WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

June 2011 • Number 50

- Leprosy is curable
- Free treatment is available
- Social discrimination has no place


Sungai Buloh resident Heng Bak Nam with author Eannee Tan (right); Tan is writing a book on the community (see p.8) Photo courtesy of Eannee Tan

MESSAGE

The Journey Continues

This is the 50th issue of this newsletter. When I was appointed WHO Goodwill Ambassador, I made publishing a newsletter one of my first tasks. In the eight years since, there have been great changes in the leprosy world.

Despite many challenges remaining on the medical front, the dedication of the WHO, national governments, NGOs, doctors and health workers has seen almost every country in the world achieve the WHO's goal of reducing the prevalence of leprosy to below 1 case per 10,000 population. Brazil, the lone exception, said at this year's World Health Assembly it will do so by 2015.

Achieving the goal of eliminating leprosy as a public health problem the world over is now within sight. However, this will not mean our work is done. Once we pass this milestone on the road to eradicating the disease, we must continue striving to reduce the disease burden further.

Concerning the stigma and discrimination faced by people affected by leprosy and their families, a resolution and accompanying guidelines were adopted at the Human Rights Council last September and subsequently at the UN General Assembly in December by all 192 member states. This was a great achievement, but it doesn't solve the problem. The resolution is merely a tool in our hands. How can we carry it into society's midst? Our work is just beginning.

Conferences around the world that focus on development or poverty almost never touch on leprosy, even though poverty and leprosy are closely related. Leprosy is viewed as a minor disease and the people suffering from it are often neglected. As a fellow human being, it makes me very angry that the existence of people affected by leprosy is ignored by the rest of society. What difference is there between us? In acknowledging their basic human rights, I am fighting for their social rehabilitation in the belief that a fair and just society is not possible otherwise. I will continue this fight for as long as I live.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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VIEWPOINT

Learning from Success

The tremendous achievements in leprosy should not lead to complacency.

AUTHOR:
Dr. Margaret Chan

Dr. Chan is Director-General of the World Health Organization

Today, leprosy has been virtually eliminated in all but a few stubborn pockets, thanks to generous long-standing donations of multidrug therapy (MDT) from The Nippon Foundation and subsequently from the pharmaceutical industry. The worldwide number of new cases continues its dramatic decline, from 515,000 in 2003 to 245,000 at the end of 2009, representing a 52% reduction. We have reached the point where we can envisage a world without leprosy.

Of all the diseases that continue to plague humanity, leprosy has the most notorious history as a cause of deformity, disability, discrimination and fear. From ancient times until the recent past, the disease was considered both highly contagious and impossible to cure. Victims were universally shunned, their physical suffering compounded by the misery of being treated as social outcasts. Because it was thought that leprosy could not be cured, the sole option for control was the isolation of patients in colonies or leprosaria.

Tireless advocacy: Yohei Sasakawa meets with people affected by leprosy on a visit to Brazil in 2006.

Nowadays, treatment which used to take decades takes a matter of months with drugs that are so safe they can be taken by pregnant women. Patients under treatment quickly lose the ability to infect others. Disabilities can be prevented by early detection and complete cure is a reality. The face of a long loathed and feared disease has changed: hard to catch and easy to cure.

> The face of a long loathed and feared disease has changed.

However, these tremendous achievements should not lead to complacency. Leprosy continues to affect difficult-to-reach populations with limited access to information and health services. Improving access to early diagnosis and treatment in order to prevent disabilities remain major challenges.

ROLE OF GOODWILL AMBASSADOR

Mr. Yohei Sasakawa, WHO Goodwill Ambassador for leprosy elimination, dedicates his time, work and passion to advocate for a world without leprosy. He tirelessly visits countries, meets with decision-makers and opinion leaders, shares his views with health workers and listens to people affected by leprosy and their families.

He is also using his energies to ensure that discrimination and human rights violations related to this disease will be brought to an end in every part of the world. I am certain that millions of people around the world, fully cured and living normal lives, will join me in expressing our appreciation. ■

LEPROSY WISH LIST

Dr. Jo Robertson
Affiliated with the University of Geneva; currently working on a book about the history of leprosy.

A NETWORK OF HISTORICAL SITES.

A network of historical sites throughout the world where people with leprosy were isolated, in memory of them and the experiences they underwent, as well as a tribute to the people who worked so tirelessly to bring about a cure for the disease.

A REFERENCE RESOURCE.

A reference resource for people, especially children, who were separated from their families, as a result of past policies against leprosy, and who are now seeking family members.

A DIGITAL ARCHIVE.

A digital archive of rare books and papers that provide a key to research into the history of leprosy. (The archive would include complete digitized copies of *Leprosy Review* and the *International Journal of Leprosy*.)

Advice from an Expert

Wise words from a human rights champion on implementing a UN resolution.

AUTHOR:
Yohei Sasakawa
Yohei Sasakawa is Chairman, The Nippon Foundation, WHO Goodwill Ambassador for Leprosy Elimination and Japanese Government Goodwill Ambassador for the Human Rights of People Affected by Leprosy.

When I first met Dr. Bertrand G. Ramcharan in 2003, it was the starting point of a resolution on leprosy discrimination that would eventually be adopted by the UN General Assembly in December 2010[1].

Dr. Bertrand Ramcharan: a man whose heart is in human rights

At the time, Dr. Ramcharan was the Acting UN High Commissioner for Human Rights[2]. I had called on him at the Office of the High Commissioner in Geneva to focus attention on a long-overlooked human rights issue: the discrimination suffered around the world by people affected by leprosy and their family members. He gave me some very good advice, setting in motion a process that reached its historic conclusion at UN headquarters in New York seven years later.

Visiting Geneva this May, I wanted to thank Dr. Ramcharan for the role he had played at the outset and also to seek his views on how best to ensure that the UN resolution and its accompanying principles and guidelines are implemented. He recalled our first encounter.

> I suggest you organize five regional seminars. You need to publicize it.

"I was really very touched when you brought this issue to me. And I was even more touched when you brought a group of people who have experienced leprosy to my office. I remember one man saying to me: 'For centuries we have been outcasts of society; now we are sitting in the office of the United Nations High Commissioner for Human Rights.'"

Speaking of the resolution, Dr. Ramcharan told me: "Even though you have done all this work, there is still considerably more to be done to make governments and experts aware of it. I suggest you organize five regional seminars in Africa, the Americas, Asia, Europe and Oceania on its implementation. You need to publicize it."

Continuing with a passion undiminished from that first meeting, he said: "The five seminars would be followed by an international seminar in Geneva, resulting in a report or a commentary on the resolution. At the end of that process, you will have more sensitization, publicity and understanding, and will have distilled ideas on how to take things forward."

ROLE OF THE MEDIA

As Goodwill Ambassador, I have frequent contact with news organizations and regard them as among my most important partners in spreading awareness and understanding of leprosy. So I was interested to hear Dr. Ramcharan's views on the role of the media in human rights.

"I have a number of positive examples of the use of the media in promoting human rights," he said. "For example, *New York Times* journalists Nicholas Kristoff and Sheryl WuDunn have sensitized the world to trafficking in women, gender-based violence and maternal mortality with their 2009 book *Half the Sky*. NGOs should look for journalists of the quality of Nicholas Kristoff and engage in personal interactions with them to draw attention to the issues."

"I am afraid we are not necessarily dealing with good intentions on human rights all over the world," he continued. "The pro human rights actor or NGO must be adept at exploiting the political environment to advantage. It is very important to have a political strategy to deal with human rights issues, and then to use the media and other partners carefully."

Returning to the subject of the UN resolution, he told me: "For people who are living with or who have recovered from leprosy, I would like to say that I think that the implementation of this declaration can make a great difference toward enhancement of their dignity and respect for their rights. Mr. Sasakawa, I look forward to your further efforts." ■

FOOTNOTES

[1] Resolution on Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members, adopted at the Plenary Meeting of the 65th Session of the UN General Assembly (21 December 2010).

[2] Dr. Ramcharan is currently president of UPR Info, an NGO based in Geneva.

INTERVIEW

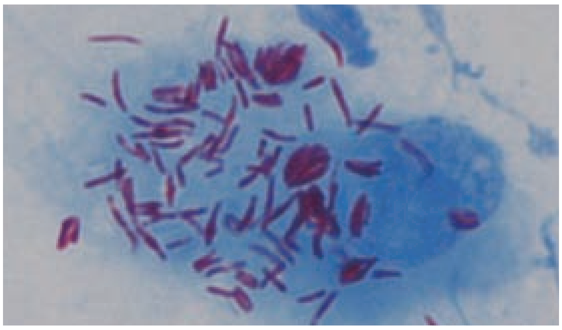
Leprosy under the Microscope

When a basic scientist discusses leprosy, he tells it like it is — especially Koichi Suzuki.

Dr. Koichi Suzuki works at the Leprosy Research Center at Japan's National Institute of Infectious Diseases, where he is chief of the laboratory of molecular diagnostics in the department of mycobacteriology. He is a basic scientist, a civil servant and he is also disarmingly frank.

How long have you worked in leprosy?
I joined the research center around 10 years ago. Until then I wasn't directly involved in leprosy research, although I had an interest in leprosy. I was working in immunology and other fields.

What got you interested in the disease?
Seeing a cluster of *M. leprae* bacteria under the microscope and thinking, "Can these tiny organisms really be responsible for such a terrible disease? Maybe there's something I can do." Also, I was curious how one type of bacteria could induce such a variety of clinical manifestations of leprosy.



M. leprae bacilli taken from female chimpanzee, Haruna

What did you bring to the field of leprosy research?
Since I had a background in molecular biology, I felt that if we introduced the newest molecular biology techniques we might make some progress. The problem is it's not possible to culture *M. leprae in vitro*. That means you can't genetically modify it, which means you can't use the latest techniques. It makes progress difficult.

How far has our knowledge come?
We know the genome sequence of *M. leprae*, but have yet to confirm the function of individual genes biologically, for the reason I've just given. We know the major components — the proteins, the cell wall lipids. But we still know very little about what role the genes perform, what other minor components there are and how important they are.

Why can't *M. leprae* be cultured?
Because *M. leprae* has such a small number of genes — about half the genes of *M. tuberculosis*, which it resembles — it is not able to survive on its own and thus has a high dependency on its host. But just what factors are needed for its survival we don't yet know.

The transmission route of leprosy has yet to be determined. True?
We have yet to discover a means of demonstrating the transmission route. Infection occurs quite some time — years, in fact — before the onset of disease, yet we have no means of demonstrating how and when. Nor are there any good laboratory animals for this purpose. With leprosy, it is generally believed that infection occurs in infancy, through the respiratory organs, as with TB. However, it's possible that a baby being cared for by someone with lesions might be infected when bacilli from the lesions enter its body through the chaffed skin of the baby's hands.

Why do some people get infected, and others not?
Like all other infectious diseases, it largely depends on their immune system, their nutrition level, their overall physical condition at the time. Another factor is genetic predisposition. For more and more diseases, we are finding the responsible gene. Where leprosy is concerned, based on genetic background, there will be people who are easily susceptible to infection when exposed, and those who are not. That said, I doubt the existence of a "leprosy susceptibility gene". The bigger factor is how many bacilli are involved and how many repeated chances they have to infect. A single exposure to many bacilli could lead to infection; on the other hand, a very small amount of bacilli entering the body daily probably would not, as the immune system would be able to cope.

It can be years after infection before someone develops the disease. What triggers its onset?
As I mentioned earlier with regard to infection, there are a couple of factors: one is genetic, which can't be helped; the other is changes in one's physical state that create conditions favorable for the bacteria to multiply. We don't yet know why someone would develop leprosy 20 or 30 years after being infected, but there must be a number of factors that disturb the immune system. This is true not just of infectious diseases, but of autoimmune diseases and diseases such as cancer as well. Over the years, a lot of things enter the body that are bad for it. That's why the possibility of developing cancer increases the older we get. On the other hand, it also implies that a person won't necessarily develop a disease by the end of life, even with these factors and infectious agents.

PROFILE:
Dr. Koichi Suzuki

Dr. Suzuki is Chief, Laboratory of Molecular Diagnostics, Department of Mycobacteriology, Leprosy Research Center, National Institute of Infectious Diseases, Japan

What do researchers find interesting about *M. leprae*?

M. leprae has a very distinctive genetic makeup. The number of genes is very small; however, the number of pseudogenes — genes thought no longer to have a function — is extremely large. Normally these non-functioning genes are eliminated from DNA; but in *M. leprae* a lot of them remain. They account for nearly half of the *M. leprae* DNA, the highest among all known bacteria. Gene researchers want to know why these pseudogenes stick around and don't get eliminated. There is an interesting possibility that they have some other function.

Another point of interest is that *M. leprae* lives inside the host's macrophage. The macrophage is the immune reaction's director of operations; its job is to ingest bacteria and to launch an immune reaction. Yet *M. leprae* survives and multiplies in its enemy's command center. It tricks the immune cells into doing nothing. It's an extremely adroit mechanism.

> *M. leprae* tricks the immune cells into doing nothing. It's an extremely adroit mechanism.

If you could understand how this mechanism worked, what could you do?

M. leprae is a typical intracellular pathogen that parasitizes in the host macrophage. If we could understand this parasitization mechanism, we would be able to design or at least seek a new treatment. It might also be possible to develop a drug delivery system that mimics *M. leprae* parasitization, enabling us to insert a drug that would kill the bacilli before the disease develops. We'd like to steal the mechanism and use it against *M. leprae*.

Do you think it will be possible to eradicate leprosy some day?

I think that once the number of people with leprosy falls to a certain level, then the number will keep falling. Children have a chance of being infected in high endemic pockets, but even there, should case numbers decline, they will keep on declining. On that basis, the disease will eventually disappear. If you think about it from *M. leprae*'s point of view, unless it is transmitted to many different hosts, it's not going to survive. But it will take time. We must also pay attention to possible natural reservoirs of *M. leprae*, such as other primates and wild armadillos.

Are we going to see a leprosy vaccine?

As a scientist, I understand that creating a leprosy vaccine or brand new drugs or diagnostic tools are interesting research subjects to get funding for and to publish preliminary reports on. But in reality, it would be difficult to test a leprosy vaccine in clinical trials because of the very long incubation period of the disease and because of the geographical location of endemic areas and of people affected. Also, we do not have any animal models to run a phase 1 study. Although such basic science is important from a scientific viewpoint, when I consider the current situation, I am not sure whether it is a good idea to allocate large amounts of funding and human resources for vaccine research. Continuing the current efforts of the leprosy program may be the most cost-effective strategy to make use of limited resources.

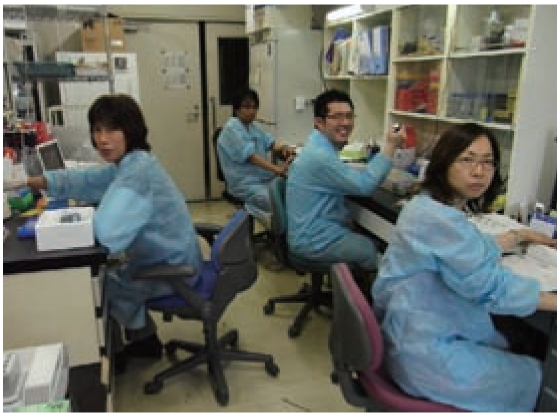
What about a faster treatment regimen?

One of the concerns is lepra reaction. Reaction occurs when the bacilli are killed, flooding the system with broken-down components. In response, a strong immune reaction takes place. If we want a treatment with no reaction, then maybe we should use a drug regimen that is actually a little less strong than MDT, and kill the bacteria slowly over three to five years, for example. That way, there may be no reaction. But the length of treatment must be balanced against such considerations as the quality of life.

Are there any areas you would like to see more emphasis on?

Treating everyone with MDT who needs it, when they need it, is very important and must continue. But I think we ought to be doing more for people *after* the infectious disease has been treated. I would like to see more emphasis on helping people with disability. Compared to the ongoing strategy for regisering patients and treating them with MDT, I feel that care for the disabled is less organized and less scientific, and relies largely on the efforst of individual caregivers. I think we could adopt a more scientific strategy to help them — for example, by providing guidelines for making a certain type of sandal for people who have a particular problem with their toes. I understand this kind of order-made medicine is not easy to supply, but I feel our efforts should shift to that direction in the future.

Will developments in regenerative medicine help people affected by leprosy?



Scientists at work in Dr. Suzuki's lab

Regenerative medicine is making a lot of progress. In the past, it was accepted that neurons don't regenerate. Yet data is now emerging that they do. A lot of big names are working on this; it's state-of-the-art medicine. It's also one of the most expensive areas of research. Since most people who would benefit from its applications are in developing countries, however, it may be some time before the fruits of this research reaches them.

Would you advise young researchers to go into leprosy?

If they are clinicians looking at patients, and want to go overseas as part of international cooperation, that is one thing; but as a basic scientist, who thinks *M. leprae* is interesting and wants to study it, I have to say it will be difficult for them to find a place to do this and attract funding. To focus only on leprosy as a career would be a risk. That said, academic science must have freedom, and I hope that creative young talents challenge whatever interests them. But if I really had their interests at heart, I would have to point out that in the scientific world, it is only research published in the best publications that is evaluated highly. From that point of view, I am not sure that leprosy research is a promising field for everyone to study. Nevertheless, I hope that basic research for leprosy can be sustained by creating research facilities supported by grants and other resources.

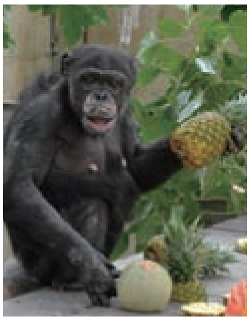
Does leprosy research have wider implications?

I like to think that the results of the research we are doing now, when looked at from a long-term perspective in a global context, will have applications in other medical and biological fields. Similarly, a breakthrough in a different field could lead to a big advance in leprosy medicine. But if people aren't still researching leprosy in 10 or 20 years' time, then we won't be able to take advantage of these breakthroughs. We need at least one center of excellence in leprosy research in the world to continue basic research. But it shouldn't be for leprosy alone. Ideally, it would cover four or five different areas of research, to act as a stimulus.

You spend a lot of time looking at *M. leprae*. What are your feelings toward it?

You will often hear researchers say, "I really like my bacterium! It's the cutest of all!" I find *M. leprae* fascinating. Over time, as is the case with other bacteriologists and their bacteria, I have come to like *M. leprae* more and more. I view it not so much as an opponent, but more as a rival with whom I'm engaged in a good conversation. "Better watch out," I'll say. "One day I'll get the better of you." ■

HARUNA MAKES LEPROSY HISTORY



It is speculated that leprosy develops after a long latency period following *M. leprae* infection in infancy. While the actual duration of this latency period has never been proven in human patients, Dr. Suzuki and his colleagues were recently able to demonstrate a long incubation period of leprosy in a female chimpanzee.

Haruna was brought from Sierra Leone to Japan in 1980 around age two. She was used in medical research for 10 years before being retired to a chimpanzee sanctuary. In January 2009, at the age of 31, she was found to have swellings and nodules on her face. Further tests resulted in a diagnosis of lepromatous leprosy. Haruna was put on multidrug therapy (administered with bananas or vegetable juice) and made a complete recovery.

Based on genetic analysis of *M. leprae* in Haruna's case, Dr. Suzuki and his colleagues scientifically demonstrated for the first time a long incubation period of leprosy. The genotype of Haruna's *M. leprae*, which has been identified only in West Africa, indicated she was infected during infancy and developed leprosy in Japan some 30 years later. Even in retirement, Haruna made an important contribution to medical research.

Reconnecting with the Past

People are returning to Culion in search of their roots — and shedding tears as they do.

AUTHOR:
Dr. Arturo C. Cunanan

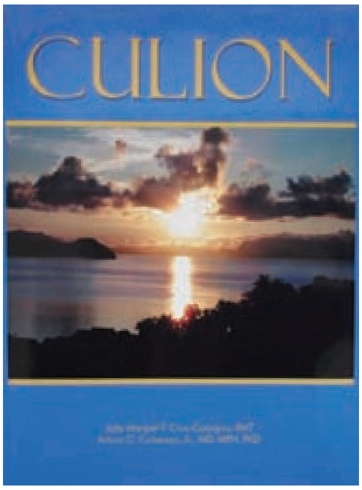
Dr. Arturo C. Cunanan is director of the Culion Sanitarium & General Hospital, and head of the Culion Leprosy Control and Rehabilitation Program. He spearheaded the establishment of the Culion Museum and Archives and is a coauthor of *Culion*.

During the first week of May, a festival of homecoming marked the 105th anniversary of the founding of a leprosy colony on the island of Culion in the Philippines. The celebrations included the launch of a new book dedicated to the pioneering health workers and to the early "colonists" — the leprosy patients sent to Culion to segregate them from the rest of the population.

The launch of *Culion* was attended by many sectors of the community, including descendants of those early health workers and colonists who had returned for the occasion from the United States, Canada, Australia, the Middle East as well as elsewhere in the Philippines. All were happy with the book, since it was the first to be authored by people from Culion itself. They feel it tells the real story of the colony, their roots and their identity.

A few days after the launch, three brothers and sisters in their mid-60s and early 70s visited. They had been born on Culion and spent their first years here, but had few memories of those days. Each now lives overseas: one in the United States, one in Indonesia and one in Australia.

Their grandparents, originally from the northern Philippines, met on Culion, where they had been sent with leprosy. Their mother was born here, placed in a nursery and later sent to Welfareville, a home in Manila for disadvantaged children, including children of leprous parents. She returned to Culion in 1944 and married an engineer.



The new book was a big help to the three siblings in learning about their roots and identity. Digging through the files at the Culion Museum and Archives, we found photos and records of their grandparents on their mother's side, and of other relatives sent to Culion. They were in tears seeing the documents, reading about Welfareville and the colony, and hearing stories of what their grandparents and parents had been through.

SEARCH FOR IDENTITY

I have seen many people cry as they look at photos of lost relatives and loved ones. There is increasing interest in reconnecting with the past. The Culion Museum and Archives, a related website and now the new book are helping people to fill in the gaps in their lives, renew family ties and discover their roots and identity.

One aspect of this process that touches me deeply is the interest that older people have in finding the answer to why they had the experiences they had as children, when others their own age didn't. Specifically, why did they suffer isolation, segregation and even humiliation, because they were the children of parents with leprosy, even though they themselves were disease free?

If it was inhumane and unwarranted to segregate people with leprosy on an island, then how much more so was it to take their children at birth and later institutionalize them at Welfareville? The negative social impact of this policy — the deprivation of parental love, the undermining of self-worth and self-confidence, the feeling of being "different" — has haunted these descendants into old age.

OVERLOOKED ISSUE

This is an important subject that has gone unremarked for many years because the focus has been on the people with leprosy. When I think of people affected by leprosy, however, I include not only those who contracted the disease, but also immediate family members who experienced the social, psychological and economic — but not the medical — consequences.

Such experiences are to be found in many part of the world, especially where structured colonies or sanitaria existed. For these people who have remained silent and have chosen not to be identified or allude to their past, sharing their experiences can be a catharsis.

At the recent 105th anniversary festivities, I met a lady from Hawaii who grew up in Welfareville and was very interested in meeting her peers and learning their stories. I have been able to compile a list of children who were sent to Welfareville. Unfortunately, a significant number are now dead.

I am now planning to organize a get-together of the remaining individuals — about 70 in number — so they can get to know each other and share their experiences. Meanwhile, I continue to research this subject and build up more information on this missing link in Philippine leprosy history. I would like to record the oral histories of all these individuals. As they are getting on in years, however, I know that time is not on our side. ■

The Way Home

Authors hope book will help encourage more family reunions at Sungai Buloh.

I first became interested in Sungai Buloh leprosarium when I made a documentary in 2007 for Malaysian television about the lives of people living there. Established in 1930 near Kuala Lumpur, it used to be one of the biggest leprosy settlements in the world[1].

Sungai Buloh is now an ageing community of people affected by leprosy. Many of its residents have spent the bulk of their lives there, after being forcibly isolated following a diagnosis of leprosy.

I was tremendously touched by the stories we filmed. Especially heartrending were the accounts of how the disease split families apart. It is this aspect of the Sungai Buloh story that drew me back to write a book with co-author Joshua Wong.

The Way Home[2] documents the lives of people who started families at the leprosarium but could not keep their children because of the rules prohibiting this. It also looks at what happened to the children, who went to live with relatives, were placed in care or given up for adoption. How both sides came to terms with their separation, and whether they have been successful in reconnecting in later life, are also themes of this book.

We interviewed ten people affected by leprosy and eight children about their experiences. Among these are Mak Liew Set and his daughter, Julie. Julie was adopted by an Australian couple and raised in Perth. Through the Internet, she was able to track down information about her parents, who had been confined to a leprosarium in Pulau Jerejek before being transferred to Sungai Buloh.

In October 2006, accompanied by her Australian foster mother, Julie was reunited with her parents at Sungai Buloh. Her story was documented in Loh Kah Seng's book *Making and Unmaking the Asylum — Leprosy and Modernity in Singapore and Malaysia.*

The account of their reunion affected me deeply. I subsequently contacted Julie, and offered to facilitate communication between her and her father. (By this time her mother had died.) I translated Julie's letters to him and helped him to reply. I was always touched by the way her father would smile when I read Julie's letters. For her part, there are no words to describe her feelings each time she received a letter from her father. She told me she reads them again and again.

SOCIAL STIGMA

The reunion between Julie and her father is one of three such cases we document in the book. I don't know how many more reunions will be possible. In some cases, it is already too late. In others, there is a reluctance on the part of the children to delve into their past and accept their birth parents. Some descendants we approached refused to be featured because of the social stigma.

Occasionally I wake up in a cold sweat in the middle of the night. In my dreams I have seen the tear-stained faces of Sungai Buloh residents I have interviewed. I worry they will not have the chance to see their children again before they leave this world. I wonder too how many children have cried at not being able to find their parents.

AUTHOR:
Eannee Tan

Eannee Tan is a freelance writer and former television journalist. She produced a series of TV reports about the Sungai Buloh leprosarium in Malaysia, including the 2007 documentary, The Everlasting Valley of Hope. She is very keen to document oral histories of people affected by leprosy and their descendents.

TO JULIE, WITH LOVE

Extract from a letter written by Mak Liew Set to his daughter Julie in Australia. It describes life on Pulau Jerejak, an island off Penang that was the site of a leprosarium until the 1960s.

"You may not know this, but your mum and I were happy during our days of being segregated at Pulau Jerejak. We had a plot of farm land. We also planted papayas. Those papayas were small and very, very sweet. We also built a small house near the sea so that we could fish. The island may not have had much in terms of entertainment, but we managed to entertain ourselves pretty well!

"We used to get together to gamble. I was usually the 'banker' (leader). We played a game called 'Fish, Prawn, Flower, Oyster'. Every afternoon, when everyone had returned from their fishing trips, we would gather under a tree. There were more than 10 of us leprosy patients gambling together with people who were not from the island. We gambled from 2 p.m. to 6 p.m.

"At night, we set out in our fishing boats to catch prawns. Whether or not we could go out to sea depended on the tide. We usually caught fish in the day time. We could catch 3 to 40 catties of fish per day. One catty of fish could be sold for more than RM6; one catty of prawn for RM2. Those were very low prices indeed! As a result, we earned very little money even though we had fished a few hundred catties of seafood.

"...I liked living on Pulau Jerejak because we had a lot of freedom. Besides gambling, drinking, and fishing, sometimes your mum and I also went across to Penang island to watch a movie. The Penang cinemas (such as Odeon, Rex, and Cathay) were some of our favorite places. Besides watching movies, we also drank brandy and ate good food. In those days, it only cost us RM10-15.

"Till this day, I can still remember the great movies that we watched, such as *The One-Armed Swordsman, Come Drink With Me, Golden Swallow*, and *The Ten Commandments*. one particular scene from *The Ten Commandments* — the parting of the Red Sea. That was an amazing scene. I heard that the tsunami swallowed an entire Indonesian island. Then, the crack in the earth joined together again. That sounds exactly like what happened in *The Ten Commandments*."

Julie (second from left) with her parents and children at Sungai Buloh

Society has failed to recognize that people affected by leprosy are human beings with feelings and emotions. They have had to endure the pain of forced isolation and the trauma of separation from their children. Although cured of the disease, the physical scars it has left and their long-term isolation have made social reintegration and family reunion difficult. If our book encourages more children to seek out their parents and allow them into their lives, we will be happy. ■

LEPROSY WISH LIST

Dr. H. Joseph Kawuma
Medical Advisor, German Leprosy and TB Relief Association
Chair, Technical Advisory Group for Leprosy, WHO

A FIELD TEST FOR INFECTION.

Knowing about the presence of infection in time would provide a timely opportunity to employ preventive measures in a better defined population. Increasing proportions of newly detected cases are contacts of known present or past patients and tend to arise from "leprosy pockets". Having a simple test for leprosy would make it easier to define the at-risk population.

A FIELD-BASED DIAGNOSTIC TOOL FOR ALL TYPES OF LEPROSY THAT IS LESS DEPENDENT ON CLINICAL SKILLS.

This becomes more relevant in the context of diminishing clinical skills and the integration of leprosy services into the general health services. The test should be one that guides the decision on the diagnosis and the need to treat, and preferably also justifies the end point of the treatment. The end point of current multidrug therapy (MDT) regimens is based on completion of the prescribed number of MDT blister packs.

A SINGLE, MUCH SHORTER TREATMENT REGIMEN FOR ALL TYPES OF LEPROSY.

When compared to the pre-MDT era, the present treatment is much shorter but it still demands too much time from both the patient and the health services. Managing separate regimens for PB and MB cases demands additional skills training and makes logistics management more complicated. Overall adherence to treatment would probably be better with shorter regimens.

A WAY OF PREVENTING OR MORE EFFECTIVELY TREATING REACTIONS, NEURITIS AND RESULTANT NERVE DAMAGE.

The MDT regimens in use at the moment are simple and robust, but do not address the problems of reactions and nerve damage that are the cause of most leprosy-related impairments and disabilities. If these did not occur, leprosy would be a much easier condition to deal with. Among other reasons, this would lead to a significant reduction in the need to maintain referral services. Most probably, there would also be a significant reduction in the psychosocial problems that accompany the disease.

Do you have a leprosy wish list?
Please write in and let us know:
smhf_an@tnfb.jp

FOOTNOTES

1 Now known as the National Leprosy Control Centre, it was integrated with Sungai Buloh Hospital in 2006. It is to be gazetted as a national heritage site.

2 Publication pending (in Chinese).

To Geneva and Back

Meetings with health ministers and officials on the sidelines of the 64th World Health Assembly, and laying the groundwork for Global Appeal 2012.

Sasakawa Health Prize winner, Dr. Eva Siracká (2nd from left) at the awards ceremony.

SWITZERLAND (MAY 17-20)

In May I traveled to Geneva for the 64th World Health Assembly. There I presented the 27th Sasakawa Health Prize, awarded annually for innovative work in health development. This year's winners were Dr. Eva Siracká from Slovakia, president of the Slovak League against Cancer, and The Pequeña Familia de María Brotherhood from Panama, an NGO providing assistance to people of all ages with HIV/AIDS.

But leprosy was also on my agenda. In a series of meetings that took place over two days at the Palais des Nations, the UN's home in Geneva, I had some productive discussions with health ministers and officials from a number of countries.

I met first with Myanmar's newly appointed Minister for Health Dr. Pe Thet Khin and his delegation. Myanmar eliminated leprosy as a public health problem in 2003 and is focused on sustaining leprosy control activities and enhancing efforts to prevent disability. In 2009, it detected around 3,000 new cases of the disease and has a new case detection rate of 5.6 per 100,000 population. The minister told me there are a number of leprosy "hotspots," including some in urban areas, and said they are investigating the causes.

Brazil is the only country where the prevalence of leprosy has yet to fall below 1 case per 10,000 population. In my meeting with Vice-Minister of Health Surveillance Dr. Jarbas Barbosa da Silva, he was keen to highlight his ministry's commitment to addressing this. "I am confident we can achieve elimination around 2015," he said. With these words, we can now look forward to the day when every country will have achieved this public health milestone.

On the subject of human rights, Vice Minister da Silva said that Brazil had made a lot of progress. Former President Lula da Silva launched an initiative in 2006 under which 6,000 people who were forcibly segregated in colony hospitals are receiving state support. "This is a very important commitment on the part of the Brazilian government to support people affected by leprosy and to fight against stigma and discrimination," the vice minister said.

In my discussions with Dr. Enrique T. Ona, secretary of health of the Philippines, he talked of providing incentives to people affected by leprosy for their social rehabilitation. In particular, he felt it was important to focus on their children and ensure they are educated and involved in society. "I am looking to conduct a survey of children and give them support for a college education," he told me.

My next meeting was with Nepal's new Health and Population Minister S.B. Basnet. Nepal achieved the elimination goal in 2010, yet still faces many challenges — one being to sustain this achievement. The minister told me he comes from a remote village, so is well aware of the problems his country faces. "But we cherish the dream of eradicating leprosy, and your goodwill and support will help us to

Vice-Minister da Silva (Brazil)

Secretary of Health Dr. K. Chandramouli (India)

Meeting with Health Minister Mphande of Malawi

achieve this dream."

After India and Brazil, Indonesia records the most number of new cases of leprosy each year. And for the past decade, the number of new cases has remained more or less constant. When I met Indonesia's Director General of Disease Control and Environmental Health, Professor Dr. Tjandra Yoga Aditama, he told me that one way that Indonesia is endeavoring to tackle this problem is through a tie up with a national alliance of the heads of provinces and districts. The idea is to strengthen leprosy control activities by involving people outside health circles as well.

> They told me that leprosy foot care is being integrated with diabetic foot care.

From Sri Lanka, Secretary of Health Dr. Ravindra Ruberu and his delegation told me that a number of leprosy hotspots had been identified at the district level and that active surveillance is being carried out. Commenting that diabetes is a huge problem in Sri Lanka, they told me that foot care for leprosy is being integrated with diabetic foot care.

Next I met with Professor David K. Mphande, the health minister of Malawi, a country I will be traveling to this year. "The leprosy program needs support to move out to the remotest parts of the country to see if leprosy is there. We need to train more people so they know how to diagnose and treat leprosy," he told me. "Many people think that leprosy is completely gone. Your visit will remind them that it hasn't."

India currently has a number of states in which the position of state leprosy officer lies vacant. Given the caseload of the disease in India, I raised my concerns with India's Secretary of Health and Family Welfare Dr. K. Chandramouli. I also proposed holding a meeting of state leprosy officers of endemic states similar to one held in Goa some years ago. The meeting would focus on states such as Orissa, Chhattisgarh and Bihar, where there are still significant pockets of leprosy, and discuss what action was needed.

In addition to these meetings with country representatives, I also held separate talks with WHO regional directors Dr. Luis Sambo (Africa), Dr. Samlee Plianbangchang (Southeast Asia), Dr. Shin-young Soo (Western Pacfic), Dr Hussein Abdel-Razzak Al Gezairy (Eastern Mediterranean), and Dr. Mirta Roses (the Americas).

I had one other important item of business. On May 18, I crossed into France to visit the headquarters of the World Medical Association. There I met Dr. Wonchat Subhachaturas, president, Dr. Jose Luiz Gomes do Amaral, president-elect, and Dr. Otmar Kloiber, secretary general. The WMA is the global federation of national medical associations that represents millions of physicians worldwide. I wanted to discuss the possibility of having the WMA endorse the 2012 Global Appeal to end stigma and discrimination against people affected by leprosy.

Doctors have a key role in clearing up the public's fears and misunderstandings about the disease, and the association's endorsement would carry great weight. The meeting went well and we reached an informal agreement to launch the 7th Global Appeal in Brazil, the home country of President-elect Dr. Gomes do Amaral, next January.

Last but not least, a special word of thanks to the WHO's Linda Aimé-McDonald. Because of her invaluable assistance and organizational skills, my busy schedule of appointments ran like clockwork. ■

10 Years On

May 2011 marks a decade since a landmark court ruling in Japan.

In July 1998, a group 13 persons affected by Hansen's disease filed a lawsuit against the Japanese government at the Kumamoto District Court. They were seeking compensation for being forcibly segregated under Japan's Leprosy Prevention Law that took effective in 1907 and was revised in 1953. More lawsuits followed, in Tokyo and Okayama, the next year.

The Kumamoto court eventually ruled in favor of the plaintiffs. It ordered the court to pay them compensation and ruled that the Ministry of Health and Welfare had been negligent in failing to alter its policy of isolation or scrap the law. The government chose not to contest the ruling.

May 2011 marks a decade since that landmark victory. Photojournalist Nobuyuki Yaegashi, a former staff photographer of the Asahi Shimbun, has spent some 15 years covering Hansen's disease. His new book, *Kagayaite ikiru* (Shining Lives), documents what the past decade has meant for all involved in that struggle. (Published in Japanese by Godo Shuppan, priced 2,000 yen.)

ILA REGIONAL CONGRESS

The International Leprosy Association (ILA) Regional Congress of the Americas will be held jointly with the 12th Brazilian Leprosy Congress in Maceio, Brazil, from November 23 to 26, 2011.

The events, which are organized by the ILA and the Brazilian Leprosy Society with support from the Ministry of Health of Brazil, will be an opportunity for people working in leprosy from the Americas and other regions to share their experiences and knowledge. See the ILA website for further details. ■

FROM THE EDITORS

TWO DISEASES, A COMMON ENEMY

It was 30 years ago this June that the first cases of a baffling new disease were reported in the United States. What the world came to know as HIV/AIDS has gone on to kill some 25 million people worldwide and left 33 million living with HIV.

In the beginning, the disease was associated with homosexuals. As it spread to other socially marginalized groups such as drug-users and sex workers, it reinforced the stigmatization they already faced. Because of its devastating impact on human health, the fear of contagion, and the discrimination suffered by those it affected, HIV/AIDS has sometimes been called "the modern-day leprosy."

In just 30 years, huge strides have been made in HIV/AIDS research and treatment. Fears and misconceptions remain, however. The stigma attached to the disease still prevents people from coming forward for testing, or causes them to conceal their condition for fear of rejection. These are issues familiar to leprosy.

In the long history of leprosy, it took centuries before the first real cure for the disease emerged in the 1940s. And it was not until the early 1980s — just as HIV/AIDS was emerging — that a truly effective cure became available in the form of multidrug therapy.

Today, leprosy is far down the list of priorities of most governments; AIDS, by contrast, is a pandemic.But political commitment remains as important to tackling leprosy as it does to HIV/AIDS. Similarly, the role of media is vital in shaping perceptions of both diseases and those who suffer from them. Leprosy can learn from global efforts to tackle AIDS-related stigma; in return, it can offer an insight confirmed down countless centuries of suffering: stigma lies not within those affected by a disease, but in the society that discriminates against them.

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