WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE

Elimination OF Leprosy

February 2012 • Number 54

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

The Goodwill Ambassador meets with people affected by leprosy at a hospital in Ucayali Region, Peru, in January.

MESSAGE

Global Appeal, Greater Awareness

The seventh Global Appeal to End Stigma and Discrimination against People Affected by Leprosy, endorsed by the World Medical Association, was launched in Sao Paulo, Brazil, on January 30. Because I had been hospitalized in Lima, Peru, the previous day with a heart emergency, I was unable to attend. However, this is the gist of the message that was delivered on my behalf.

In the long history of leprosy, it has been customary to view the disease as dangerous and to fear those suffering from it. Regrettably, such attitudes persist, even today. They represent an invisible wall preventing people affected by leprosy and their families from participating in society. The wall becomes higher and thicker each time someone seeks to justify his or her discriminatory actions or prejudiced ideas.

We can't change the past, but we can shape the future. I believe that reaching as many people as possible through the Global Appeal and making them aware of their discriminatory behavior and sentiments is the first step to tearing down that wall.

To tear it down completely requires the efforts of the people on the other side as well — people affected by leprosy and their families. Long-existing prejudices and the discriminatory treatment they have received have given root to feelings of fear, resignation and surrender. Yet when they sense even a small sign of change within themselves, I hope they will find the courage to speak out and blast a hole through that wall. In Brazil, India and various other countries, advocacy organizations of people affected by leprosy are attempting to do just that. I am hoping more such groups will emerge and I assure them of my full support.

On the medical front, we are one step away from eliminating leprosy as a public health problem in every country, with Brazil affirming it will eliminate the disease in the next few years. But the road to resolving the social consequences of leprosy is a long one and we are only at the beginning. So let us strengthen our solidarity, close ranks and move ahead.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Doctors Speak Out

World Medical Association endorses anti-discrimination call in Sao Paulo.

Medical professionals from around the world have put their names to the latest Global Appeal to End Stigma and Discrimination against People Affected by Leprosy, saying they have “the first responsibility to set the record straight” regarding the many myths and misconceptions surrounding the disease.

Launched in Sao Paulo, Brazil, on 30 January 2012, the seventh Global Appeal was endorsed by the president of the World Medical Association (WMA), Dr. José Luiz Gomes do Amaral, and the heads of more than 50 national medical associations.

In his remarks, Dr. Amaral noted that the WMA had unanimously approved the Global Appeal initiative at its general assembly in Montevideo, Uruguay, last October. It has also developed its own policy recommending all national medical associations to defend the rights of people affected by leprosy and their families.

> Doctors have “the first responsibility to set the record straight.”

“Hansen’s disease, or leprosy as it is more commonly known, can be eliminated. This is feasible and we should not fall short of our aspirations,” he said. “But we also have to care for those who have acquired the disease. We have to treat them and we have to make sure they are not discriminated against, segregated or otherwise stigmatized.”

‘TRULY SIGNIFICANT’

Representing Yohei Sasakawa, who initiated the annual Global Appeal in 2006, Tatsuya Tanami of The Nippon Foundation said that it was “truly significant” that medical professionals have lent their voices to let the world know that leprosy is a mildly infectious disease, not spread by casual contact and that there are no medical grounds for isolating a person with the disease.

Dr. Florentino de Araujo Cardosa Filho, the president of the Brazilian Medical Association, which hosted the event, said “you can count on us” to help eliminate the stigma attached to leprosy. The association has a leprosy unit, has information about the disease on its website, and is working closely with the health ministry and different branches of the medical profession to tackle it.

Maravilha and Matogrosso (holding microphones) read the Appeal.

The president of Mozambique's medical association, Dra. M. Rosel Salomao, stressed the importance of political commitment in tackling leprosy. She also recognized the need for doctors to speak out on behalf of patients, “because patients’ voices are not being heard.”

Artur Custodio, national coordinator of the Movement for the Reintegration of People Affected by Hansen’s Disease (MORHAN), said the involvement of medical associations was very important to the cause of eliminating discrimination and he hoped that everyone in the medical community would now familiarize themselves with the Global Appeal text.

The ceremony heard directly from a number of Brazilians who had personally suffered from leprosy-related discrimination. Cristiano Torres described the pain and hurt of losing his freedom and citizenship rights. Valdenor Rodrigues da Cruz recalled being treated “like an animal.” Teresa Oliveira, who was taken from her parents because they had leprosy, said, “We were alienated from society and treated it with indifference. We must make it clear once and for all that leprosy is curable and stigma needs to be consigned to the past.”

CELEBRITY PRESENCE

As the audience looked on, the text of the appeal was read out by two popular Brazilian celebrities, Ney Matogrosso and Elke Maravilha. Both have been closely involved with MORHAN over the years in working to restore the rights of people affected by leprosy in Brazil.

“Leprosy affects the poor, the voiceless,” said Matogrosso. “Unless the disease is treated with humanity and compassion, those affected by leprosy will remain on the margins of society.” Added Maravilha, “"What scares me most is the indifference of people. This must change.”

The event, held at the Paulista Medical Association, was attended by some 150 invited guests from government, international organizations, media, the medical profession, NGOs and people affected by the disease. ■

Putting Principles into Practice

Rio kicks off first in a series of symposia on leprosy and human rights.

Michelle Reis Ledur of Brazil's Special Secretariat for Human Rights makes a point at the February 1 symposium.
Photo: Lúcio Alves

The UN General Assembly Resolution adopted in December 2010 on "Elimination of discrimination against persons affected by leprosy and their family members" includes Principles and Guidelines that serve as both a "bill of rights" for those affected by the disease and a roadmap for states to follow in formulating policies that recognize, restore and uphold those rights.

But how to ensure these Principles and Guidelines are put into practice? Following a conversation he had with former Acting UN High Commissioner for Human Rights Dr. Bertrand G. Ramcharan last May, Goodwill Ambassador Yohei Sasakawa decided to organize a series of regional symposia with the goal of implementation in mind. In particular, he felt it was important to focus on three actions among those listed in the Principles and Guidelines, which he felt would accelerate efforts to end discrimination.

KEY ACTIONS

The first requests states to review whether any laws or institutions still exist that discriminate against people affected by leprosy, and asks that they be amended or abolished. The second calls on states to raise public awareness of, and foster respect for, the rights and dignity of persons affected by the disease. The third urges states to provide opportunities for education and employment and help those living in poverty to improve their standard of living.

However, it is not just states that must act. NGOs, civil society, media organizations and people affected by leprosy also have a key role.

The first symposium was held in Rio de Janeiro on February 1. Organized by The Nippon Foundation and the Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN), the event drew speakers from several Latin American countries and beyond.

After opening remarks from the organizers, there was a panel discussion with representatives from the Pan American Health Organization, the WHO, the Office of the UN High Commissioner for Human Rights and Brazil's Special Secretariat for Human Rights. This was followed by a presentation by Professor Yozo Yokota. As a former member of the UN Sub-Commission on the Promotion and Protection of Human Rights, he helped lay the foundations of the UN resolution.

Later in the day, Professor Yokota was in action again, chairing a discussion on "Leprosy and Human Rights — Brazil and South America." Participants included Brazil's Cristiano Torres, vice-coordinator of MORHAN, and Colombia's Jaime Molina Garzon of Corsohansen, who discussed their experiences as persons affected by leprosy.

NEXT STEPS

A resolution approved unanimously at the end of symposium called on states (in particular, those in the Americas) to implement actions recommended in sections 13 and 14 of the Principles and Guidelines. These urge states to formulate policies and action plans to raise awareness of, and foster respect for, the rights and dignity of persons affected by leprosy, and to consider creating or designating a committee to oversee these activities.

In addition, the resolution contained a recommendation to establish a working group to discuss and formulate action plans and a mechanism to monitor steps taken by states and other actors. The Nippon Foundation is entrusted to play a lead role in organizing the working group, which will consist of experts, NGO representatives, and people affected by leprosy. ■

FILM

Love in a Small Place

A new film documents the lives of an elderly couple on an island sanatorium in Japan.

Takashi and Yasue Tojo, a couple in their 70s, live on an island in Japan's Inland Sea. Their home is National Sanatorium Oshima Seishoen, one of 13 facilities in the country where the Japanese government once isolated people with leprosy under the Leprosy Prevention Law. Takashi arrived in 1946, Yasue in 1948. They have been there ever since.

When filmmaker Kazuyuki Nozawa came to know the Tojos on a visit to the island in 2005, he was struck by the way the couple supported each other. Yasue is blind, having lost her sight to the disease when she was 24, and suffers other leprosy-related disabilities. Takashi (“Taka”) is also disabled, but to a lesser degree. Over the next six years, Nozawa returned repeatedly to Oshima Island to film the Tojos. The result is the documentary *61 Hectares — Kizuna.*

The first part of the title refers to the size of the island, which is less than one kilometer square; the second part is the Japanese word for bond — in this case both the legal fetters that confined the couple to the island as well as the ties of love that Nozawa found so affecting and which inspired his film.

Takashi and Yasue married in 1951, when he was 21 and she was 18. “Taka has looked after me well all these years,” Yasue explains in the film. “At first, when I was still healthy, I took care of him. I washed and ironed his clothes, repaired his suit. But that happy time lasted only four or five years. After that, it was Taka who looked after me. The husband got the worst deal in this marriage.”

Scenes from the film: Yasue and Taka Tojo at home (top); Taka looks out over Oshima Island's 61 hectares.

EVERYDAY ROUTINE

The film shows scenes from their everyday routine — Yasue undergoing rehabilitation, Takashi at work on his vegetable patch, the couple eating meals and attending church — as well as their preparations for a karaoke contest that will take them to a different sanatorium in another part of the country.

Yasue does most of the talking, as Taka listens or gets on with the household chores. She also writes poems, which reflect her tender feelings for her husband. A poem about Taka doing the laundry is “my way of saying thank you,” she explains. “It's really how I feel happy when you do it without making any fuss,” she tells him.

The film does not dwell on the reason why they are on Oshima, but focuses on the life they have made together, how they cope with their disabilities and the bond between them. The reason for their isolated existence does not go unremarked, however.

“They told me, ‘You'll be cured in three years.’ But it was a lie. A trick to enforce the isolation law,” Yasue explains. “I was so sure I'd be going home in three years. People who had been here 30, 40 years laughed at me. ‘Idiot, nobody goes home…’ Everyone had been fooled into coming by the same lies.”

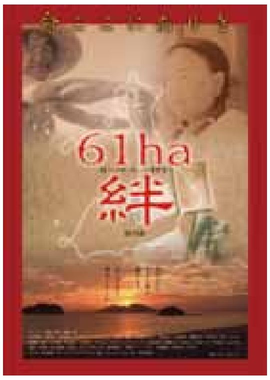
CHRISTIAN FAITH

Yasue draws strength from her Christian faith — only Jesus is more important to her than Taka, she says. Taka converted after he promised God that he would if Yasue recovered from a fever.

The attitude of the outside world to those on the island is encapsulated in an anecdote Yasue relates about the days when residents used to be called “zashiki buta” — a term likening them to pigs that lay around all day, getting fed and taking it easy. It was even used by some sanatorium inmates about their fellows. “It was terrible, especially for those of us who had always worked hard and done our best. It hurt a lot,” Yasue said.

Toward the end of the film, she tells Nozawa: “There's one thing I really want the world to know. There are people who lived on this island, who did their best in life, despite the leprosy.”

Viewers will come to know an engaging couple, brought together by the disease, who have cared for one another for 60 years. ■



Flyer for *61 Hectares — Kizuna.* At upper right is an image of Yasue on her wedding day in 1951, aged 18. The film is available with English subtitles.

POEM

Seeing my glass eyes
My husband said
The black pupils
Brought back
The beauty of my youth.
(Yasue Tojo)

‘A Documentary Is a Trigger’

The director of *61 Hectares — Kizuna* on why he wanted to make the film.

AUTHOR:
Kazuyuki Nozawa

Kazuyuki Nozawa is a film director working with International Motion Picture Co., Inc. in Tokyo. He can be contacted at impc.nozawa@gmail.com

As a filmmaker I’ve always been interested in the subject of discrimination, in people living on the periphery of society. I’ve made television documentaries about social minorities, circus folk, street entertainers, blind artists, the homeless, a Korean woman living in Japan. The theme of my work has been to look at how marginalized people get by and to discover what really matters in life.

The theme of *61 Hectares* is not leprosy per se, but about how this couple, who have been marginalized by this disease, help each other out. The wife who can’t see, the husband who has problems with his hands…they have a way of looking after each other that really opened my eyes to the bond that exists between them.

ENCOURAGEMENT

There is no “story” as such. The film shows how they live, their affection for each other, and how they transcend the disease. My hope is that people will draw encouragement from their relationship. A friend of mine who saw the film said he was envious of Taka and Yasue. He said they have something the rest of us have lost.

There were things that I wanted to film but because of privacy issues we agreed on a line that I was not to cross. For example, I had hoped to accompany Taka and Yasue on a clandestine visit to their hometowns to visit their ancestors’ graves. I also wanted to film their relatives. But that is really difficult because of the stigma attached to the disease. People don’t want it known that there is leprosy in the family.

> I want people to think about what is important to them as human beings.

Let me be clear. I’m not a leprosy activist, I’m just a filmmaker. I’m not trying to push a particular agenda. A documentary is a trigger to make you think. I want people who see *61 Hectares — Kizuna* to think about their lives, to think about what is important to them as human beings. ■

TEXT OF GLOBAL APPEAL 2012

GLOBAL APPEAL
To end stigma and discrimination against people affected by leprosy
2012
Endorsed by members of The World Medical Association

There are many myths and misconceptions about leprosy. As members of the medical profession, we have the first responsibility to set the record straight.

Leprosy is a mildly infectious disease. It is not spread by casual contact. It is curable with multidrug therapy that kills the bacteria and stops the disease from spreading. Early diagnosis and prompt treatment help prevent the onset of disability and deformity associated with leprosy. There are no medical grounds for isolating a person with the disease.

Yet people with leprosy continue to face social discrimination, even after they are cured. Whole families are marginalized, sometimes with devastating results.

Drugs can cure leprosy, but only greater public awareness can end the stigma it attracts.

Without the social stigma, more people would come forward for treatment. New cases would be detected sooner and be less likely to result in disability. The burden of leprosy in the world would be reduced.

We affirm the right of people affected by leprosy to receive treatment at any hospital. We call for an end to discrimination against them and their families. We support their right to live in dignity as full members of the community with equal access to opportunities and enjoying all their human rights.

World Medical Association President Dr. José Luiz Gomes do Amaral	Order of Physicians of Albania President Dr. Din Abazaj	American Medical Association President Dr. Peter W. Carmel	Australian Medical Association President Dr. Steve Hambleton
Austrian Medical Chamber President Dr. Walter Dorner	Azerbaijan Medical Association President Dr. Nariman N. Safarli	Association Belge des Syndicats Médicaux President Dr. Lemye Roland	Associação Médica Brasileira President Dr. Florentino de Araújo Cardoso Filho
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Icelandic Medical Association President Dr. Margrét Aðalsteinsdóttir	Indian Medical Association President Dr. Vinay Aggarwal	Indonesian Medical Association President Dr. Prijo Sidipratomo	Irish Medical Organisation Chief Executive Mr. George McNeice
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Slovak Medical Association President Prof. Peter Kristufek	Swedish Medical Association President Dr. Marie Wedin	Taiwan Medical Association President Dr. Ming-Been Lee	Tanzania Medical Association President Dr. Namala P. Mkopi
Medical Association of Thailand President Dr. Jongjate Aojanepong	Sindicato Médico del Uruguay President Dr. Martín Rebella	Medical Association of Uzbekistan President Prof. Abdulla Khydayberganov	

Launched in São Paulo, Brazil, on January 30, 2012, Global Appeal 2012 is an initiative of Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, Japanese Government Goodwill Ambassador for the Human Rights of People Affected by Leprosy, and Chairman of The Nippon Foundation.

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(Endorsed by members of the World Medical Association and launched in Sao Paulo, Brazil on 30 January 2012.)

CASE STUDY

Helping Hands

Turned down for a loan to repair his roof, Md. Babul received something far better.

Md. Babul and wife Fulbanu in front of their house (left) and together with other members of the self-help group

When Md. Babul applied to his self-help group* for a loan to repair a leaking roof, his application was rejected. But the story didn't end there. Instead, he received building materials to carry out the repairs and willing hands to get the job done.

Babul, 46, lives with his wife Fulbanu and family in a village in northern Bangladesh. Physically disabled, he finds it hard to get work. When he does, he receives only half pay. To make ends meet, the couple rely on income from Fulbanu's job selling ornaments and cosmetics.

> The members felt they couldn't justify lending him the money.

At the end of December 2010, a self-help group was formed in Babul's community. It has 15 members, the majority of whom have physical disabilities due to leprosy. Babul, whose disability is not related to the disease, regularly attends meetings and contributes money from his small earnings.

During the rainy season, Babul became concerned about the condition of his house. The roof was leaking and he applied to the group for a loan to make repairs. But the members felt they couldn't justify lending him the money, given the as-yet limited pool of funds the group had accumulated, the fact the loan wasn't for a income-generating purpose, and the difficulty Babul would have paying it back. Rather than simply turn him down, however, they decided to help him make the repairs themselves.

Four members donated two pieces of bamboo each, a fifth member gave a small amount of money and another contributed cord and the use of his rickshaw to transport the materials to the Babul's house. Then they went to work and fixed the roof.

"All the group members are poor like me, but they proved that to give a donation there is no need for wealth, only willingness to help," Babul said. "I am proud to be a member of this group." (Reporting and photos by Uttom Bonik) ■

FOOTNOTE

* One of a number of self-help groups being formed in Dinajpur district as a project of The Leprosy Mission International-Bangladesh. Members are responsible for running their groups.

LEPROSY WISH LIST

Mark Anthony Bengan
(Philippines)

EMPLOYMENT OPPORTUNITIES

I would like to see a company employ persons affected by leprosy in the same way that Lamoiyan Corporation employs the hearing-impaired. Lamoiyan, a major player in the personal care and household products sector in the Philippines, gives opportunities for persons with disability to be productive citizens.

SHARING OF EXPERIENCE

I would like people who have been treated and cured of leprosy, who have enjoyed success in life, to speak out and share their experiences. I think society will listen to them and take note of what they have to say.

SKILLS TRAINING

I would like to see a training program to develop or enhance the skills of persons affected by leprosy. For example, I'd like to see the Philippine Leprosy Mission (PLM) partner with the Technical Education and Skills Development Authority (TESDA) and implement skills training for groups of people affected by leprosy. Also, I would like to see such institutions write letters of recommendation for people affected by leprosy when they apply for jobs.

Notes from Home and Abroad

The Goodwill Ambassador details some of his recent activities in Japan and on the road.

Visiting with people affected by leprosy at the Hospital Amazónico de Yarinacocha in Peru's Ucayali Region in January

MYANMAR (DECEMBER 12-20)

During a visit to Myanmar in December, I took time to visit the Yenanthar Leprosy Hospital in Madaya Township, around 50 kilometers from Mandalay. It is one of two specialist leprosy hospitals in the country.

Showing me around was the medical superintendent, Myat Thida, who dreams of the day when the hospital becomes a general hospital and rehabilitation center. She also took me to visit the nearby Nanthar Myaing resettlement village.

The village has a population of 1,400, of whom 360 are persons affected by leprosy. They generate income from woodcutting, charcoal-making, agriculture and animal husbandry. The village is also home to a women's sewing group.

JAPAN (JANUARY 17)

Mozambique's new minister of health, Dr. Alexandre Manguele, visited me in Tokyo at the start of the year. Although Mozambique has achieved elimination of leprosy as a public health problem, he told me there are still pockets of the disease where the prevalence rate is high, particularly in the northern provinces, and the ministry is focusing on these.

At the same time, parts of the country rarely see leprosy nowadays and so health workers are losing the skills to detect patients early. It is a problem that many countries face, and Dr. Manguele told me Mozambique is working to address this.

Flanked by Mozambique's Ambassador to Japan Belmiro Jose Malate (left) and the country's new health minister, Dr. Alexandre Manguele

PERU (JANUARY 28–30)

Peru reports only a few cases of leprosy each year. In 2011, it registered 32 new cases. Most are found in the Loreto Region and the Ucayali Region. On a recent visit I flew to Ucayali's capital, Pucallpa, to visit the Hospital Amazónico de Yarinacocha.

Many of the patients it sees live far away, and most are poor. The distances involved make it hard for the hospital to examine family members and close contacts of those diagnosed with the disease. The regional authorities, it seems, do not pay much attention to leprosy.

About 20 people affected by leprosy had come from the surrounding area to meet with me, including a number who were still under treatment. An elderly lady told me how happy her grandchildren made her — one of whom was with her that day.

I was interested to find out that revolutionary leader Che Guevara had come here in the early 1950s on his travels made famous in *The Motorcycle Diaries.* From Pucallpa, it is a four-day boat journey along the Ucayali River to the San Pablo leprosy colony where he worked as a volunteer. ■

Movie Producers Agree to Changes

Protest over portrayal of leprosy in animated feature has positive outcome.

The producers of a forthcoming animated feature have agreed to make changes after a trailer for the film in which leprosy was depicted in a misleading light became the subject of an international protest.

Aardman Animations of the United Kingdom issued a statement in which they said they would change the scene in *The Pirates! Band of Misfits* "out of respect and sensitivity for those who suffer from leprosy."

Jose Ramirez, Jr., editor of *The Star* newspaper, was the first to alert colleagues around the world after seeing a trailer for the film at a cinema in Texas. In the scene in question, a pirate captain boards a vessel demanding gold, only to be told, "Afraid we don't have any gold, old man. This is a leper-boat. See…," the character says, and then his arm drops off.

Ramirez's initial email triggered a flurry of activity, with U.K.-based charity Lepra Health in Action and its chief executive Sarah Nancollas taking a leading role. Also weighing in were Douglas Soutar, general secretary of the International Federation of Anti-Leprosy Associations (ILEP) and member organizations.

From Tokyo, Goodwill Ambassador Yohei Sasakawa dispatched letters to the producers, who included Sony Pictures Animation, the distributor Columbia Pictures and other companies involved. In his correspondence he decried the use of the term "leper" and rapped the producers for perpetuating misconceptions about the disease and "worse, for playing the disease for laughs."

"It is not an easy task to change the image of leprosy, and it is a task made all the harder through regrettable depictions of the disease – especially when they feature in a family film that will be seen by a worldwide audience," the Goodwill Ambassador wrote. In a letter of reply, Sony Pictures Entertainment Vice Chairman Jeff Blake assured him that the scene would not be in the film when released and that the trailer had been withdrawn.

The Pirates! Band of Misfits! goes on release in April in many parts of the world.

DR. P.K. GOPAL HONORED

Dr. P.K. Gopal is to be awarded one of India's top civilian honors, the Padma Shri, for his decades of leprosy work. Diagnosed with leprosy at the age of 19, Dr. Gopal has dedicated his life to championing the cause of people affected by leprosy.

He is one of the founding members of Integration, Dignity and Economic Advancement (IDEA), the NGO established in 1994 that he serves as international president. More recently he has also been active as chairman of the National Forum, India's network organization of people affected by leprosy established in 2006.

Padma Shri recognizes distinguished contributions of Indian citizens in different fields, including social work. Dr. Gopal will receive his award at a ceremony later in the year. ■

FROM THE EDITORS

A LONG WAY TO GO

While the final form of *The Pirates! Band of Misfits* won't be known until the film is released, those who campaigned for the removal of a misleading scene about leprosy can take heart from the way the producers responded positively to their efforts.

"We are all bound to fight collectively against the stigma and discrimination toward leprosy-affected people…Hope this unity will continue till the end," wrote V. Narsappa, the Hyderabad-based leprosy activist, in an email to colleagues as the protest movement mounted.

If the outcome of the campaign showed what fighting collectively can achieve, the heated online response to it also revealed the nature of the opponent — namely, the levels of ignorance, indifference and animosity of the public toward leprosy, people suffering from the disease and efforts to "censor" what was "just a joke" in an animated movie.

There may be less leprosy in the world today, but it seems that stigma and discrimination are alive and well — although not, to their credit, in the studios of Aardman Animations.

FOR THE ELIMINATION OF LEPROSY

Publisher
Yohei Sasakawa
Executive Editor
Tatsuya Tanami
Editor
Jonathan Lloyd-Owen
Associate Editor
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: +81-3-6229-5388
smhf_an@tnfb.jp

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