WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination OF Leprosy

August 2012 • Number 57

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

The Goodwill Ambassador speaks with Maria, a resident of Ukraine's national leprosarium in Kutschurgan, when he visited in July 2012.

MESSAGE

My Task

Working to eliminate leprosy is a primary part of my responsibilities. I am also committed to seeing that the human rights of people affected by leprosy and their families are restored and that they regain their dignity.

My strategy to achieve this began in 2003, when I first approached the United Nations. In 2010, the UN General Assembly adopted a resolution on ending discrimination against people affected by leprosy, endorsed unanimously by 192 countries.

But the resolution will have no meaning unless it is implemented. To this end, I have initiated a series of symposia on leprosy and human rights in five regions of the world — the Americas, Asia, Africa, the Middle East and Europe. The first symposium was held in Brazil in February and the second takes place in India this October.

The purpose of these symposia is two-fold: to draw the attention of governments and other bodies to the measures for ending discrimination outlined in the resolution's accompanying principles and guidelines, and to see that they are put into practice. Those attending include representatives of international organizations, governments, human rights bodies, NGOs and associations of people affected by leprosy.

A person living in a leprosy colony in India once asked me, "Do I have human rights too?" His question troubled me. To uphold and protect his rights and the rights of all people affected by leprosy, a multilayered, multifaceted strategy is needed. It is not enough to reach out to governments; it is necessary to appeal to the conscience of every member of society.

Eleanor Roosevelt once said that universal human rights begin in the "small places, close to home, so close and so small that they cannot be seen on any map of the world." So, while we must encourage international organizations and governments to act, spreading awareness at the grassroots level is even more important. I can only do so much on my own, but with your cooperation, moving forward together one step at a time, we will make progress.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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REPORT

Building Bridges

Astrakhan meeting aims to bring Russia, Central Asia into the global picture.

Conference participants from Central Asia

Leprosy has been endemic to parts of Russia and Central Asia, but in recent years there have been almost no reports of new cases from former Soviet countries. To gain a better picture of the situation, an international conference was held in the southwest Russian city of Astrakhan on June 29.

The occasion was the first visit to the Leprosy Training and Research Institute by Goodwill Ambassador Yohei Sasakawa. Through his visit, Sasakawa was seeking to learn more about the status of leprosy in the region and to link the work of leprologists there with global efforts to tackle the disease.

Taking part were experts from Russia, Kazakhstan, Turkmenistan, Tajikistan and Karakalpakstan, an autonomous republic within Uzbekistan. Representing the WHO's Global Leprosy Program was its team leader, Dr. Sumana Barua.

Also present was Dr. Romana Drabik, a German physician who has built up extensive knowledge of the disease in Russia and the Commonwealth of Independent States (CIS) over the past two decades. "Through the connections being made at this conference, our work for leprosy patients will improve," she said.

Country presentations confirmed that new cases of leprosy have been in decline. Dr. Victor Duyko, the director of the Astrakhan institute and Russia's top leprologist, reported no new cases of the disease in Russia in 2011, and only nine since 2001. As of January 1 there were 382 patients registered — although in Russia and the CIS, anyone diagnosed with leprosy remains registered for life, even after they have been cured.

"We have made progress. We see only a few new cases. But we still have work to do," said Dr. Duyko, who added that despite the break-up of the Soviet Union, his institute confers regularly with counterparts in former Soviet states.

Where numbers were concerned, it was a similar picture in other countries. Kazakhstan, for example, has 524 'patients' as of 2012, but has detected only four new cases since 2001. In Karakalpakstan, where men were not allowed to serve in the Soviet army between 1952 and 1962 because of the incidence of leprosy among them, there are 315 registered 'patients' but no new cases since 2007.

But as presenters made clear, there is more to the story. The possibility of undetected cases is real, and there are concerns about the circumstances of people affected by the disease.

In Tajikistan, which shares a 1,400-kilometer border with Afghanistan, the presence of some 25,000 migrants from that country is seen as a potential source of hidden cases; so too are difficult-to-access areas of the Pamir Mountains. In Turkmenistan, meanwhile, where there were also no reports of new cases, the situation for its 63 registered patients was described as "difficult" following the closure of the country's only leprosarium early in the last decade.

Additional information supplied by Dr. Drabik based on past visits to CIS countries indicated the sometimes desperate plight of people affected by leprosy and her suspicions that cases were going undetected.

'HOW CAN WE HELP?'

Dr. Barua reported on the activities of the Global Leprosy Program and invited participants to tell him how the WHO can support their national programs. He stressed the need to improve data collection and capacity building, saying, "We need to know where cases of leprosy might still exist."

He paid tribute to the important research that has taken place in Astrakhan in the past and hoped there would be a way to collaborate with the institute — including bringing it into the drug resistance surveillance program.

One practical step agreed on was for WHO documentation to be translated into Russian, including the current global strategy for leprosy for 2011-2015 and its accompanying operational guidelines. Discussions are also now taking place on conducting training courses on leprosy at the institute.

Other presentations included ones on research and international cooperation; on medical rehabilitation, including an introduction to Russian "liquid bandages" for ulcer care developed by military surgeons; and on new skin lesion treatments made possible by the biodiversity of the Astrakhan region.

Commenting on the significance of the visit by the Goodwill Ambassador and the Global Leprosy Program team leader, Dr. Drabik said, "It is very important for the institute, for Russia and for the CIS to be engaging with the WHO at this level. This is a historic moment for leprosy in these countries." ■

Preventing Disability

TENLEP study investigates ways to prevent and better treat nerve damage in leprosy.

Leprosy is a curable disease, yet delayed diagnosis can lead to permanent disability. The main cause of disability in leprosy is nerve damage.

Early detection and adequate treatment can prevent this, but leprosy is frequently diagnosed too late and often patients develop nerve damage to the hands, feet or eyes while on treatment. Prednisolone, a synthetic steroid, is the drug of choice to prevent this.

The TENLEP study involves two related drug trials aimed at preventing nerve damage or treating it when it is still in the early stages. TENLEP stands for Treatment of Early Neuropathy in Leprosy.

The project is funded by five different organizations: Netherlands Leprosy Relief, German Leprosy and TB Relief Association, Order of Malta, American Leprosy Missions and the Turing Foundation.

One trial deals with *Clinical Neuropathy:* nerve damage that has already resulted in loss of sensation in hands or feet, or weakness or paralysis of muscles. It looks at whether treatment with steroids for 32 weeks is better than the WHO-recommended regimen of 16 weeks.

The second trial deals with *Sub-clinical Neuropathy*: nerve damage that has not yet resulted in functional loss. It investigates if treatment with steroids at this very early stage can prevent loss of sensation and/or muscle strength.

MULTICENTER STUDY

TENLEP is a multicenter study taking place in Bangladesh, Indonesia, India and Nepal. A total of seven centers are participating. The study is coordinated through the Royal Tropical Institute in Amsterdam, with local teams responsible for the day-to-day running of the project.

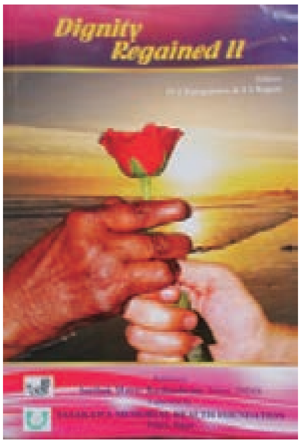
TENLEP training session at The Leprosy Mission International-Bangladesh research site at Nilphamari

The study started in 2011 with training sessions and workshop meetings for all centers. Patient intake started in April 2012 and will continue through most of this year and into 2013.

Many centers are participating because the study demands large numbers of patients to be able to show the effect of different doses and durations of treatment with prednisolone.

If activities go as planned, preliminary results will be available in 2014. Researchers hope these may lead to better treatment recommendations to prevent or treat nerve function loss, thus preventing the 'disabilities' so characteristic of leprosy. (Contributed by Erik Post, study coordinator, and Wim Brandsma, study manager, Royal Tropical Institute, Amsterdam.) ■

BOOK



Several books of testimonials by people affected by leprosy have been published in different countries with the support of Sasakawa Memorial Health Foundation. *Dignity Regained II* returns to India, where the series began in 2005, with the stories of 13 individuals whose lives were transformed by the disease.

Many of the accounts follow a similar trajectory: a happy childhood blighted by a diagnosis of leprosy; rejection; despair; treatment and cure; and 'dignity regained' through work, marriage, a determination to succeed, a settled home life and the support of others.

Along the way there are reflections on suicide contemplated and attempted; on resorting to grain smuggling and the illicit liquor business to survive; and on the shame of begging.

Perhaps hardest to bear is leprosy's impact on family relations. As Goswami Tribhuwan Giri tells his interviewer, "I was isolated in my own house. I was dejected, and was all alone among my own parents, brothers and sisters. They never cared [for] my feelings."

In the end, everyone featured in this book finds a way forward in life. Mangilal Chouhan wants the same for all people affected by leprosy: "The endless sky is open before us, it is up to us how high we can fly."

Global Emissary

The Goodwill Ambassador's travels take him to Brazil, Russia and the Ukraine. He also greets a visitor to Japan.

JAPAN (JUNE 15)


With American Leprosy Missions President and CEO Bill Simmons

On June 15 I welcomed visiting American Leprosy Missions President and CEO Bill Simmons to The Nippon Foundation. Mr. Simmons took up his post last year after two decades in management. He spent his teen years in Zaire (now DR Congo), where his parents worked as medical missionaries.

Like Mr. Simmons, I had a business background when I started my involvement in leprosy work some 40 years ago. I told him that the new perspective he brings would be very welcome.

His reaction on first learning that the number of new cases of leprosy had fallen below 300,000 was, "That's still a big number." His desire to do something about it was one reason why he joined ALM.

"I don't come from a medical field," he told me, "but I believe we can bring about an end to the disease. Some people may question that, but I believe we can do it."

He went on to say that he didn't intend to keep his organization alive beyond its stated purpose. "Leprosy is our focus, and when leprosy ceases to exist, we will cease to exist," he said. "I want to be the leader of one of the few NGOs to close the door when the job is done."

I told Mr. Simmons that his arrival on the scene was like "a fresh wind." I look forward to collaborating with him to achieve our common goal of a world without leprosy.

BRAZIL (JUNE 20-22)

The Rio+20 U.N. Conference on Sustainable Development took place in Rio de Janeiro in June. I attended in my capacity as chairman of The Nippon Foundation, which is committed to securing the future of the world's oceans. During my brief stay in Rio, I arranged meetings with Artur Custodio, the national coordinator of the Movement to Reintegrate People Affected by Hansen's Disease (MORHAN), and with Brazil's Health Minister, Dr. Alexandre Padilha.

Since its founding, MORHAN has worked very hard to fight against leprosy, to educate the community about the disease and to end stigma and discrimination. Through its efforts, it has secured compensation for those who spent years isolated in hospital-colonies. More recently, it has been pursuing redress for the "second generation" — children separated at birth from parents with the disease. Artur introduced me to Thiago, a law student and a member of this second generation, who is writing a thesis on the subject.

I am impressed by the way that MORHAN is evolving and bringing new people into its ranks. It doesn't always have an easy relationship with the government — "we are social activists," says Artur — yet despite the occasional conflict, the two sides have built up a close connection based on trust. Indeed, I can think of few civil society organizations that have the ear of government in quite the way MORHAN does.

Symbolic of their working relationship, Artur was present at my meeting with Dr. Padilha the next day. The minister assured me that Brazil remains focused on eliminating leprosy as a public health problem by 2015, plans to expand education about leprosy in schools and is pushing for early detection of the disease.

Artur reminded me that Brazil is one of the few countries to mention leprosy in its Millennium Development Goals. In addition, President Dilma Rousseff has made the elimination of leprosy part of her strategy to eliminate extreme poverty from Brazil. As ever, I continue to follow Brazil's progress with keen interest.


With MORHAN in Brazil; law student Thiago is at far left

Touring the wards at the Institute of Leprosy Training and Research in Astrakhan

RUSSIA (JUNE 28-JULY 3)

A noticeable absence from the WHO's annual Leprosy Update has been the vast area covered by its European Regional Office (EURO), which stretches from Western Europe to Central Asia and the Russian Far East and is made up of 53 countries. In many of these nations, leprosy is no longer considered a problem. Nonetheless, there are countries and regions where leprosy has a history, and cases still get reported.*

To find out more, I decided to travel to the WHO's EURO region. I was particularly interested in the situation in Russia and Central Asia. In this, I was very much inspired by the trailblazing efforts of Dr. Romana Drabik, a retired German physician who has made it her life's mission to address the medical needs of persons affected by leprosy (see Issue No. 55 of this newsletter). Since the early 1990s she has made repeated visits to the lands of the former Soviet Union, where she has established very good contacts with leprologists and is warmly regarded. Dr. Drabik accompanied me on my mission and was an invaluable presence. Indeed, without her efforts, the visit would not have been possible.

My first destination was the city of Astrakhan in southwest Russia, in the delta region of the Volga River near the Caspian Sea. The Institute of Leprosy Training and Research was founded here in 1948, on the site of a leprosy hospital that had existed since 1896.

The institute was the center of leprosy research and technical guidance on the disease in the former Soviet Union. Under its energetic director, Dr. Victor Duyko, it remains the focus of leprosy activities in Russia and also serves as a resource for Russian-speaking leprologists in the Commonwealth of Independent States (CIS).

Some of those leprologists were on hand to greet me at a small international conference that had been arranged to coincide with my visit (see page 2). I learned that, like Russia, countries such as Tajikistan or Turkmenistan report few new cases, but that the possibility of undetected cases cannot be ruled out. I also discovered that a person diagnosed with leprosy in Russia and the CIS remains registered as a patient even after they are cured, which makes it hard to interpret the numbers and know how many patients are under treatment.

Representing the WHO was Dr. Sumana Barua, team leader of the Global Leprosy Program, and Dr. Alain Disu from the WHO's Moscow Office, whose input was very helpful. If one of the outcomes of the conference is closer cooperation between the leprologists in the region and the Global Leprosy Program, then it will have served an important purpose.

> The Astrakhan institute remains the focus of leprosy activities in Russia.

As of January 1, Russia had 382 registered patients. I met several of them when Dr. Duyko took me on a tour of the institute, which also functions as a sanatorium. Some have been there for years, while others come temporarily for medical checkups, rehabilitation and treatment for leprosy-related conditions.

Among those I spoke to were a pair of sisters, Maria and Nina. They were staying in comfortable residential accommodation and had nothing but praise for the treatment they received from the doctors and nurses.

I gather that Dr. Duyko has done much to make the institute more patient-friendly. He has also brightened up the grounds — sowing lawns, planting flowers, putting up colored lights and even adding some garden gnomes.

There are reminders, too, of an earlier era in the shape of a large statute of Lenin as well as a

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FOOTNOTE

* Data for the European Region is scheduled to appear later this year in the *Weekly Epidemiological Record.*

shuttered prison. In Soviet times, registered leprosy patients who were convicted of crimes were sent here to serve their sentences. I was told that the last prisoner was released in 1987.

My stay in Astrakhan included a visit to the village of Vostochnoe. About an hour's drive from the city, this out-of-the-way community of about 1,000 people was established by the government in 1960 to provide people released from treatment with somewhere to live. Today, only around 10 or 15 households have connections with leprosy.

I visited several residents, spending time in the garden of Galina and her husband, who live off their pensions in a house provided by the government. They proudly introduced me to their 14-year-old son, Aleksander, who excels at judo.

I also met a 76-year-old widow. She first moved to the village with her late husband in 1968 after being discharged from the sanatorium at Astrakhan. She has no gas or running water, as she can't put aside enough from her pension to pay to have her home connected. In addition to her daily hardships, she told me, she had been the victim of a burglary. Everything of value was taken from her house, she explained, even her iron. The incident occurred during one of her stays at the sanatorium.

After I concluded my stay in Astrakhan, Dr. Duyko led me on an overland journey between the Caspian and the Black Seas. My destination was the North Caucuses, where I would visit two long-established leprosaria. After an 11-hour drive that took us across the vast plains of the Kalmyk steppe and past fields of sunflowers that seemed to spread out forever, we arrived at the town of Geogievsk in Stravropol territory.

This elderly resident of Vostochnoe said she had no gas or running water and had been the victim of a burglary.

The next morning we drove on to Tersky leprosarium. The oldest leprosarium in the Russian Federation, it marked its 115th anniversary earlier this year. At the time of my visit, Tersky had 51 inmates and a total of 43 staff. The most recent person to be admitted with leprosy was in 2009. The leprosarium's director, Dr. Mikhail Gridasov Ivanowic, grew up in Tersky village, and it was always his ambition to become a doctor and work here.

Dr. Duyko and Dr. Drabik (standing left and right) with sisters Nina and Maria

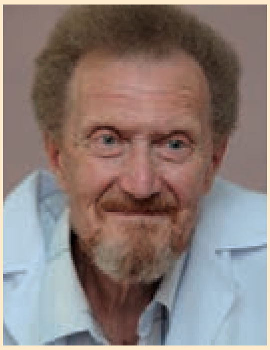
Tucked away deep in the countryside, Tersky is home to people who are cured of the disease but still require care, as well as others who are cured but have their own reasons for staying. As one elderly man told me, "I remain here because I don't want to cause problems for other people."

From Tersky I traveled on in the direction of the Black Sea. After spending the night in Krasnodar, I arrived at Abinsky leprosarium. This is another facility with more than a century of history. It was established in 1905 by a military surgeon who was concerned about the large number of cases of leprosy he found in the ranks.

The assistant director, Dr. Marina Gieorgievna, has worked at Abinsky for 29 years and is the daughter of a previous director who worked there for 30 years. In her father's time there were as many as 500 patients, but now there are just 40 — and three times that number of staff to care for them. The last patient with leprosy was admitted in 1998.

Given the facilities and staff on hand, I asked whether people with other illnesses could seek treatment at Abinsky. But I gather this is not permitted, because it was established by law to function as a leprosarium.

Some of the residents have lived here for many years. When I asked if they could leave, I was told this was possible, but that in reality it was



Dr. Naumov, Kutschurgan's director: "I have seen so much," he told me.

difficult for various social reasons. In contrast, it was emphasized to me, at Abinsky they are well looked after, don't have to worry about food or accommodation, have access to newspapers and magazines for free and can even be fitted with artificial limbs if necessary. In all, I was told, they lead a good life and there is no reason to leave.

UKRAINE (JULY 4-5)

After departing Krasnodar for Moscow the previous evening, on July 4 I flew to the Black Sea port of Odessa in the Ukraine. The country's only leprosarium, Kutschurgan, is a one-and-a-half hour drive west of Odessa, close to the border with Moldova.

The leprosarium was established in 1945 by an Odessa-born ophthalmologist who saw cases of leprosy earlier in his career when working at a hospital in Samarkand in present-day Uzbekistan. Noticing that he was coming across more patients with the disease in Odessa, he decided to do something for them.

As we drove to the leprosarium, the deputy director, Dr. Yuriy Rybak, explained that the area had been settled by German immigrants some two centuries earlier. When the German population evacuated during the later stages of World War II, the leprosarium took over some of the empty houses they left behind.

Kutschurgan has seen about 300 patients in total, with as many as 150 present in the early days. Today there are just 12 — seven men and five women — out of a total of 17 registered patients in the whole country. The most recent case was admitted in 2004.

I was surprised to learn that multidrug therapy (MDT), the WHO-recommended treatment for leprosy, only reached the leprosarium in 1997. It didn't come from the health ministry, but was brought by Dr. Drabik on her first visit.

The residents live in their own houses, with gardens that were blooming with flowers at the time of my visit. Among those I called on was Anastasia. She showed me around her home, which was decorated with family photographs and paintings. A widow, she said she had a son in Odessa "and four cats to keep me company." Speaking with another resident, Maria, I was moved when she told me that she had prayed for the people of Japan after the earthquake and tsunami disaster of March 2011.

The grave of the Korean at Kutschurgan cemetery

Calling on a resident of Tersky leprosarium

The director of the leprosarium is Dr. Vladimir Feodovich Naumov. He has been at Kutschurgan for 43 years. He was employed at a nearby hospital when he was asked to work at the leprosarium. "I wanted to help and it became my destiny," he said. "In the past it was a tough disease. There were people who couldn't walk. I have seen so much."

He told me about one patient, of Korean descent, who was in poor shape when he was admitted to Kutschurgan. One day, his teenage son turned up out of the blue, having traveled from Kazakhstan. Twenty-four hours later, the boy was found dead.

Following a police investigation, the father was convicted of murder, over the objections of Dr. Naumov, who doubted his patient was physically capable of such an act. The father spent six years behind bars, receiving regular visits from leprosarium staff, who brought him food. But prison weakened him, and by the time he was released he was sick with tuberculosis. He died soon after and is buried in the leprosarium's cemetery. I gather that the exact circumstances surrounding his son's death remain unclear.

I concluded my visit by going to the cemetery to see the father's grave, and the graves of others who had seen out their days in Kutschurgan, separated from society. Like the Korean, many were originally from outside the Ukraine and had died far from home. As Dr. Drabik noted, "They remain apart in death, as they were in life."

I am very grateful to Dr. Duyko in Russia, to Dr. Drabik, and to the WHO offices concerned for helping to make the arrangements for my visit. I gained a better understanding of the status of leprosy in the region, and of the leprosaria that have been a part of that history.

National Forum Elects New Chairman

Indian networking organization chooses Andhra Pradesh activist as leader.

Vagavathil Narsappa has been elected chairman of the National Forum India, succeeding Dr. P.K. Gopal as head of the national networking organization of people affected by leprosy founded in 2005.

President of the Society of Leprosy Affected People (SLAP) in Andhra Pradesh, and serving as a National Forum trustee up until his present appointment, Narsappa was elected chairman at a meeting of the trustees in June.

"I see the National Forum as a forum completely dedicated to the upliftment and welfare of people affected by leprosy," he says. "No affected person should face stigma or discrimination and should enjoy equal participation, equal rights, equal opportunity, equal dignity and equal integration."

Concerning the latter, he believes that leprosy colonies should no longer be labeled as such and that awareness programs should be undertaken in surrounding communities to promote integration.

Among the tasks he has set for the National Forum are to develop good leadership qualities at the grassroots level among people living in colonies; to teach people affected how to access government benefits available to them; and to forge links with other persons with disabilities to fight for rights and entitlements provided under the Persons with Disabilities Act.

Showing the younger generation of colony residents that they have choices in life and that there are alternatives to begging is a particular priority. "Young people should be counseled that by going on courses available to them and by attaining a minimum educational qualification, they can get better jobs and choose from among more options," he says.

Former chairman of the National Forum, Dr. P.K. Gopal, a social scientist and recipient of a prestigious Padmashree award earlier this year, stays on as senior consultant.

INDIA 2011-2012

India's National Leprosy Eradication Program reports that 127,000 new cases of leprosy were detected during the year to March 31, 2012. Of this number, multibacillary cases accounted for 49%, female cases for 37%, child cases for 9.7%, and cases with visible deformity for 3%.

Of India's 35 states/union territories, 32 have achieved a level of elimination defined as a prevalence rate of leprosy of less than 1 case per 10,000 population. A total of 543 districts out of 642 have reached this level.

One state (Chhattissgarh) and one Union Territory (Dadra & Nagar Haveli) have a PR between 1 and 3 per 10,000 population. Although Bihar has reached a PR of below 1, it is considered too soon to declare it has achieved elimination.

During the year, reconstructive surgery was performed on 2,548 people affected by leprosy, 55,162 received multi-cellular rubber (MCR) footwear and 43,016 received self-care kits.

To date, 12.67 million people in India have been cured of leprosy since the introduction of multidrug therapy. ■

FROM THE EDITORS

FRIENDSHIP IS INFECTIOUS

It is sometimes said that while leprosy is a disease that's hard to catch, the friendships that form among those working in leprosy are very infectious. As toast followed toast at a dinner rounding off a conference in July at the Institute of Leprosy Training and Research in Astrakhan, Russia, it was clear that friendships were spreading fast.

The conference had been called to help open up a channel of communication between the global leprosy program and experts in Russia and Central Asia. It certainly succeeded in promoting friendships among those taking part. On this basis, a closer working relationship beckons. The beneficiaries will be the national leprosy programs concerned and the people affected by leprosy whose needs they serve.

FOR THE ELIMINATION OF LEPROSY
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With support from:
Sasakawa Memorial
Health Foundation,
The Nippon Foundation

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