

Valley of HOPE

The Sungai Buloh National Leprosy Control Centre



Date	19/5/06
Supplier	General Claims
Invoice No.	172506
Price	Rm 30.00
Requestor	Dr Lim Ho Peng
Category	OS: 2

Phiang Siew Sia
Wong Chau Yin

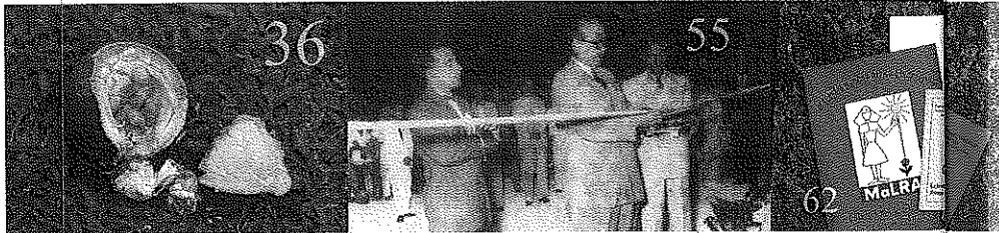


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Lee Wei Kiat
Chairman, MCA Subang Division

Preface

Remembering The Past As We Look Forward

I wish to congratulate the authors, Chau Yin and Siew Sia, for providing invaluable insights into the untold history of the Leprosarium and the life of its inmates. Indeed, this book is a special gift thoughtfully presented by the two authors who passionately and specially dedicated it to the inmates, and to the public as a whole.

Reading between the lines, one can easily feel the natural strong bonding, affinity and friendship among inmates, caregivers and the authors. Further reading beyond the lines, one is certain to be deeply touched by the humanitarian spirit reflected in the entire book.

With deep commendation for the MCA Subang Division's mission, i.e. to create healthier political culture and to provide better community service, we decided to undertake the publication of *Valley of Hope*. In fact, we are so committed to this noble cause that we use "Valley of Hope" as the main theme throughout the Sungai Buloh Floral Exposition held from 5th to 7th May 2006. It is our hope that the event would make Sungai Buloh a famous local brand name for its well-known pottery, floral products and landscaping expertise, whilst instilling public awareness of the Leprosarium, or the Sungai Buloh Leprosy Control Centre.

I wish to express a token of appreciation to IITC Sdn. Bhd. and Gemilang Publishing Sdn. Bhd. for supporting this book project generously and wholeheartedly. I personally envision that the stories told by the inmates about their hardships in the Leprosarium would inspire the young generation of Malaysians to face challenges in life with greater resilience, perseverance and endurance. One shall never give up hope under all circumstances, even if it was an extremely desperate situation, such as in the case of leprosy patients. Despite prolonged sufferings, physical disabilities and social discrimination, they live with dignity and do not depend heavily on others for their well-being. The fact that they persevere till old age is indeed a success story and we should all learn the art of living from these great souls.

As stipulated in the Ninth Malaysia Plan (2006-2010), Sungai Buloh Hospital where the Leprosarium is situated will soon be developed into a superb healthcare centre and an advanced research centre for the entire nation. Nevertheless, we shall never forget the past while eagerly awaiting a bright future ahead. *Valley of Hope* is hence a timely tribute to the survivors of leprosy, as well as an important documented literature for those who wish to research deliberately on this topic.

Prologue

The idea of Valley of Hope was conceived in 2002 out of our sentimental attachment to this place whose uniqueness was slowly fading away. We started to work on this project towards the end of 2002, by which time the construction of the new hospital complex had already started on the site that stretched from the former main entrance of the National Leprosy Control Centre (Pusat Kawalan Kusta Negara) to the colonial-styled government quarters for the nurses.

For almost four decades since its establishment in 1930, the inmates in the Leprosarium had lived in confinement, isolated from the outside world. It was run like a small state, having a population of over 2,000 inmates; managed by the Medical Superintendent with his medical staff, and its operation was fully supported by the able-bodied inmates. It had its rules and regulations, currency for internal circulation (only for a short period), school, clinics, community hall, places of worship for different religions and beliefs, social clubs, prison and even a security force and fire brigade.

Except for the ongoing medical treatment, the inmates led a normal life, living and working together as a closely-knit community. They were represented by a Council whose members were elected among themselves. The Sungai Buloh Settlement Council still serves the inmates today. Valley of Hope has lived up to its name. Over the past few decades, it had seen many of its inmates exit through the Leprosarium's main gate and started a new life outside. As we get to know more about this place and its people, the more we come to appreciate it. It is a shame to leave its story untold.

The Leprosarium has undergone massive changes, especially since the 1990s. Since the era of total isolation during the 1930s to 1960s, it has come a long way to become a well-known destination among flowers and plants lovers. The changes in the post-isolation years have inevitably washed away its original unique culture, economy and social characteristics. In this book, we shall travel back in time to relive those days. *Valley of Hope* is intended to be a memoir for the inmates, ex-inmates, their families and friends and the general public who have never had an insight into the lives in the Leprosarium until recent years. The story will be told from the eyes of the insiders, people who have lived there and are part of the unique culture and lifestyle. It revolves around their way of life, daily routine, social activities and the customs. Most importantly, it will depict the evolution of the inmates' struggles from rejection and self-degradation to hope of recovery, and acceptance by the public. This book encompasses the various aspects and changes in their lives and the place since the 1930s. It will touch on the administration and policies implemented by the authorities within the Leprosarium from the British colonial era, the Japanese Occupation to the post-independence years.

Valley of Hope is the story about the Leprosarium in Sungai Buloh and its people. It is not about the disease. A large part of our data collection revolved around interviews, visits to old buildings and observations of the daily life at the Leprosarium. We also managed to compile a number of photographs, which are the testimony of the Leprosarium's history. Over 80% of its inmates is Chinese, who also dominated the population of leprosy patients in the country before the disease was brought under control by effective medication. Naturally, the culture and lifestyle as well as the major events in the Leprosarium mostly revolve around the Chinese community. Inmates of other races like Malay, Indian and Eurasian had blended well with this environment since they have been living together for decades. Many older inmates of Malay and Indian descent can understand spoken Chinese and some even speak certain Chinese dialects fluently.

One may notice that not many inmates are seen in the photographs of the current state of the Leprosarium due to the dwindling and ageing population. Moreover, most inmates would prefer to remain anonymous. Although the social stigma attached to leprosy had greatly diminished over the last few decades, being exposed to public as a former leprosy patient is still very much a sensitive issue to them. Out of respect for the interviewees' privacy, some of their real names are not used in this book.

While there was a lot of data on the disease, not much was found on leprosariums or asylums. Most of the relevant information we came across were the early events that led to the establishment of the Leprosarium and some general statistics until the end of the 1950s. We realized how little has been documented about this place.

The Leprosarium is now in its twilight years and is currently being transformed into a modern medical centre. In a couple of years, the untold story of this place may be buried forever with the rubbles of the demolished colonial buildings. It is our hope that this book would perpetuate the essence of this unique place and its community for posterity.

Acknowledgement

This book would not be possible without the inmates and ex-inmates who were willing to share their precious experiences and thoughts. They also supplied us the nostalgic snapshots in the book. Their stories have given this book a "soul". *Valley of Hope* is specially dedicated to them.

We would like to record our thanks to Dr Hj Zainab Bt Ramli, the Director of National Leprosy Control Centre, Mr Lim Thiam Chye, the senior medical assistant and Encik Azman Abd Majid, the senior medical laboratory assistant for their valuable information and materials. Through Encik Azman, we managed to get hold of *Leprosy in Malaysia. Past, Present and Future* written by the late A. Joshua-Raghavar, a former inmate, teacher and journalist. Mr Joshua-Raghavar's book provided us a lot of useful information. We would also like to thank the Sungai Buloh's Malaysia Leprosy Relief Association (MaLRA) office, the Sungai Buloh Settlement Council and the Sungai Buloh Buddhist Temple for allowing us access to their materials.

Special thanks to the staff at the National Archives of Malaysia and the library of the Institute of Medical Research for their kind assistance. We are also grateful for the support extended by the Research Committee of INTI College Malaysia. The Committee had granted a fund that partly relieved us of the cost of conducting this research project.

We have been very fortunate to meet a number of individuals who have helped us in some ways or other in completing this project. Our heartfelt appreciation goes to Mr Bae Dae Hoon, a talented photographer, who has taken some of the most beautiful shots of the Leprosarium and its inmates. Our thanks also go to Ms Tan Lee See who publicized our project in *Sin Chew Daily Metro* Edition on 17 May 2005. Through this write-up, we came to know a number of kind individuals who have come forward to support and assist us in completing our work. We also indebted to Dr Yong Hoi Sen and Mr Yeo Beng Kong for spending their precious time reading and commenting on the manuscripts and not forgetting Mr Wong Gin Chuan for his creativity in producing some of the illustrations for the book.

We are deeply grateful to the Malaysian Chinese Association (MCA) Subang Division who has undertaken the publication of this book. With their help, *Valley of Hope* can finally reach out to the public and hopefully it would touch many hearts.

Last but not least, we would like to record our thanks to all those who have contributed in one way or another to make this book a reality.

LEPROSY A Misunderstood Disease



LEPROSY – the mere mention of the word itself was enough to send a shiver down the spine during those days. Some even associated it with evil spirits and considered it a curse for those who contracted it as a punishment for doing something morally wrong. More often than not, the victims were subjected to abuse (both verbal and physical), prejudice and isolation. It is not difficult to imagine the feelings of the victims and the trauma they have to go through in coming to terms with their fate.

Leprosy is one of the oldest scourges of humankind. Accounts of disease similar to leprosy were found in ancient Egyptian papyrus inscription dated back to 1550 BC. In ancient India, leprosy was referred to as Kushtha. Instructions for its prevention were stated in the Vedas, written as early as 1400 BC. The disease appeared 54 times in the Bible. It was perhaps the most badly understood disease for a long time and its patients have suffered much of it.

The cause of leprosy was not scientifically identified until 1873 when Dr Gerhard Hansen discovered the bacterium called *Mycobacterium leprea*. Thus, it is also

Epilogue

The past two years have been a fulfilling time for us. Although we were constantly juggling with our heavy work schedules and the research project, of which the latter would often have to make way if there was a clash in timetable, it has been a meaningful journey of learning and growth for us.

Our very first encounter was with an elderly lady in her 80s with a remarkably good memory, whom we call Saw Cheng in the book. Through her, we saw the misfortune that befell most of the leprosy patients especially before the Second World War when effective medication for the disease had not been discovered. What impressed us was her optimism and strong will. Most of the inmates in the decrepit ward where Saw Cheng now lives are handicapped in some ways or in advanced age. They are confined to wheelchairs or their own beds most of the time. Yet, they are able to look after themselves independently. Watching Saw Cheng tending her small garden of vegetables – using her hands to move her body around which she claimed was more convenient without wearing the prosthetic leg – really amazed us. We have never heard Saw Cheng complain about her own disabilities or her dull life in the decrepit ward.

Soon, we befriended almost all the inmates in Saw Cheng's ward. Their what-are-these-young-strangers-doing-here look slowly turned into warm smiles that greeted us every time we visited them. Our new elderly friends seem to be happy to see us. Normally, we would spend time talking and listening to them, helping them with very trivial tasks, such as making phone calls, reading letters, teaching them how to use a television remote control for which they were so grateful and thanked us repeatedly. We always left thinking, "How simple it takes to make them happy."

On one particular visit, when we were about to drive away in our car, Saw Cheng waved us back. One of our friends had dropped some needles of her old sewing machine on the floor and needed our help to find them. She was so grateful when we retrieved the needles for her. With her deteriorating eyesight, it was impossible to see such a tiny needle. Squatting down is impossible as she has only one leg. Getting new needles is extremely troublesome as they are not able to go anywhere far with their conditions. What we take for granted everyday is a big thing for them. Count our blessings, these few words now mean much more to us and we are learning to live by it. We have also come to appreciate the joy of giving. One does not have to be wealthy to be able to give. A small gesture is enough to make one's day.

We are not the only ones who give. Our friends, without realizing it, have been giving us something special too. Often, after a pleasant weekend visit, they made us feel like we have done something great, and appreciate life more - our health, our friends and families, our jobs, our freedom, our dreams. The pressure from work that had built up during the week and what lied a week ahead suddenly did not seem to be a big deal. We are grateful for being blessed with this friendship and a good lesson about life.

During the course of our pursuit, we have received moral support and assistance from families, friends and colleagues as well as the inmates of the Leprosarium. While these had truly overwhelmed us, we feel that we owe them all a good piece of work. Since this is our first attempt in writing a book, we cannot help being concerned whether the results would be up to standard. We were committed to make the best of it. As we were approaching the final stages and the book started to take shape, we felt an indescribable joy over the final product. Writing, like everything else, would be a good piece of work if it comes from the heart.

December, 2004

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