owned by government and those facilities that were directly used by the patients during the colonial years. One of the buildings that will be restored is the colony hall which was constructed in 1912. It used to be the office of the Culion Advisory Council and served as the court room of the chief of the colony. The ground floor of the building was once upon a time the library and the post office of the island.

Culion: Land of the living Dead

DR. RENE R. ESCALANTE
CHAIR, NATIONAL HISTORICAL COMMISSION OF THE PHILIPPINES



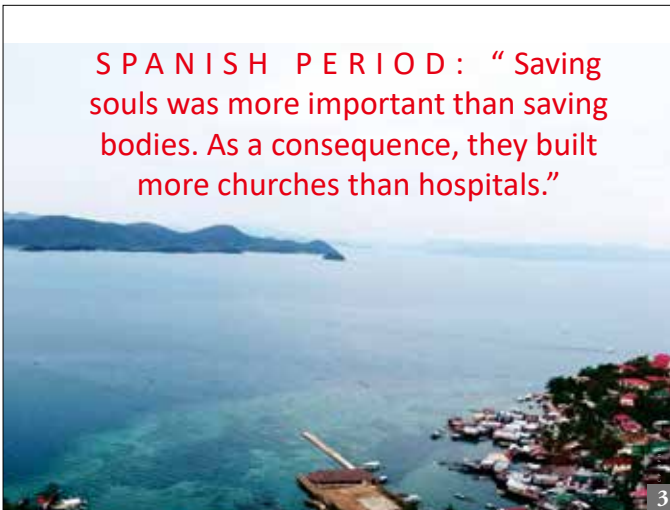
1

Hansen Disease is an old disease in the Philippines



2

SPANISH PERIOD: "Saving souls was more important than saving bodies. As a consequence, they built more churches than hospitals."



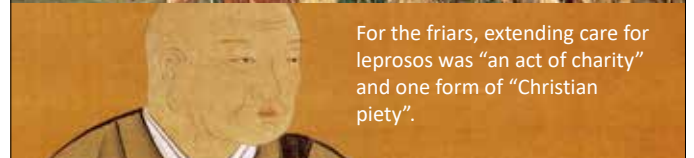
3

1632

130 Japanese Christian leprosy patients were exiled from Nagasaki to Manila. They were welcomed by Gov. Gen. Juan Niño de Tabora and were attended to by the Franciscans in their Hospital de San Lazaro.



For the friars, extending care for leprosy patients was "an act of charity" and one form of "Christian piety".



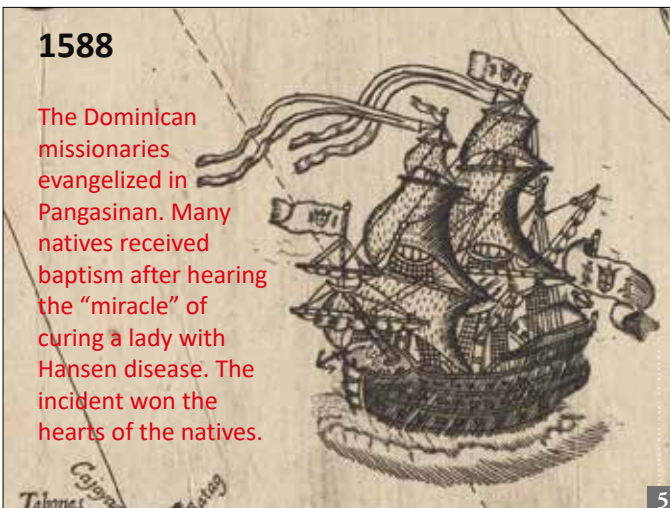
Filipinos contributed alms for the Japanese leprosy patients. The King ordered Tabora to increase the subsidy to San Lazaro to 200 ducats and convert San Lazaro into a leprosy hospital.



4

1588

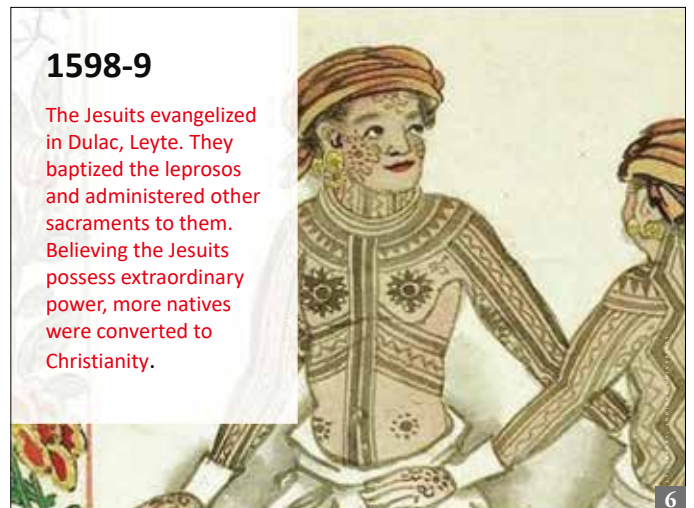
The Dominican missionaries evangelized in Pangasinan. Many natives received baptism after hearing the "miracle" of curing a lady with Hansen disease. The incident won the hearts of the natives.



5

1598-9

The Jesuits evangelized in Dulac, Leyte. They baptized the leprosy patients and administered other sacraments to them. Believing the Jesuits possess extraordinary power, more natives were converted to Christianity.



6

1672

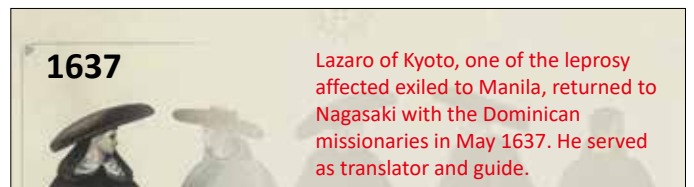
King Charles II declared Hospital de San Lazaro a leprosarium with annual subsidy from the colonial government.



7

1637

Lazaro of Kyoto, one of the leprosy patients exiled to Manila, returned to Nagasaki with the Dominican missionaries in May 1637. He served as translator and guide.



Lazaro was martyred with 14 other missionaries and laymen in Nagasaki in September 1637.



Also among the martyred was Lorenzo Ruiz of Manila. Both Lorenzo and Lazaro, along with 13 others, were canonized in Manila in 1987.



8

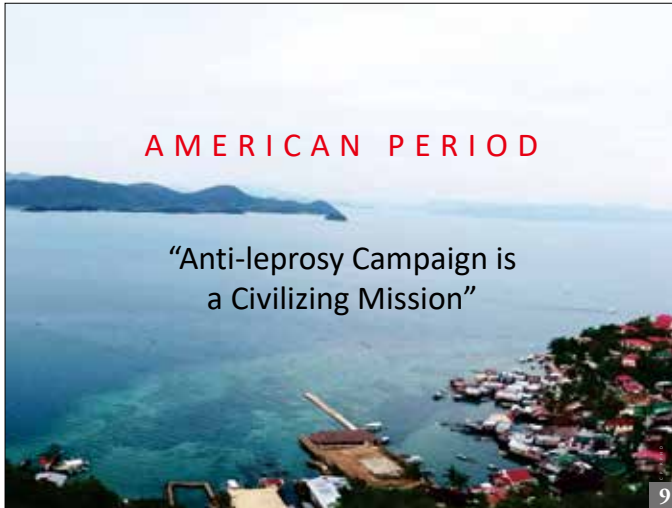
Another structure that NHCP will renovate and refurbish is the Grand Stairway. During the early years of the colony, the Grand Stairway was part of the plaza where many of the activities of the colony were held. The stairway added magnificence to the place and was the site where various official photographs of Culion's bureaucrats and other authorities were taken. The NHCP also included the Teatro in the list of buildings to be restored. During their free time, residents of Culion used to hold concerts, plays and other performances there. It also served as meeting or assembly place, dancing hall and venue for sports competition. The last structure in the NHCP list is the Glorietta, the place where patients held their social gatherings and community celebrations. During the colonial years, they often organized Sunday afternoon concerts and the performers were the musically talented patients who always drew large audiences.

NHCP will also retrofit and beautify the monument of Jose Rizal and Leonard Wood in Culion. The former was built in 1927 to honor the memory of our national hero. The Leonard Wood monument is another important landmark in Culion and it was installed in 1931 to immortalize the memory of Governor Leonard H. Wood. Patients voluntarily built his statue in the Plaza Basa Avellana as an expression of their gratitude for the support and concern he extended to Culion residents during his term of office.

In the coming years, NHCP also intends to improve and modernize the archives, library and museum of Culion. Officials of the former colony were able to salvage a lot of important documents and medical records that would be useful and of great value to future researchers. A lot of them are in the archives and the printed materials are in the library. To further preserve them and to make them more accessible, NHCP will digitize these archival documents and possibly upload them in the website of the Commission. This move will surely generate a lot of interest among present and future scholars because it will make Culion research more economical and sustainable. Lastly, NHCP will also modernize the Museum in Culion in order to attract more visitors. It will repackage the medical equipment, artifacts and pictures that are currently displayed in the museum. Hopefully, all these initiatives taken together will preserve the memory and history of Culion as a former leprosy colony. Moreover, there is also a big possibility that it will become a major tourist attraction in this part of Palawan.

AMERICAN PERIOD

"Anti-leprosy Campaign is a Civilizing Mission"



9



Victor Heiser: Director of the Bureau of Health.

Leonard Wood ; Governor General of the Philippines from (1921-1927):

10

Culion Leprosy Colony

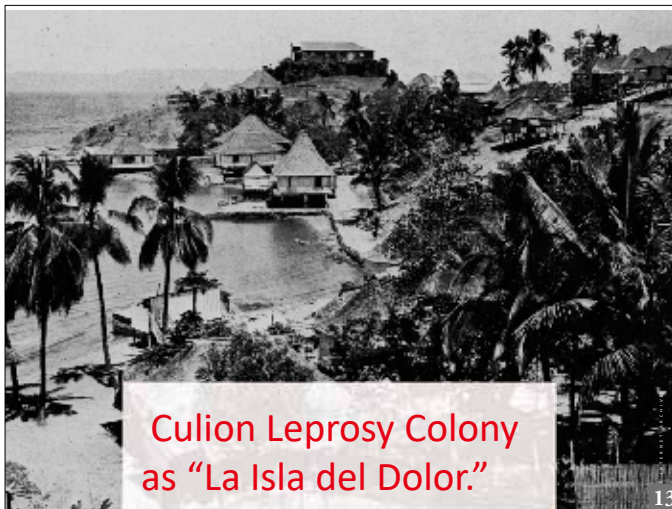
The Philippine Commission enacted Act. No. 1711 on 12 September 1907 to formalize the implementation of the segregation policy. It provided the legal basis for the compulsory apprehension and detention of suspected leprosy affected people for treatment and segregation in Culion.

11



Culion was a Spanish fortress.

12



Culion Leprosy Colony as "La Isla del Dolor."

13

1907

The Culion Leprosy Colony, Palawan



14

Culion Leprosy Colony

Building a leprosarium in Culion was a long arduous process. It took almost four years before it could accommodate the first batch of segregated lepers. This was because before the structures could be built, the local residents had to be relocated. The shortage of skilled workers and the difficulty of transporting construction materials from Manila to Culion also contributed to the delay.

15

Culion Leprosy Colony

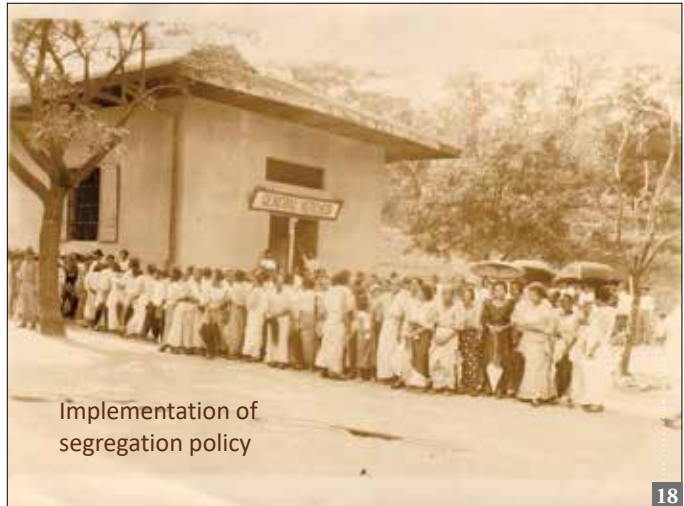
Problems Encountered:

1. People refused to cooperate
2. Lack of medical practitioners
3. It is a costly program and hard to sustain
4. Internal conflicts among leprosy patients
5. Local politicians opposed it

16

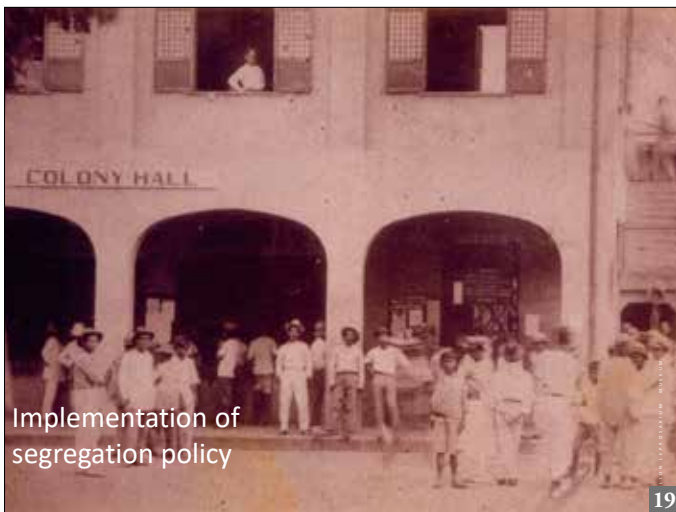
Culion as Research Center: The search for a cure for the disease became an essential component of their anti-Hansen disease program. Culion became a huge laboratory where medical experts conducted research. It became a place for clinically testing the efficacy of a particular drug because the island was under government control and the subjects were readily available. Doctors carried out trials on experimental drugs which were used in other leprosaria overseas. Towards the latter part of the American period, Culion was a mecca for scientists doing research on Hansen disease.

17



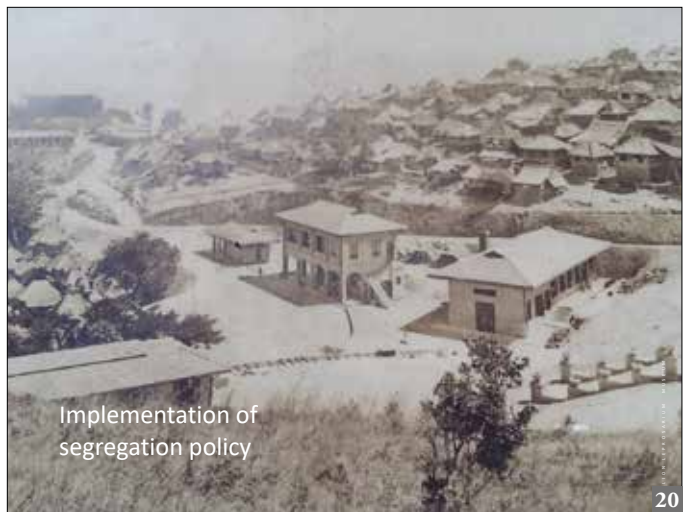
Implementation of segregation policy

18



Implementation of segregation policy

19



Implementation of segregation policy

20



Special Lepar Currency being exchanged with legal tender.

21



The Culion Leprosy Colony Coins

22



End of centralized segregation policy on Hansen Disease

23



24

Decentralizing the Segregation Policy

By the 1930's, new information on how the disease could be transmitted and the ways to cure it emerged. Health officials discovered that Hansen disease is not that contagious and deadly. These new developments forced colonial officials to re-examine the segregation policy and institute new approaches on how to deal with leprosy.

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Regional Leprosaria

1. Sta. Barbara, Iloilo
2. Mandaue, Cebu
3. Bongabong, Nueva Ecija
4. Tala Estate in Rizal

26

1998

"Leprosy was 'eliminated' as a public health problem in 1998 after the Philippines achieved its target of having less than one case per 10,000 population."

- Philip C. Tubeza, "PH urged to make leprosy history", *Philippine Daily Inquirer*, August 23, 2013



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**NHCP INITIATIVES:
Preserving
An Important Heritage
Site and Tradition**



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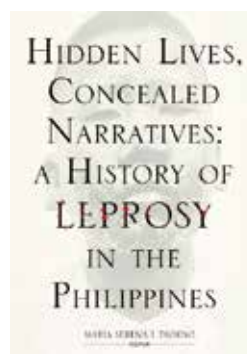
2016

The National Historical Commission of the Philippines and the Sasakawa Foundation published the first book on the history of Hansen Disease in the Philippines.



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**HIDDEN LIVES,
CONCEALED
NARRATIVES:
A HISTORY OF
LEPROSY
IN THE
PHILIPPINES**



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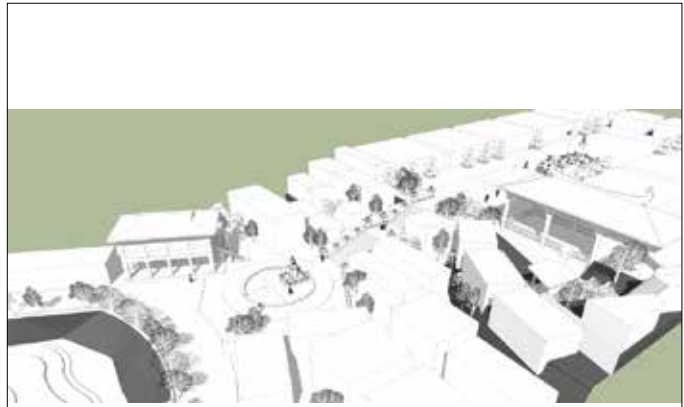
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Culion Projects (2017: Php. 35M)

As part of NHCP's mandate to promote the preservation of historical, cultural and social sites it is therefore fitting to fund Culions Colony Town complex.

- a. Colony Hall
- b. Leonard Wood Monument
- c. Grand Stairway
- d. Teatro
- e. Glorietta

33



34

35

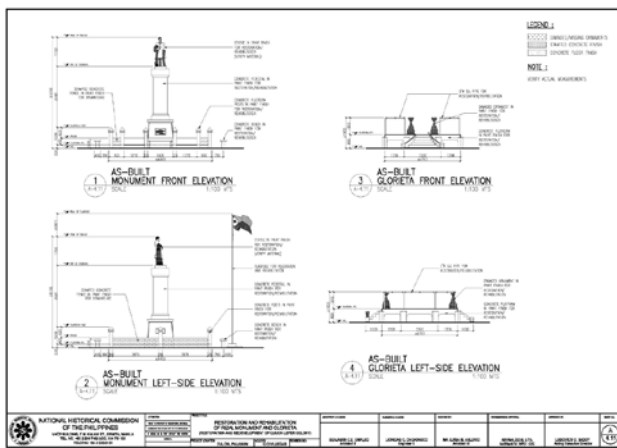


Rizal Monument

36



37



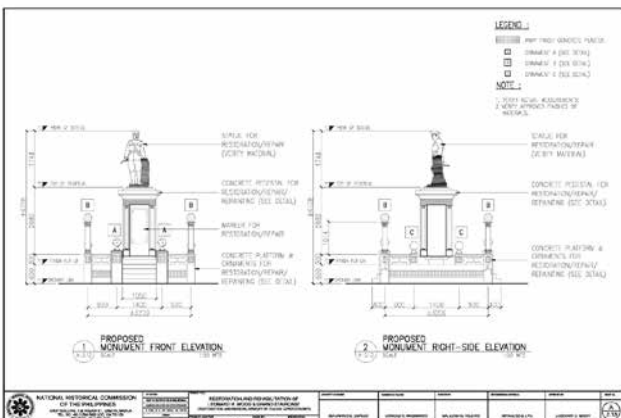
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39



Leonard Wood Monument



40

Grand
Staircase



41



42

Theater

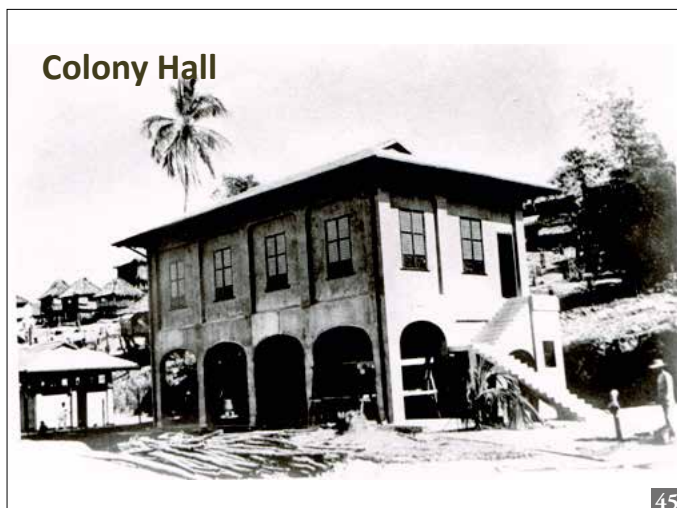


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Colony Hall



45



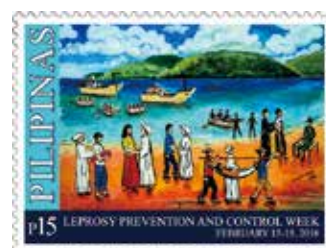
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2016

PhilPost launches commemorative stamp in solidarity with observance of Leprosy Prevention and Control Week.



47



48

FY 2018 (Php. 20 million) (Archives and Museum)

- a. Modernize and enrich the archives and the museum in Culion
- b. Digitize the files
- c. Audio Visual Material about the Culion Museum
- d. Influence CHED and DepEd to include the Culion story in the curriculum of both for basic and tertiary curriculum

49



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Session C: “Various Initiatives to Preserve the HD History”**Preserving our social memory****Ms. Joana Rizza Aspiras Bagano**

Programme Officer for Communication and Information
Philippine National Commission for UNESCO

The Philippine National Commission for UNESCO (PH NatCom) is a government agency that serves as the primary liaison between UNESCO and the Philippine government.

The MOW Programme is one of three UNESCO Programmes that feature a list. The other two are the World Heritage and the Intangible Cultural Heritage programmes. Established in 1992, the MOW Programme is the baby among the three. The other two are guided by Conventions, while the MOW Programme is being guided a Recommendation recently adopted in 2015. The MOW Programme is committed to “facilitate preservation of the world’s documentary heritage” as it believes that “the world’s documentary heritage belongs to all, should be fully preserved and protected for all...”



The Recommendation concerning the preservation of, and access to, documentary heritage including in digital form, adopted in 2015 by the UNESCO General Assembly, aims to assist UNESCO Member States both at national level through identification of documentary heritage and policy measures ensuring preservation of and access to it, and at international scales through bilateral or multilateral research projects and publishing guidelines, policies and best practice models.

In 2016, Ph NatCom received a letter of interest from Dr. Arturo Cunanan, Chief of Culion Sanitarium and General Hospital, to nominate the Culion Museum and Archives in the former leper colony of Culion, Palawan. So far, the Elpidio Quirino Foundation and the Culion Museum and Archives have expressed progress in accomplishing the nomination forms for their respective archival holdings.

We are now working on the nomination of The Culion Museum and Archives to the regional and/or international registers. The Culion Museum and Archives house and protect numerous rare volumes of leprosy journals, text books and other reference materials for leprosy. It has the complete set of Culion coins, different laboratory apparatus used in early leprosy research, old Culion pictures, Dr. Wade’s memorabilia’s and other items reflective of early patients’ community life. It has also provided necessary information and data regarding the early Culion, its mission, the patients’ lives inside the sanitarium and the resulting community that emanates from the early settlers.

Through the UNESCO Memory of the World (MOW) Programme, memory institutions can gain access to a wide network of experts and organizations involved in documentary heritage work. For instance, the Jose Maceda Collection of the Philippines was able to secure part of the UNESCO Jikji Prize awarded to Vienna's Phonogrammarchiv. Dr. Dietrich Schuller and his team decided to donate part of the prize to train Filipino sound engineers in the digitization of the collection.

The Culion Museum and Archives, and other memory institutions involved in leprosy, for that matter, can receive the same benefit from being inscribed in any of the UNESCO MOW registers, especially in the international and regional registers.

PRESERVING OUR SOCIAL MEMORY

Joana Rizza A. Bagano
Programme Officer for Communication and Information
Philippine National Commission for UNESCO

1

Memory of the World (MOW) Programme

- Established in 1992
- Committed to “facilitate preservation of the world’s documentary heritage”
- “The world’s documentary heritage belongs to all, should be fully preserved and pro



2



Philippine Paleographs (Hanunuoo, Buid,
Tagbanua and Palawan Tribes) (1999)

© Jacob Maentz

3

Philippine Paleographs (Hanunuoo, Buid, Tagbanua and Palawan Tribes) (1999)

- Gives us a glimpse of the connections among Southeast Asian syllabaries
- Nominated by the National Commission for Culture and the Arts (PH national cultural agency)
- Housed at the National Museum of the Philippines

4



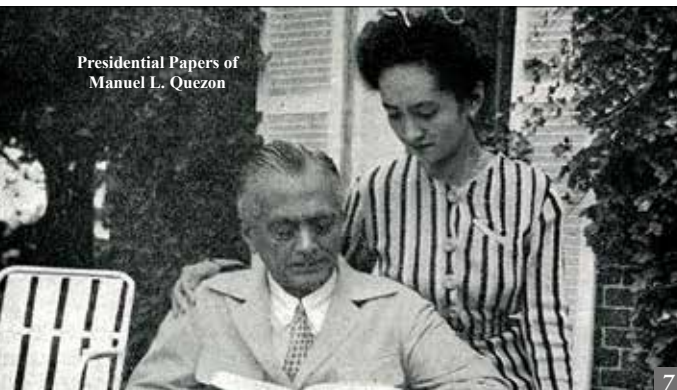
The José Maceda Collection (UP
Center for Ethnomusicology)

5

Jose Maceda Collection (2007)

- Reflects traditional music of the Philippines and Southeast Asia
- Nominated by and housed in the UP Center for Ethnomusicology

6



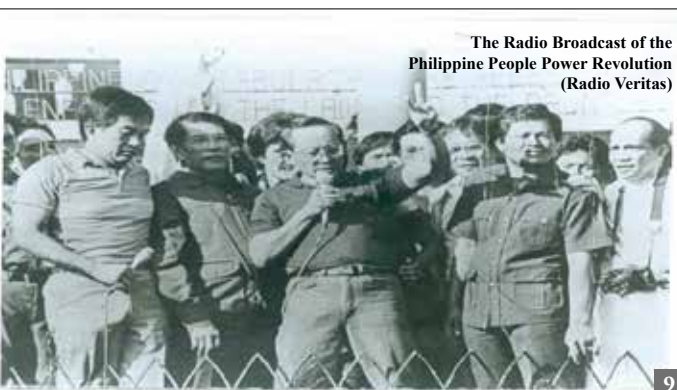
Presidential Papers of
Manuel L. Quezon

7

Presidential Papers of Manuel L. Quezon (2011)

- Documentation of the events and politics involved in the long history of the Philippine independence movement conducted both in the Philippines and in the United States
- Nominated by Dr. Bernardita Churchill and housed in the National Library and the Bentley Historical Library, University of Michigan

8



The Radio Broadcast of the
Philippine People Power Revolution
(Radio Veritas)

9

Radio Broadcast of the Philippine People Power Revolution (2003)

- Recordings of a unique and nonviolent revolution, one that is unmatched in scale
- Nominated by Dr. Renato Velasco and owned by Radio Veritas and Radio Bandido

10

Ganito Kami Noon, Paano Kayo Ngayon? (This Is How We Were; How Are You Doing Now?)



- Only documentary heritage inscribed in the National MOW register
- Nominated by Prof. Nick Deocampo and housed in the ABS-CBN Archives

11

MOW in the Philippines



- Awareness-Raising Seminars and Nomination Writeshops with the Center for New Cinema (2015-2016)
- Iloilo, Cebu, Manila, Baguio, Davao

12

MOW in the Philippines



- The Jawi Documents of Mindanao, Philippines

13

Recommendation concerning the preservation of, and access to, documentary heritage including in digital form (2015)

"The Recommendation aims to assist Member States both, at national level through identification of documentary heritage and policy measures ensuring preservation of and access to it, and at international scales through bilateral or multilateral research projects and publishing guidelines, policies and best practice models."

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The Nomination Process

- The International Advisory Council (IAC)
- Three registers: international (1), regional (2), national
- Steps:
 - Submission to PH NatCom (not required, but encouraged)
 - Preliminary desk review by PH NatCom
 - Review by a local expert (MOW Committee member or CI Commissioner)
 - Submission to MOWCAP or the IAC

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Moving forward



- Establish a national MOW Committee
- Ongoing assistance to MOW nomination bids
- Strengthen the PH National Register
- Establish/strengthen links with the MOWCAP, National Archives, National Library of the Philippines

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The Culion Museum and Archives



- House numerous rare reference materials for leprosy
- Complete set of Culion coins, laboratory apparatus, old Culion photos, Dr. Wade's memorabilia

17

3.6 Bibliography

Although no books were written regarding the Culion Museum and Archives, the history of Culion inside the museum can also be found in these books:

1. *Culion* by Arturo C. Cunanan Jr. (Manila Philippines 2011)
2. *Dignity Regained Philippines* by Arturo C. Cunanan Jr. (Manila Philippines 2010)
3. *Hidden Lives, Concealed Narratives: A History of Leprosy in the Philippines*, by Maria Serena Dikso (Manila Philippines 2016)
4. *Culion Island: A Leprosy Colony's 100 years journey towards healing*, published by Culion Foundation Inc. and ANED/NUAD 2009

The following are some of the comments of the guests of the museum:

1. *Ms. Kay Yamaguchi of Sasakawa Memorial Health Foundation May 6, 2016* – "It is a place that has become an asset to the people of the Republic of the Philippines"
2. *Rev. Ver Obispo - Minister Welfare Ministry, Hawaii* – "Classroom: A masterpiece, good job!"
3. *Dr. Sumana Barua - Medical Officer, WHO-WPRO, Manila* – "Remarkable improvement since I visited in 2002. Congratulations!"
4. *Dr. P.K. Gopal - President IDEA*, "Excellent Museum shows the history of the people affected by leprosy"
5. *David Norman Watt - Journalist, Brighton England* – "Congratulations. A superb collection"
6. *Jay Fernandez - Beacon School* – "Thank you museum staff, good job!"
7. *Adrian C. Morales - Executive, Manila Bulletin* – "There is no word to describe my gratitude because you were able to preserve this history"
8. *Dr. Josefina T. Baro* – "Page 10 of 14" – "The image of Culion is being preserved, keep up the good work"

18

3.6 Names, qualifications and contact details of up to three independent people or organizations with expert knowledge about the values and provenance of the documentary heritage

Name	Qualifications	Contact details
1. Dr. Josephine Robertson	Researcher-Historian Faculty of Humanities & Social Studies University of Queensland	jrobertson@uq.edu.au / +61733652147 Brisbane St Lucia QLD 4072 Australia
2. Prof. Eisaku Kita	Chairperson, Board of Trustees, Sasakawa Memorial Health Foundation	1000, Sakuragaoka, Tokyo 113-8501 Japan 1-2-2 Akasaka Minato-Ku, Tokyo 107-0052 Japan

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3. Dr. Rene Escalante	National Historical Commission of the Philippines	T.M. Kalaw St., Ermita Manila 1000 +639171121562
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4.3 Legal status

Provide details of legal and administrative responsibility for the preservation of the documentary heritage

The Culion Museum and Archives is operated and maintained by the Culion Sanitarium and General Hospital

4.4 Accessibility

All collections of Culion Museum and Archives can be accessed thru visitation to Culion Museum and Archives in Culion Palawan. Researchers are encouraged to set up an appointment before coming to Culion so the needed materials can be prepared prior to their arrival or to check if it's available in the collections.

Culion Museum and Archives is in the process of digitizing and publishing its collections on the web; however restrictions such as slow internet connections in Culion Island and copy right privacy of the collections is still an issue we are facing right now.

Last year the museum opened its new gallery, the Leprosy Social History and Memories Gallery, which contains the oral history of the leprosy patients from different sanitarium in the Philippines. Their struggles, experiences, survival and their arts and crafts during the segregation era.

All access restrictions should be explicitly stated below:

All collections of Culion Museum and Archives (CMA) are available for viewing and research but should be handled with care. However, delicate items such as old books and records can only be accessed in the

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Evidence to support criteria

- Authenticity
- World/regional/national Significance
- Comparative Criteria
 - Time
 - Place
 - People
 - Subject
 - Theme
- Social/spiritual/community significance

21



MEMORY OF THE WORLD REGISTER – NOMINATION FORM

Norway: The Leger Archives of Bergen

PART A – ESSENTIAL INFORMATION

Today many people think of leprosy only as a Third World disease. But the sickness has been an all too common element also of European daily life through the centuries, especially in the coastal regions. In Western Norway there have still many people suffering from this disease after it was practically wiped out from the rest of Europe.

This might be one of the reasons why Bergen in the middle of the 19th century became the scientific centre of the efforts to cure leprosy through the work of Dr. Carlsen and Dr. Arntsen Hansen, who discovered the Mycobacterium leprae in 1873. Today leprosy is practically non-existent in Europe, and although there are still 10-15 million leprosy in the rest of the world (where it is often called Hansen's Disease) the number of new cases is said to have reached almost a standstill.

The Leprosy Archives of Bergen document the breakthrough of the scientific understanding and description of leprosy on a world basis. The documentary heritage from this turning point of the fight against one of the world's most dreadful diseases is still internationally sought after and used, and deserves both a safeguarding and wider dissemination.

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Why MOW?

- UNESCO recognition (benefit by association)
- Access to a wide network of experts and organizations involved in documentary heritage work; access to funding
 - The UNESCO Jikji Prize, Vienna's Phonogrammarchiv, and the Jose Maceda Collection
- Publicity
- Local and international awareness on the state of documentary heritage in the country and around the world

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SALAMAT PO!

24

Session C: "Various Initiatives to Preserve the HD History"

Our Stories, Our Legacy

Ms. Ean Nee Tan

Councillor
Sungai Buloh Settlement Council

It was in 2007 when I set foot in the Sungai Buloh Settlement. At that time, the government wanted to tear down the historic buildings at the East Section of the settlement. I and my ex-colleague visited the residents for an interview and then produced a documentary entitled, "The Everlasting Valley of Hope". The documentary recorded the tug of war between the residents and the government in the preservation of the affected area.

During the filming, we became good friends with many of the residents there. With our deepened relationship, I came to realize the richness of their personal life stories, and how unique the history of the place is and so, all the more, I felt the urgency of recording their personal stories and the history of the community.



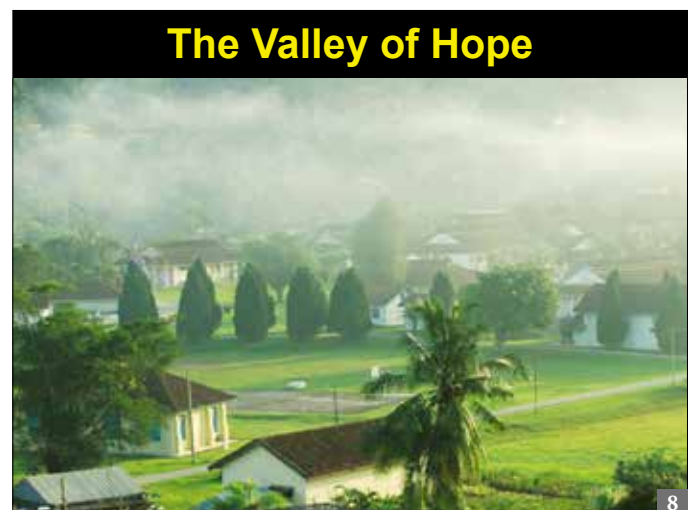
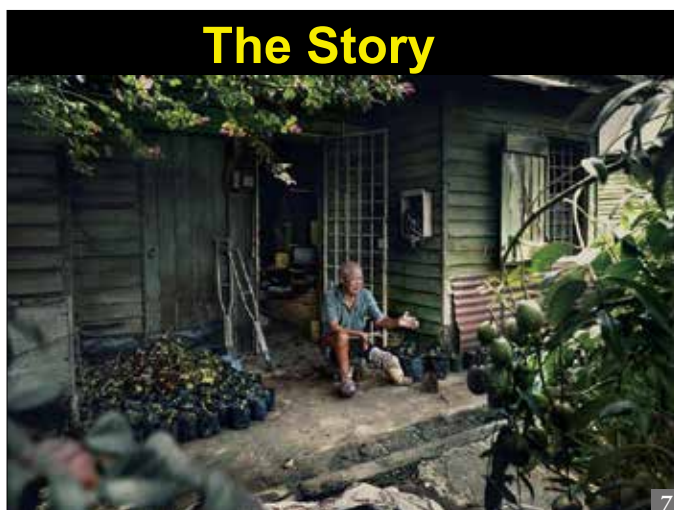
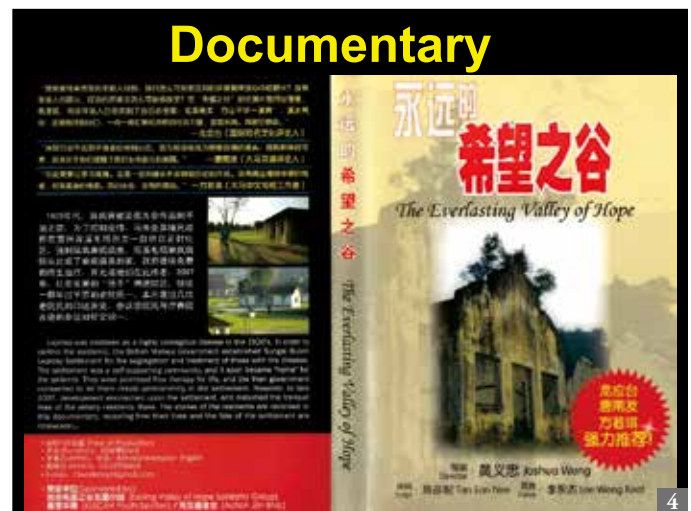
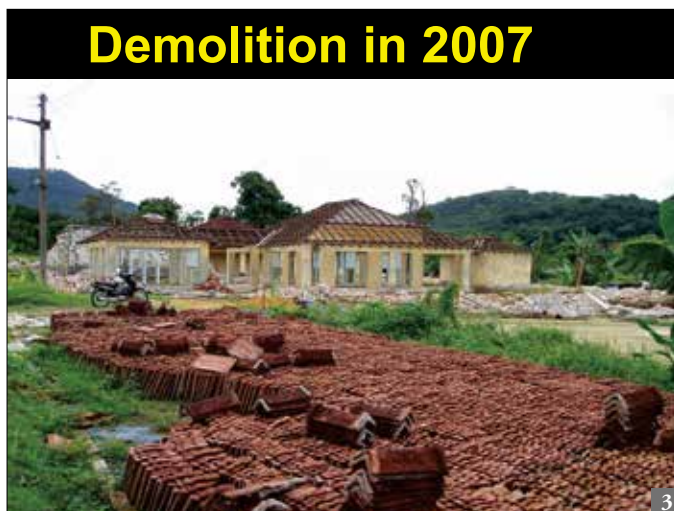
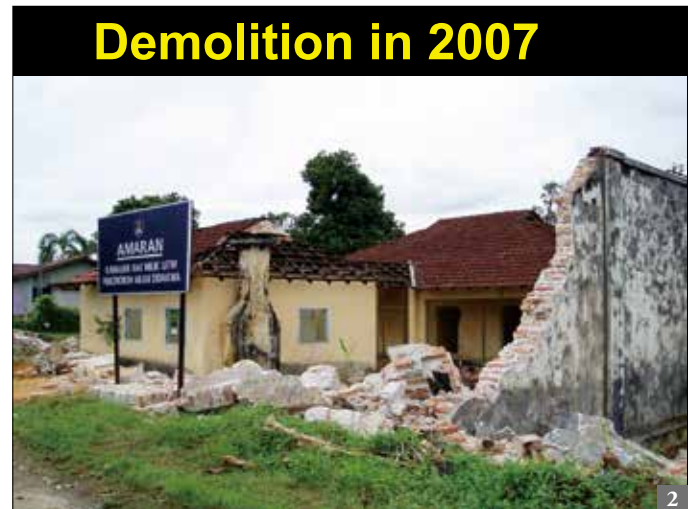
Heroes Hidden in the Valley

The Sungai Buloh Settlement was established in 1930, and was also known as the "Valley of Hope". The Settlement is nestled amid the green valleys and misty mountains. During the segregation period, the leprosarium was operated by the patients themselves, including administration, managing the farms, carpentry, cleaning, food distribution, and some patients were even trained to become nursing assistants. There was a distinct set of social rules, its own currency, and it was complete with a school, a community hall, clinics, decrepit ward, religious sites, a prison, a cemetery, social clubs and associations, and even its own police and fire brigade! The Sungai Buloh Settlement Council was formed by the patients, which is still in operation up to this date.

A Story Gallery to Transmit Life Histories

During its heyday, the settlement had 2,440 residents, but it has now diminished to only 138 residents. This place will indeed become a heritage site soon. Setting up a story gallery has always been my dream so in 2015, I proposed to the Council to establish a "Valley of Hope Story Gallery" to preserve the inspiring stories of the residents.

The purpose of establishing a story gallery is to commemorate the contribution of the former leprosy patients. We hope that through the collection and preservation of the oral histories of the leprosy survivors, our future generations will appreciate the legacy of this settlement and ensure that the stories of the residents will live forever in our hearts. After my proposal was accepted, the story gallery project dubbed as "You Are the Hero", was launched on 14 August 2016.



You Are the Hero

This project is called “You Are the Hero”, because the elderly ex-patients have come a long way and have been through a lot in life since the time of the segregation. By sharing what they have witnessed in life, each and every one of them can inspire the future generations. We have produced a series of stories about their lives and their emotions during the isolation. So, with this project, the voices of the PEOPLE, their perspectives, their emotions and their personal life histories will be highlighted.

Design Concept of Story Gallery

1. The story gallery will be located on the second floor of the community hall.
2. It will be made up of light weight structure built on steel plate by using reversible construction methods to avoid demolition of existing structure.
3. The first floor will consist of corridors, with essential information about the place, and provide the visitors with a clear overview about leprosy and the settlement.
4. It is also a common space for multi-purpose uses, such as functions, exhibitions and etc.
5. An additional timber mezzanine floor will be built at the second floor, which will be able to accommodate 40-50 people. This floor will showcase the past social and oral history of the residents, thus giving the visitors a closer look at the life experiences and collective memories of the settlement.
6. The story gallery is designed to connect the landscape of the environment (the Valley of Hope) with the building (Community Hall), with external fire-safety and disable access friendly staircase and lift.
7. The outdoor space will be converted into an attractive playground that will invite more young people to visit the place.

Fundraising Activities

In 2016, we developed an on-going guided heritage tour, targeted at parents and children so that the public can get close with this historical place. As the settlement gained popularity, it became more and more lively, with teachers bringing in students for guided tours and charity sales, private businesses joining the bazaar, groups of artists going there to sketch, local and overseas dancers shooting videos of their experimental dances at the heritage site. We also had an internationally well-known director who came to do some filming here.

Our Mission

We hope that this story gallery will become a “cultural lobby of the settlement” that will attract visitors from the art, literary and academic community, and help them in their research and creations by capitalising on the resources of the cultural heritage.

Meanwhile, the hospital authorities are also working on six galleries, to turn the settlement into an open museum. However, they are more on displaying the history of the disease and also the medical equipment and artefacts of the residents but have few stories of the ex-patients.

The story gallery will be a part of the open museum, where the public can listen to the stories of the residents, besides exploring the artefacts on display. The collection of the residents’ oral histories will tell the world of their life in the settlement, their sweet and bitter memories so that our future generation can have correct information about the leprosy community and understand the ordeal that the former leprosy patients and their families have undergone. We hope the story gallery will help to enrich the content of the Sungai Buloh Open Museum and make the history of the settlement more complete. Thank you!

Heroes in the Valley



9

Own Currency



10

Travers School



11



Community Hall

Food Distribution Centre



Decrepit Ward

Gospel Hall

12



Prison

Social Club



Cemetery

Chinese Association

13

Police Force



14

Council Hall



15

Valley of Hope Story Gallery



16

Valley of Hope Story Gallery



You are The Hero



You are The Hero



You are The Hero



You are The Hero



Trailer of People's Life



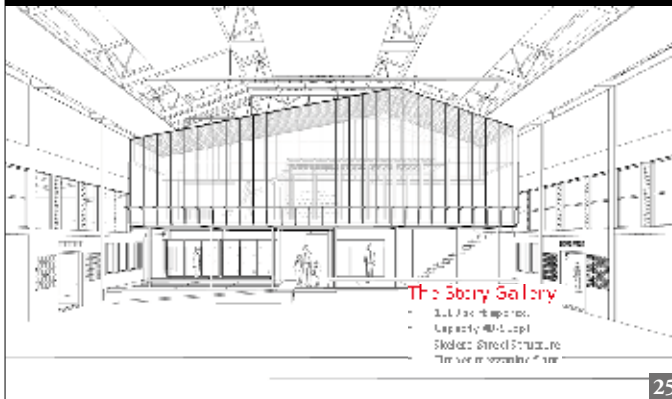
Valley of Hope Story Gallery



Design Concept

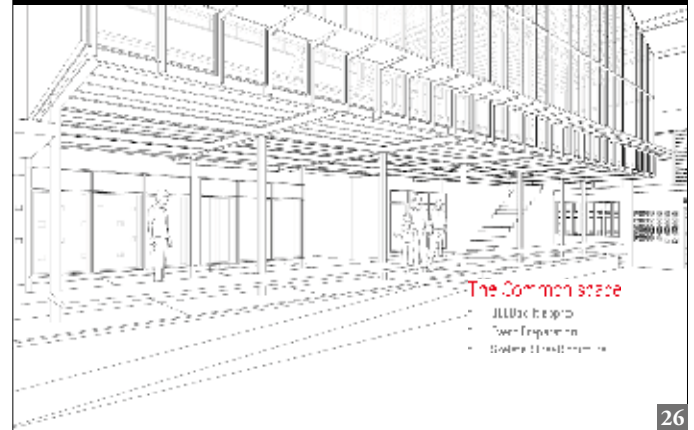


Design Concept



25

Design Concept



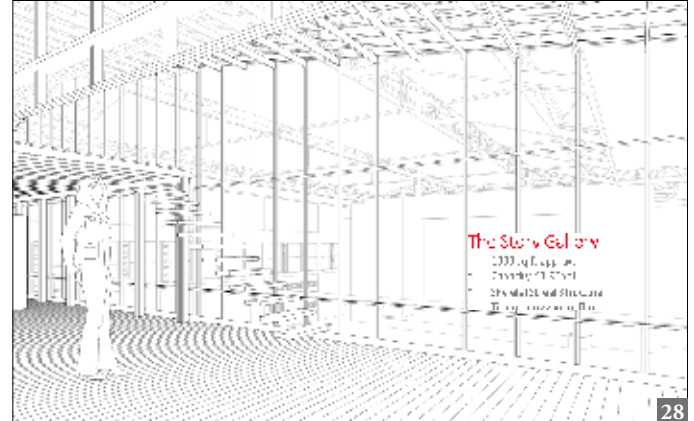
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Design Concept



27

Design Concept



28

Design Concept



29

Design Concept



30

Heritage Tour



31

Heritage Tour



32

Bazaar



Sketch Activities



Video Dance



Film Shooting



Cultural Lobby



Revive Memories



Government's gallery



Government's gallery



Story Gallery



Story Gallery



Story Gallery



Trailer of Story Gallery



Valley of Hope



*Session C: "Various Initiatives to Preserve the HD History"***Agua de Dios, Colombia—City of Joy and Memory****Dr. Yanit Esther Mora Moscote**Mayor
Agua de Dios

Slide 1: AGUA DE DIOS CITY OF HAPPINESS AND MEMORIES

Slide 2: AGUA DE DIOS AND THE WORLD.

Slide 3: PANORAMIC VIEW OF AGUA DE DIOS

Slide 4: FAMILY TREE OF YANIT MORA.

How did I end-up in Agua de Dios? My great grandmother along with my grandmother and all her children (among them my mother) arrived at Agua de Dios after being forced out of their home in a town near the sea called Cano del Oro in Cartagena, Colombia.

My mother did not have the illness and was forced to live with her godmother. My grandmother Silvia eventually became a nurse because there were not medical personnel available at that time and place, which in turn helped her for her family livelihood. As years passed by my mother Hilda met my father Miguel Enrique Mora Morale who came to Agua de Dios with his family for the same reasons as ours. My grandmother on my father's side had leprosy, some of my uncles were born with leprosy but the next generation were all born healthy. My father, my mother and six siblings were all healthy as well as their generation.

Slide 5: GENEALOGY TREE OF DRA. YANIT MORA

I was born in Agua de Dios in 1971 and did my elementary and high school studies there. In 1991, I met Fernando Elias Duque my husband and we have a son named Felipe Elias Duque Mora born in 1996.

I majored in financial management and specialized in administrative law.

I have 25 year experience in governmental and private offices. Today I hold office as the Mayor of Agua de Dios.

Slide 6: GRAPHIC GENEALOGIC OF THE MORA/MOSCOTE FAMILY

Slide 7: AGUA DE DIOS, CITY OF HAPPINESS AND MEMORY.

Slide 8: DISTRICT CHURCH NUESTRA SENORA DEL CARMEN

CARRASQUILLA BUILDING / MUNICIPAL BUILDING (BEFORE)/ MUNICIPAL BUILDING (AFTER)

Slide 9: MAIN CITY PARK (BEFORE) / MAIN CITY PARK (TODAY) / MAIN CITY PARK (TODAY)
CARRASQUILLA'S PARK

Slide 10: MONUMENT TO THE FOUNDERS / SIMON BOLIVAR'S PARK / COSCOJA'S ACOUSTIC SHELL / BETANIA'S MONASTERY

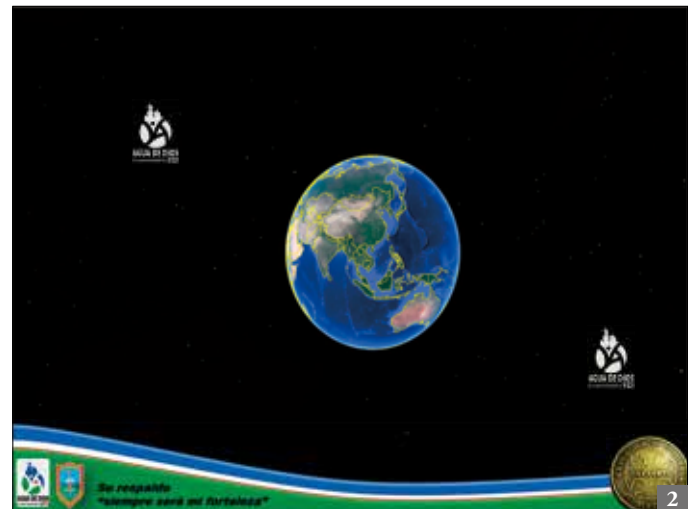
Slide 11: THE CROSS HILL / MAIN STREET (BEFORE) / MAIN STREET (TODAY) / MUNICIPAL LIBRARY: JOSE OLIMPO ALVAREZ SANCHEZ



Agua de Dios, Colombia Ciudad de la Alegría y la Memoria

Su respaldo
"siempre será mi fortaleza"

1



ARBOL GENEALOGICO DRA YANIT MORA

Como llego a Agua de Dios , mi bisabuela, abuela con sus hijos y entre ellos mi madre llegan desplazadas por la enfermedad de la lepra de un lugar cerca al mar llamado Caño del Oro en Cartagena Colombia.

Mi madre no tenía la enfermedad y fue separada de mi abuela por miedo al contagio, entregándola a una madrina para su crianza. Mi abuela Silvia se convirtió en enfermera debido a que no había mucho personal médico de igual manera le sirvió como sustento.

Es así como al transcurrir los años mi madre Hilda conoce a mi padre Miguel Enrique Mora Morales que llega a Agua de Dios con sus padres por la misma situación. Mi abuela paterna era enferma de Lepra. Algunos de mis tíos nacieron enfermos de lepra, pero las siguientes generaciones han nacido sanas. Mi padre y madre, mis seis hermanos y sus generaciones han nacido sanos.

Su respaldo
"siempre será mi fortaleza"

4

ARBOL GENEALOGICO YANIT MORA

Nací en el año de 1971 en Agua de Dios donde estude mi primaria y bachillerato en el colegio salesiano Miguel Unia. En el año de 1991 conocí a Fernando Elías Duque quien es hoy mi esposo; de esta unión tengo un hijo llamado Felipe Elías Duque Mora, nacido en 1996.

Soy Tecnóloga en Gestión Financiera de la Universidad del Tolima, Profesional como Administradora en el área financiera, especialización en Derecho Administrativo, Cursos en contratación estatal en la escuela Superior de Administración Pública, estudié gerencia de proyectos en la Escuela Superior de Administración Pública.

Experiencia Laboral de 25 años en cargos públicos y privados de los cuales he sido asesora del Congreso de la República de Colombia, jefe de los bienes inmuebles en la gobernación y Gerente General de la Beneficencia de Cundinamarca en la Gobernación de Cundinamarca y hoy Alcaldesa del municipio.

Su respaldo
"siempre será mi fortaleza"

5

FAMILY MORA MOSCOTE



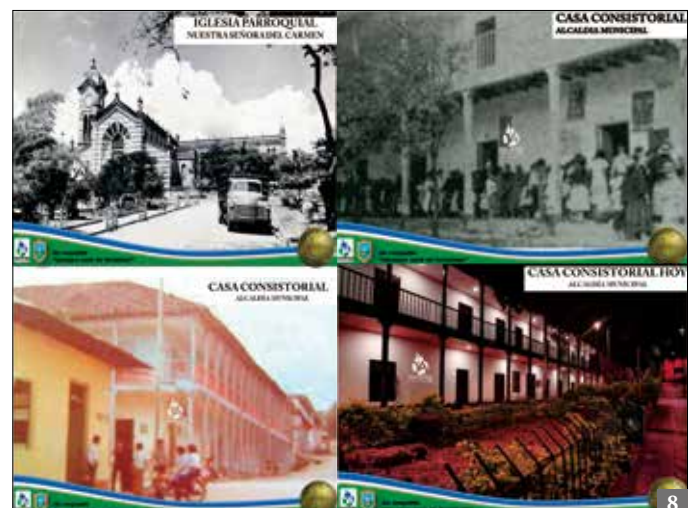
Su respaldo
"siempre será mi fortaleza"

6

Agua de Dios, Colombia Ciudad de la Alegría y la Memoria

Su respaldo
"siempre será mi fortaleza"

7



8

Slide 12: VISION.

In 2030, the Municipality of Agua de Dios in Cundinamarca will be part of an important economic development based on a productive cluster of urban development and cultural richness. Incentives to the private industrial investment with a high grade of investigation and development when focused on the Agricultural, Environmental and Historical fields. This will allow us to overcome the barriers of poverty and exclusion and form an important cultural destiny. The important point is to assure an attractive cultural and agricultural eco-tourism destination in Colombia.

Slide 13: PAST PRESENT

Slide 14: CENTER OF TOURIST INFORMATION.

The center of tourist information is nationally designed to provide the general public with information to help guide them and satisfy the visitor of the tourist development in the municipalities. In Agua de Dios the setting of a Center of Tourist Information is part of the necessity to strengthen the touristic development. This concept gave the foundation for the creation of the museum of artists and craftsmen. It started already with the space lay-out and assignment of physical space for paints, sculptures and crafts, making this exhibit open to the public.

Slide 15: CENTER OF TOURIST INFORMATION.

Slide 16: MUNICIPAL ACADEMY OF HISTORY OF AGUA DE DIOS

This academy is an educational institute under the municipality management. Its objective is to recover and spread the historical memories of the municipality through the analysis, systematization of oral and written testimonies in the process of the birth and development of local entities.

Slide 17: MUSEUMS

Slide 18: LUIS A. CALVO HOUSE MUSEUM

Slide 19: LUIS VARIARA MUSEUM

Slide 20: MEDICAL MUSEUM OF LEPROSY

Slide 21: AGUA DE DIOS LIVES MUSEUM

Slide 22: Three RURAL MUSEUMS: CAVE ART MUSEUM, ANA MARIA LOZANO MUSEUM, MANA DULCE FAMILY MUSEUM

Slide 23: REPRESENTATIVE PERSONAGES

Slide 24: PIOUS REVEREND LUIS VARIARA

Born in Asti, Italy 1875. Attended the Don Bosco School in Turin, came to Colombia in August of 1894 at the early age of 19 with the first group of Salesian missionaries by request of Father Miguel Unia who was searching for a young musician to help him with his project. Luis Variara was the founder of the musical band and of the congregation of "The daughters of the sacred heart of Jesus and Maria." He died in 1923 in Cucuta, Colombia.

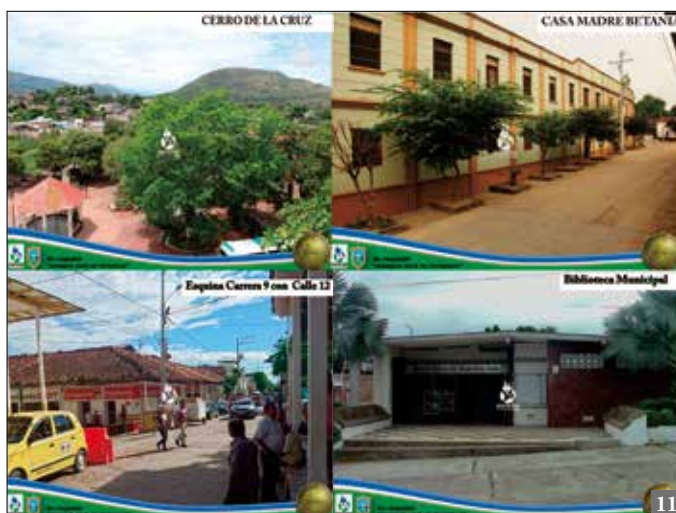
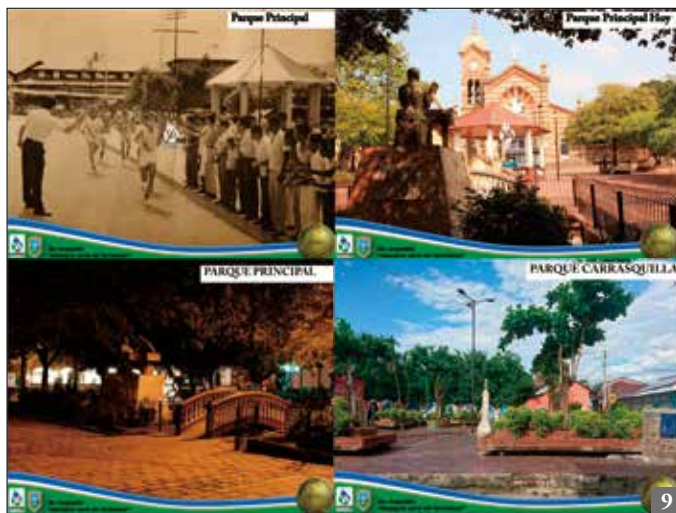
Slide 25: LUIS A. CALVO (1882 – 1945)

Musician and composer born in Santander and died in Agua de Dios. He was sequestered in Agua de Dios in 1916. The Salesian religious order provided him with all the resources necessary including a house for him to live with his family. He devoted himself to his piano. In 1942 he married Ana Rodriguez who inspired him to create many of his songs. He was one of the maximum maestros of the national music and his music reflects the essence and sensibility of the common people. He composed intermezzos 1, 2, 3 and 4 in addition to more than 165 melodies.

Slide 26: JOSE ANGEL ALFONSO

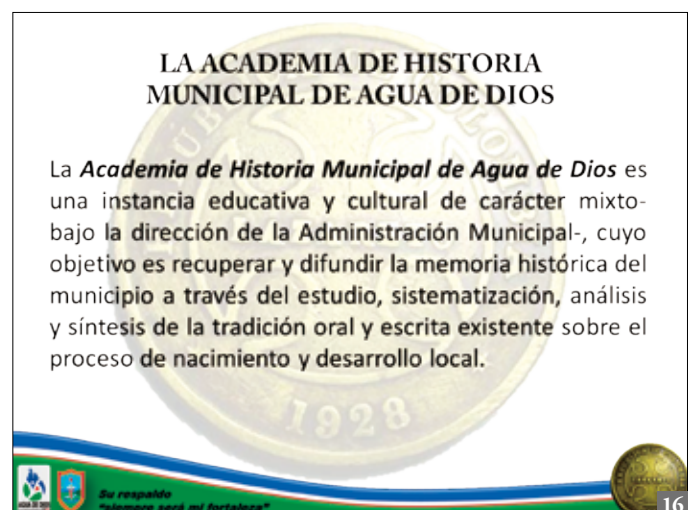
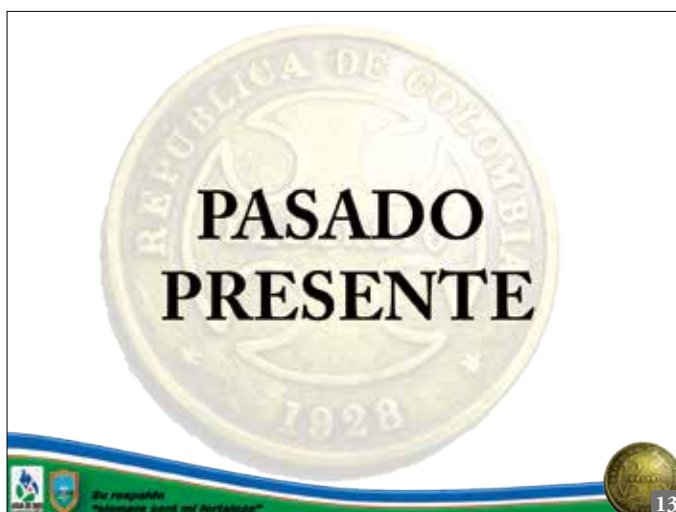
Painter and writer born in 1936. He designed the Agua de Dios Coat of Arms and he wrote three autobiographic books: "Brush strokes of Agua de Dios" "Little rascal" and "The leper child on his way to triumph"

Slide 27: CHAPELS



VISIÓN

En 2030 el municipio de Agua de Dios hará parte de la ciudad región centro oriente de Cundinamarca, con un importante desarrollo económico local basado en clúster productivos sostenibles, desarrollo urbanístico y riqueza cultural, incentivando la inversión privada y aplicando un alto grado de investigación y desarrollo en asuntos agropecuarios, ambientales e históricos, que permitirá a toda su población y sus futuras generaciones, superar las barreras de la pobreza y la exclusión, para que sea un importante destino cultural y agro-ecoturístico en Colombia.



LA ACADEMIA DE HISTORIA MUNICIPAL DE AGUA DE DIOS

La *Academia de Historia Municipal de Agua de Dios* es una instancia educativa y cultural de carácter mixto-bajo la dirección de la Administración Municipal-, cuyo objetivo es recuperar y difundir la memoria histórica del municipio a través del estudio, sistematización, análisis y síntesis de la tradición oral y escrita existente sobre el proceso de nacimiento y desarrollo local.

Slide 28: AGUA DE DIOS CHAPELS

Slide 29 AGUA DE DIOS CHAPELS

Slide 30 AGUA DE DIOS CHAPELS

Slide 31: EL SALTO CHURCH

Slide 32: TRAINING SCHOOLS. - MORE THAN 1200 BENEFICIARIES IN EIGHT SCHOOLS.

Slide 33: "TRIBUTO PANCHE" DANCE MUNICIPALITY SCHOOL. MORE THAN 200 BENEFICIARIES, YOUNG AND OLD PEOPLE / BAND MUNICIPALITY SCHOOL. "LUIS VARIARA" YOUTH SYMPHONY ORCHESTRA, TRADITIONAL GROUP. MORE THAN 265 CHILDREN AND YOUNG PEOPLE BENEFICIARIES / CORO, GUITAR AND TUNA MUNICIPALITY SCHOOL. MORE THAN 144 DIRECT BENEFICIARIES / THEATER AND AUDIOVISUALS MUNICIPALITY SCHOOL. 289 DIRECT BENEFICIARIES.

Slide 34: COMMUNITY DANCE SCHOOL "FURIA FOLCLÓRIKA". 29 DIRECT BENEFICIARIES / MARCIAL BAND. 50 CHILDREN BENEFICIARIES / MUSICAL INITIATION SCHOOL. INSTRUMENTAL ORFF. 50 CHILDREN BENEFICIARIES / "GILBERTO ZAMORA" COMMUNITY SCHOOL OF ARTISTIC PAINTING. 80 DIRECT BENEFICIARIES/

Slide 35: CRAFTSPEOPLE ASSOCIATIONS

Slide 36: AGUA DE DIOS'S CRAFTSWOMEN ASSOCIATIONS/ AGUA DE DIOS'S CRAFTSWOMEN ASSOCIATIONS / AGUA DE DIOS'S HANIDCRAFTS / HANDICRAFTS MADE IN FIQUE (HEMP)

Slide 37: HANDICRAFTS OF TOTUMO CARVED AND OPENWORKED

Slide 38: HISTORICAL HERITAGE

Slide 39: THE BRIDGE OF "LOS SUSPIROS / THE BRIDGE OF "LOS SUSPIROS / THE BRIDGE OF "LOS SUSPIROS AND THE NEW BRIDGE "ANTONIO NARIÑO" / DISINFECTION HOUSE

Slide 40: DISINFECTION HOUSE (TODAY) / CARRASQUILLA'S BUILDING (BEFORE) / CARRASQUILLA'S BUILDING (TODAY) / BOYACA'S LODGE

Slide 41: OSPINA PEREZ'S LODGE / SAN VICENTE'S LODGE / HOSPITAL "HERRERA RESTREPO" / HOSPITAL "HERRERA RESTREPO" (TODAY)

Slide 42: HOSPITAL "SAN RAFAEL" / HOSPITAL "SAN RAFAEL" (TODAY) / HOSPITAL "SAN RAFAEL" / HOSPITAL "SAN RAFAEL" (TODAY)

Slide 43: SANTA ANA'S BOARDING SCHOOL/ SANTA ANA'S BOARDING SCHOOL (TODAY) / CRISANTO LUQUE'S BOARDING SCHOOL/ DOCTOR'S HOUSE

Slide 44: DOCTOR'S HOUSE (TODAY) / MARIA INMACULADA SCHOOL'S CHAPEL / LUIS A. CALVO HOUSE MUSEUM / MIGUEL UNIA'S HIGH SCHOOL

Slide 45: MIGUEL UNIA'S HIGH SCHOOL (TODAY) / MIGUEL UNIA'S HIGH SCHOOL (TODAY) / VARGAS TEJADA'S GRAND THEATER / PLACE NAMED "LOS CHORROS" AND THERMAL BATHS (BEFORE)

Slide 46: PLACE NAMED "LOS CHORROS" AND THERMAL BATHS (TODAY)

Slide 47: PROPOSAL 1

To make a love, drama and survivor movie to narrate the history of leprosy in the world. Developed in Colombia.

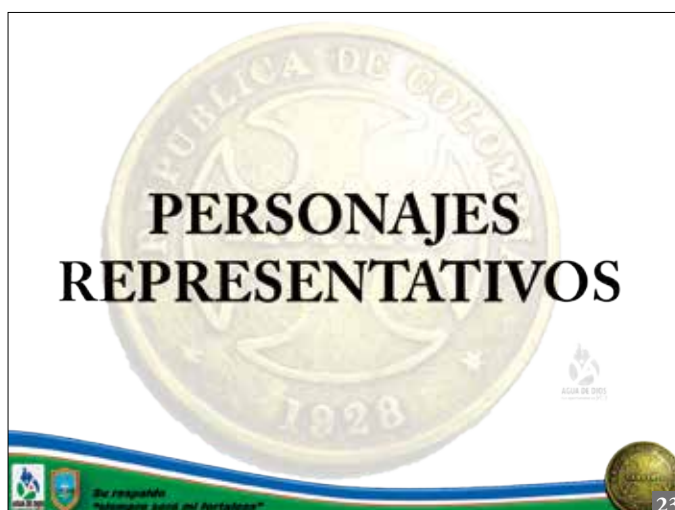
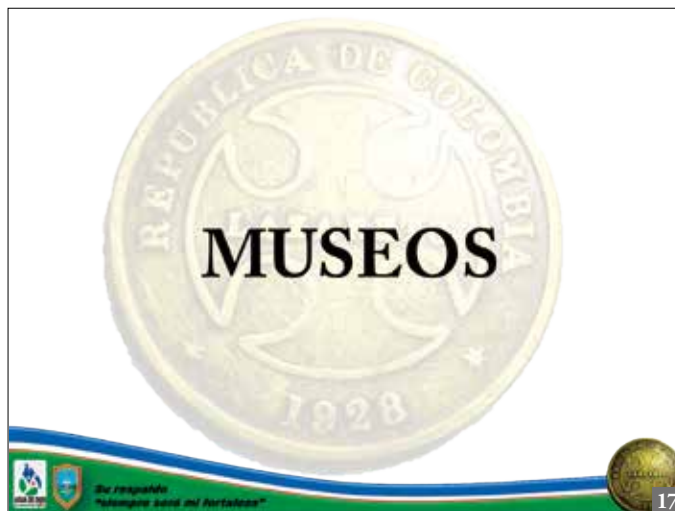
Slide 48: HISTORICAL FILM.

The objective here is to strengthen the historic identity of the municipality. To support the educational history. To minimize the stigma. To motivate tourism and to motivate the private enterprise in the filming industry.

Slide 49: PROPOSAL 2

VIRTUALIZATION OF HISTORY

Modular each one of the places and procedures related to leprosy by software.



Slide 50: OBJECTIVE: Virtual interactivity and pedagogical.

Slide 51: PROPOSAL 3

Slide 52: BUY THE MONUMENT TO ACOUSTIC SHELL.

We want to have a monument of the COSCOJA (coins used at the leprosarium) similar to the monument built in Contratacion. To place it at the COSCOJA's Acoustic Shell named "COSCOJA".

The objective here is that the history and memories be reflected at the places where people share their cultural interest.

Slide 53: PROPOSAL 4

Slide 54: STUDENT EXCHANGE

Exchange Japanese citizens with Colombian citizens, especially from Agua de Dios, who will have the opportunity to learn from each other.

Objectives: To develop cooperation policies in learning at all levels.

Find points of rapprochement for the development of the happiness of both nations.

Slide 55: PROPOSAL 5

Slide 56: CONSTRUCTION OF THREE-LEVEL MUNICIPAL LIBRARY 595 SQUARE METERS.

First level: Reading area and computer area.

Second level: Classrooms for 11,000 beneficiaries.

Slide 57: CONSTRUCTION OF THREE-LEVEL MUNICIPAL LIBRARY 595 SQUARE METERS.

Third level: Projection rooms and conference halls. Total area to build: 1,700 square meters

The cost of this project is 3,400.000.000.00 (at 2865/\$ US) = 1,186,736 US

Slide 58: MUNICIPAL LIBRARY / MUNICIPAL LIBRARY / MUNICIPAL LIBRARY / MUNICIPAL LIBRARY

Slide 59: PROPOSAL 6.

Slide 60: CONSTRUCTION OF THE SENSORY LIFE CENTER.

CONSTRUCTION OF TWO LEVELS IN 462 SQUARE METERS

Total area to be built:

900 square meters. More works of urbanism, platforms and landscaping

The cost of this project is \$ 1,876,500,000. 00 (at 2865/\$ US) = 654.974 US

Slide 61: THE SENSORY LIFE CENTER / LAND TO BUILD THE SENSORY LIFE CENTER / THE SENSORY LIFE CENTER

Slide 62: PROPOSAL 7.

Slide 63: RESTORATION OF THERMAL BATHS

Due to provisions of an Ecological Corporation that regulates the norms of environmental contamination they provide that the baths should not be near.

Slide 64: LOS CHORROS

Slide 65: LOS CHORROS

Slide 66: PROPOSAL 8

Slide 67: TO BUY SITES CALLED RETAINS

Complete restoration of the thermal baths. Due to provisions of an Ecological Corporation that regulates the norms of environmental contamination they provide that the baths should not be near.

Slide 68: TOCAIMA RETAIN / TOCAIMA RETAIN / BARRERO RETAIN / LAS LOMAS RETAIN

Slide 69: IBAÑEZ RETAIN / EL SALTO RETAIN / BERLIN HOTEL

Slide 70: MORE INFORMATION

Slide 71: MUNICIPAL SYMBOLS

Slide 72: BIBLIOGRAPHY

LUIS A. CALVO (1882-1945)

Músico y compositor colombiano. Nació en Gambita (Santander) y murió en Agua de Dios (Cundinamarca). El 12 de mayo de 1916 ingresó al lazareto Agua de Dios, donde los padres salesianos le proporcionaron todos los recursos necesarios, y una casa para que viviera allí con toda su familia. En Agua de Dios, Calvo se dedicó por completo al piano. El 18 de octubre de 1942 contrajo matrimonio con Ana Rodríguez, quien le sirvió de inspiración para componer muchas de sus canciones. Fue uno de los máximos cultores de la música nacional, en cuya obra late la esencia y sensibilidad de su pueblo. Compuso los intermezzos 1 2 3 y 4 y más de 165 melodías entre vals, pasillos, bambucos y danzas.



Su legado
"siempre será mi fortaleza"



25

JOSE ANGEL ALFONSO

Pintor y Escritor santandereano nacido en Charalá, el 1 de marzo de 1936.

Autor del Escudo de Agua de Dios, ha escrito tres libros de Carácter Autobiográfico: Pinceladas de Agua de Dios, cuentos y leyendas de Agua de Dios y Angelillo pillo, un niño leproso camino del triunfo, viven Agua de Dios desde Diciembre de 1951.



Su legado
"siempre será mi fortaleza"



26

CAPILLAS



Su legado
"siempre será mi fortaleza"



27

CAPILLAS DE AGUA DE DIOS



Su legado
"siempre será mi fortaleza"



28

CAPILLAS DE AGUA DE DIOS

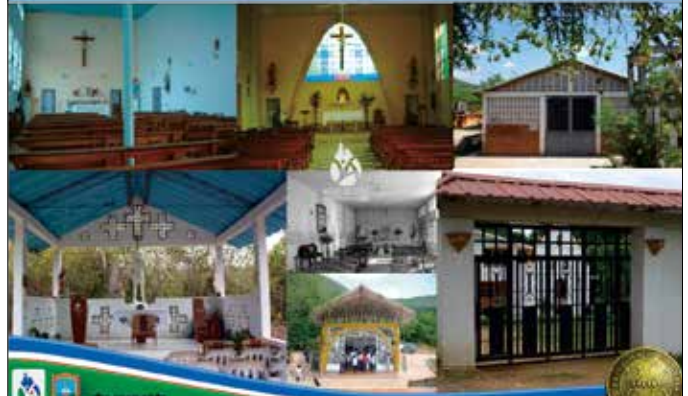


Su legado
"siempre será mi fortaleza"



29

CAPILLAS DE AGUA DE DIOS



Su legado
"siempre será mi fortaleza"



30

IGLESIA EL SALTO



Su legado
"siempre será mi fortaleza"



31

ESCUELAS DE FORMACIÓN



Su legado
"siempre será mi fortaleza"



32

ESCUELA DE FORMACIÓN MUNICIPAL DE DANZAS "TRIBUTO PANCHE"

ESCUELA DE FORMACIÓN MUNICIPAL EN BANDA SINFÓNICA JUVENIL LUIS VARIARA GRUPO TRADICIONAL

Max de 200 beneficiarios entre jóvenes y adultos

Más de 265 niños y jóvenes beneficiarios

ESCUELA DE FORMACIÓN MUNICIPAL EN CORO, GUITARRA Y TUNA

ESCUELA DE FORMACIÓN MUNICIPAL EN TEATRO Y AUDIOVISUALES

Más 144 beneficiarios directos

En total 289 beneficiarios directos

33

ESCUELA COMUNITARIA DE DANZAS "FURIA FOLCLÓRICA"

BANDA MARCIAL

En total 29 beneficiarios directos

50 Beneficiarios entre niños y niñas

ESCUELA DE INICIACIÓN MUSICAL CON INSTRUMENTAL ORFE

ESCUELA COMUNITARIA DE PINTURA ARTÍSTICA GILBERTO ZAMORA

50 Beneficiarios entre niños y niñas

En total 80 beneficiarios directos

34

ASOCIACIONES DE ARTESANOS

1928

Su lema es: "Siempre será el Portaleón"

35

ASOCIACIÓN ARTESANAS DE AGUA DE DIOS

ARTESANIAS HECHAS EN AGUA DE DIOS

ARTESANIAS HECHAS EN AGUA DE DIOS

Artesanías en Figue

36

ARTESANIA DE TALLADO Y CALADO DE TOTUMO

37

PATRIMONIO HISTÓRICO

1928

38

Puente de los Sargines Antio

Puente de los Sargines Abasco

Puente de los Sargines

Puente Antonio Turiel

39

Casa de Don Juan Antonio Alvar

Edificio Carroquella

Edificio Carroquella

Albergue Boyacá

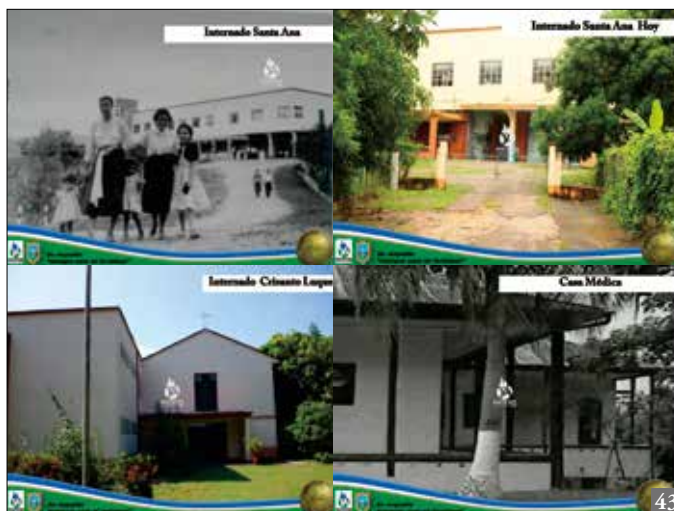
40



41



42



43



44



45



46



47

PELÍCULA HISTORICA

Realizar una PELÍCULA de amor, drama y sobrevivencia, en la cual se narre la historia de la Lepra en el mundo y desarrollada en Colombia, Agua de Dios.

Objetivos:

- Fortalecer la identidad Histórica del Municipio
- Soporte Educativo Histórico a través de este medio
- Desestigmatización. Desmitificación
- Motivación Turística
- Inversión empresa privada

PLUS DE LA PROPUESTA: No existe obra en esta forma



48

PROPUESTA 2



49

VIRTUALIZACION DE LA HISTORIA

Virtualización de la historia, Modelar cada uno de los lugares y procedimientos a través del software. Llevar a la Realidad Virtual Lugares y procedimientos que tenían relación con la Lepra.

Objetivo:

- Pedagógico
- Interactividad

PLUS DE LA PROPUESTA: No existe aplicación conocida en esta forma, implementación de las Tecnologías de la Información y la Comunicación.



Su respuesta
"siempre será mi fortaleza"

50

PROPUESTA 3



51

MONUMENTO DE LA CONCHA ACÚSTICA

Al igual que el municipio de Contratación en Santander; se desea tener un Monumento de la moneda La Coscoja en la concha acústica que lleva por nombre según acuerdo municipal No. 011 De 31 de Agosto de fecha 2016 Concha Acústica la "COSCOJA".

Objetivo: Que la historia y la memoria se encuentre reflejada en un lugar donde se comparte las muestras culturales.

Servir de Atractivo histórico para los ciudadanos.



Su respuesta
"siempre será mi fortaleza"

52

PROPUESTA 4



53

INTERCAMBIO DE ESTUDIANTES

Intercambiar ciudadanos Japoneses con ciudadanos Colombianos, especialmente de Agua de Dios, los cuales tendrán la oportunidad de aprender mutuamente de las dos culturas.

Objetivos: Desarrollar políticas de cooperación en el aprendizaje a todo nivel.

Buscar puntos de acercamiento para el desarrollo de la felicidad de ambas naciones.



Su respuesta
"siempre será mi fortaleza"

54

PROPUESTA 5



55

CONSTRUCCION BIBLIOTECA MUNICIPAL

CONSTRUCCION DE TRES NIVELES EN 595 m2

Primer piso:

Sala de lectura y salón de cómputo

Segundo piso:

Aulas de capacitación en programas de aprendizaje a todo nivel de población, es decir para beneficiar a 11.000 personas



Su respuesta
"siempre será mi fortaleza"

56

CONSTRUCCION BIBLIOTECA MUNICIPAL

CONSTRUCCION DE TRES NIVELES EN 595 m²

Tercer piso:

Salas de conferencias de uso múltiple para proyecciones de programas académicos

Área total a construir:

1.700 m²

Valor total proyecto:

\$ 3,400.000.000.00



Su respaldo
"siempre será mi fortaleza"



57



58

PROPUESTA 6



Su respaldo
"siempre será mi fortaleza"



59

CONSTRUCCION CENTRO DE VIDA SENSORIAL

CONSTRUCCION DE DOS NIVELES EN 462 m²

Área total a construir:

900 m². Más Obras de Urbanismo, andenes y paisajismo

Valor total proyecto:

\$ 1,876.500.000.00



Su respaldo
"siempre será mi fortaleza"



60



61

PROPUESTA 7



Su respaldo
"siempre será mi fortaleza"



62

RESTAURACION DE LOS CHORROS

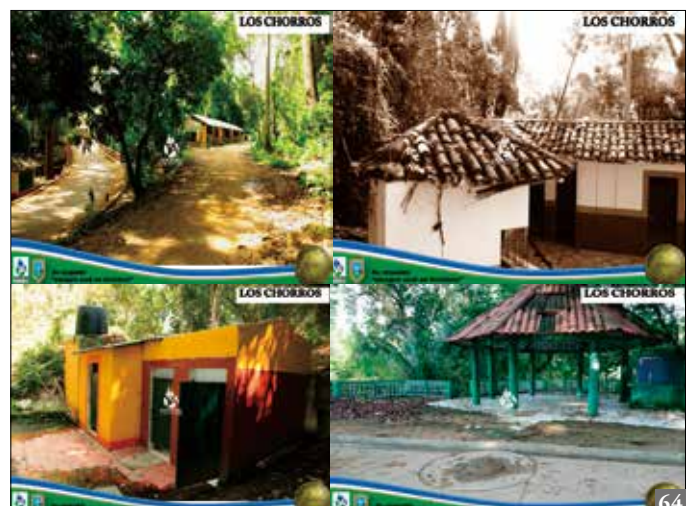
Restauración por completo de los baños. Debido a disposiciones de una corporación ecológica que regula las normas de contaminación ambiental dispone que los baños no deben estar cerca.



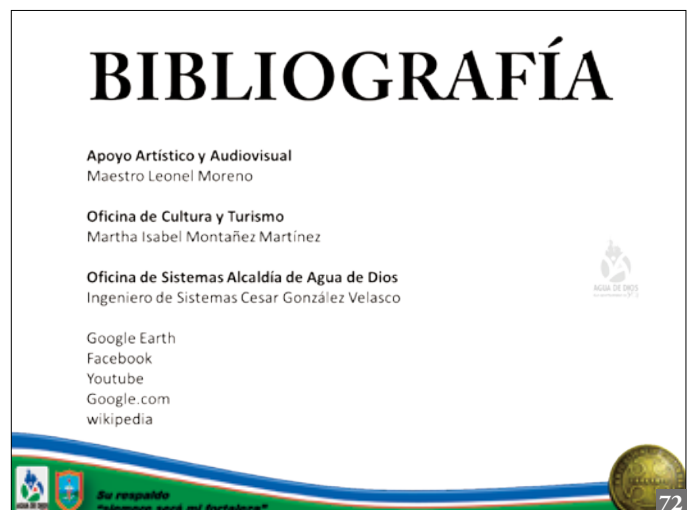
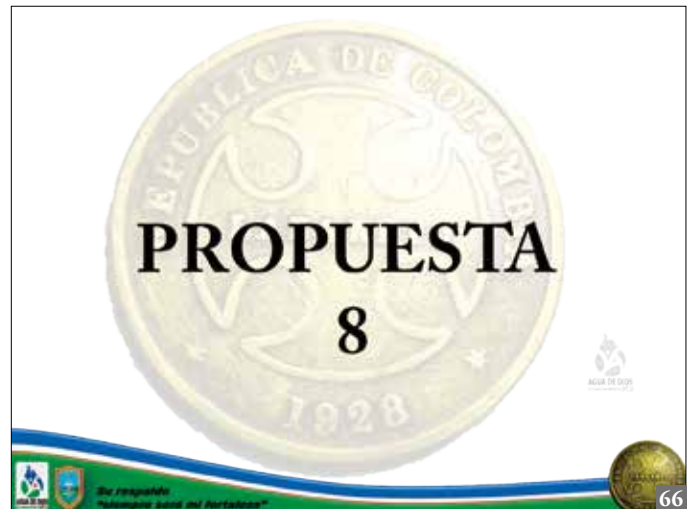
Su respaldo
"siempre será mi fortaleza"



63



64



Session C: "Various Initiatives to Preserve the HD History"

Conserving the History of Leprosy in Italy

Dr. Sunil Deepak

Consultant

Associazione Italiana Amici di Raoul Follereau (AIFO)

Leprosy in Italy

Leprosy had arrived in Italy about 1,500 years ago. It reached its peak in early medieval period. Over the next 700 to 800 hundred years, slowly it became less common. Now there are only some rare cases of leprosy among the Italians, and a few cases among the immigrants.

The information about the historical sites and documentation related to leprosy in Italy have been conserved in different ways and are relatively easy to access for researchers and academics.

At its peak, there were around 20,000 leprosariums or leprosy villages in Western Europe. We do not know exactly how many leprosariums were in Italy but almost all the Italian cities had at least one. These were usually known as "San Lazzaro hospital" or "Lazzaretto" and were managed under the Catholic Church.



Factors Affecting Conservation of History of Leprosy in Italy

There are two main factors influencing the conservation of history of leprosy in Italy:

Role of the Catholic Church: Catholic Church has played a dominant role in running of the leprosariums in Italy. It is a hierarchical body with a tradition of maintaining a written record of its activities and conserving those records. Thus, usually there are written records about each leprosarium including who lived there in which year, what were the main events of that year, etc.

Mixing up with other persons in need: Often the church played a role in care of other sick persons as well. For example, in 18th to 20th centuries, the church played an active role in care of persons with tuberculosis and mentally ill persons. Often the same persons, who took care of persons affected with leprosy, also took care of other needy persons. Thus, histories of these institutions are not limited only to leprosy but they are also linked with other marginalising conditions.

Discovering the History of Leprosy in Italy

It is easy to discover the stories about leprosy in different cities of Italy simply by:

- Checking if a city has an area called “San Lazzaro” or “Lazzaretto” (or, less commonly areas called “leprosetti” and “San Martino”)
- Asking the local Parishes of these areas/churches if they have records of any leprosariums in their books.

Sometimes the old leprosariums are also known to people as the places used for persons with tuberculosis or with mental illness. Usually these areas were located in old peripheries of the cities, though today they may not seem to be very far from the city-centres.

If you go to the parish churches of these areas and ask the parish priests about the history of the area, you can easily discover that they have documents about the period when they had a leprosarium. Many times, some of the old documents, including maps and illustrations, are kept in the local museums or their warehouses. Often some local persons have already carried out some research on the history of leprosy in their parish. A wealth of such information is available in Italy, though often it is in old books, sometimes hidden in the basements of museums and document centres, not easy to access and not available on internet.

Research was carried out to identify information about leprosy from 20 randomly selected cities in Italy including some big cities such as Rome, Venice, Florence, Naples, Bologna, and Genoa, and some small cities such as Assisi, Capua, Lucca, Reggio Emilia, Rapallo and San Sepolcro. In all the 20 cities, historical documents about old leprosariums were identified.

Challenges in Conserving the History of Leprosy in Italy

There are different challenges in keeping alive and conserving the history of leprosy in Italy. These challenges include the following:

- History of leprosy in Italy is mainly about the church and its role in taking care of the persons. The records have little information about the affected persons themselves and about their lives.
- The places associated with leprosy in the past, were also associated with many other conditions such as plague, tuberculosis and mental illness. This means that for them leprosy is only one small part of their story. They do not see their history as being limited to leprosy and thus are not willing to specifically “conserve” the history of leprosy
- The local administrators of the cities are not always keen to publicise leprosy-related sites, because they see it as a negative publicity for their areas.

Ideas for Conserving the Histories of Leprosy in Italy

This is the digital age and technology allows us to create online museums with pictures, videos and documents about the history of leprosy in Italy. Thus, even when local histories are difficult to maintain and human right approach is not always accepted, it is possible to create an online museum site which can bring together information about sites from different cities, encouraging students and other interested persons to discover similar sites in their own areas and to critically explore their histories.

At the same time, by looking at the composite and complex histories of places which hosted leprosy affected persons in the past, conserving the local histories can become an opportunity for networking with other marginalised groups of persons and their organisations to promote discussions on crosscutting themes such as human dignity, stigma, prejudice and discrimination.



Conserving the History of Leprosy

Leprosy in Italy

DR. SUNIL DEEPAK

1

Evolution of Leprosy in Italy

- First document about leprosy from 5th Century CE (Edict of Rothari)
- **Highest number of persons affected with leprosy in 12th-13th centuries – hundreds of leprosariums were created, usually run under the Catholic church**
- From 14th century till 20th century, a gradual decline
- **Today leprosy is seen as an “immigrant issue”**

2

Conserving History of Leprosy in Italy

- **The challenges of conserving the history of leprosy in Italy can be understood from the example of a leprosy related sites in Venice**

3

Leprosy in Venice

- First San Lazzaro dei Mendicanti church and leprosarium on the main island (till 11th century)
- **Then the small island today known as Island of Armenians (12th century)**



4

Island of Armenian Monastery - Venice



- Benedictine monks of St. Hillary in 9th century
- **St Lazzarus leprosarium in 12th century**
- Hospital for the sick & poor in 16th century
- **Dominican friars from Crete island in 17th century**
- Armenian monks since 18th century

5

Some Issues & Challenges

- Easy to identify old sites related to leprosy – linked with St. Lazzarus (San Lazzaro) – in a large number of cities
- **Parish churches and local museums have all records and information, though not always accessible digitally.**
- Information about places, buildings and management but not so much about persons affected with leprosy living there.
- **The approach is more linked to charity, compassion and helping the persons in need. Understanding as a human rights and human dignity issue is lacking.**

6

Some Existing Italian Sites Open to Tourists

7

With St. Francis - Assisi, Rivotorto ..



- **In 2012, the Franciscan friars organised a pilgrimage tour to different sites linked with the period of St. Francis' life when he lived with leprosy affected persons**

8

Island of Armenians in Venice

- **There are guided tours to the San Lazzaro degli Armeni island in Venice – once a day at 3.25 PM and during the visit, the monks explain that the island was once a leprosarium**



9

The Medieval House from Rapallo



- **The medieval house that hosted a leprosarium is famous for its frescoes, is mentioned in the tourist guide books of Liguria region and people come to visit it.**

10

The Leprosarium of Valloncello

- The mountain commune of Valloncello in Umbria region publicises the medieval buildings of the leprosarium as the places to visit for the tourists



11

Leprosy related sites in Some big Italian Cities

12

Rome



- San Lazzaro Church – Hostel for pilgrims affected with leprosy coming to visit St. Peter's church in Rome and Vatican. The building used for the hostel collapsed in 1937. In its place today a parking place.

13

Bologna

- Chapel of the Condemned
- San Michele de Leprosetti
- San Lazzaro church, leprosarium and cemetery
- Leprosarium of Bertalia



14

Florence



- The hospital and the well at Prato di Ognisanti (All Saint's Park) – research done by Dr Silvio Berti in 1928 about its use as leprosarium in 13-16 centuries

15

Future Efforts

- A lot of material about the history of leprosy in Italy is present but is scattered between Parishes and local museums. It is not easy to access. The material is mainly about buildings, church-related persons and management issues, while voices of people are missing.
- **Creating an online archive-museum by bringing together the scattered information can be useful.**
- It will be useful to work together with centres and organisations that manage leprosy related tourist sites for adopting a human-rights based approach

16

Thank You



17

Session C: "Various Initiatives to Preserve the HD History"

The Pride of a Nation ~Produced by Ka 'Ohana O Kalaupapa~

Ms. Anwei Skinsnes Law

International Coordinator
IDEA

*"Some people who are trying to learn about their family history
will come to find out that 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 'aina, part of the soul of this land."*

— Bernard K. Punikai'a, composer, musician,
International human rights advocate

Between 1866 and 1969, an estimated 8,000 individuals, at least 90% of whom were Native Hawaiians, were taken from their families and communities because they were thought to have leprosy.



Kalawao Choir, 1901.
Collection of IDEA



Makanalua Peninsula, commonly
known as Kalaupapa, Hawaii.
Collection of IDEA

The oldest was 105 . . . The youngest was 4.

The lack of immunity in the Native Hawaiian population resulted in virtually every family being affected by this disease.

Kalaupapa's history is filled with lives lost to family histories . . .

Lives lost to the history of Hawai'i.



Two young girls, Kalaupapa. Collection of IDEA

Traditional accounts have focused largely on the tremendous efforts of Father Damien, Mother Marianne and others who dedicated their lives to improving life at Kalaupapa.

In recent times, with the assistance of family members and the translation of letters, petitions, and newspaper articles from Hawaiian . . .

The lives of hundreds of people sent to Kalaupapa have been re-discovered . . .

Shining a new light on this history.

In the words of Mercy Hutchison Bacon (relative of Ambrose Hutchison), the people sent to Kalaupapa have become "the pride of a nation."

Photos of Kalaupapa Residents:

Kapoli Kamakau: Composer, Musician, Music Teacher, Treasured Friend of Queen Lili'uokalani and Mother Marianne.

Jonathan Napela: Superintendent, Kokua, Magistrate, Translated the *Book of Mormon* into Hawaiian.

Joseph Manu: Canoeing expert, Resident of Pelekunu Valley, Close Friend of Father Damien

Ephraim Kanoë: Secretary of Siloama Church, Husband, Father, Eloquent Writer

Ambrose Kanewalii Hutchison: Lived at Kalaupapa for 53 years (1879-1932) Resident Superintendent for 10 years, Husband, Brother, Close Friend of Father Damien.

Thomas Nakanaela: Clerk – Supreme Court, Part-Owner of Holomua Publishing Company, Author, Composer, Signed Petition Against Annexation.

John T. Unea: School Principal, Store Manager, Took First U.S. Census at Kalaupapa.

Haumea Kaaumoana: Musician, Age 18, Ocean Swimmer.

Adelaide Bolster: Accomplished Pianist, Tennis Player, Teacher, Bishop Home Resident.

Alana & David Kamahana: Owners of the Kamahana Store.

Kahealani Emakia: Musician (autoharp), Godmother, Inspiration, Bishop Home Resident.

Kiki Opio: Musician, Made Ukulele from a Bull Durham Cigar Box.

Lillian Awai Kahoohalahala: Donated to the European Relief Effort After World War I, Buried in Siloama Churchyard.

David Ono Kupele: Father, Grandfather, Expert Horseman, Delivered Mail & Movies to Upper Molokai.

Annie Aiona Kupele: Wife, Mother, Expert Baker, Founding Member of the Ladies' Social Club.

Alice Kamaka: Person to live at Kalaupapa the longs – 81 years (1919-2000).

Sammy Kuahine: Composer of "Sunset of Kalaupapa," Musician, Ham Radio Operator.

Kenso Seki: Scoutmaster, Baldwin Home Resident, World Traveler, Artisan.

Paul Harada: Husband, Brother, Master Gardener.

Olivia Robello Breitha: Author, Human Rights Advocate, Daughter, Wife, Sister, Aunt.

William K. Malo: Photographer, Docent for "Quest for Dignity" Exhibit, Member of the Lions Club, Son, Brother, Husband.

Richard Marks: Owner of Damien Tours, Son, Brother, Husband, Father, Grandfather, Visionary.



Kenso Seki. Photo by Wayne Levin

Bernard K. Punikai'a: International Human Rights Advocate, Composer, Musician, Son, Democrat.

Ernest Kala: Composer of "En Na Kini" (song being sung in PowerPoint), Director of Music, Kana'ana Hou Church.

Text & Photos -- Anwei S. Law

Production Coordinator: Valerie Monson

Music by Kalapana Collars (Nose flute)

Dennis Kamakahi & Stephen Inglis



History walk of the National Sanatoriums "Oku Komyo-en" & "Nagashima Aisei-en"

Open Sessions

I. Our Legacy

II. Our Legacy for Our Future

III. Preservation and Beyond

IV. UNESCO World Heritage



Session I: "Our Legacy"

Voice from Japan, Philippines, and Malaysia

Mr. Shinji Nakao

President of Residents' Association
National Sanatorium Nagashima Aisei-en



I am Shinji Nakao, president of the Residents' Association at National Sanatorium Nagashima Aisei-en. I have been a resident of Aisei-en for 69 years, ever since I was diagnosed with leprosy in 1958 at the age of 13. As a result, I have spent most of my life on Nagashima Island, which is separated from mainland Japan by the Seto Inland Sea. As Mr. Lee from Malaysia and Mr. Flores from the Philippines just mentioned, once we were taken to the leprosy sanatoriums, it was almost impossible for us to leave. Before I started living at Aisei-en, special money only for use within sanatoriums still existed. It was even worse than entering a prison, and there was in fact a special prison at the sanatorium. Because there were so many leprosy patients in prewar Japan, sufferers were turned over to the secret police by medical authorities; patients and other disabled people were considered "polluted". It is not too much to say that this practice had been commonplace until the segregation law was repealed almost 20 years ago.

1) How are the voices and wishes of people affected by the disease reflected in the initiatives to preserve leprosy history?

I have been working nationwide for the permanent preservation of 13 sanatoriums in Japan. Moreover, I have been involved in an ongoing project for UNESCO World Heritage nomination, which is being implemented by the national sanatoriums Nagashima Aisei-en, Oku Komyo-en, and Oshima Seisho-en on the Setouchi islands. Just like the cases in Malaysia and the Philippines, there are preservation movements for leprosy history worldwide, including Japan. I believe that we need to preserve this history for present and future generations.

2) What do you want the present and future generations to learn from your legacy?

We were not treated as human beings in Japan. We went through years of mistreatment that saw "polluted" victims rounded up and condemned to a life of isolation and neglect. It seems that the same practice was carried out in the Philippines and Malaysia as well. However, in other countries, the people in the sanatoriums were freed earlier than in Japan. I suppose this is because of the "leprosy-free movement" that was unique to Japan. Not only medical doctors but also ordinary people joined this movement. Japan rounded up thousands of patients and forced them to live in sanatoriums located in mountains or on remote islands. When the sanatoriums no longer had any room to take more new arrivals, some patients simply had to go on a wandering journey without a destination. For this reason, we strongly wish that the true stories are handed down to future generations.

3) What are the messages for younger generations?

For sure, we were not treated as human beings and were mistreated by the Japanese state. We talk to people about our past through storytelling activities. These days, young people come to Aisei-en. We hope they will learn about what we experienced; we tell them not to repeat such inhumanity when they face any human diseases. What makes leprosy very different from other diseases is that decades of stigma and discrimination caused family connections to be destroyed. Therefore, I sincerely hope that the truth about our history will be passed down to high school students and young people.

Mr. Bernardo Rodriguez Flores

Chairman
Better Living Consumer Cooperative



1) What has been done to preserve the leprosy history where you are?

The Western Visayas Sanitarium started as a leprosarium. However, when the prevalence rate of leprosy cases reached less than 1 person in 100,000, there was a Department of Health (DOH) Administrative Order 2005-0013 for the sanitarium to expand into general care services.

In 2010, the general care services of Western Visayas Sanitarium became full blast. And so, to preserve the history, we gathered memorabilia, relics, and artifacts from the treated leprosy patients in the community and hospital personnel who had been with Western Visayas Sanitarium when it was only functioning as a leprosarium. Also a committee was set up for the preservation of leprosy history. The leprosy museum was set up and then it was improved by the help and sponsorship of the Sasakawa Memorial Health Foundation in Tokyo, Japan. We thank you and much appreciate your benevolence. We have an existing document on the history of the Western Visayas Sanitarium—how it was started as a leprosarium—and at the same time we have also a written history of our museum. We have also compiled several written true stories of our leprosy patients that are soon to be published.

2) How are the voices and wishes of people affected by disease reflected in the initiatives to preserve leprosy history?

When we were looking at the old pictures of the long-gone patients, we saw reflected in the expressions on their faces and in their activities that they wanted to be accepted as ordinary people with feelings and desires. They loved to smile. They wanted to be seen as ordinary people, for they joined the Boy Scouts and Girl Scouts of the Philippines. We saw them wearing their old costumes: they sang, they danced, they joined a basketball league. They expressed their faith in God that they wanted to be healed.

In the beginning, we used to receive work at the sanitarium for almost no wages; gradually, we got part-time jobs and were even hired as permanent employees. In the past there was discrimination in the community, but over many years of living here, we have come to be accepted not as leprosy patients or persons affected by leprosy, but as ordinary people.

3) What is the involvement of people affected in preserving leprosy history where you are / in your country?

We, the leprosy patients, were utilized as resource persons and interviewed about what happened in the past. We provided and donated old pictures, memorabilia, and materials to be displayed in the museum. We advertise to students and promote tours to our museum. We continued to be involved in leprosy advocacy, so that we never forget our rich historical past.

We are encouraged to be a member of CLAP (Coalition of Leprosy Advocates of the Philippines) as one way that will make the community more knowledgeable and aware that leprosy is not only a disease, but a curable one, and should not be stigmatized. CLAP is a nationwide organization that gives awareness to the people of the Philippines to eliminate stigma and discrimination. We attended conventions, trainings and seminars about leprosy and how to relate ourselves to the community and to live normally. We are also trained in livelihood programs for our own living, and empowered by creating and managing a cooperative of our own with leprosy patients as members. We are also given a chance to speak in public and give our testimonies. This is one way that will elevate our self-esteem and self-confidence to face the public and to make people understand what leprosy is.

Every year, we celebrate Leprosy Week and World Leprosy Day to show the community and the whole country that leprosy should not be stigmatized. Our institution has a periodic orientation for all employees, especially the new ones, with regards to leprosy. We promote advocacy for leprosy by having several activities such as "Kutis Kilatis" or flawless skin, Miss Hansen's Valentine, Talents Showcase, Food Festival, Livelihood Products Showcase and Selling, Organic Gardening, Making Organic Fertilizer, Christmas Tree/Lantern Showcase, Lace and Embroidery Exhibit in one of the prestigious hotels in Iloilo City, etc. All of these activities are participated in by the leprosy patients, spearheaded by some of the hospital personnel. I am sure that the rest of the Sanitaria in the Philippines are likewise doing similar activities to us, being visible in the community and doing such activities like these with proper documentation and pictures so as to preserve our legacy for future generations.

4) Do you feel that your voices are reflected and represented enough in preserving this history?

A big yes, and we are so happy, proud and blessed that people like us are given attention, love and care. Especially, our history is preserved as our legacy.

5) What do you want the present and future generations to learn from your legacy?

We would like as much as possible for our legacy and good learning experiences to be discovered and for our children and children's children to follow in our footsteps, and that they should not forget their forefathers' life experiences in accepting their life condition wholeheartedly. New generations should be proud and thankful that despite their forefathers' physical condition they tried their best to live a normal life.

6) What history do you NOT want to see repeated?

We don't want to continue what we experienced in the past. However, if we did not get sick from

leprosy and we did not experience the pain, shame, insult, struggles, stigmatization, and separation from loved ones, perhaps we would not be stronger and we wouldn't understand the feelings and sufferings of people affected by leprosy. Sometimes we asked ourselves: What if we did not get sick from leprosy? However, I still believe that whether or not we had leprosy, our future will still be determined by the choices that we make. I then realized that I still have the privilege to be happy and enjoy my life, for it is only a matter of choice. And maybe if I did not have leprosy, perhaps I would not be here in Japan facing you today.

7) What messages do you have for younger generations (including 2nd and 3rd generations, and youth in general community)?

My message to the younger generations is that I would like to promote continuous education and advocacy on leprosy to all people in the community and even to the whole country, so that having leprosy should be accepted, should be understood and empathized with. What we felt and experienced is not easy—the feeling of being an outcast in society and even within our family. I would like to say that we should help with compassion those who are affected by Hansen's disease.

The most important thing is to be kind and compassionate to everyone, especially the less fortunate; to be aware of not to discriminate against people because of their ailments, disabilities and appearance. People who have leprosy are among the kindest and most compassionate people.

8) What do you enjoy in your free time?

First of all, I set a time with our Almighty God in going to church and doing God's service by singing in the church choir and helping other people in the community through some church programs. At home, I tend to my organic vegetable garden, ornamental plants and mini poultry raising. I also help with household chores, and most especially spend quality time with my wife and children.

Mr. Chor Seng Lee

Vice President
Sungai Buloh Settlement Council



1) What has been done to preserve the leprosy history where you are?

In 2013, Ean Nee established the Sungai Buloh Online Museum, and appointed me as the consultant of the Oral History Team. We conducted public talks to tell the public about the importance of preserving the history of our community. Two years later, the government also set up an artefacts museum and an information gallery to showcase some of the resident's artefacts and medical equipment of Sungai Buloh Settlement.

2) How are the voices and wishes of people affected by the disease reflected in the initiatives to preserve the leprosy history?

Through the online museum and physical museums, our old photos and artefacts tell the history of Sungai Buloh Settlement.

3) What is the involvement of people affected in preserving leprosy history where you are / in your country?

In 2007, the government demolished the East Section of our settlement, knocked down our monuments, and forced us to shift. We protested against the government, but unfortunately our fight failed, the heritage buildings were torn down and we were very disappointed. I then went to Taiwan to attend an international symposium on behalf of the Patients' Council. At that time, Taiwan was also facing the same fate—part of their sanatorium had been demolished too—and we appealed to the international community to pay attention to the preservation issue.

Recently, our government again planned to demolish some abandoned chalets at our Central Section. The Patients' Council requested the government to stop their project and we talked to our hospital director about our wish that we want this place to be gazetted as a national heritage.

4) Do you feel that your voices are reflected and represented enough in preserving the history?

The government heard our voices this time, so they cancelled their demolition plan. This decision made us very happy. However, two years ago, when the government established the artefacts museum and information gallery, Zaitun, a nurse, asked me to go to the empty chalets to find artefacts for them; and Dr Radhiah, the doctor in charge of the galleries, asked me to give her some old photos, and help her to find the old hand-operated sewing machine and the mould used by the patients to make Nyonya kuih [a popular snack] so that they can display them in their museum. However, they did not let us join their committee or interview us about our life history when they set up the museum, so our personal stories were not included in their museum.

5) What do you want the present and future generations to learn from your legacy?

In the past, when we were admitted, the government treated us like white mice: they cut our flesh and extracted our blood for research. We suffered a lot; that is why there is now a cure for leprosy. I hope people will remember our contribution to leprosy research.

Secondly, in order not to affect the life of mainstream society, the government arrested us and isolated us in the settlement. We had no freedom; we were not allowed to take public transport—we could only hitch rides by lorry—we were not allowed to stay in hotels either because it was feared that we would spread the disease. We were not allowed to return to our own families and even our children were not allowed to be raised in the settlement. I hope that the future generations learn from this history and know that the isolation policy was very harmful to us. It caused us to be marginalised and discriminated against by the general public.

Thirdly, we did not give up our life after admission; we strived to live, and cultivated land and planted flowers and earned our living by selling flowers. As a result, we produced a lot lime trees, roses and all kinds of flowers and trees. I hope people will remember our contribution to our country's economy.

I hope the government will care more about us and will not demolish our heritage anymore. We hope Sungai Buloh Settlement can be gazetted as a national heritage site as soon as possible so that future generations can learn about our history. We are human beings who have thoughts and feelings; we have the right to fight for our own interests. I hope that the government will not threaten us by saying that they will discharge us when we fight for our rights. We will not be able to accept such intimidation. We are a democratic country and we should be given the opportunity to express our views.

I hope that the Heritage Department can meet with us and listen to our voices, so that we can work together to make Sungai Buloh settlement listed as a world heritage site. With that, more people will come, understand the history of leprosy, know about our lives in the settlement and our history. When more visitors come to buy flowers from us, our living place will be livelier. So I hope that if the government has any plan that will affect our home, they will discuss it with us first.

6) What history do you NOT want to see repeated?

The forced segregation policy and the Lepers Act that led people to discriminate against leprosy patients'.

7) What messages do you have for younger generations (including 2nd and 3rd generations, and youth in general)?

If they find any red or white patches on their bodies and do not feel any sensation, please go to the doctor; but do not worry. Leprosy is not a hereditary disease and it is curable now. I hope young people have correct information about leprosy and will not be afraid of it. We now have MDT, and they will be cured easily.

I hope they do not look down on leprosy patients and people that suffered from any disease, because discrimination will bring harm to others.

8) What do you enjoy in your free time?

I usually spend my leisure time at the coffee shop, drinking coffee, smoking and reading the newspaper.

*Session II: "Our Legacy for Our Future"***Hansen's Disease Heritage in Bergen, Norway****Ms. Grete Kristina Eilertsen**Museum educator
Leprosy Museum - Bergen City Museum

Leprosy has been a well-known disease in Norway for more than 1,000 years. In 1856, approximately 3 per thousand of Norway's total population were diagnosed with leprosy, and in some areas as much as 3 out of every 100 persons were affected. In the second half of the 19th century, the number of new cases decreased quite rapidly, but from about 1840 to about 1900 this illness was seen as one of the major threats to public health in Norway. From 1885 a special legislation could be used to send people to hospital if it was not possible to isolate them in their own homes. However, segregation policy seems to have been less strict in Norway than in many other countries, and it is a fact that quite a few persons would continue to live at home with their families. We also know that many people who were hospitalized could still have contact with their relatives, while for others the social stigma may have broken the family relations.



Altogether there have been five leprosy hospitals in Norway, three of them in the city of Bergen. The oldest one was established in the 15th century, and the two others were erected in the mid 19th century. All of them were placed inside the city, even though in the outskirts. From 1920 there were only two hospitals left in Norway, both of them in Bergen; the old St. George's Hospital, run by a foundation, and the state-run Nursing Foundation. The Nursing Foundation opened in 1857. From 1957 it was partly used as a general rehabilitation institution, but still retained a ward for Hansen's disease patients until the last resident passed away in 1973. Today this large wooden building complex is used as offices for employees at the University of Bergen. The buildings and the surrounding park have recently been protected by national heritage legislation and demolition or major changes to the buildings will not be allowed.

The old St. George's Hospital received its status as a protected heritage site as early as in 1927, only a few years after the first national protection law was approved, and while the institution still had a few residents. The Norwegian Directorate for Cultural Heritage has stated that the buildings' cultural value is related to their continuous use as a hospital for people affected with leprosy for more than 500 years. The hospital closed in 1946, when the two last residents in St. George's passed away, after having lived here for more than 50 years. In 1970 the Leprosy Museum opened in the old hospital's main ward.

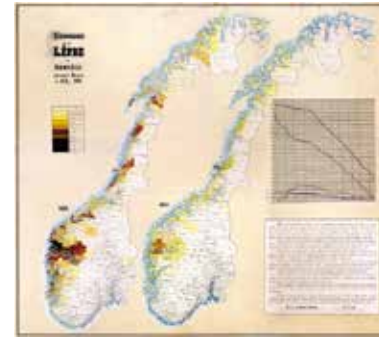
For many years the museum was run mainly by the guidance of medical professionals, and the focus was mainly on Dr. Danielssen's and Dr. Hansen's scientific work, as well as on the emergence of a public healthcare system in Norway. Later, the museum's orientation has changed. We want our visitors to learn about all the individuals whose lives were changed by this illness, and what daily life was like in the

Hansen's Disease Heritage in Bergen, Norway



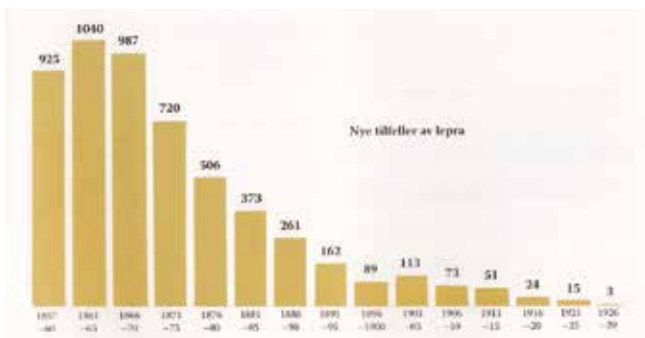
Grete Eilertsen - Bergen City Museum

1



The prevalence of leprosy in Norway in 1856 and 1890.
In the areas coloured dark brown/black, approximately 3% of the inhabitants were diagnosed with leprosy.

2



Number of persons to be diagnosed with leprosy in Norway 1857-1929

3



Map of Bergen from 1907, the blue names showing approximately where the three hospitals were situated. (Map from The Norwegian Mapping Authority)

4

**The Nursing Foundation.**

Established in 1857. The last resident died in 1973.
Protected by Norwegian heritage legislation from 2013.

5

**St. George's Hospital**

Established in the 15th century, rebuilt after a fire in 1702. In use as a leprosy hospital until the last residents passed away in 1946.

Protected by national heritage legislation from 1927. The Norwegian Directorate for Cultural Heritage has stated that the buildings' cultural value is related to their continuous use as a hospital for people affected with leprosy for more than 500 years.

6



The main ward in St. George's Hospital, which today holds the permanent exhibit of the Leprosy Museum.

7



Johan Jacobsen, 55 years old, from Hammer, resident in St. George's Hospital in 1816.

8

hospitals. Our permanent exhibit includes portraits of some of the residents, including their names and when possible their stories. We also include all the names of the 8,231 individuals in Norway known to be diagnosed with leprosy from the establishment of the national leprosy registry in 1856 and up until the last cases were detected in the 1950s.

Sadly it is a fact that we do not have many extensive testimonies from people who lived in the leprosy hospitals in Norway or at home with their families. For instance, there is only one recorded interview that I know of, where Harald Fjeldsbø, a resident in one of the hospitals in Bergen from 1912 to 1957, tells what it was like to find out that he had leprosy and move to a hospital at the age of 18. Our main sources of information to the individual stories today are family members and descendants of residents, and written documentation from the archives.

Most of the medical and administrative records from the three hospitals in Bergen in the 1800's and 1900's have been preserved, and together with the national Leprosy Registry these records are the core of the so-called Leprosy Archives in Bergen. This archive consists of more than 60 shelf meters of documents, protocols, letters and photographs.

Since 2001 The Leprosy Archives of Bergen have been included on the UNESCO Memory of the World list. The missions of the Memory of the World programme are to facilitate preservation, to increase awareness of—and to assist universal access to—documentary heritage. At the same time legislative and other limitations on the accessibility of archives are recognized. In Norway, it will usually be possible to get access to records older than 80 years, if they are not considered to contain very sensitive information. Medical records less than 80 years old are accessible mainly for family members or for scientific use, and require written application to the archives.

Every year, both our museum and the two archives in Bergen receive inquiries from people who are looking for information about family members who had leprosy. Some of them know for a fact that grandparents, great-grandparents or other relatives were ill, while others are trying to confirm whether this is the case or not.

Genealogy has been very popular for some years now, and quite often people are surprised to find that ancestors have had leprosy in the past. Sometimes, this may have been kept as a family secret, while other times people simply don't know much about their relatives after a few generations. One of many examples of genealogy web pages giving information about family members with leprosy is the one showing portraits and a description about Hartvik Maarnes, who was diagnosed with leprosy in 1880 and lived at home with his family until he passed away in 1918.

My impression is that most Norwegians today do not experience any stigma or shame in being open about the fact that someone in their family has been affected with leprosy in the past. Many write about their findings on their blogs and bring other family members to visit the museum. For instance, we had a visit from a teacher who brought his students to teach them about the history of leprosy in Norway, telling the story of his great-grandfather named Rånund Steinsvåg, who was admitted to hospital in 1908.

The Leprosy Registry will often give information about the duration of the disease, the conditions in the home, and if any other family members also were diagnosed. Then the patient records from the various hospitals can provide information like possible treatments, the duration of the stay, if the



Some of the 18th century protocols in Bergen City Archive.

9



- The missions of the Memory of the World programme are to facilitate preservation, to increase awareness worldwide of the existence and significance of documentary heritage, and to assist universal access to documentary heritage.

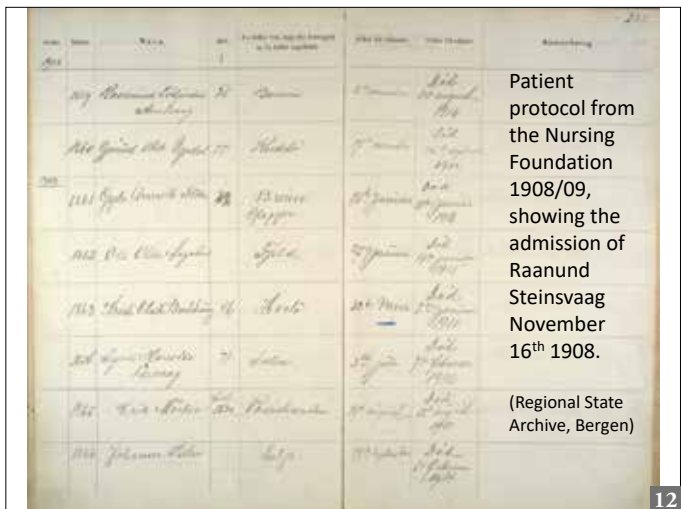
- The vision is that the documentary heritage should be permanently accessible to all without hindrance, but also legislative and other limitations on the accessibility of archives are recognized.
- In Norway, it will generally be given access to records older than 80 years.

10



From a genealogy web page giving information about Hartvik Maarnes, who was diagnosed with leprosy in 1880 and lived at home with his family until he passed away in 1918.

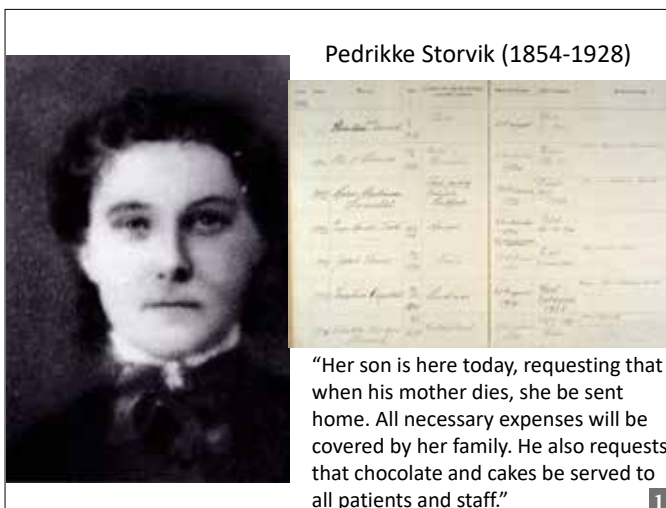
11



Patient protocol from the Nursing Foundation 1908/09, showing the admission of Raanund Steinsvaag November 16th 1908.

(Regional State Archive, Bergen)

12



Pedrikke Storvik (1854-1928)

"Her son is here today, requesting that when his mother dies, she be sent home. All necessary expenses will be covered by her family. He also requests that chocolate and cakes be served to all patients and staff."

13



One of the rooms in St. George's Hospital in the 1930's.

(Photo: Olav Espesvoll, Bergen Museum)

14

patient was allowed permission to leave for a few weeks to visit their family, if they ran away and didn't return, if they made money by producing handicraft products for sale and so on. Sometimes it is also possible to find letters where persons are asking permission to be admitted to a certain hospital, often describing how their illness has progressed and giving explanations on why they want to be admitted to this institution.

As an example of the archives' ability to provide valuable information and bring confirmation to family members today I want to tell you about Paul Johnsen, who contacted our museum a few years ago. At the age of 78 he was looking for information about his grandmother's life. His grandmother Pedrikke Storvik died in 1928, two years before Paul was born, and his older sister was the only relative who could remember her.

When Paul contacted us he knew that his grandmother had leprosy, but had no written documentation about her illness and in which hospital she had lived. From the archives we could tell that Pedrikke was diagnosed with leprosy in 1919, at the age of 65, and that she moved to the Nursing Foundation in Bergen two years later. The archive also gives information about her symptoms, how the disease progressed and what kind of treatment she requested and received. Pedrikke died after 6 years and 8 months in hospital, and was brought home by her family to be buried next to her husband – a journey of more than 970 kilometers, which at that time took about 6 days by boat.

Paul had been told that in spite of the distance between Pedrikkes family home and the hospital her husband and her youngest son had been visiting her at least twice. We were able to confirm at least one of their visits from a note in one of the patient protocols: "Her son is here today, requesting that when his mother dies, she be sent home. All necessary expenses will be covered by her family. He also requests that chocolate and cakes be served to all patients and staff." Paul later wrote an article about his grandmother and her life in a local history book.

The history of leprosy is an important part of Norwegian history, and in our museum we want to tell both the medical history and the social history, and not least the many individual stories. In this work it has been important to protect the hospital buildings as heritage sites, as well as preserving archives and making them accessible.

To visit the old St. George's Hospital where so many people spent parts of their lives makes a powerful impression on many visitors, even if it has been a fairly long time since anyone lived here. In our museum's guestbook some of the more frequent comments from visitors are that they found the museum interesting and moving and that it is important to preserve this site and this history for future generations.

It is my hope that it will be possible to preserve Hansen's disease heritage sites, archives and testimonies in many parts of the world, and make the history and the experiences of the people who lived here known to the general public. Through bringing knowledge about how so many people have fought against stigma and discrimination, and bringing recognition of their strength and dignity, we can make sure that we never forget the mistakes made, and bring hope of a more inclusive society.

Session II: "Our Legacy for Our Future"**Spinalonga: A Monument to Human Pain****Mr. Nikolaos Panoutsopoulos**

Curator of Antiquities

Ephorate of Antiquities of Lasithi, Ministry of Culture and Sports

Spinalonga forms a rocky and waterless islet in the region of Lasithi (island of Crete, Greece). In the 16th century a Venetian bastion-type fortress was erected that was used as an army camp. In 1669 Crete became a part of the Ottoman Empire with the exception of three fortresses—among them Spinalonga—that remained Venetian possessions. In 1715 the Ottomans conquered the islet and installed a permanent garrison. A small marginalized militarized Muslim settlement was gradually developed that was also used as a place of exile. During the 19th century Spinalonga was transformed into a significant commercial and shipping center. In 1897 the Autonomous Cretan State was created initiating administrative changes that led the Muslim population to emigrate, mainly to the coastal areas of Asia Minor. In 1913 Crete was united with Greece.

**Hansen's disease worldwide and in Crete**

In Crete, as in some Aegean islands, the disease was widespread but until the Ottoman period it was not considered a serious social issue endangering public health. In 1717 an Ottoman decree ordered the removal of the patients outside cities' walls and their transfer to settlements located in the outskirts, called "meskinies". The Ottoman authorities provisioned to the inhabitants a ration of half an ounce of bread in order to isolate them from the urban centres.

In 1873 Dr Armauer Hansen discovered the bacillus of leprosy, which was considered a highly contagious disease. The isolation of patients was deemed necessary for the eradication of the disease and strict segregation policies were applied in Norway ordering their confinement into state-run institutions. As a result, leprosy rapidly retreated, not through medical treatment but rather the demise of the isolated patients. In 1897 during the international leprosy conference in Berlin the segregation policies were adopted as an appropriate measure.

In Crete in 1901 a law was passed concerning the isolation of patients and in 1903 Spinalonga was designated as a colony. In 1904 the first 251 persons arrived, forcing the remaining Muslim inhabitants to depart. Hansen's disease patients were sent to the island in actual exile under difficult conditions. For the most part they were from the illiterate lower social classes of rural Crete. During the first decades of the function of the colony they were forced to live in the existing derelict houses of the Ottoman settlement that could not satisfy even their most rudimentary needs. There was no

running water and food supplies were purchased by local producers. There was also a total lack of any treatment infrastructure or medical care. A doctor was appointed to the island for the first time in 1911, who resigned shortly afterwards. On the other hand, priests or monks, some of them with leprosy themselves, lived among the patients.

After the union of Crete with Greece in 1913 patients from all over the country were gradually transferred there. Prime Minister Eleftherios Venizelos, under his various administrations, attempted to eradicate the disease. In 1918 a report by a committee of prominent scientists deemed Spinalonga unsuitable for housing Hansen's disease patients. In 1919 the Hellenic Pasteur Institute was created in Athens, in which eventually various methods of treatment were applied. In 1920 a National Law for the restriction of leprosy was issued, following a previous decree in 1836. According to its stipulations a strict segregation policy was introduced. Marriage between patients or between patients and non-patients was banned as well as their contact in any way. In Spinalonga eventually marriage was allowed and as a result many inmates were married bearing healthy children, who were also obliged to live in confinement. In 1924 E. Grammatikakis was appointed as the first director-doctor of Spinalonga and in 1925 a decree was passed regulating the function of the institution under the Ministry of Health.

In 1927 Charles Nicolle, the director of the Pasteur Institute in Tunis visited the island. After his return to Paris he sent 10,000 doses of Hygranol to Spinalonga, the first drug to be applied on its patients. During the second international conference on leprosy the segregation policies were severely criticized as unproductive and inhumane by many scientists, among whom was probably the most prominent leprologist in the 20th century, Ernest Muir of Britain.

In 1929 large scale public construction works were initiated on Spinalonga, while in the same year the new anti-leprosy station of Ayia Varvara was founded in the Greek capital. By 1931 Spinalonga was one of six functioning anti-leprosy facilities in Greece but the only one in which patients lived in total isolation. There were still no nursing staff, pharmacy or visiting doctors and only wealthier patients could purchase drugs.

As a response the patients demanded better living conditions through mass demonstrations or riots like the one in 1923. The arrival though of young, educated patients with progressive ideas resulted to the creation of a syndicalist union for the community called "The Brotherhood of the Sick". Its most distinguished and fighting leader was Epameinondas Remoundakis of Siteia, a law student and intellectual, who was banished to Spinalonga at the young age of 21. His persistent struggle resulted in the actual improvement of the living conditions in the colony. In 1938 a separate children's branch was founded at the Ayia Varvara Hospital and the children of the colony were transferred there living under medical supervision, until they reached maturity.

During World War II and the Italian and German occupation living conditions in the colony deteriorated substantially. After the Liberation in 1944 no significant improvement in the medical treatment was actually achieved until 1948, when the new cure that was discovered in the U.S.A (promin – dapsona) was applied for the first time. The dispensing of the new drug had impressive results, leading to the gradual cure of the patients and their reintegration into the public healthcare system in other parts of Greece. Subsequently the colony was closed in 1957.

Spinalonga: A Monument of Pain



1

Spinalonga: A Monument of Pain



2

Spinalonga: A Monument of Pain



3

Spinalonga: A Monument of Pain



4

Spinalonga: A Monument of Pain



Venetian map, 1638, Francesco Basilicata

- Barren, arid, waterless island
- Protects one of the most natural harbors of Crete: gulf of Elounda
- Spinalonga < Stinalonde, 13th century (corruption of the Greek phrase "Stin Elounda", translation: "in Elounda").
- Spinalonga = "Long thorn", island in Venice (present day Giudecca)
- 16th century: Venetian seaside bastion – type fortress.

5

Spinalonga: A Monument of Pain

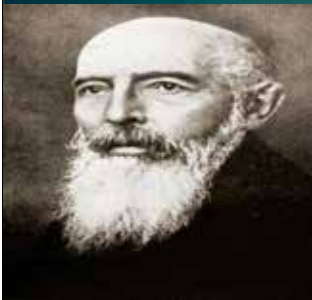


Ottoman map of Crete by Piri Reis

- 1669: Ottoman conquest of Crete (Spinalonga remains Venetian possession)
- 1669 – 1715: Small Christian settlement
- 1715: Ottomans conquer Spinalonga
- 1715 – 19th century: Small marginalized militarized Muslim settlement/place of exile
- 19th century: Commercial/shipping center
- 1897: Autonomous Cretan State
- Emigration of Muslim inhabitants to Asia Minor.
- 1913: Union with Greece

6

Spinalonga: A Monument of Pain



Dr. Armauer Hansen

- Leprosy: widespread disease in the island of Crete and the Aegean
- 1717: Ottoman Decree → removal of patients outside city walls → outskirts → "meskinies"
- 19th century: debate among the medical community, whether Hansen's disease is hereditary or contagious
- 1873: Armauer Hansen discovers the bacillus of leprosy → isolation of patients
- 1897: First International Conference on Leprosy in Berlin: segregation policies adopted worldwide.
- Many critics

7

Spinalonga: A Monument of Pain



- Autonomous Cretan State → measures against leprosy
- 12 July 1901: following an advice by Edvard Ehlers → law concerning the isolation of patients
- Patients → report to local authorities → medical diagnosis → banishment
- 30 May 1903: Designation of Spinalonga as a Colony
- 1904: First 251 patients to the island
- Remaining Muslim inhabitants depart.

8

Spinalonga: A Monument of Pain



- Rules for the function of the Leper Colony
- Visits to the island → permitted for staff of Department for the Leper Colony → relatives of the lepers (special permission).
 - Leper's clothes (washed only inside the island).
 - Only the Department boat could approach the island → Leper Colony doctor responsible for correspondence → disinfection.
 - Fishing was forbidden.
 - The dead were to be buried on the islet.
 - A yellow flag was to be hoisted on the island every day.
 - Appointment of personnel (Director – doctor, superintendent, cleaners, priest).
 - The Director – doctor had many competencies and responsibilities on the islet.
 - Permission was given for a maximum of two general stores to be run on the islet, in order to supply essential goods at prices determined by the Prefecture.
 - Finally, the first decree provided for the daily distribution to each sufferer of 200 drams of bread, 20 cents (lepta) for food and 8 cents (lepta) for clothing, shoes and bedcovers".

9

Spinalonga: A Monument of Pain



- Patients → live in actual exile
- Illiterate lower classes of rural Crete
- Live in the houses of the Ottoman settlement → could not afford even their most rudimentary needs
- Unsanitary conditions → no running water
- Foodstuffs → purchased by local communities
- Total lack of medical care
- 1911: appointment of the first doctor
- Priests or monks live among the patients

10

UNESCO

In 1963 Spinalonga became a Public Tourist Property under the National Greek Tourism Organization; in 1970 it was declared a site of “outstanding natural beauty” and in 1976 as an “archaeological site”. From the 1990’s onwards extensive restoration works were undertaken in the fortifications and the settlement by the Hellenic Ministry of Culture under the funding of the European Union. New restoration works are planned to begin in 2017 with the contribution of significant E.U. resources. In 2014 Spinalonga was included on the Tentative List of Greece for the UNESCO World Heritage Sites (<http://whc.unesco.org/en/tentativelists/5866/>).

*Spinalonga PV: <https://www.youtube.com/watch?v=DDbliss3OH4>

Spinalonga: A Monument of Pain



- 1913: Union of Crete with Greece → gradual transfer of patients from all over the country
- Prime Minister E. Venizelos → attempts to eradicate the disease
- 1918: Committee of prominent scientists → Spinalonga unsuited for housing patients
- Proposal for transfer to Dionysades
- 1919: Creation of the Hellenic Pasteur Institute in Athens
- Scientific mission to India and the Philippines.

11

Spinalonga: A Monument of Pain



- 1920 → Greek Law for the restriction of Leprosy
- Strict segregation policy
- Confinement → leper colonies → medical institutions → at home (non contagious cases)
- Marriage banned (eventually allowed in Spinalonga)
- Application under the Penal Code
- 1924 → E. Grammatikakis → first Director – Doctor
- 1925 → Decree regulating the function of Spinalonga → theoretically a hospital
- 1926: Memorandum of Prefect Anagnostakis → laments the situation of patients.

12

Spinalonga: A Monument of Pain



- Many of the Colony's running expenses → wealthy benefactors
- Medical care: continues to be nonexistent
- Hellenic Pasteur Institute → various treatment methods: Antileprol pills/ Hygranol injections
- 1927: Charles Nicolle (later awarded with the Nobel Prize in Medicine) visits the island → sends 10.000 doses of Hygranol to Spinalonga → stock not renewed
- Second International Leprosy Conference → segregation policies severely criticized → Ernest Muir

13

Spinalonga: A Monument of Pain



- 1929: first large public works → mosque repaired and transformed to a "Hospital"
- 1929: foundation of the Ayia Varvara Anti – Leprosy Station in the vicinity of Athens
- Application of other forms of treatment: chaulmoogra/hydnocarpus oil
- No treatment in Spinalonga
- Harsh application of the Leprosy Law
- No doctor on the island/visits only after request
- Patients purchase drugs at their own expense.

14

Spinalonga: A Monument of Pain

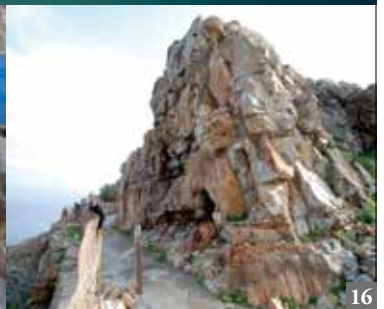


Epameinondas Remoundakis

- Patients protest → mass demonstrations/riots
- Syndicalist union: "The Brotherhood of the Sick"
- Most distinguished leader: Epameinondas Remoundakis
- Improvement of living conditions: sanitary measures, fight against gambling and alcohol, communal places for recreation, religious festivities, organization of various events, supplying cooperative
- New regulation → nurses stationed in the fortress for the first time → medical provisions
- 1938: separate children's branch in Ayia Varvara
- Public works: Dormitories/peripheral road.

15

In 1939 under State supervision a new peripheral road was constructed.



16

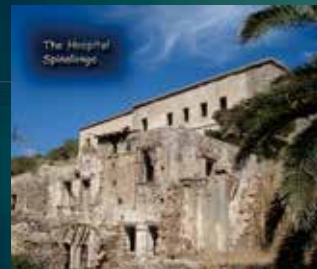
Spinalonga: A Monument of Pain



- World War II → German and Italian occupation → deterioration of living conditions
- Death of more than 100 patients (famine, diseases)
- 1944: Liberation
- Power generator to the island → Public works → New dormitories
- 1948 : application of new cure discovered in U.S.A. (promin – dapsone)
- 1957: shutdown of colony → transfer of patients to Ayia Varvara
- Shutdown delayed: strong prejudice → establishment essential for the sustainability of local economies.

17

Surviving buildings from the Colony Hospital - Washtubs



The Hospital (previously Ottoman mosque)



Row of washtubs next to the Venetian cisterns

18

Surviving buildings from the Colony Dormitories complex - Disinfectory



Dormitories complex, Modernistic and Bauhaus architecture



Kiln inside the Disinfectory (old Venetian garrison room)

19

Spinalonga: A Monument of Pain



- Cemetery of the Leper Colony → was placed on the Donato Bastion, initially at the artillery area and later due to lack of space to the cannon embrasures, where the cement graves lay.
- An ossuary was also erected.

20

Spinalonga: A Monument of Pain



- 1963: Spinalonga → Public Tourist Property
- 1970: Declared a site of "outstanding natural beauty"
- 1976: Declared as an "archaeological site"
- Restoration works by the Ministry of Culture
- 2014: Inclusion in the Greek Tentative List for the UNESCO World Heritage Sites
- 2017: New restoration works planned to begin → E.U. funding

21

Restoration works by the Hellenic Ministry of Culture



22

Restoration works by the Hellenic Ministry of Culture



23

Restoration works by the Hellenic Ministry of Culture



24

View of the settlement (after extensive restoration works by the Hellenic Ministry of Culture)



25

Spinalonga: A Monument of Pain



- UNESCO Operational Guidelines: "Nominations of properties considered to be of 'Outstanding Universal Value' for inscription to the World Heritage List"
- Conditions of authenticity and integrity
- Nomination format → Dossier:
 1. Identification
 2. Description
 3. Justification
 4. Conservation/threats
 5. Protection/Management
 6. Management Plan
 7. Statistical data/Facilities

26

Spinalonga: A Monument of Pain



- Spinalonga → Outstanding Universal Value → architectural remains of different historical periods coexist on the island. Moreover, due to the colony, Spinalonga is a monument to human pain. It symbolizes the concept of incarceration and is synonymous with torment
- Criterion (ii): It demonstrates human values over a long period of time, as regards developments in urban planning, the fortification of the islet and the use of space
- Criterion (iv): It is an important example of a seaward bastion – type fortress that portrays important phases of human history
- Criterion (vi) – used always in conjunction with other criteria: The use of Spinalonga as a leper colony, the most tragic part of its history, emphasizes the unique character of the island"

27

Similarities of Spinalonga with other Venetian fortresses.



Fortress of St. Andrea, Venice, Italy



Fortress of St. Felice, Venice, Italy

28

Similarities of Spinalonga with other colonies



Robben Island, South Africa

29

Spinalonga: A Monument of Pain



- The statement of authenticity is based on the fact that: "the fortress complex is in a very good state of preservation due to its solid construction and use of quality materials. Large parts of the village on the island have also remained authentic. The streets, the paths, the houses with their pebble courtyards, the walls with several layers of whitewash, the traces of games on the house doorsteps, are all imbued with the aura of the people who lived here. The island is a fascinating monumental and historical palimpsest".
- The statement of integrity is based on the fact that: "the integrity of the site is protected given that the islet is a designated archaeological site. The restoration work carried out in recent years is under the Ministry of Culture and Sports control and has helped preserve and promote the archaeological and architectural riches of Spinalonga".

30

“La Crete sans les dieux”, R. Zuber & R. Leenhardt (1935).



31

“L' Ordre”, Jean - Daniel Pollet (1973).



32



33



34

Spinalonga: A Monument of Pain



35

Spinalonga: A Monument of Pain
Trailer for a TV series based on the Victoria Hislop's novel "the Island".



36

Session II: "Our Legacy for Our Future"

Contratacion Has Magic!

Dr. Carlos E Sanchez Santamaria

Teacher

Instituto Técnico Industrial San Juan Bosco

The city of Contratacion was established in 1833 and it was later recognized as a leprosarium from 1861 to 1961. It was then that the Law 148 was officially announced by which all Lazarettos were dissolved as such and became Municipalities with the recognition all their civil rights and their liberties.

As a professor in the only college of Contratacion Municipality I proposed a plan to create a course of studies focusing on Information and Communication Technologies (ICT) which was accepted by the college staff. At the beginning nobody in Contratacion believed in my proposal so I searched for help from the international NGOs and right away I received economic support to implement my initiative. During the past seven years, I have received national and international recognition and my proposal has been selected among the 20 best proposals in Latin America for the implementation of ICT in the college classrooms. What is my role as of this point? My role is to recover our historical memory throughout the written texts and carefully save and use them later to make virtual books to share throughout the internet.



How do we do it?

Each student comes out with a family tree of his own family and highlights the places within his generation where there was a person affected by leprosy. This exercise excited the need to communicate with their families because some of them did not remember their roots real well; by doing so, this helped to complete the missing blocks. Today these family trees are displayed on the classroom walls and on social media.

After the family tree exercise, each student works on writing their personal life history: How their first relative arrived at the leprosariums, what they did once they got there, what anecdotes they have, where they went to school, experiences while in school that most impacted them and—the most important—how they imagine their lives will be in the following 10 years and what they need to do to achieve those dreams. The written texts are carefully saved and kept as memories and then they will create virtual books to share throughout the internet.

Another significant project is ITIS (Salesian Industrial Technical Institute) TV. Here we bring up documentary programs to strengthen the sense of belonging to our birthplace. We narrate the life experiences of persons of the municipality giving priority to those persons affected by leprosy. By means



1



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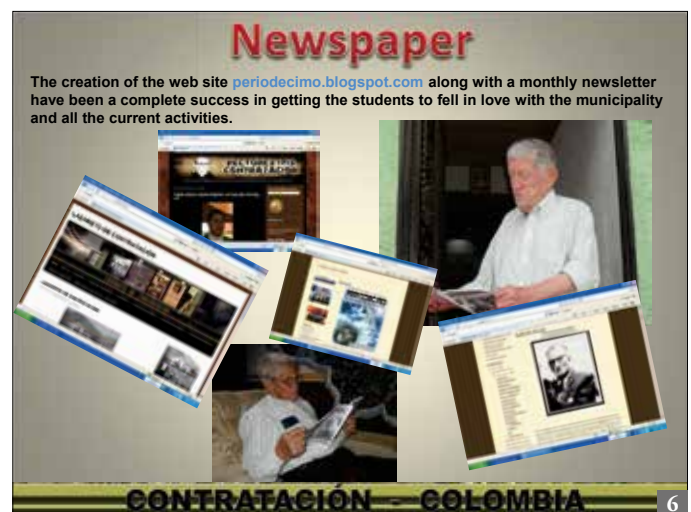
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6



7



8

of the web page <http://www.ustream.tv/> we do live transmissions on significant events that occur in the community on a daily basis. On this web page, we share the students' experiences and they enjoy learning and evaluating their experiences and socializing.

The creation of this website along with a monthly newsletter has been a complete success in getting the students to fall in love with the municipality and all the current activities. This monthly newsletter is called the "Decanews" because it is done and managed by the 10th graders. They published 250 copies and sell them to the general public and later on upload them on the internet. The topics are all concerning the activities of the municipality, local personages and preservation of our local history. With the proceeds, we buy materials for our technical areas such as jackets or CDs etc. We also create blogs at free places to let the public know of our history, cultural activities and upcoming events in Contratacion.

On the web page: <http://ciberitis.blogspot.com/> you will find evidence of the work done on the technical specialty "Informatica and Communication" and the Designed discipline involved by which we want to project the students toward the future from the present parameters. You will also find links to the most outstanding blogs.

During dialogues with the students and ex-students talking over the future of the municipality I like to present the following proposal: "Contratacion—The first historical-cultural park in the world in honor of all the Hansen's patients." On this link, we will get more detailed information on the subject, in general terms it proposes the following:

1. SET UP A MUSEUM OF LEPROSY to preserve our legacy and, in addition, create a museum of happiness to preserve our autochthonous values and the diverse contributions from different places in the country where these people came from. Among the contributions are the Matachines lanterns, the stone of happiness, music, art and literature. Our Mayor has already presented a project with the design of the spaces required for the planned museums, and it has been approved.

2. NAMES AND TRAFFIC SIGNS

This plan proposes to re-name all the City streets and roads of the municipality with names of illustrious personages of our leprosarium. Of course it will comply with the norms of toponymy established for such cases: all the inhabitants of the town must participate and space must be provided on the website for information from every important place in the municipality through a QR code.

3. RECONSTRUCTING OUR LEGACY

We also would like to solicit support to get through all necessary procedures with the purpose of presenting solid proposals to the Cultural Minister to restore all six buildings declared National Heritage by President Juan Manuel Santos.

4. REDESIGNING THE STREETS

Re-design sidewalks and streets with sign spaces chronologically organized to project details of our history along with statues of the important personages who contributed to the development of our town during the hardship of the leprosarium. Today we have four life-size statues which were selected by virtual votes and we are now working on fundraising so that we can install them permanently at the city central park.

1. MUSEUMS

CREATION OF THE LEPROSY MUSEUM: In order to preserve our history.

CREATION OF THE MUSEUM OF HAPPINESS: To preserve our cultural values such as: Lanterns, dancers, stone of happiness, etc.



The projects have already been submitted and the Mayor of Contratación has made arrangements for the construction of the CULTURE house, there the corresponding spaces will be allocated to the museums.

CONTRATACIÓN - COLOMBIA

9

2. NAMES AND SIGNAGE

Give names of PERSONAGES ILLUSTRATES OF LAZARETO to the different streets of the municipality, chosen in common agreement by the residents of each street.

Signage important sites with QR CODES to tell the story through different technological resources.



3. RECONSTRUCTION OF OUR HERITAGE

To present proposals to recover the Monuments declared Heritage of the nation.

They are SIX:

Hospitals "María Mazzarello" and "San Juan Bosco", Medical and Employee Houses, Carrasquilla Building and Administration House.



CONTRATACIÓN - COLOMBIA

10

4. INTERVENTION OF SPACES

Creation and arrangement of parks. Creation of SCULPTURES with personages representative of the time of the lazaretto.



CONTRATACIÓN - COLOMBIA

11

4. COINS

Minting coins of Leprosariums as a tourist strategy for circulation in the municipality.



5. TOURISM, MICROENTERPRISE

To motivate ecological, historical-cultural and religious tourism strategically organized and encourage the creation of self-sustaining micro-enterprises.



CONTRATACIÓN - COLOMBIA

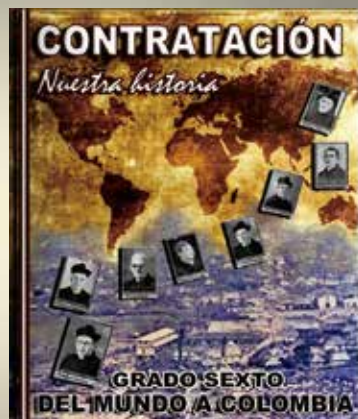
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6. HISTORICAL MEMORY CHAIR.

Design, structuring and implementation of the chair of our historical memory in the curriculum of the San Juan Bosco's Industrial Technical Institute.

Elaboration of primer-books and teaching material, invitation and approach to the elderly as first hand story-tellers of their anecdotes and knowledge.

(Publication of Interactive Encyclopedia, books and documentaries)



CONTRATACIÓN - COLOMBIA

13

THANKS TO:

Sasakawa Memorial Health Foundation

For giving us the opportunity to tell the world how proud we feel to be of Contratación.



Setouchi, Okayama, Japón

14

5. MINTING COINS

The idea here is to mint coins used in the Leprosarium in order to use in the municipality as a strategy of historical tourism.

6. TOURISM AND MICRO ENTERPRISES

We have great potential to organize, strengthen and promote the ecological, historical, cultural and religious tourism. Right now we do have some micro enterprises whose potential can be realized with our internal support. We want to create consciousness in our municipality to support the producers so that they expand their vision and project us to national markets of excellent quality.

7. HISTORICAL MEMOIRS CHAIR

We are designing, structuring and implementing the historical memoirs chair in our school. The objective is to prepare the students to speak up with a great sense of ownership of their history. To prepare for this we are setting up interactive encyclopedias and games so that the smaller children can learn in a more dynamic and entertaining mode.

Session III: "Preservation and Beyond"

Si'an Leprosy Heritage Park

Mr. Yonhong Huang

Founder

Sian Leprosy Heritage Park

Sian Leprosy Heritage Park is located in Dongguan and will be China's most distinctive museum attraction and its only public welfare tourism destination related to leprosy.

Making full use of a leprosy hospital site built more than 50 years ago, it has a role to play in health science education while also serving as a venue for ecological leisure tourism based on the natural landscape. This latter function will contribute to maintaining operation of the museum.

Since the pursuit of ticket revenue is not a priority, we will be able to maintain the ecology and tranquility of Si'an by limiting the number of visitors.

The largest source of visitors should be students from Guangzhou, Shenzhen and Dongguan. Let them visit the heritage park and, at the same time, try to serve the old people living there and feel in close contact with farming civilization.





Si'an Leprosy Heritage Park

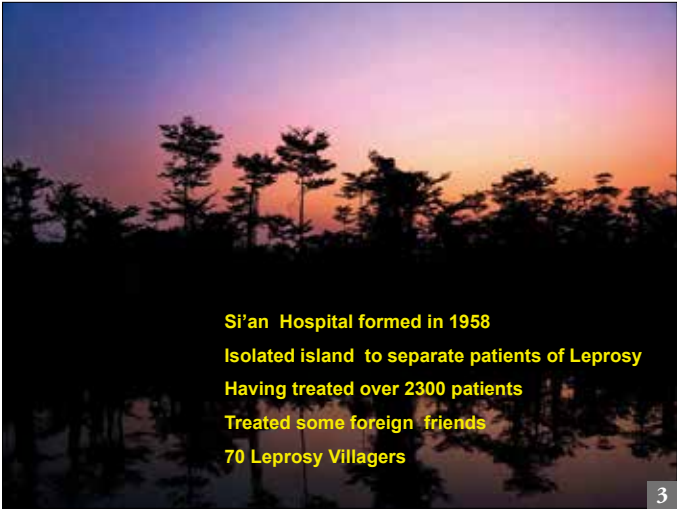
Huang Yanhong
Si'an Museum, Guangdong, China



Chapter

- 1. Natural Sceneries
- 2. Old Buildings in Si'an
- 3. Si'an Museum of Leprosy
- 4. Ideas about the Leprosy Heritage Park

2



Si'an Hospital formed in 1958
Isolated island to separate patients of Leprosy
Having treated over 2300 patients
Treated some foreign friends
70 Leprosy Villagers

3



Leprosy Heritage Park
based on Si'an
Leprosy Museums


Basic Conditions
Beautiful Scenery
Historical Relics
Solemn Stories



5

Chapter 1

Natural Sceneries



930,000 square meters

- Forests
- Wet Land
- Orchards
- Ponds

6





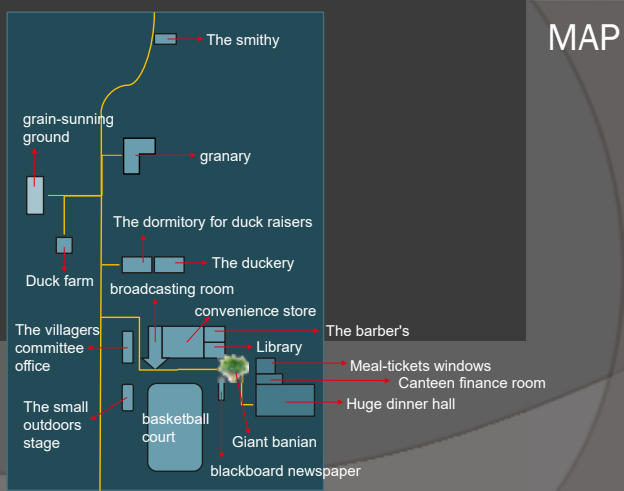
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Chapter 2

Old Buildings in Si'an



10



11



12



13



14



15



16



17

The Core of the Heritage Park——The Giant Banian Tree



18

Huge Dining Hall
Contain 1,000 People
A Stage for Performance
Symbol of the Old Era



19

The giant banian
strong roots
busy video hall



20



little store
800 people shopped here

21



The small outdoors stage

22



The Old Buildings still in Use

23



The Old Out-patient Department

24

Chapter 3

Si'an Museum of Leprosy



25

Established in August, 2014
2,000 Pieces of Collections
from 102 Leprosy Villages
Stories behind the Collections



26



- Story of a Mini Cutting Board
- by Mr.SUN Tianhong
- "I live by myself. It's enough."
- Simple Life

27



Edified by this
discovery

Record the Stories of the
Villages

Get to know their
miserable Past

Present Difficulties

Completed 200 Stories

28



Anti-Tiger Gate

29



"50 years ago,
we used it to prevent
tigers get into our village."

You can take away this pole.

Tiger can't do it because
they are a little stupid .



30



The oldest Barber in the World

31



He lived in TingLiang village of leprosy.
From he was young until last year
he has been the barber.
Many years ago, the haircut was for free,
later it need to pay 0.5 Yuan.
Last year, it need to pay 3 Yuan.



32



33



34



35

- More importantly,
- add our feelings and the sense of aesthetics
- into the arrangement of the collections
- In the preparation of the museum
- we think of different ways to arrange the exhibitions
- The following are some designs in Si' An Museum



36

Suffering cannot be weighed



an art piece
Four Chinese balance connected together
Collections are very old and very poor.

37



We want to say:
Suffering cannot
be weighed.
Who under go
and who did
know.

38

The village of only one person



39



There are seven special
villages
every villages just has one
villager
medical treatment are
so bad.

40

- ◉ We gathered the pictures making it noticeable
- ◉ grab people's attention.
- ◉ started to gathered them
- ◉ take good care of them
- ◉ 5 "one-person villagers" have been taken to Si' An Hospital.
- ◉



41



Big wall clock

42



- ◉ consist of 12 pictures
- ◉ 2 wooden crutches
- ◉ important moment: ten thirty-five, January 9th, 2011
- ◉ 44 villagers of Leprosy left DaJin Island to Si' An Hospital

43



DaJin hospital of leprosy was set up in 1927. Because of it is Far away from the land. it was the most hard and remote Leprosy village in Guangdong province.

44

Si'an Photo Wall



45



- ◉ The 40 pictures are all taken in Si' An hospital, old buildings.
- ◉ natural scenery.
- ◉ We put 3 wooden crutches
- ◉ Step on history.
- ◉ Rely on natural
- ◉ they helped each other
- ◉ walked out from deep suffering.

46

Stand up



- ◉ This exhibition is called "stand up".
- ◉ There are some artificial limbs.

47



oldest one
60 years ago



wooden artificial limb
most precious,

48

Sit down



This exhibition is called "sit down", made of local materials.

49



One leg



Two legS



Three legS

50



Four legS



Five legs



No leg

51

Chapter 4

Ideas about the Leprosy Heritage Park



52



- The area around the dining hall is appropriate for a group of museum.
- The leprosy museum encompasses not only material heritages and objects, but also immaterial heritages that have historical meanings.

53



recover some sceneries of "Town of River", build a wooden path through the forest build a bridge across the wet land arrange boats for entertainment on the river design 3 tourist routes the long one the short one land-river combined one

54



build a bridge across the wet land

55



Hire leprosy rehabilitees as tour guide "Sit on the wheelchairs, tell the stories." push the wheelchairs visit the museums.

56

- Repair and refine the old buildings
- revive the old slogans of the past era
maintain their original functions
- broadcasting old songs in the broadcasting room
- playing old films on TV set
- selling souvenirs in the store
- selling food at the dining hall's windows
- listing notes on the blackboard



The empty old buildings.

57



The dining hall becomes Cultural Arts Center
attracting artists to hold free action art salons
photography exhibitions
painting exhibitions
performances
Cultural Arts Festivals
parties and speeches will be held on the stage

58



Under the giant banyan
teahouse or a coffee bar
public forums
reading clubs
art speeches will be held.

59



60



provide
wedding
photography
services
in the old
buildings
and natural
scenery

61



Thanks for watching

62

Session III: "Preservation and Beyond"

Making Art Work —National Sanatorium Oshima Seisho-en

Prof. Nobuyuki Takahashi

Professor
Nagoya Zokei University of Art and Design

Oshima is located at a distance of about 8 km from Takamatsu Port, in Kagawa Prefecture. The island, which is about 61 hectares (150 acres) in size, is used almost exclusively by a Hansen's disease sanatorium, the National Sanatorium Oshima Seisho-en. Among the 13 national sanatoriums throughout Japan, it is the only one that is on a remote island.

I first visited Oshima in 2007. I met the people, saw the scenery, felt the breeze of the island. Eventually, I was thinking that "Oshima is expressing itself. I want to convey it to the outer world." I wondered whether there would not be some objects that the people of the island hesitated to discard. I decided to collect items that harbor memories, and are the testimonies of people living there.



In July 2010, I was notified that they found an abandoned 'autopsy table' on the western shore. It was immersed in seawater at high tide, and reappeared during low tide. I was overwhelmed by its presence, but strongly felt that we must somehow raise it out of the water and bring it to higher ground. At once I consulted Mr. Takahisa Yamamoto, who was then the president of the residents' association, and arranged to have it be placed in a vacant lot of former housing facility, Dormitory #14.

Oshima is surrounded by ocean on all sides. To prevent the residents from escaping, using ships or boats were prohibited. However, in 1956, a 'fishing club' was organized by the residents, and it became possible for them to own boats. Recently, one such boat was found half buried in sand at the boathouse, and we excavated it in 2012. I set this boat 'afloat' inside Dormitory #15. Beneath the boat, we dug out a pit in the floor that is big enough for a grown person to enter, so one can gaze up at the bottom of the boat. This boat is given buoyancy from the gazing eyes of the visitors to Oshima.

One day in 2010, I was asked to look after the photos and films of a resident who had passed away, accumulated over the years. The photographer's sanatorium name was Noriaki Akamatsu. He called himself "Takashi Tosu," when expressing himself in creative work, such as photography and writing.

A photograph is the meeting point between the photographer's vision and that of the person looking at the photo. I would look at his films daily, and in doing so, felt as if the memories of Takashi Tosu were being woven into my own memories. A large quantity of gadgets to assist him in photographing were also found. They were handmade from rubbish and pieces of wood by Tosu, who had difficulties maneuvering the camera as the result of Hansen's disease.

Among his photos, there were some that were taken with telephoto lenses of over 1,000 millimeters, to shoot the horizon and beyond. This act of capturing far away objects up close, may perhaps have been his efforts in setting free his sight to the greater world, when in fact he continued to be bound to Oshima. Through the lens, Tosu succeeded in jettisoning his eyes to infinity.

The work of one creator's activities ended up with me. They are not unrelated to the erroneous policy of the government or the unfounded stigma and discriminations he suffered; the artistry was born in Oshima. What was most important, was that the art expressed the genuine strengths that enable humans to endure and survive. I longed to get closer to his pain; let the bud of expression seep into me.

I assumed the name Takashi Tosu in December 2013, and exhibited works at the "Setouchi Triennale 2016," an art festival. Walls of five dormitory rooms were pierced horizontally to connect the rooms: it was a place where one could meet Takashi Tosu, transcending time and space. Such experience through artwork solicits further exploration of Hansen's disease and human dignity issues, beyond the ordinary tour of facilities or human rights education. The artwork gained new value in the least expected manner, and cast its message deep and far, spanning other generations. The creativity would never be confined and isolated, but would reverberate throughout the world.



Session IV: “UNESCO World Heritage”

Cultural Heritage of Hansen’s Disease

Dr. Deirdre Prins-Solani

Education, Culture and Heritage Specialist
IDEA/International Coalition for Historic Sites of Exclusion and Resistance

“While we will not forget the brutality of apartheid, we will not want Robben Island to be a monument of our hardship and suffering. We would want it to be a triumph of the human spirit against the forces of evil; a triumph of wisdom and largeness of spirit against small minds and pettiness; a triumph of courage and determination over human frailty and weakness; a triumph of the new South Africa over the old.”

Ahmed Kathrada



Cultural heritage can serve as a catalyst for healing; at an individual level, a collective or societal level and at a global level.

Reports and research studies reviewed* on community based approaches to psychosocial support during trauma by members of the academy or by development and aid organisations, demonstrate a growing awareness of the value of culture for peace. There was an acknowledgement among agencies that to ignore culture and cultural heritage as a factor for peace building and rebuilding efforts within and by local communities, could have at worst, disastrous consequences and at best, unsustainable recovery effects. (Examples are cited in the full presentation.)

Cultural Heritage Sites and Landscapes as spaces for dialogue.

There is sufficient evidence the world over, just how meaningful it can be, when the fabric of a building as grey and austere as the Robben Island prison walls or the ruins of Hiroshima after the brutality of atomic attack on people’s lives or the remains of Auschwitz concentration camp, interlaces with the power of the word, with song, with poetry and memory to create a poignant and potent cauldron for transformative humane practices.

Mind the Gaps: Where is the leprosy heritage, cultural heritage of Hansen's disease?

While sites such as Robben Island are listed and others such as; Spinalonga are on the tentative list and others such as Sorokdo and Aqua de Dios are on national lists and receiving national attention and protection, there is an opportunity for this shared heritage of humanity at large to receive greater protection and attention within all spheres of life. The storied lives associated with leprosy heritage, criss-crossing the globe whilst uniquely different, share a resonant gentle power to remember, commemorate and celebrate the resistance of repression and resilience of spirit of individuals and collectively of families and communities. The creativity and innovation demonstrated by peoples affected by Hansen's disease, to assert their humanness, their place in the world when rejected through their acts of kindness, craftsmanship and ingenuity, caregiving, artistic expression have much to teach a world escalating in its exclusionary practices and hardening of prejudices.

Though Robben Island is listed as a world heritage site and has in its Outstanding Universal Values identified the leprosy heritage, the narratives of the island and so many sites needs amplification. A greater amplification is possible when this takes place in concert. And whilst not all sites may qualify against the operational directives, attention and focus generated through world heritage status would bring context and a new lens through which to view heritage of similar nature.

Though there are many challenges going forward – to NOT continue the work of speaking truth to power or amplifying the voices of those who have already spoken, humanity would be missing a crucial piece of its own painful, conflicted and yet hope filled story.

* By the author in 2017

Session IV: “UNESCO World Heritage”

The Possibility of Nominating Leprosaria to the UNESCO World Heritage List

Dr. Yong Long Lim

Senior Lecturer
Universiti Teknologi Malaysia

The Concept of World Heritage

A World Heritage site is a priceless legacy. All heritage sites, as stated in UNESCO’s World Heritage Convention website, “belong to all the peoples of the world”, regardless of their locations. There are three categories in the UNESCO World Heritage lists—cultural property, natural property, and mixed property, which refers to culturally and naturally mixed property. So far, as of the end of 2016, 1,052 properties around the world have been inscribed on the World Heritage List. Of these, 814 belong to cultural properties, 203 are natural properties and 35 are mixed properties.



The main purpose of the UNESCO World Heritage recognition is to protect these irreplaceable heritage sites from any possible threats such as vandalism, riots, terrorist actions, wars or any harmful developments. This picture shows one of the events that shocked the world in 2001—the standing Buddha statues at Bamiyan Valley were destroyed by Taliban before they were inscribed on the World Heritage list in 2003. Recently, the destruction of a few cultural heritage sites in Syria has prompted the UN Security Council to adopt a resolution to declare that unlawful destructions of cultural heritage sites may constitute war crimes.

Nominating Leprosaria as UNESCO World Heritage

Leprosy is one of the most tragic events in human history. The implementation of segregation laws to confine leprosy sufferers, starting from the mid-19th century to the mid-20th century, was unjust and it had created serious and long-term inhuman consequences that last to this day. The segregation laws, which amounted to a violation of human rights, were against humanity. For instance, the practice of compulsory sterilization of male patients in Japan, Korea and Taiwan, forced abortion of female patients, forced child adoptions, forced labour, and involuntary medical trials.

An ICOMOS publication titled “The World Heritage List: Filling the Gaps—an Action Plan for the Future” urged state parties to recognise and nominate their cultural heritage, especially the under-represented properties, to the World Heritage List and the Tentative Lists as a contribution to the development of “a credible, representative and balanced World Heritage List” (ICOMOS: P.12)—the Global Strategy introduced by the World Heritage Committee. A leprosarium is a unique institution where humans were forced to be segregated for a single medical reason—leprosy. The typology of leprosarium evolved from a medical institution into a form of human settlement. It is shaped by public health policies, modern planning and social ideologies. The Sungai Buloh Leprosarium is a distinct model of such a settlement.

The Possibility of Nominating Leprosaria in the UNESCO World Heritage List



Lim Yong Long

1

The Concept of World Heritage

- World heritage is the invaluable common legacy and heritage of all humankind



Listed: 1052 properties Cultural: 814 properties Natural: 203 properties Mixed: 35 properties
(Source: Unesco World Heritage website)

2

The Concept of World Heritage

They are irreplaceable – they deserved to be protected from any possible threats such as vandalism, wars and developments



Buddha of Bamiyan Valley was destroyed in 2001. Only listed in World Heritage in 2003
(Source: Pinterest.com)

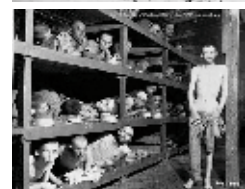
3

World Heritage: Humanity, Human Right and Peace

1979 - Auschwitz Concentration Camp (1940-1945), Poland.



Auschwitz Concentration Camp (Source: BBC, Encyclopedia Britannica,)



4

World Heritage: Humanity, Human Right and Peace

- 1996 - Hiroshima Peace Memorial



(Source: https://en.wikipedia.org/wiki/Hiroshima_Peace_Memorial)



5

Nominating Leprosaria in UNESCO World Heritage

The segregation laws violated human right and against humanity

- Compulsory sterilization /Abortion
- Forced adoption of patients' children
- Forced labours
- Involuntarily medical trials



Sungai Buloh Leprosarium. A patient received injection, new born baby and searching for biological mother (Source" Tan F.M.)

6

Nominating Leprosaria in UNESCO World Heritage

The cultural landscape of leprosaria illustrate how these leprosy segregated policies were executed.



Historic remnants of old colony in Jerejak Island, Malaysia (Source; Lim Y.L. & Culion Archive)

7

Nominating Leprosaria in UNESCO World Heritage

- Historical buildings and relics should be handed down to next generations.
- Remind us about the sense of justice in dealing with human segregation and diseases.



Historic remnants of old colony in Jerejak Island, Malaysia (Source; Lim Y.L.)

8

It is the product and synthesis of history and this human tragedy. Hence, the leprosarium is, no doubt, a public health property that is seriously under-represented in the World Heritage List. The cultural landscapes of leprosaria illustrate how these leprosy segregation policies were executed. These legacies should be handed down to the next generations. They remind us and provide valuable lessons about equality and justice in dealing with human segregation and diseases.

What are the main threats faced by leprosaria today that may affect their nomination to the World Heritage List? The first threat is the lack of heritage protection and management plans to protect leprosaria from losing their integrity and authenticity. We have seen many leprosaria that have been modernised and renovated, without proper guidelines, to suit modern medical needs and patients' modern lifestyle. Some leprosaria have even demolished some of their old buildings and added new buildings. This not only undermines the authenticity and integrity of the sites but also destroys the context of leprosaria.

World Heritage Nomination

There are two options for nominating leprosaria to the World Heritage List. The first option is nomination by an individual country. It could be a single site or a few sites within the country. The second option is Transboundary Nomination. The concept is to link key leprosaria around the world in one nomination.

The Malaysia Government is preparing to nominate the Sungai Buloh Leprosarium as a World Heritage site. In 2007, part of the leprosarium was demolished; this does reduce the overall integrity and authenticity of the leprosarium. However, the compound of the Sungai Buloh Leprosarium is huge, so the overall context is still able to illustrate the character of the institution. Besides, the active agricultural and social activities in the settlement help to portray the Sungai Buloh Leprosarium as a living heritage or settlement. To support the nomination, the Malaysian government is actually considering to link the Sungai Buloh Leprosarium with other leprosaria in Malaysia, particularly the Pulau Jerejak Leper Settlement.

The idea of Transboundary World Heritage is to link key leprosaria around the world in a single nomination. Every leprosarium proposed for the nomination to the World Heritage List needs to fulfil the criteria of OUV and the conditions of integrity and authenticity. The advantage of a transboundary World Heritage nomination is that the nominated properties can help complement each other in fulfilling the nomination's requirements. More importantly, the transboundary approach is more meaningful because these leprosaria might be able to represent and illustrate a complete historical phenomenon of this tragedy from the 19th to 20th century.

Another advantage of transboundary nomination is a higher chance of success to be inscribed on the World Heritage List. The main challenges of connecting these leprosaria around the globe are to form an intergovernmental committee and to find a common theme to link these leprosaria for the nomination. Japan has the experts and experiences in dealing with transboundary World Heritage sites. Last year, a transboundary World Heritage site—The Architectural Work of Le Corbusier, was successfully inscribed on UNESCO World Heritage List. This transboundary World Heritage site comprises 17 sites in seven countries: Japan, India, Belgium, France, Germany, Switzerland and Argentina.

Conclusion

The key leprosaria around the world should be linked together so that people will remember this unforgettable and extraordinary chapter in human history. These sites serve as a reminder and provide valuable lessons concerning equality and justice in facing human segregation and diseases. Heritage protection and management plans are urgently needed to protect leprosaria from further destruction.

Selection Criteria: Outstanding Universal Values (OUV)**Cultural Criteria**

- i. to represent a masterpiece of human creative genius;
- ii. to exhibit an important interchange of human values, over a span of time or within a cultural area of the world, on developments in architecture or technology, monumental arts, town-planning or landscape design;
- iii. to bear a unique or at least exceptional testimony to a cultural tradition or to a civilization which is living or which has disappeared;
- iv. to be an outstanding example of a type of building, architectural or technological ensemble or landscape which illustrates (a) significant stage(s) in human history;
- v. to be an outstanding example of a traditional human settlement, land-use, or sea-use which is representative of a culture (or cultures), or human interaction with the environment especially when it has become vulnerable under the impact of irreversible change;
- vi. to be directly or tangibly associated with events or living traditions, with ideas, or with beliefs, with artistic and literary works of outstanding universal significance. (The Committee considers that this criterion should preferably be used in conjunction with other criteria);

9

Selection Criteria: Outstanding Universal Values (OUV)

- i. to represent a masterpiece of human creative genius;



Giza Pyramid in Egypt (source: UNESCO WH)



Sydney Opera House (source: UNESCO WH)



Taj Mahal (source: UNESCO WH)



Great Wall of China (source: UNESCO WH)

10

Selection Criteria: Outstanding Universal Values (OUV)

- iii. to bear a unique or at least exceptional testimony to a cultural tradition or to a civilization which is living or which has disappeared;



Angkor Wat in Cambodia (Source: UNESCO WH)



Longman Grotto in China and Fujian Earth building in China (Source: UNESCO WH)



11

Selection Criteria: Outstanding Universal Values (OUV)

- ii. to exhibit an important interchange of human values, over a span of time or within a cultural area of the world, on developments in architecture or technology, monumental arts, town-planning or landscape design;



Melaka and Penang Old Towns in Malaysia (Source: UNESCO WH)



Sungai Buloh Leprosarium 's mosque, church and graveyard

12

Selection Criteria: Outstanding Universal Values (OUV)

- iv. to be an outstanding example of a type of building or architectural or landscape which illustrates a significant stage in human history;

Moravian Church (source: UNESCO World Heritage and <https://collectionpostcards.wordpress.com>)

13

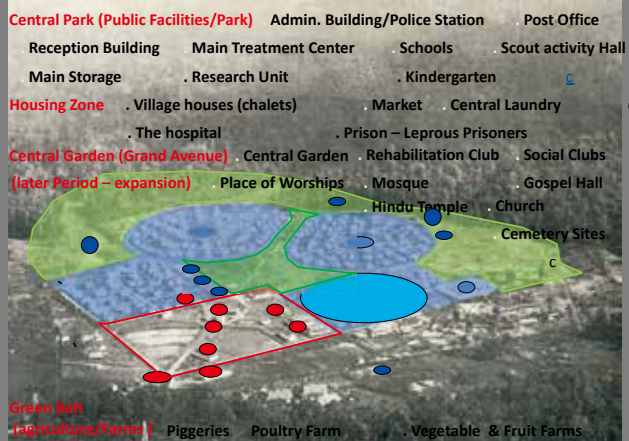
Selection Criteria: Outstanding Universal Values (OUV)

- iv. to be an outstanding example of a type of building or architectural or landscape which illustrates a significant stage in human history;



Sungai Buloh Leprosarium

14

Eastern Section of Sungai Buloh Leprosarium

15

Selection Criteria: Outstanding Universal Values (OUV)

- v. to be an outstanding example of a traditional human settlement, land-use, or sea-use which is representative of a culture (or cultures), or human interaction with the environment;



Falun Mining Settlement, Sweden (Source: UNESCO WH)

16

Selection Criteria: Outstanding Universal Values (OUV)

v. to be an outstanding example of a traditional human settlement, **land-use**, or sea-use which is representative of a culture (or cultures), or human interaction with the environment;



Sungai Buloh Leprosarium

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Integrity and Authenticity

- Important criteria judge by World Heritage technical panels
- If a heritage site has lost its integrity and authenticity, one will difficult to visualise the meaning and historical context of the place.
- Visual integrity and contexts of the site must be remained and controlled by heritage management plan.



Panorama view of Sungai Buloh . New buildings reduced the integrity of the settlement (Source: <https://niknuramirah.wordpress.com/>)

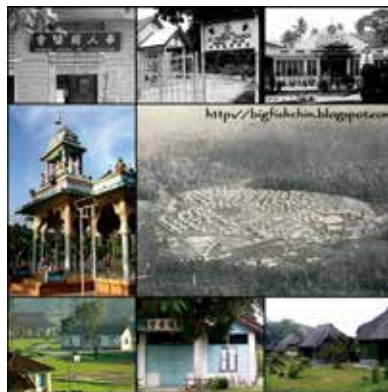
18

Integrity

Three aspects of integrity

1. Representativeness

a leprosarium should include all necessary elements, such as buildings, structures and infrastructures, that crucial to express the character of a leprosarium.



19

Integrity

2. Wholeness - the size or boundary of designated area for nomination must be sufficient enough to illustrate the setting of outstanding universal values of a leprosarium.



Greater area of Sungai Buloh

20

Integrity

3. Intactness

whether or not the heritage property suffers from adverse effects of development and/or neglect. – it should be address in the heritage management and protection plan



The new development in Sungai Buloh . New buildings reduced the integrity of the settlement (Source: <https://niknuramirah.wordpress.com/>)

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Authenticity

Each attribute need to be truthfully and credibly to express its outstanding universal values.

- Form and design
- Materials and substance
- Use and function
- Traditions and techniques
- Location and setting
- Other forms of intangible heritage - living tradition



An old residential block was renovated in Japan. New materials and finished have reduced the authenticity

(Source: edited from Susan Denyer World Heritage Adviser, ICOMOS, 2011)

22

Leprosarium's Threats: Integrity and Authenticity

Lack of conservation guidelines and heritage protection plan

Modernised facilities and living – undermine the leprosarium's authenticity

Reducing population – converted into other medical facilities

Demolish old building and added new buildings



Two buildings in the compound of Japanese Leprosarium. The form and character of both buildings do not merge into the existing contexts of old leprosaria. (Suruga Sanatorium <http://www.at-s.com/>.)

23

Heritage Protection and Management Plan

World Heritage sites or cities are continue developing (Macau).

a Heritage plan to control the future development and to reverse its integrity and authenticity (Melaka's photo)

Buffer Zone - To make sure no future developments will be encroaching to the core conservation area



Georgetown's Buffer Zone (red) – to protect the site from encroaching developments Melaka – heritage guideline reverse back the character of the old town(<http://www.alamy.com>)

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Options: World Heritage Nomination

Option 1: Single country nomination (one site or serial sites within the country)

Option 2: Transboundary nomination



25

Individual Country World Heritage Nomination

1. Challenge - 25% of original site was demolished in 2007
2. Valuable features (prison + substantial part of residential) were demolished.
3. Strength – living heritage and 75% of overall leprosarium context still clear
4. Need to further justify the leprosarium is critically important in the world history of leprosy



Sungai Buloh Leprosarium was demolished and part of the residential areas were cleared for development

26

Transboundary UNESCO World Heritage Nomination

Transboundary - to link key leprosaria (which possess OUV) + high degree of integrity and authenticity

Representativeness - more meaningful - world phenomena of the tragedy & history of leprosy.

Complement each other



Culion, The Philippines



Losheng, Taiwan

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Transboundary UNESCO World Heritage Nomination

Many countries participate – increase nomination chances (each country can only nominate 1 cultural + 1 natural World Heritage sites)

Challenges – Intergovernmental committee + find a common theme

Japan and has experiences - The Architectural Work of Le Corbusier.



The Architectural Work of Le Corbusier. Source: <http://whc.unesco.org/en/activities/807/>

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Conclusion

The key leprosaria around the world should be linked to commemorate this part of unforgettable and extraordinary events in the human history.

They remind us and provide valuable lessons about the sense of righteousness in dealing with human segregation and diseases.

To protect leprosaria from further deviating, heritage protection and management plans are urgently needed.

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Thank you

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Conclusion

Discussion summary

At the end of symposium, participants agreed on the following points:

- In seeking to preserve leprosy history, one of the most important aspects is to preserve the histories and experiences of individuals who had the disease, so that their stories can be passed on to succeeding generations.
- Efforts to preserve leprosy history need to be imbued with a sense of urgency as the generation of those who experienced leprosy and its consequences before the era of MDT is fast being lost.
- The work of preserving leprosy history and the role leprosy museums brings into focus the issue of human dignity, and this can contribute to social transformation by fostering greater respect for human rights.
- Efforts are needed to find a way to make leprosy history part of the permanent history of the world.
- Fostering a spirit of collaboration is essential. It may also be appropriate to contact relevant organizations such as the International Oral History Association and the Coordinating Council of Audiovisual Archiving Associations.

Based on the above points, four areas were discussed in detail with a view to further work being undertaken:

1. Preservation of Historical Sites

- The “sense of urgency” mentioned above with respect to people also extends to physical locations and the need to preserve them in some fashion before they disappear. The various options available for preserving historical sites were listed as follows:
 - World Heritage
 - National Heritage
 - Heritage Park
 - Online Virtual Museum
- By designating physical locations as World Heritage, etc., they will become better known and more accessible to the public, and can also be promoted as destinations for school tours.

2. Preservation of Material Culture and Oral Histories

- Material culture to be preserved takes the form of:
 - Medical materials, e.g., equipment and records
 - Sanatorium residents' materials, e.g. arts, crafts, photos, clothes, letters and journals
 - Databases
 - Oral histories, e.g., testimonies of persons affected, family members, medical staff, members of neighboring communities
- Developing an inventory and categorizing the contents are very important first steps.
- Proper techniques are required for preservation and restoration of materials to protect them from ruin, e.g. techniques such as use of acid-free boxes and digitalization.
- It is important that the materials are given context when displayed. Having a quote from the owner about what the item meant to them, or from a close friend in the event that the owner is deceased, could be effective
- Interactive displays incorporating 3D or 4D technology would also be effective.
- Accessibility of materials and their availability in translation are more important than ever. Need to make effective use of social media such as Facebook, YouTube, and Twitter, online virtual museum and new technologies.
- Education packages at all levels from primary school to university could be a key to increase access.

3. Research

- Research plays an important role in preserving leprosy history. Research helps us find out how to open up new ways of thinking and writing about the long intergenerational legacy of people affected and their families.
- Research should not be limited to medical areas but include social science and oral history.
- Oral history relates to everything, including site closures and transfer of people. More efforts are needed to publish findings in scientific and social science journals. Capacity building in terms of how to write and do research is needed.
- There is a huge gap between what needs to be preserved and what is actually happening in terms of preservation efforts, and a lot more could be done.
- Local researchers, scholars, and historians are expected to be involved in the work of preserving leprosy history in their country.

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Pledge of C

We, the p

The 5th International Symposium on Hanso

hereby solemnly pledge our commitment to make our utmost efforts to realise our comm
 the world and to hand it
 April

Dr. Josephine Robertson

Australia

Jo Robertson

Dr. Carly Machado

Brazil

Carly Machado

Mr. Artur Sousa

Brazil

Artur Sousa

Ms. Patricia Devia Angarita

Colombia

Patricia Devia Angarita

Mr. Juan Kuhnlenz

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Mr. Nikolaos Panoutsopoulos

Greece

Nikolaos Panoutsopoulos

Mr. Eddle Khoo

Malaysia

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Mr. Chor Seng Lee

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Dr. Rene Escalante

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Mr. Ryotaro Harada

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Mr. Yanhong Huang

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Yanhong Huang

Dr. Minghua Zou

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Mr. Unarat Gomes

Thailand

Unarat Gomes

Ms. Anwei Law

USA

Anwei Law

Ms. Kay Yamaguchi

Japan

Kay Yamaguchi

Mr. Takeshi Oku

Japan

Takeuchi Oku

Mr. Akinari Takehisa

Japan

Akinari Takehisa

Commitment

Participants of

Human's Disease History as Heritage of Humanity

Common objectives to accelerate the preservation of the heritage of the humanity throughout
down to future generations.

24, 2017



Dr. Marcos Virmond

Brazil

Marcos Virmond

Dr. Yanit Mora Moscofe

Colombia

Yanit Mora Moscofe

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Ms. Mi Young Baek

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Dr. Arjin Chalapand

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Mr. Tomohisa Tamura

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田村 朋久

Mr. Kazuo Mori

Japan

森 和 男

Mr. Shinji Nakao

Japan

中尾 伸 治

Sasakawa Memorial Health Foundation

Japan

喜 多 悦 子

Appendix: Agenda

Day1: 22nd April (Sat) (Venue: Yume Topia Osafune)

- | | |
|---------------|--|
| 09:30 – 10:00 | Introduction in groups |
| 10:00 – 10:50 | Session A “Preserving Materials & Testimonies”
Lecture: Mr. Tomohisa Tamura (Japan) |
| 10:50 – 11:15 | Lecture: Dr. Arturo C. Cunanan Jr. (Philippines) |
| 11:15 – 11:40 | Q&A / tea break |
| 11:40 – 12:30 | Making the Materials and Testimonies Available to Public
1) Ms. Mi-Young Baek (Korea)
2) Dr. Arjin Chalapand (Thailand)
Q&A |
| 12:30 – 13:45 | Lunch |
| 13:45 – 14:45 | Session B “Reports from Countries”
1) Ms. Angelina Jong Siew Phing (Malaysia)
2) Mr. Artur Custódio Moreira de Sousa (Brazil)
3) Mr. Eduardo Miguel Selma (Spain)
Q&A |
| 14:45 – 15:10 | Tea break |
| 15:10 – 16:40 | Session C “Various Initiatives to Preserve the HD History”
1) Dr. Rene Ramajo Escalante, Ms. Joana Rizza Aspiras Bagano (Philippines)
2) Ms Joana Rizza Aspiras Bagano (Philippines)
3) Ms. Ean Nee Tan (Malaysia)
4) Dr. Yanit Esther Mora Moscote (Colombia)
5) Dr. Sunil Deepak (Italy)
6) Ms. Anwei Skinsnes Law (USA)
Q&A |
| 16:40 – 16:50 | Introduction of “Art” - ILA History of Leprosy website
(https://leprosyhistory.org/art/) |
| 16:50 – 17:00 | Sasakawa Memorial Health Foundation’s commitment to history preservation |

Day 2: 23rd April (Sun) OPEN TO PUBLIC (Venue: Yume Topia Osafune)

- 10:00 – 10:15 Opening remarks:
 Prof. Kenzo Kiikuni, President, SMHF
 Mr. Akinari Takehisa, Mayor, Setouchi City
 Mr. Kazuo Mori, President, Residents committee, Oshima Seisho-en
- 10:30 – 11:30 Keynote lecture: Dr. Tetsu Nakamura, Representative, Peshawar-kai in Pakistan and Afghanistan
- 11:30 – 12:00 **Session I “Our Legacy”**
 1) Mr. Shinji Nakao (Japan)
 2) Mr Bernardo Rodriguez Flores (Philippines)
 3) Mr. Chor Seng Lee (Malaysia)
- 12:00 – 13:00 **Session II “Our Legacy for Our Future”**
 1) Ms. Grete Kristina Eilertsen (Norway)
 2) Mr. Nikolaos Panoutsopoulos (Greece)
 3) Dr. Carlos E Sanchez Santamaria (Colombia)
- 13:00 – 13:05 Remarks by Mr Takeshi Oku, President, Residents committee, Oku Komyo-en
 13:05 – 14:00 Lunch
- 14:00 – 15:00 **Session III “Preservation and Beyond”**
 1) Mr. Yanghong Huang (China)
 2) Dr. Nobuyuki Takahashi (Japan)
- 15:00 – 15:30 Tea break
- 15:30 – 17:00 **Session IV “UNESCO World Heriage”**
 1) Dr. Deirdre Marina Prins-Solani (South Africa)
 2) Dr. Yong Long Lim (Malaysia)
- 17:00 – 17:05 Closing remarks: Prof Etsuko Kita, Chair, SMHF
 18:00 – 20:00 Reception

Day 3: 24th April (Mon) (Venue: Setouchi City Office)

- 09:30 – 17:00 Discussion: The Way Forward

Day 4: 25th April (Tue)

Visit to the Oku Komyo-en and Nagashima Aisei-en

Appendix: Speakers List

Australia

Dr. Josephine Robertson Lecturer, University of Queensland

Brazil

Dr. Carly Barboza Machado Professor, Federal Rural University of Rio de Janeiro

Mr. Artur Custódio Moreira de Sousa Vice National Coordinator, MORHAN

Dr. Marcos Da Cunha Lopes Virmond Director, Institutio Lauro de Souza Lima
Former President, International Leprosy Association

Colombia

Ms. Patricia Devia Angarita Adviser, IDEA

Dr. Yanit Esther Mora Moscote Mayor, Agua de Dios

Dr. Carlos Enrique Sánchez Santamaria Teacher, Instituto Técnico Industrial San Juan Bosco

Greece

Mr. Nikolaos Panoutsopoulos Curator of Antiquities, Ephorate of Antiquities of Lasithi, Ministry of Culture and Sports

Italy/India

Dr. Sunil Deepak Consultant, Associazione Italiana Amici di Raoul Follereau (AIFO)

Korea

Ms. Mi-Young Baek Curator, Sorokdo National Hospital Hansen's Disease Museum

Dr. Gue-Tae Chae Chief, Department of Dermatology, Sorokdo National Hospital

Malaysia

Mr. Chor Seng Lee Vice President, Sungai Buloh Settlement Council

Mr. Kah Fah Khoo Treasurer, Sungai Buloh Settlement Council

Ms. Ean Nee Tan Councillor, Sungai Buloh Settlement Council

Dr. Yong Long Lim Senior Lecturer, Universiti Teknologi Malaysia

Ms. Angelina Jong Siew Phing President, Heritage Society of Rajah Charles Brooke Memorial Hospital

Norway

Ms. Grete Kristina Eilertsen Museum Educator, Leprosy Museum - Bergen City Museum

Philippines

Ms. Joana Rizza Aspiras Bagano Programme Officer for Communication and Information, Philippine National Commission for UNESCO

Dr. Arturo Cabusura Cunanan Jr Medical Center Chief I, Culion Sanitarium and General Hospital

Dr. Rene Ramajo Escalante Commissioner and Acting Chair, National Historical Commission of the Philippines

Mr. Bernardo Rodriguez Flores Chairman, Better Living Consumer Cooperative

Portugal

Prof. Vítor Miguel Jacinto de Matos Professor, Research Centre for Anthropology and Health, University of Coimbra

PR China

Ms. Fengqin Ge	Director, Administrative office, China Leprosy Association
Mr. Ryotaro Harada	Founder, Joy in Action (JIA)
Mr. Yanhong Huang	Founder, The Si'an Museum of Leprosy Consultant, Si'an Hospital
Dr. Minghua Zou	Vice Director, Si'an Hospital

South Africa

Dr. Deirdre Marina Prins-Solani	Education, Culture and Heritage Specialist, IDEA/International Coalition for Historic Sites of Exclusion and Resistance
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Spain

Mr. Eduardo Miguel Selma	Head of International Projects, Fontilles
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Thailand

Dr. Arjin Cholapand	Director, Raj Pracha Samasai Institute
Mr. Unarat Gomes	Technical Public Health Officer, Raj Pracha Samasai Institute

USA

Ms. Anwei Skinsnes Law	International Coordinator, IDEA
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Japan

Prof. Nobuyumi Takahashi	Professor, Nagoya Zokei University of Art and Design
Mr. Tomohira Tamura	Curator, History Museum, National Sanatorium Nagashima Aisei-en
Ms. Kathryn Tanaka	Lecturer, Otemae University
Ms. Kay Yamaguchi	Former Executive Director, Sasakawa Memorial Health Foundation

SMHF

Ms. Nao Hoshino	Director, Sasakawa Memorial Health Foundation
Ms. Aya Tobiki	Chief Programme Officer, Sasakawa Memorial Health Foundation
Ms. Kaoru Ogasawara	Programme Officer, Sasakawa Memorial Health Foundation
Ms. Satoko Kuroda	Staff, Sasakawa Memorial Health Foundation
Ms. Chiemi Sanga	Chief Administrative Officer, Sasakawa Memorial Health Foundation

Special Thanks to

Mr. Kazuo Mori	President, Resident committee, National Sanatorium Oshima Seisho-en
Mr. Shinji Nakao	President, Resident committee, National Sanatorium Nagashima Aisei-en
Mr. Takeshi Oku	President, Resident committee, National Sanatorium Oku Komyo-en
Mr. Daisuke Kamai	Officer, Human Rights Promotion section, Civil Service division, Setouchi City Office
Mr. Shinsuke Kosugi	Officer, Tourism section, Industry and Construction division, Setouchi City Office
Mr. Hironori Mori	Civil Service Division Manager, Setouchi City Office
Ms. Mizuki Tamefusa	Civil Service Section Manager, Civil Service division, Setouchi City Office
Ms. Keiko Tsuchida	Adviser, Civil Service section, Civil Service Division, Setouchi City Office

Why do we need to preserve the history? The question is asked many times. Despite many challenges that many of us are facing day to day, do we want to and do we need to spare our efforts in preserving the history? The answer is a definite yes. Preserving the history and narrating the history for the current and future generations means we can right the past wrongs, and we can learn not to repeat the similar mistakes. The history of leprosy is unique in each place, yet it is also universal. It is a history of segregation and harsh discrimination, and it is also a history of fighters who have overcome the plight with wisdom and courage, showing a great hope to the current and future generations.

The 5th international symposium was held in April 2017 inviting people affected, family members, national agencies, NGOs and researchers from 16 countries, focusing on 2 themes; preservation efforts and utilisation of the preserved historical materials.

We have learned from other country's initiatives, shared progresses made, become united with a mission to preserve the heritage of humanity. Each of us who participated in the 5th symposium are carrying on with their endeavour in their country to see a day and a world where leprosy poses no stigma but that its history is a beacon of hope and wisdom of human kind.

Nao Hoshino

Director

Sasakawa Memorial Health Foundation



Day 3@Setouchi City Office



Day 4@History Museum, National Sanatorium Nagashima Aisei-en

Sasakawa Memorial Health Foundation

<http://www.smhf.or.jp/e/>