WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE

Elimination of Leprosy

August 2008 • Number 33

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

Goodwill Ambassador Sasakawa (front row, fourth from right) with health officials and outpatients at a health center in Conakry, Guinea, in June.

MESSAGE

To People Affected by Leprosy

It is five years since I first approached the Office of the United Nations High Commissioner for Human Rights (OHCHR) in 2003 to raise leprosy as a human rights issue. Since then, with support from all of you, I made repeated visits to the UN Commission on Human Rights and to its Sub-Commission to encourage them to pursue this long-overlooked topic.

It has taken much time, but at last, on June 18 this year, the United Nations Human Rights Council unanimously passed a resolution to eliminate discrimination against people affected by leprosy and their families. This resolution adds an important new page to the history of our fight against leprosy, and I am delighted at its passage.

The resolution was submitted by the Japanese government in response to my appeal. Thanks to the government's courteous and diligent approach work, the resolution was ultimately co-sponsored by 59 countries, among them states that are not currently members of the Human Rights Council.

This is truly an epoch-making event. Each government recognized that the problem of discrimination against people affected by leprosy is universal in nature, transcending politics, religion, race, age and sex, and I commend them for their understanding.

The stage is now set for the OHCHR to collect information on measures to eliminate discrimination, and, based on these findings, for the Human Rights Council Advisory Committee to compile a set of draft guidelines to present to the Council by September 2009. I am confident that a specific set of measures will emerge from these guidelines.

Through the ages, countless millions of people affected by leprosy and their families have suffered from discrimination and lived out their days in isolation and exclusion. On the back of their sacrifices our movement has reached this point. I urge all of you to go forward each day with courage and pride. The developments in Geneva represent a big step forward in the quest for dignity and social reintegration.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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History Is Made in Geneva

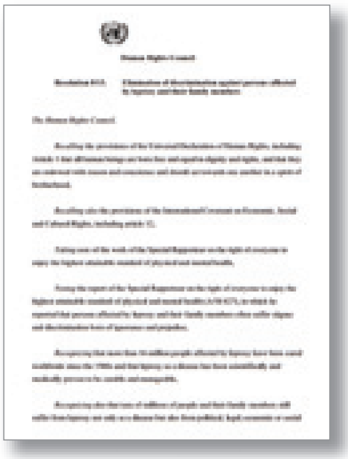
UNHRC resolution to end leprosy-based discrimination breaks new ground.

On 18 June, the Human Rights Council unanimously adopted Resolution 8/13 on "Elimination of discrimination against persons affected by leprosy and their family members." This is the full text.

The Human Rights Council,

Recalling the provisions of the Universal Declaration of Human Rights, including Article 1 that all human beings are born free and equal in dignity and rights, and that they are endowed with reason and conscience and should act towards one another in a spirit of brotherhood,

Recalling also the provisions of the International Covenant on Economic, Social and Cultural Rights, including article 12,



Taking note of the work of the Special Rapporteur on the right of everyone to enjoy the highest attainable standard of physical and mental health,

Noting the report of the Special Rapporteur on the right of everyone to enjoy the highest attainable standard of physical and mental health (A/58/427), in which he reported that persons affected by leprosy and their family members often suffer stigma and discrimination born of ignorance and prejudice,

Recognizing that more than 16 million people affected by leprosy have been cured worldwide since the 1980s and that leprosy as a disease has been scientifically and medically proven to be curable and manageable,

Recognizing also that tens of millions of people and their family members still suffer from leprosy not only as a disease but also from political, legal, economic or social discrimination and ostracization due to society's lack of knowledge and misguided notions, such as leprosy being incurable or hereditary, and that the issue of leprosy is not only a matter or medicine or health but also one of discrimination that can give rise to a clear violation of human rights,

Taking note of the previous work done by the Commission on Human Rights and its mechanism on discrimination against persons affected by leprosy and their family members,

Encouraging States to share best practices on combating discrimination against persons affected by leprosy and their family members and also on their efforts to achieve full recovery from and manage this disease,

1. *Affirms* that persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all basic human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws;

2. *Calls upon* Governments to take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members, including awareness-raising;

3. *Requests* the Office of the United Nations High Commissioner for Human Rights to include the issue of discrimination against persons affected by leprosy and their family members as an important matter in its human rights education and awareness-raising activities;

4. *Also requests* the Office of the United Nations High Commissioner for Human Rights to collect information on the measures that Governments have taken to eliminate discrimination against persons affected by leprosy and their family members, and, if extra-budgetary funding is available, to hold a meeting to exchange views amongst relevant actors, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and programmes, non-governmental organizations, scientists, medical experts as well as representatives of persons affected by leprosy and their family members, and to transmit a report to the Council and the Human Rights Council Advisory Committee;

5. *Requests* the Human Rights Council Advisory Committee to examine the report referred to in paragraph 4 above, and to formulate a draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and to submit it to the Council for its consideration by September 2009;

6. *Decides* to consider this issue based on these reports submitted to the Council in September 2009. ■

The UNHRC Resolution Explained

Why it represents a major step forward for people affected by leprosy.

What is the Human Rights Council?

The Human Rights Council is a United Nations body established on 15 March 2006 by a vote of the UN General Assembly. Its role is to promote universal respect for the protection of human rights and fundamental freedoms, and address violations of same. The 47-seat Council replaced the 53-seat UN Commission on Human Rights. The Commission was an independent body, but the Council is a subsidiary organ of the UN General Assembly. Members of the Council are elected to staggered three-year terms from among the 192 UN member states.

Who proposed the resolution?

It was proposed by the Japanese government in response to an appeal led by Yohei Sasakawa on behalf of people affected by leprosy around the world. Sasakawa is WHO Goodwill Ambassador for Leprosy Elimination and, since September 2007, the Japanese Government's Goodwill Ambassador for the Human Rights of People Affected by Leprosy.

Who co-sponsored it?*

At the time the resolution was submitted to a vote, it was co-sponsored by 58 states (31 of which were member states of the Human Rights Council). After the resolution was adopted, Bhutan became the 59th state to sponsor it.

What are the main points?

(1) Each country must be aware of the fact that leprosy-related discrimination is a serious violation of human rights. (2) Each government is requested to take measures to eliminate leprosy-related discrimination. (3) The Office of the United Nations High Commissioner for Human Rights (OHCHR) is requested to conduct human rights education and awareness-promotion activities concerning leprosy. (4) The OHCHR is requested to conduct research on the efforts made by each country to eliminate leprosy-related discrimination and gather information. (5) The Human Rights Council Advisory Committee (a body composed of 18 experts that acts as a think-tank for the Council) is requested to draw up guidelines by September 2009 to end leprosy-based discrimination.

How does this resolution differ from previous resolutions adopted by the Sub-Commission for the Promotion and Protection of Human Rights?

The Human Rights Council meets in Geneva.

The Sub-Commission was the main subsidiary body of the Commission on Human Rights. It comprised 26 human rights experts and met for the last time in August 2006. Between 2003, when the issue was first brought to the Sub-Commission's attention, and 2006, it passed a total of three resolutions calling for an end to discrimination against people affected by leprosy. Although the Sub-Commission was entitled to adopt and issue its own resolutions, as an independent research body attached to the Commission on Human Rights, its resolutions were by way of recommendations. The resolution adopted by the Human Rights Council in June is different in nature and effect. It has been co-sponsored by 59 governments and unanimously adopted by the 47 member states, all of whom have thus agreed to abide by it and are expected to implement whatever steps are necessary to fulfill its objectives.

What does this mean for people affected by leprosy?

This is the first time so many countries have officially agreed that discrimination toward people affected by leprosy exists and have shown an interest in tackling it. People affected by leprosy who want to see progress made on this issue can now expect to count on their government's understanding and support.

What happens next?

The OHCHR has already been in touch with all Permanent Missions to the United Nations to request information in order to prepare a report to transmit to the Council and the Council's advisory committee by September 22, 2008. There are also plans to hold a meeting to exchange views among relevant actors in December 2008 or January 2009. It is likely that people affected by leprosy will be approached by their governments to assist in the information-gathering process, and also that they will be asked to attend the meeting. ■

Reference

* CO-SPONSORS

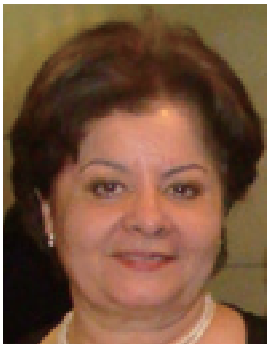
Japan*, Cuba*, Ireland, Spain, Guatemala*, Bangladesh*, Venezuela, Greece, Andorra, Bolivia*, Romania*, Slovenia*, Finland, Brazil*, Montenegro, Egypt*, Philippines*, Netherlands*, Sri Lanka*, Indonesia*, Maldives, Chile, Djibouti*, Mauritius*, Mali*, Austria, Cyprus, Italy*, Timor-Leste, United Kingdom*, Denmark, Thailand, Cameroon*, Nigeria*, Uganda, Serbia, Jordan*, Germany*, Israel, Madagascar*, Slovakia, Australia, Republic of Korea*, China*, Ukraine*, Honduras, Czech Republic, Pakistan*, Turkey, Colombia, Senegal*, Saudi Arabia*, Bulgaria, Estonia, Bosnia and Herzegovina*, Nicaragua*, Portugal, Nepal, Bhutan. (* denotes HRC member states)

Action Plan Targets Child Cases

Government focuses on reducing the number of transmission sources.

The annual meeting of Brazil's National Hansen's Disease Program (PNCH) was held July 2-4 in Brasilia.

AUTHOR:
Dra. Maria Leide W. de Oliveira



Dra. Maria Leide is coordinator of Brazil's National Hansen's Disease Program

Brazil has yet to move past the interim goal of eliminating Hansen's disease as a public health problem, but is making efforts in this direction by focusing on reducing the number of transmission sources. Recent federal administrations have made the disease a priority, and this can be seen in the latest Ministry of Health action plan for 2008-2011. The goal to 2011 is to reduce the child detection rate by 10%, which calls for strengthened epidemiological surveillance activities.

Of new cases in Brazil, 8% occur among children under the age of 15, representing a major challenge for the country's National Hansen's Disease Program (PNCH). This indicates that adults with Hansen's disease who have not been diagnosed are transmitting the disease to children and adolescents, usually within the same family.

> Undiagnosed adults are transmitting the disease to children and adolescents.

This could be related to the fragile performance of household contacts surveillance, given that under 50% of contacts were examined in 2006-2007. One of the priorities of the action plan, therefore, is to improve surveillance in identified clusters.

The action plan also includes several measures for providing financial support to Brazil's most endemic regions, in addition to projects to strengthen organizations of people affected by the disease. The government is also paying a monthly stipend to help people isolated in colony hospitals in the past to recover their citizenship rights.

To ensure the technical, political and social sustainability of PNCH, several partnerships have been formed with different stakeholders. These stakeholders include members of the International Federation of Anti-Leprosy Associations (ILEP), scientific societies, religious leaders and organizations of people affected by Hansen's disease such as the Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN), GAMAH (a group of women affected by the disease) and the International Association for Integration, Dignity and Economic Advancement (IDEA).

CLOSE COOPERATION

To reinforce the permanent integration of the PNCH within the basic health care system, with a view to expanding patient access and refining epidemiological surveillance, the program is working closely with the health ministry's Basic Care Department (DAB) and Information System (SINAN) and is also liaising closely with state and municipal authorities. In addition, PNCH recently issued five new learning materials on Disability Prevention and Rehabilitation.

Investment in the managerial training of technical personnel at the regional and local level has focused on program improvement. This is in view of the importance of monitoring and evaluation (M&E) as key administrative instruments to improve the effectiveness of the program. A total of 380 technicians from the most endemic municipalities have been trained.

At PNCH's annual meeting held in Brasilia on July 2-4, the 220 stakeholders attending gave their enthusiastic backing to the government's action plan and also welcomed the Hansen's disease awareness campaign that was to launch on July 6 (see facing page). ■

LEPROSY FACTS

In the past five years, Brazil has identified around 47,000 new cases of leprosy annually.

Media Campaign Promotes Awareness

Initiatives focus both on clinical symptoms and patient rights.

In July, Brazil's health ministry launched a 15-day nationwide campaign to control Hansen's disease. Under the slogan, "It's good to know about health!" the July 6-20 campaign was designed to educate the public about the disease and promote early diagnosis and treatment, particularly among adolescents under the age of 15.

As well as 15- and 30-second TV and radio spots that featured testimonials from people who once had the disease, the campaign also utilized a poster, a pamphlet and a handbook targeting health professionals, educators and media as well as the general public.

Appearing on the poster and pamphlet was Maria das Gracas, identified as someone who had been cured of Hansen's disease. The poster headline asked, "How do I know I have Hansen's disease?" while the body copy described symptoms and included a toll-free number at the ministry of health to call for further information.

One hundred telephone operators trained to answer basic questions about leprosy and with access to a database on the disease were standing by to take calls. Campaign materials also included the toll-free number for Telehansen, the telephone counselling service run by MORHAN.

Over 70 pages long, the colorfully illustrated handbook *Hansen's Disease and Human Rights: Brazilian Unified Health System (SUS) User Rights and Responsibilities* included sections on the rights of affected persons to treatment, reconstructive surgery, psychological support and rehabilitation, while also stressing their responsibilities, such as adhering to their treatment, conducting household contacts surveillance and practicing self-care to prevent disability. The ministry distributed 100,000 copies of the handbook, together with a further 2 million pamphlets with facts about the disease.

The combination of a campaign to promote early diagnosis together with the publication of information on human rights emphasizes the government's commitment not only to reducing the number of new cases of Hansen's disease but also to ensuring that all those cured of the disease who suffer from impairment receive appropriate care. ■

Campaign poster (top), cover and sample pages from handbook (center), and TV commercial (above)

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Guinea: A Work in Progress

A first visit to this West African republic for the Goodwill Ambassador, coinciding with the formation of a new cabinet.

REPUBLIC OF GUINEA (JUNE 18-22)

In June I made my first visit to the Republic of Guinea. A country of 9.7 million located in West Africa, Guinea reached the WHO's goal of eliminating leprosy as a public health problem in 2006. For succeeding in this endeavor, working with limited resources, it is regarded as a model case in Africa. However, as I would learn during my stay, it still has much to do.

As is usual on these missions, my visit had several purposes: to meet with political leaders to secure their ongoing commitment to leprosy control, to encourage health officials and people working in the field in their work, to spend some time with people affected by leprosy, and to promote efforts to end social discrimination, especially through media coverage of my visit.

However, on this occasion, because of the fluid political situation, it was unclear up until the last minute who I would be meeting, or even if I would reach Guinea at all. A month earlier, President Lansana Conte sacked the prime minister he had appointed only a year earlier, replacing him with Ahmed Tidiane Souare. Adding to the air of uncertainty, the new prime minister was to take several weeks to name his new cabinet. Then, just two days before I was due to arrive, the police went on strike over pay and conditions, emulating the military who had staged a similar (and successful) protest weeks earlier. The police were joined by customs officials, which led to the closure of the airport. Eventually, the strike was put down by the military on June 17, but at a cost of 8 deaths and 64 injuries.

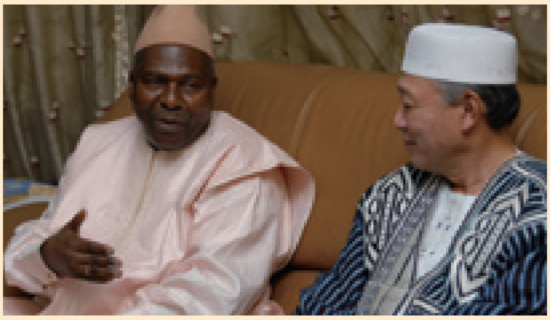
In the end, I arrived on June 18 as scheduled in the capital, Conakry, and was greeted at the airport by Health Minister Sangare Hadja Maimouna Bah. As it turned out, this was her last week on the job, as she was to be replaced when Prime Minister Souare finally named the new ministerial line-up a couple of days later. When we met again the following morning, I thanked her for the ministry's commitment to fighting leprosy, and she promised me that this would continue, while noting that pockets of high endemicity persist and that greater efforts are needed to prevent cases of disability.

Later in the day I was briefed by Dr. Fatou Sakho, the coordinator of Guinea's national leprosy program, which was established in 1985. In 1990, Guinea had a registered prevalence of 11.9 per 10,000 population; in 2007, the rate had dropped to 0.74. Of the 803 new cases reported last year, 70% were cases of multibacilliary leprosy, 12% showed grade 2 disability and 9% were child cases.

Dr. Sakho said that of Guinea's 34 prefectures, 28 have achieved elimination. Four of the remaining six currently have a prevalence rate of between 1 and 2, and the two others (which border Sierra Leone and Liberia, respectively) of over 2. It is in these six prefectures especially that more work must be done to reinforce surveillance activities and to alleviate the social, physical and economic consequences of the disease.

On the morning of June 20, I paid a short visit to a health center in Madina, a suburb of Conakry. This is an outpatient facility that sees some 80 patients a day, including those with TB and leprosy. I arrived when the center opened at 9 a.m., and there were already many people present, including some 10 people affected by leprosy who had come especially to meet with me. I am told that Guinea has a well-developed system of primary health care, which has played its part in the country achieving the elimination goal.

From the health center I went straight to an appointment with Prime Minister Souare, who had just announced his new cabinet the night before. In my brief remarks, I asked him to pass on the three messages that leprosy is curable,



Meeting with the president of Guinea's National Assembly, Elhadj Aboubacar Sompare

The Goodwill Ambassador is given a rousing welcome during a visit to a health post in Damakanya, Kindia.

treatment is free, and that social discrimination has no place. For his part, the prime minister gave me his commitment to fighting leprosy and discrimination. Next, I called on the president of the National Assembly, Elhadj Aboubacar Sompare, to deliver a similar request, and he impressed me greatly with his knowledge of the disease.

Supporting Guinea in its fight against leprosy are several NGOs, and I had an opportunity to meet with them that afternoon. Of the international NGOs, the Mission Philafricaine has had the longest presence in Guinea, dating back to 1982. It operates in Forest Guinea, where it opened a center in Macenta and began treating people with MDT. Currently it provides support by training people affected by leprosy to become self-reliant and offers reconstructive surgery. The Raoul Follereau Association has been in Guinea since 1985, where it works in Upper and Lower Guinea, supporting the health ministry by supplying drugs, training staff, providing vehicles and fuel and also conducting awareness campaigns in rural communities. A third international NGO, the Order of Malta, operates in Middle Guinea, but its representative had just been appointed to the new cabinet, and could not be present at our meeting.

There are also two local NGOs. One is the Raoul Follereau Guinea Association (AGUIRAF), which covers the whole country, going into the interior, investigating patients' needs, providing assistance to help people affected by leprosy become self-reliant, and promoting social integration. Another is an association representing people affected by leprosy, founded in 2005. To date, however, its activities have been constrained by lack of funds.

On June 21, I left Conakry at 8 a.m. to visit a health facility in Kindia, an upland city 135 kilometers east of the capital. With a population of some 135,000, Kindia is a major producer of fruit and vegetables, which are shipped by truck to Conakry each morning. The health post at Damakanya is one of 20 in Kindia prefecture, and specializes in patients with HIV/AIDS, leprosy and TB. Originally set up to treat cases of sleeping sickness caused by the Tsetse fly, the health post sees an average of 20 patients a day. At the back is a garden cultivated by persons affected by leprosy, who grow mangoes, oranges, grapefruits, coconuts and more for sale in Conakry.

To welcome me, about 20 persons affected by leprosy had come in from the surrounding area. There was a colorful welcoming ceremony with music, song and dance, as well as a short skit performed by people affected by leprosy that went as follows. A man visits a health center, where he is diagnosed with leprosy, registered as a patient and prescribed MDT. On his return home, his wife flees in horror to her parents when she discovers what's wrong with him. But after being given the facts about leprosy by her mother, who is properly informed about the disease, the sobbing wife calms down and goes back to her husband. It was quite a performance, and all played their parts with gusto.

Based on what I saw and heard in Guinea, I hope that the health ministry will be able to execute an effective plan of action to tackle the prefectures where leprosy remains a problem, focusing on early detection and prompt treatment, and on conquering the stigma that prevents people coming forward for diagnosis and which makes their social rehabilitation harder. I especially urge the health ministry and its partner NGOs to work together closely and in a coordinated way at every level, so that their efforts achieved the desired outcome. I intend to follow Guinea's progress with interest. ■

People with Leprosy Welcome at Olympics

China retracts earlier ban to reflect support for recent UNHRC resolution.

When on June 2 the Beijing Olympic Organizing Committee issued guidelines for foreigners attending this summer's Olympics, it became apparent that people suffering from leprosy would not be granted entry visas. Although based on existing immigration law, the ban was soon at odds with China's co-sponsorship of a Human Rights Council resolution on June 18 calling for an end to discrimination against people affected by leprosy.

Goodwill Ambassador Yohei Sasakawa immediately sent letters protesting the ban to the Olympic organizers as well as to Chinese Premier Hu Jintao, saying it would only serve to reinforce the stigma and discrimination faced by individuals with leprosy. The Japanese government, which proposed the HRC resolution, raised the issue at a human rights dialogue with China in Beijing on July 15.

Two weeks before the start of the games, China announced that it was reversing the ban, in line with its position in support of the Geneva resolution, and a spokesman said the new rules would remain in place after the Olympics.

JAPANESE SANATORIUMS

On June 11, Japan passed a new law that permits outside entities to utilize the facilities of Japan's 13 leprosy sanatoriums. This is to ensure that residents can stay there for the rest of their lives, banning their discharge or transfer against their will. The new legislation stipulates that any changes with regards to the future of the sanatoriums cannot take place without the prior agreement of residents.

Some 2,700 people affected by leprosy, whose average age is nearly 80, remain in the sanatoriums, where they were originally confined under Japan's leprosy prevention law. With the law's abolition in 1996, any resident wishing to leave is entitled to financial assistance, but many have no home to return to, or are unable to care for themselves. ■

FROM THE EDITORS

IMMIGRATION POLICY

The Chinese government is to be commended for overturning its ban on people with leprosy attending the 2008 Summer Olympic Games. But the Beijing Olympic Organizing Committee also deserves a mention. Had it not published an advisory for foreigners stating that persons with certain infectious diseases, including leprosy, were barred from entering the country, few people would have known such a regulation existed in the first place.

In fact, China is not alone in having such policies. Shortly after the advisory appeared, it was reported that the United Arab Emirates was to include leprosy among the medical fitness tests required of foreigners intending to live, study or work in the UAE for not less than six months.

This led us to ask: just how many other countries have visa or immigration rules that make mention of leprosy? Research conducted over the Internet by the Sasakawa Memorial Health Foundation has found to date that over a dozen countries cite leprosy as a reason for refusing entry or as grounds for deportation. In addition to China and the UAE, they are, in alphabetical order: Barbados, Hungary, Iraq, Namibia, the Philippines, Russia, Taiwan, Thailand, South Africa, and the U.K. and the U.S.

To look in detail at one example, persons planning to reside in Hungary for more than 90 days must submit an official medical certificate showing that "the foreigner does not suffer from a disease endangering public health, is not contagious and is not a carrier of such pathogens." Listed as "diseases and bacterium carrier conditions endangering public health" are TB, HIV, leprosy, lues (syphilis), and typhoid or paratyphoid.

Leprosy today is a completely curable disease. Within days of the first round of multidrug therapy, a person infected with Mycobacterium leprae can no longer pass the disease to anyone else.

No doubt these immigration policies were drawn up with the best of intentions, to protect the public from what was regarded at the time as a feared disease. Times have changed, however, and immigration policies must change with them.

FOR THE ELIMINATION OF LEPROSY
Publisher
Yohei Sasakawa
Executive Editor
Tatsuya Tanami
Editor
Jonathan Lloyd-Owen
Associate Editors
Sumiko Okamoto,
James Huffman
Layout
Eiko Nishida
Photographer
Natsuko Tominaga
Editorial Office
5th Floor, Nippon
Foundation Building,
1-2-2 Akasaka, Minato-ku,
Tokyo 107-8404
Tel: +81-3-6229-5601
Fax: +81-3-6229-5602
smhf_an@tnfb.jp

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Sasakawa Memorial
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www.nippon-foundation.or.jp/eng/