

# FOR THE Elimination OF Leprosy

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



Residents of a leprosy colony in Balangir, Odisha state, India, visited by the Goodwill Ambassador in September.

MESSAGE

## UNESCO Memory of the World

Many of the leprosy hospitals and sanatoria I have visited in pursuit of my life's work of eliminating leprosy are becoming relics of an earlier time. Before the development of an effective treatment, segregating people with leprosy had been seen as the best defense against a disease feared as highly infectious and incurable. Around the world, patients were shut away in these institutions.

Individuals who had committed no crime were isolated for decades. Even when released, they and their families remained tainted by the stigma of leprosy. Today Brazil is the only major country yet to pass the WHO's interim target of reducing the prevalence of leprosy to less than 1 case per 10,000 population, yet leprosy-related discrimination remains deep-rooted in many parts of the world.

In other words, this discrimination is not confined to past history; it is part of our own history and we must work to ensure that this mindset is not transmitted to succeeding generations.

UNESCO established the Memory of the World program in 1992 to safeguard humanity's

valuable documentary heritage from loss and destruction. As part of this, I believe the heritage associated with leprosy very much deserves to be registered as a Memory of the World.

The discrimination that patients and their families have endured, and their struggle to regain their dignity and their rights, is a memory that humanity must preserve for succeeding generations.

One day, leprosy will become a disease of the past, but the knowledge that it was a starting point of discrimination in the world, that it is a negative legacy of humanity, needs to be kept alive through the ages.

A negative history also contains positives, and we can learn from the strength and grace of people who experienced those times. This is another reason why I would like to garner support for leprosy's documentary heritage to be registered as a Memory of the World, and for this goal to be realized at an early date.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Leprosy by the Numbers

The current situation of leprosy in the world based on WHO figures for 2014.

The Global Leprosy Update, 2014, published in the WHO's *Weekly epidemiological record* for 4 September 2015, indicates that the disease still exists at least in small numbers of cases in many countries of the world and highlights the need for early detection.

## How many new cases of leprosy were there in 2014?

213,899 new cases were reported to the WHO by 121 countries.

## How does this compare to 10 years ago?

In 2005, there were 299,036 new cases, making for an average decrease of 2.8% a year over the past decade.

## Which countries have the most cases?

India, Indonesia and Brazil each reported more than 10,000 new cases of leprosy and together accounted for 81% of new cases globally. A further 10 countries reported between 1,000 and 10,000 cases — DR Congo, Ethiopia, Madagascar, Nigeria, Tanzania, Bangladesh, Myanmar, Nepal, Sri Lanka and the Philippines. Of all new cases in 2014, 94% were in these 13 high-endemic countries and the remaining 6% in 108 other countries.

## How many new cases were MB cases?

The proportion of multibacillary (MB) cases of leprosy globally was 60.6%. The five countries with the highest proportions of MB cases were Burkina Faso (94.7%), the Philippines (91.7%), Egypt (91.1%), Argentina (87.9%) and Indonesia (83.4%).

## How many new cases were among women?

Globally, 37.7% of new cases were women.

## How many new cases were among children?

18,869 new cases were children, or 8.8% of total cases. The five countries reporting the highest percentages of child cases were Micronesia (39.8%), Comoros (34.5%), Yemen (13.3%), Indonesia (11.1%) and Brazil (7.5%).

## How many new cases were reported with Grade 2 disability?

14,110 new cases were detected with Grade 2 (visible) in 2014, or 6.6% of total cases. The five countries reporting the highest percentages of G2 cases were Laos (31.7%), Uganda (28.0%), Pakistan (17.6%), Thailand (14.9%) and Colombia (12.2%).

## How many relapse cases were reported?

During 2014, 106 countries reported relapses, totaling 1,312 cases.

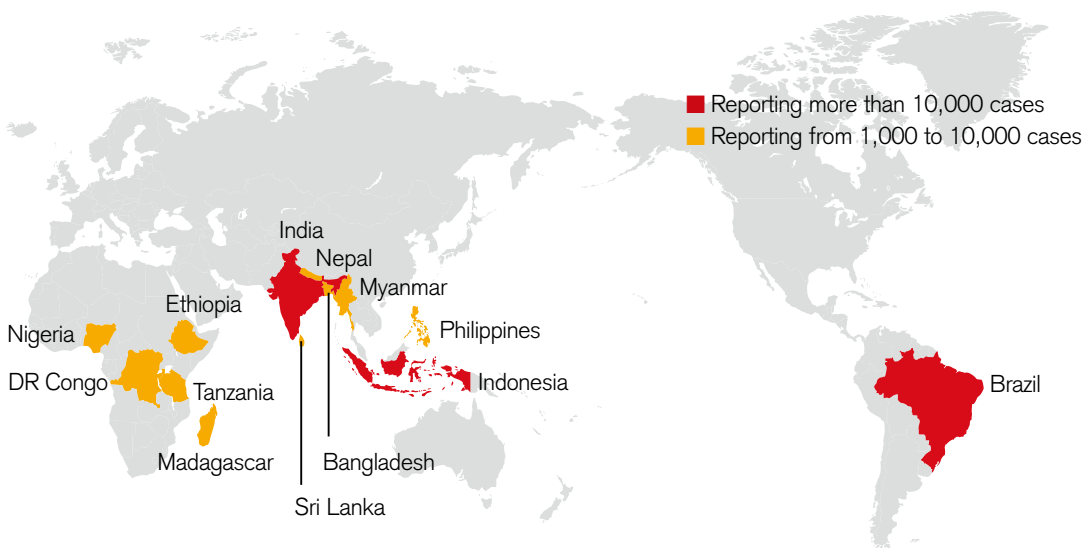
## What do the figures mean?

Trends in new case numbers and new Grade 2 cases indicate stagnation in leprosy control. Child cases and advanced forms of leprosy, i.e. multibacillary cases, indicates continued transmission of leprosy in the community. The target of reducing Grade 2 cases per 100,000 population by 35%, set by the WHO's Enhanced global strategy for reduction of the disease burden due to leprosy (2011-2015), will not be met.

## What happens next?

"Focusing on 13 high-burden countries that report 94% of global leprosy cases is the obvious choice to achieve immediate and demonstrable results," writes *WER* in an editorial note. The WHO is now preparing to launch its new global strategy for leprosy for the years 2016 to 2020. ■

13 COUNTRIES ACCOUNTED FOR 94% OF NEW CASES OF LEPROSY IN 2014



# Sisters United

Raised in different countries and cultures, two siblings finally come face to face.



Nurul (left) pictured with younger sister Esther in Japan on October 24.

Audiences in Japan were privileged in October to hear the stories of two sisters who met for the first time earlier in the month and who learned of each other's existence only recently. Esther Harvey of New Zealand and Nurul Ain Yap binti Abdullah of Malaysia were born to ethnic Chinese parents in a leprosy settlement on Pulau Jerejak, an island off Penang, Malaysia. Their parents were not allowed to keep them, and both girls were eventually adopted — Esther by New Zealand missionaries and Nurul by a Malaysian couple.

Esther's adoptive parents told her when she was 16 that her birth parents had contracted leprosy. Nurul was given differing accounts of her origins, among them the story that she was the child of leprosy patients.

The girls grew up, married and raised families, each unaware she had a sibling. In 2006, Esther felt ready to trace her roots. Her search led ultimately to Nurul. But before that, she would discover that her biological parents were already dead. "Words can't describe the sense of disappointment when I received that news. I really felt quite devastated," she said.

In the course of her research, however, she learned that her father had a younger brother and sister. She was eventually able to make contact with her aunt, who told Esther she had a sister. She was stunned.

Sometime later she was introduced to Eannee Tan, who has made it her mission to reconnect families separated by leprosy. It was Eannee and her team at Care & Share Circle who tracked down a birth certificate for Nurul on March 25 this year and an address for her in Kuala Lumpur on April 9.

Elated, they went to Nurul's home in Kuala Lumpur that night. En route, they sent Esther a message via Facebook that they were going to meet her sister. Several hours later, Esther received a photo of Nurul. "I just stared and stared at the photo for such a long time. I could hardly believe it," she said.

If Esther was startled at the speed of developments, imagine Nurul's reaction when three strangers arrived at her door, telling her she had a sister and confirming the story her parents were from a leprosy settlement.

"I was really shocked and confused. All the while I thought that I was alone, so when Eanee told me about my sister, I was not sure that Esther truly existed and that she was looking for me. In fact, I did not know how to react," she said.

But after learning that Esther had spent the past nine years searching for her family, Nurul felt it would not be fair to reject her. She also decided to visit the Sungai Buloh leprosy settlement outside Kuala Lumpur where her parents had moved after Pulau Jerejak. In doing so, she was following in the footsteps of her sister, who had met people who knew her parents and dedicated a plaque at the Buddhist temple there.

## 'NO CHILDREN TO CARE FOR THEM'

It pains Esther and Nurul greatly that they never met their mother and father and were unable to do anything for them in their old age. "Getting to see with my own eyes how my parents had spent the rest of their days with no children to care for them, and being confined in the settlement all by themselves to their dying day, is very sad," said Nurul.

But now the two sisters have each other — they met face to face for the first time in Malaysia in October and their ties blossomed on a speaking tour of Japan later in the month. They also have an uncle, aunt and assorted cousins to add to their existing families. "It seems like we have never been apart and we have known each other forever," says Esther. "We are comfortable as family — that is very, very special."

Having had much less time than Esther to process the information about her origins, Nurul is understandably protective of her sons and their feelings, and cautious as to how society will react. "I feel I should first educate myself to accept the truth, then educate my children in accepting our roots, and then society."

She is angry at the law that segregated her parents and caused her and her sister to be taken away, but appreciates they are lucky to have found each other when others have not been so fortunate. "It depends on us now to bring the family back together, because we cannot bear the pain of being separated again." ■



Esther and Nuru took part in a series of four symposia organized by Sasakawa Memorial Health Foundation promoting understanding of leprosy issues.

# A First Visit to Sorokdo

International forum on Hansen's disease provides historian with new perspectives.



A view of Sorok Island, South Korea (September 2015)



The island's museum depicts the lives of patients.

## AUTHOR:

**Waka Hirokawa**

Waka Hirokawa is Associate Professor of History at Senshū University in Tokyo.

On 17 September 2015, the “Third International Hansen Forum” was held at Sorokdo National Hospital in South Jeolla Province, South Korea. Specialists in the treatment, care and socio-economic rehabilitation of people affected by Hansen's disease gathered from South Korea, Vietnam, Myanmar and Japan. I was invited to be one of the presenters from Japan and was making my first visit to Sorok Island.

These international forums are organized by the hospital and South Korea's Ministry of Health and Welfare to promote international cooperation on eliminating the disease, removing the stigma and helping people affected by leprosy move on with their lives.

The theme of the third forum was “Human Rights and Independent Lives of Ex-Hansen Patients.” Presentations included those on mental health issues in South Korea, national leprosy elimination programs and community-based support for people affected by leprosy in Vietnam and Myanmar, and healthcare for elderly residents at a Japanese sanatorium.

**What I found remarkable was how many young volunteers attended the forum.**

I talked about Hansen's disease in Japan after the 1990s and the role of historical studies, arguing that historians should not only expose the failings of past government policy that violated patients' human rights but use their research to help promote reconciliation between individuals affected by the disease and their families, society and the government. Mr. Sun-Bong Kang, a former patient living in Sorokdo, gave an impressive speech about his life and what he and his fellow residents do to support themselves.

While the audience seemed to consist mainly of hospital staff, what I found remarkable was how many young volunteers attended the forum. Many,

including students, are active in Sorokdo and have stayed a long time. For me, the fact that one of the aims of the forum was to provide them with an educational opportunity seemed to show the hospital's passion for enhancing understanding of Hansen's disease among young people.

## DIFFERENT PATHS

Korea was under Japanese colonial rule between 1910 and 1945. From 1916, the colonial authorities implemented a policy of isolating Hansen's disease patients. Nevertheless, there exists a significant difference between South Korea and Japan in terms of the relationship between a sanatorium and society.

The different course taken by each nation in dealing with Hansen's disease issues in the 70 years since the end of World War II may explain this. While Japan accelerated the institutionalization of the patients, Korea built resettlement villages as a way to integrate people affected by the disease into society.

Even after Japan abolished the Leprosy Prevention Law in 1996, and even after the major changes that followed the legal victory by sanatoria residents in the compensation lawsuits against the government in 2001, volunteer activities in sanatoria have not been as evident as in Sorokdo. Japanese sanatoria do not go out their way to accept volunteers and, practically speaking, there are only a limited number of roles that volunteers can fill.

There is a museum showcasing Sorokdo's past with a courtyard at the rear that serves as a communal area for residents. It looked as if their day-to-day lives and the space that tells their history have been naturally integrated. Some colonial-era buildings have been preserved as cultural assets.

The national hospital is now planning a number of major events to mark its 100th anniversary in 2016.\* I respect it for the sincere efforts it is making to further enhance understanding of Hansen's disease issues and promote international cooperation through these activities. ■

## FOOTNOTE

\* The forerunner of Sorokdo National Hospital, Sorokdo Jikei Hospital, was established by the Japanese colonial authorities in 1916.

# Safeguarding the Past

A pictorial history marks the 90th anniversary of Borneo's last leprosarium.



A "patient worker" fits a prosthesis.

The Rajah Charles Brooke Memorial Hospital began life in 1925 as an isolated settlement for people with leprosy on the island of Borneo. Now transformed from a leprosarium into a district hospital, the RCBM Hospital in Sarawak, Malaysia marked its 90th anniversary in October with a celebration and the publication of a pictorial history.

*In the Sanctuary of the Outcasts: Life within the Rajah Charles Brooke Memorial Leprosarium* describes how patients lived in wooden longhouses, "surrounded by miles and miles of deep forest," and had little contact with the outside world. Able-bodied patients took on the role of "patient workers," carrying out tasks such as fetching water, cooking, cleaning and tending to the sick. One such



patient, "John," continued to live and work at the leprosarium after completing his treatment. He did so both out of a sense of calling and a realization that it would be difficult for him to be accepted by friends, family and the community because of the stigma of the disease.

The settlement was transformed under its fifth superintendent, who oversaw the building of new administrative blocks, a dispensary, wards, dormitories, staff quarters and a multipurpose hall during the 1950s. Patients were offered vocational training and employment at the hospital. Those released from treatment were encouraged to

return to their families, although, as the example of "John" showed, this was not always easy. A "Village of Hope" was initiated in 1980 to promote rehabilitation.

"Not many people actually look at this hospital from the perspective of a leprosy patient, from the perspective of a family member, and from the perspective of an ordinary human being," writes the hospital's director, Dr. Goh Xi Yiong. This

book does that, and is part of a movement to preserve the hospital's history in the form of an "open museum" — a national heritage site where visitors can encounter the past through buildings, artifacts, and the arts and crafts made by those for whom RCBM was their sanctuary and home.\* ■

## FOOTNOTE

\* The chief minister of Sarawak has given approval for the hospital's museum to be gazetted as the state's cultural heritage.

## MUSEUM PIECE

### WOODEN HOT SPRING PIPES

Kusatsu is a famous spa resort in the mountains of Japan's Gunma Prefecture. In the 19<sup>th</sup> century the town's hot springs drew people with leprosy in the belief that the acidic, sulphurous waters could provide relief from their disease. An informal settlement grew up at one end of the town and authorities granted the area the status of a "free recuperation zone." Residents of Yunosawa district operated their own businesses, owned their own homes and lived as free citizens.

In 1932, a national leprosy sanatorium was opened on the other side of town. In line with government policy, the residents of Yunosawa were required to move into the new sanatorium, called Kuryu Rakusen-en. But from the very beginning there had been resistance from those who didn't want to give up their homes, livelihoods and liberty and be isolated in an institution. And there was another sticking point: the planned sanatorium had no hot spring baths.

To resolve the latter issue, the authorities constructed an underground conduit to convey spring water from the town's "yubatake" (hot water field) to Kuryu Rakusen-en over a distance of around 3.5 kilometers.



Seen in the photo are sections of wooden piping on display at the sanatorium's museum. Made from Japanese red pine, they are approximately 40 centimeters in diameter and 180 centimeters long. Patients were involved in the work of hollowing out the logs, which were laid end to end and buried in the earth.

To complete the job in time for the opening of the sanatorium was said to have been a challenging undertaking. Furthermore, carrying out maintenance and repairs during Kusatsu's harsh winters also imposed a heavy burden on patients. Of the many types of forced labor that they had to endure, this was noted for being especially hard.

On the plus side, however, inmates regarded the baths at Kuryu Rakusen-en as the best in town. Kusatsu's hot spring waters are noted for being extremely hot, but their journey through the red pine pipes was said to cool them to just the right temperature for bathing.

# Life on the Margins

The Goodwill Ambassador visits self-settled leprosy colonies in India's Odisha, Uttarkhand and Bihar states to learn more about the challenges their residents face.

INDIA (SEPTEMBER 11-19)



With a man exiled from his village due to leprosy

From Raipur, the capital of Chhattisgarh in central India, it is a six-hour drive east to Balangir in neighboring Odisha. There I was met by Umesh Nayak, the state leader of the Association of People Affected by Leprosy, who had arranged for me to visit a leprosy colony in the city

Leaving my hotel the next morning, I saw people from Kallaripalli colony begging in the street. An elderly woman told me she made between Rs.30 to 50 a day. Given that the monthly pension for people affected by leprosy in Odisha is Rs.300, she could make two to three times that amount by begging for 20 days. Clearly there is a need to increase the pension. In Bihar, the equivalent pension is Rs.1,500 a month — enough so that this lady would not have to beg for a living.

I walked with Umesh to the colony. It was just

15 minutes away, but under the scorching sun it seemed much further. At the entrance, women were drawing water from a well. Residents, young and old, gathered around in greeting.

Their homes were rudimentary: brick walls with roofs of black sheeting held down by stones. The windows were very small and the temperature inside must have been approaching 50 degrees Centigrade. Although it was midday, the rooms were very dark.

I spoke with a woman whose roof had collapsed just two weeks earlier because of a buildup of rainwater. She had been at home at the time and the experience had left her traumatized.

I also met a young couple. The husband, who was not from colony originally, told me he could not get work because his wife was a person affected by leprosy. It is a sad fact that such discrimination still exists; at the same time, their marriage shows how the barriers of prejudice are being broken.

The next morning I went to see members of the colony begging near a Hindu temple. Although it was still only 9 a.m., it was already extremely hot. The best positions on the approach to the temple were taken by other beggars, with people from the colony on the other side of the road. Even in the world of begging, there is discrimination. Krishna, the leader of the colony, told me they took no pleasure in asking people for money. "We do this because we have to live," he said.

My last stop in Odisha was a village about



Ganga Mata Kusht Ashram: colony leader Keshav Choudhary is third from right

Sheetal started this chaat stall with microfinancing from Sasakawa-India Leprosy Foundation.



90 minutes' drive from Balangir. Nearby lived a man who had been exiled from the village after developing leprosy. After greeting the village head, I was taken by Umesh to the man's home. The villagers appeared put out by our sudden arrival and the purpose of our visit, but some of them followed us to the man's house anyway.

It was a simple dwelling of mud walls and a straw roof. From the gloomy interior emerged a white-haired man who appeared all skin and bones. He told me he had been living there for the past 30 years and had built the house himself. His wife still lived in the village, but he chose to remain by himself so as not to be a nuisance to her and the other residents.

### The husband could not get work because his wife was a person affected by leprosy.

The man told me his wife would sometimes visit and bring water and vegetables, but would not touch him. He has two sons, and grandchildren too, but they rarely visit. In the 30 years since he left the village, no one has held his hand, he said.

Some people in the village apparently thought he was being punished by God. I told them that leprosy was just a disease and was no cause to ostracize someone. But I fear there are still too many people like this man who are living a life apart because of leprosy.

Returning to Delhi, I travelled five hours by road to Haridwar in Uttarakhand state, which was created in 2000 from parts of Uttar Pradesh. The state is home to the source of the Ganges River, and thus attracts many Hindu pilgrims.

With residents of Ganga Mata Kusht Ashram is by the banks of the Ganges. It consists of a collection of simple dwellings made of corrugated metal walls and plastic sheeting. On arrival, I was greeted by colony leader Keshav Choudhary, a charismatic man swathed in orange.

People affected by leprosy receive a pension of Rs.1,000 in this state, so the colony residents have more security than their counterparts in Odisha. Among them was Santosh Gupta, 48. Originally from Kolkata, where he knew Mother Teresa, he has four children and eight grandchildren, all of whom are going to school.

I spoke with one of the younger residents, 10-year-old Bhim, who had just learned to write his name. As we talked, his older brother Vikash, 18, returned from class. A handsome youth, he said he doesn't experience any discrimination from living in the colony. He told me his dream is to attend technical college.

The colony attracts people from many parts of the country; more would like to live here but there is not enough land to accommodate them.

The last leg of my journey took me to Bihar. In Patna, the state capital, I visited Prem Nagar leprosy colony, adjacent to a bridge construction project. Gravel and other building materials were lying about and the air was full of dust. The colony dates back more than 60 years, but two years ago it was forced to move from its original location to make way for the bridge. According to the patriarch of the colony, 75-year-old Saudagar, the new site was swampland. Money had to be spent on landfill, leaving little left over for housing.

I met 50-year-old Sheetal. He started a business with micro financing from Sasakawa-India Leprosy Foundation. He sells savory, deep-fried snacks filled with spiced mashed potato and other ingredients from a chaat stall just outside the entrance to the colony. The food cart is patronized by passers-by and Sheetal told me that life has been good since starting the business with a helping hand from S-ILF.

I felt this colony had more energy than those I have visited where people mostly rely on begging to survive. But sad to report, I also met a family who told me that someone had attempted to set their home alight the previous evening. The discrimination and harassment that people affected by leprosy face is by no means at an end. ■

# Sasakawa Addresses JCI Congress

Welcomes JCI support for next year's Global Appeal to be launched from Japan.

Goodwill Ambassador Yohei Sasakawa recently attended the General Assembly of the Junior Chamber International (JCI) World Congress 2015 held in Kanazawa, Japan. JCI, a worldwide community of active young citizens aged between 18 and 40, is endorsing next year's Global Appeal to end stigma and discrimination against people affected by leprosy. The appeal will be launched at a ceremony in Tokyo on January 26, 2016.

Sasakawa told delegates that he was delighted to be partnering with JCI on Global Appeal 2016, saying that he wanted to send out a message to the younger generation in particular on the need to end discrimination. "JCI has a global network and channels the power of youth to tackle social challenges," he said. "Your activities have a sustainable impact on your communities."



With JCI International President Ismail Hazendar (left) and JCI Japan National President Kousuke Shibata

## ELIMINATION PROJECTIONS

A new study concludes that although country-level elimination of leprosy will be achieved by 2020, leprosy is likely to remain a problem in high-endemic regions that account for most cases in a country.

The aim of the study, published in the journal *Parasites & Vectors*, was to investigate whether the WHO target to interrupt transmission of leprosy globally by 2020 is feasible given current control strategy. Authors Blok, De Vlas and Richardus focused on the three most important endemic countries — India, Brazil and Indonesia.

According to the study's projections, country-level leprosy incidence will decrease to 6.2, 6.1 and 3.3 per 100,000 in India, Brazil and Indonesia, respectively, meeting the elimination target of less than 10 per 100,000. However, elimination may not be achieved in time for high-endemic regions within those countries. Leprosy incidence in 2020 is predicted to be 16.2, 21.1 and 19.3 per 100,000 in Chhattisgarh (India), Pará (Brazil) and Madura (Indonesia), respectively, and the target may only be achieved in another five to 10 years.

[www.parasitesandvectors.com/content/8/1/548](http://www.parasitesandvectors.com/content/8/1/548)

## 19th ILC BEIJING

The website for the 19th International Leprosy Congress that takes place in Beijing from September 18 to 21, 2016 is now open. The theme of the congress is "Unfinished business:

stopping transmission, preventing disability, promoting inclusion." Abstract submission opens on November 1, and registration begins from March 2016. ■

## FROM THE EDITORS

### TEARS AND JOY

"I read about how it only required a scratch on a piece of paper or a fingerprint to 'sign' your child away. This information encouraged me to pursue my search for my history, for a piece of my heritage, for family." So explained Esther Harvey when she spoke of the nine-year journey that led her to her sister, Nurul, earlier this year.

Esther and Nurul are the daughters of leprosy patients who were forced to give up

their baby girls and never saw them again. Few who heard them speak during their recent visit to Japan (see page 3) could fail to have been moved by what they heard. Their sadness at never meeting their parents was heart wrenching; their astonishment and joy at discovering each other was uplifting. It takes courage to express such feelings in public. Thank you, Esther and Nurul, for sharing your stories.

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