

Leprosy *in* Our Time



Leprosy is one of the oldest diseases known to humankind. Once dreaded as contagious, disfiguring and without cure, today it is easily treated with antibiotics.

Yet for many people diagnosed with the disease, those who have been cured, and even family members, the outdated image of leprosy that persists in the public mind means they continue to face rejection and social exclusion.

What is leprosy?

Leprosy is a chronic bacterial disease that mainly affects the skin and nerves. Left untreated, it can cause impairment and result in permanent disability.

Since the beginning of recorded history, there have been numerous references to leprosy. Accounts can be found in the Bible, documents from ancient China and Indian classics from the 6th century B.C.

Over the centuries, the appearance of sufferers and fear of contagion led to the stigmatization of those affected. Society's response was to cast people with leprosy from its midst. Many people who came down with the disease were banished to islands or other remote locations, where they were forced to live out their days stripped of their freedoms and branded as "lepers".

In the 1980s, an effective cure for leprosy was developed and is now available free of charge to all who need it. Nevertheless, people affected by the disease and their loved ones continue to be marginalized by mainstream society.

"Leprosy is curable," "Treatment is free," and "Social discrimination has no place" are the three fundamental messages advocated by Yohei Sasakawa, Chairman of The Nippon Foundation and WHO Goodwill Ambassador for Leprosy Elimination.

The nature of the disease

The bacillus that causes leprosy was identified in 1873 by a Norwegian doctor, Gerhard Henrik Armauer Hansen. Today, leprosy is also known as Hansen's disease.

Mycobacterium leprae, or *M. leprae*, multiplies very slowly and has an incubation period of about five years. However, symptoms can take as long as 20 years to develop. The first tell-tale signs of the disease are patches that appear on the skin, accompanied by sensory loss in the affected areas.

While the route of transmission has yet to be conclusively demonstrated, leprosy is thought to be passed on via droplets from the nose and mouth during close and frequent contact with untreated, infectious individuals. Nonetheless, leprosy is not highly infectious and over 99% of people have a natural immunity or resistance to leprosy. This is why it is sometimes called the least infectious of infectious diseases.

Development of an effective cure

Only in the middle of the 20th century did the first real breakthrough occur in the treatment of leprosy. With the development of the drug dapsone, a way was found to arrest the disease.

But dapsone treatment lasted for years, making it difficult for patients to adhere to it. Furthermore, *M. leprae* began to develop resistance to dapsone, and so a new remedy was required.

Two new drugs, rifampicin and clofazimine, were discovered in the 1960s. Together with dapsone, these became the components of a new treatment administered as multidrug therapy, or MDT.

In 1981, the World Health Organization recommended MDT as the best way to treat leprosy. Safe, effective, and easily administered under field conditions, MDT comes in monthly blister packs. A course of MDT cures a patient of leprosy within 6 to 12 months. Since 1995, the WHO has supplied MDT free to all registered leprosy patients, initially with funding from The Nippon Foundation and, subsequently, through MDT donated by Novartis and the Novartis Foundation for Sustainable Development.



Leprosy—a curable disease

A mother with her daughter, who is being treated for leprosy, in Jayapura, Indonesia.



Blister packs containing MDT, the drug combination used to treat leprosy



Teaching aid for health workers produced in 10 languages

Toward a leprosy-free world



Residents at the Khokana leprosarium, Nepal.

Eliminating leprosy as a public health problem

The introduction of multidrug therapy has had a significant impact on leprosy control. Over the past two decades, 16 million people have been cured of the disease and there has been a dramatic reduction in the number of new cases reported annually.

In 1991, encouraged by MDT's effectiveness, the World Health Assembly passed a resolution to eliminate leprosy as a public health problem. As defined by the WHO, leprosy is no longer considered a public health problem when the prevalence rate of the disease falls below one case per 10,000 people.

The Nippon Foundation, together with its associate the Sasakawa Memorial Health Foundation, has played an important role in supporting the effort to eliminate leprosy, working in close partnership with the WHO, governments of endemic countries, and international and local NGOs.

Of 88 countries where leprosy was considered a public health problem at the time of the World Health Assembly resolution, just one—Brazil—has still to reach this goal. Yet elimination is only a staging post on the road to a world without leprosy. Completing the “last mile” is the hardest.

Sustaining political commitment

In 2012, there were 215,656 new cases of leprosy reported, with 95% of these cases found in 14 countries, mostly in Southeast Asia and Africa. In many of these countries, new case detection rates are static or showing signs of increasing, and hyperendemic pockets of the disease exist. Having “eliminated” leprosy, countries have shifted their health priorities elsewhere. Complacency threatens to undo the progress that has been made.

Recognizing the need for renewed political commitment, in July 2013 the WHO and The Nippon Foundation organized an International Leprosy Summit in Thailand. At this summit, 17 countries that annually report more than 1,000 new cases issued the Bangkok Declaration, reaffirming their commitment to achieve a leprosy-free world “at the earliest.”

The tasks ahead

In a world with fewer cases of leprosy, it is essential to ensure that expertise in diagnosing, treating and managing the disease and its complications is not lost. In particular, efforts need to focus on endemic pockets, such as urban slums and border areas, where leprosy persists. In this regard, opportunities to form synergistic partnerships with other neglected tropical disease programs should be explored.

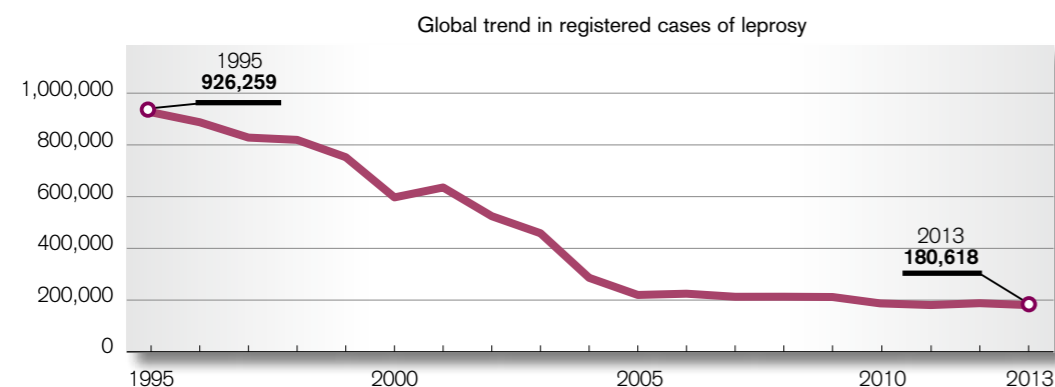
A key challenge is to prevent disability, of which leprosy is a major cause. Disability occurs when the disease goes undetected and leads to irreversible nerve damage. An estimated 2-3 million people today are living with disability due to leprosy. The Bangkok Declaration calls for achieving a global target of reducing the occurrence of new cases with Grade II (visible) disability to less than 1 case per million population by 2020. Achieving this target would indicate that the disease is being diagnosed in a timely fashion.

Research priorities

While leprosy can be cured with multidrug therapy, and while early diagnosis and treatment help prevent nerve involvement leading to disability, there remains plenty of scope for further research. Research priorities include: a simple diagnostic tool to identify persons and communities at risk of developing the disease before symptoms appear; an effective treatment for leprosy reaction, one of the causes of disability; and a new drug regimen in anticipation of the emergence of drug-resistant bacteria.

Role of people affected by leprosy

As part of efforts to sustain the quality of leprosy services and reduce the burden of leprosy in the world, the WHO has recognized the important contribution that people affected by leprosy can make.¹ Areas of involvement include helping in the early detection of leprosy in persons around them and identifying those in need of rehabilitation. The guidelines also recognize that by having people affected by leprosy share their experiences with opinion leaders and the mass media, this will help to lessen the stigma attached to leprosy in society.



FOOTNOTE:
1 Guidelines for strengthening participation of persons affected by leprosy in leprosy services. (WHO, 2011)

Everyone has a role to play in tackling stigma

The human rights dimension

While medical efforts to conquer leprosy have made tremendous progress in recent decades, it is fair to say that efforts to tackle the disease's social aspects have lagged behind. Due to the general public's ignorance, misunderstanding, indifference or fear, millions of people cured of leprosy and even their families still suffer from the stigma associated with the disease.

At different times and places, the way leprosy patients and their families have been treated by governments, communities, schools, companies, hospitals and other organizations, including religious institutions, has constituted a serious violation of their human rights, stripping them of their dignity in the process. Enforced isolation, limited or no access to social services, discrimination in the job market, obstacles in the way of getting an education, and problems finding a place to live are just some of the ways in which people affected by leprosy have suffered.

Creating an inclusive society

Over the centuries, the stigma visited upon people affected by leprosy represents one of the most pervasive forms of social injustice suffered by any one group of human beings.

Article 1 of the Universal Declaration of Human Rights states: "All human beings are born free and equal in dignity and rights." This includes every person affected by leprosy—yet legal, social and economic discrimination persists.

For society to live up to Article 1, it is essential that the inherent rights of people affected by leprosy, embodied in the Declaration, are acknowledged.

Putting this age-old issue to rest will help to realize a society in which every human being is able to enjoy his or her fundamental human rights, and in which the dignity of every human being is recognized.

Achieving a UN resolution

In September 2010, the UN Human Rights Council unanimously adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members, together with accompanying principles and guidelines. Three months later, the resolution was adopted at the UN General Assembly. This historic achievement for people affected by leprosy was the culmination of a process initiated by Yohei Sasakawa, then president and now chairman of The Nippon Foundation, in July 2003 (see chart).

Turning words into deeds

Between 2012 and 2015, The Nippon Foundation is organizing a series of five regional symposia (in the Americas, Asia, Africa, the Middle East and Europe) to promote awareness of the UN resolution and explore how the principles and guidelines can be implemented. The symposia bring together government officials, organizations of people affected by leprosy, NGOs, representatives of the WHO, human rights experts and other stakeholders. In parallel with these symposia, an International Working Group consisting of people affected by leprosy, human rights experts and NGOs has been established to discuss a sustainable mechanism to follow up on the UN resolution and the principles and guidelines. Discussions are under way to formulate a model plan of action and mechanism to monitor actions taken by stakeholders.

The road to a UN resolution

July 2003	Yohei Sasakawa visited the Office of the High Commissioner for Human Rights in Geneva to draw attention to the problems faced by people affected by leprosy.
August 2003	The Nippon Foundation made an official approach to the UN Sub-Commission on the Promotion and Protection of Human Rights. This was the first time that the human rights concerns of people affected by leprosy had been brought before the UN.
August 2005	The UN Commission on Human Rights (UNCHR) adopted a resolution to push governments and UN bodies to improve the situation of people affected by leprosy.
March 2007	The Japanese Government took a request for action to the UN Human Rights Council (the successor to the UNCHR) on the issue of leprosy and human rights.
June 2008	A resolution titled "Elimination of discrimination against persons affected by leprosy and their family members" was submitted by 59 countries under the leadership of the Japanese Government at the 8th meeting of the UN Human Rights Council (UNHRC). The resolution was adopted on June 18. On the basis of this resolution, the UNHRC Advisory Committee started to draw up principles and guidelines for ending discrimination.
September 2010	A resolution to eliminate discrimination against persons affected by leprosy, together with principles and guidelines, was unanimously adopted at the 15th Session of the UNHRC.
December 2010	The United Nations General Assembly adopted the resolution and its set of principles and guidelines without a vote on December 21.

Principles and Guidelines: Key Points

Principles

Persons affected by leprosy and their family members should be treated as people with dignity and are entitled to all human rights and fundamental freedoms.

Guidelines

States should ensure:

- no discrimination on the grounds of leprosy
- equal protection and equal benefit of the law
- special attention to rights of women, children and other vulnerable groups
- reunification of families
- access to education
- employment and vocational training opportunities
- full inclusion and participation in the community
- voting rights
- removal of discriminatory language
- access to public places
- same standard of healthcare enjoyed by persons with other diseases
- adequate standard of living
- formulation of policies and plans of action to promote respect for rights and dignity.

Grassroots empowerment and networking

Around the world, different groups are working to bring an end to the stigma suffered by people affected by leprosy. In addition to long-established anti-leprosy organizations that support their cause, there has been an increase in the number of groups of people affected by leprosy working for their own self-empowerment.

ILEP (the International Federation of Anti-Leprosy Associations) traces its roots back to 1966 and the creation of a European federation of anti-leprosy associations. In 1975, organizations from North America and Japan became members, and the federation became truly international. ILEP supports medical, scientific, social and humanitarian activities for the relief and rehabilitation of persons affected by leprosy. It collaborates with the WHO and other partners.

IDEA (Integration, Dignity and Economic Advancement) is an international network of people affected by leprosy that grew out of a seminar held in Brazil in 1994. Participants included representatives from Brazil, China, Ethiopia, India, South Korea and the United States. IDEA is the first international network of individuals and organizations of those who have been affected by leprosy.

APAL (Association of People Affected by Leprosy) is an umbrella organization of self-settled leprosy colonies across India. Established in 2006, it is working for the economic and social advancement of people affected by leprosy and their reintegration into society.

MORHAN has been the leading voice representing persons affected by Hansen's disease in Brazil since the 1980s. It has been actively lobbying the government and other sectors of society to better the lives of people affected by the disease and to ensure they enjoy the same rights as every other citizen.

PerMaTa (Indonesia), **ENAPAL** (Ethiopia), and **HANDA** (China) all have people affected by leprosy at their center and engage in a broad range of activities, from advocacy and awareness campaigns to capacity-building and community empowerment.

Work camps in China, Vietnam, Indonesia and elsewhere in Asia involve groups of student volunteers spending a week or more at communities of people affected by leprosy. Living alongside the residents, they undertake construction projects, carry out repairs and provide other assistance. The results are measured in more than physical improvements. The residents, who have been living in seclusion, enjoy mixing with the students; the students learn things about themselves and the importance of bonds between people; and neighboring communities discover they have nothing to fear when they see villagers and students having a good time. Friendships form and the experience is transformational for all.

The Sasakawa-India Leprosy Foundation (SILF) helps people affected by leprosy who don't have the opportunity to work because of discrimination. It provides grant loans to fund microenterprises. It also provides educational support and works to spread correct knowledge about leprosy among the general public.



Income-generating activities, the work of volunteers and the formation of organizations of people affected by leprosy contribute to financial independence, dignity and self-empowerment: (Clockwise from top right) Members of APAL, India with Yohei Sasakawa; work camp in Guangdong province, China; the oldest resident at Romania's only leprosarium, Tichilesti; income-generating activity in Addis Ababa, Ethiopia; activity in a leprosy colony in Lucknow, India supported by SILF; a family affected by leprosy who live on the banks of the Amazon.

“People affected by Hansen’s disease do not need charity, but the opportunity to show we are capable.”
— Cristiano Torres, Brazil



The Global Appeal

In order to raise public awareness of the issues, an annual Global Appeal to End Stigma and Discrimination against People Affected by Leprosy was launched in January 2006 at the initiative of Yohei Sasakawa, Chairman of The Nippon Foundation. The first Appeal was issued from New Delhi and signed by world figures including Nobel Laureates Elie Wiesel, the Dalai Lama and former U.S. President Jimmy Carter. Subsequent appeals have been endorsed by

leaders of people affected by leprosy (Manila, 2007), international human rights organizations (London, 2008) faith leaders (London, 2009), corporate executives (Mumbai, 2010), heads of leading universities of the world (Beijing, 2011), the World Medical Association and its member associations (São Paulo, 2012), the International Bar Association and its member associations (London, 2013) and the National Human Rights Institutions (Jakarta, 2014).



Scene from the launch of Global Appeal 2014 in Indonesia (January 27, 2014)

GLOBAL APPEAL 2014

To end stigma and discrimination against people affected by leprosy

Endorsed by National Human Rights Institutions

Leprosy is one of the world's oldest diseases. Caused by a bacillus, it is completely curable today with modern drug therapy. Contrary to widespread belief, leprosy is not hereditary, it is not untreatable, it is not highly infectious and it is not divine punishment.

Yet because of the myths and misconceptions that surround leprosy, discrimination is never far away. This discrimination can limit opportunities for education, employment and marriage. It can restrict access to public services. It can marginalize entire families.

In December 2010, recognizing the disease's devastating social, economic and psychological impact, the U.N. General Assembly adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members.

The resolution is accompanied by principles and guidelines and reaffirms that people affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws.

As national human rights institutions, we applaud the U.N. resolution and condemn all leprosy-related human rights violations. We uphold the right of people affected by leprosy to live in dignity, free from discrimination. We pledge our support to help to bring down the remaining barriers of stigma and prejudice that stand in their way.

Dr. Sima Samar Chairperson Independent Human Rights Commission Afghanistan	Dr. Mizanur Rahman Chairman National Human Rights Commission Bangladesh	Ms. Maria do Rosário Nunes Ministra-Chefe Secretaria de Direitos Humanos da Presidência da República Brazil	Mr. Emmanuel Ntakarutimana President Independent National Human Rights Commission Burundi
Mr. David Langtry Acting Chief Commissioner Canadian Human Rights Commission Canada	Ms. Lorena Fries Monleón Director National Institute of Human Rights Chile	Mr. Boutros Boutros Ghali President National Council for Human Rights Egypt	H.E. Ambassador Teruneh Zenna Chief Commissioner Ethiopian Human Rights Commission Ethiopia
Mr. Michel Forst Secretary General Commission Nationale Consultative des Droits de l'Homme (CNCODH) France	Mr. Ucha Nanuashvili Public Defender (Ombudsman) Office of Public Defender of Georgia Georgia	Dr. York Chow Yat-ngok Chairperson Equal Opportunities Commission Hong Kong SAR, China	Justice K. G. Balakrishnan Chairperson National Human Rights Commission of India India
Ms. Siti Noor Laila Chairperson National Commission on Human Rights Indonesia	Dr. Mousa Suleiman Burayzat Commissioner General The National Centre for Human Rights Jordan	Ms. Anne Muniyva Kyalo Ngugi Commissioner (Acting Chair) National Commission on Human Rights Kenya	Mr. Sami Kurteshi Ombudsman Ombudsperson Institution of Kosovo Kosovo
Mr. Juris Jansons Ombudsman Ombudsman Office of the Republic of Latvia Latvia	Dr. Augustinas Normantas Head of the Office The Seimas Ombudsmen Lithuania	Mr. Hasmy Agam Chairman Human Rights Commission of Malaysia (SUHAKAM) Malaysia	Ms. Kadidia Sangare Coulibaly President Commission Nationale des Droits de l'Homme du Mali Mali
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Ms. Amal Hassan Eltinay Chairperson National Commission for Human Rights Sudan	Mr. Amiri Ramadhani Manento Chairman Commission for Human Rights and Good Governance Tanzania	Ms. Amara Pongsapich Chairperson National Human Rights Commission of Thailand Thailand	Ms. Lynette Anthea Stephenson Ombudsman Office of the Ombudsman of Trinidad and Tobago Trinidad and Tobago
Mr. Med S. K. Kaggwa Chairperson Uganda Human Rights Commission Uganda	Ms. Valeriya Lutkovska Parliament Commissioner for Human Rights Ukraine		

Launched in Jakarta, Indonesia, on January 27, 2014, Global Appeal 2014 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.

Q: What is leprosy?

A: Leprosy is a disease caused by a rod-shaped bacillus called *Mycobacterium leprae*, or *M. leprae* for short. It affects mainly the skin and the nerves.

Q: How is leprosy transmitted?

A: Leprosy is thought to be transmitted through the air via droplets from the nose and mouth during close and frequent contact with untreated infectious individuals.

Q: Is leprosy very infectious?

A: On the contrary, leprosy is sometimes called the least infectious of infectious diseases. More than 85% of cases of leprosy are non-infectious and do not spread the disease. Over 99% of people have a natural immunity or resistance to leprosy.

Q: Is leprosy hereditary?

A: No.

Q: Is leprosy curable?

A: Yes. Leprosy is cured by multidrug therapy (MDT), a highly effective treatment that became available in the early 1980s. MDT is a combination of three drugs—dapson, clofazimine, and rifampicin—administered over a 6- to 12-month period. The first dose of MDT kills 99.9% of the microorganisms in the body that cause leprosy.

Q: What are the symptoms of leprosy?

A: The first sign of leprosy is usually the appearance of patches on the skin. These patches are accompanied by a loss of sensation in the areas affected.

Q: Where is treatment available?

A: Leprosy can be diagnosed and treated at the nearest health center or health post as leprosy services are being integrated into the general health services in every country.

Q: Is treatment expensive?

A: Treatment costs nothing. Since 1995, the WHO has supplied MDT free to all patients in the world, initially with funding provided by The Nippon Foundation, and subsequently through MDT donated by Novartis and the Novartis Foundation for Sustainable Development.

Q: Is leprosy widespread?

A: Currently, less than 250,000 new cases of leprosy are diagnosed each year. Since the introduction of MDT in the early 1980s, some 16 million people around the world have been cured of the disease. Today, leprosy remains a public health problem in only one country.¹ However, many countries continue to see new cases of the disease.

Q: Why can leprosy result in disfigurement?

A: If untreated, leprosy causes nerve damage and other complications. Patients lose feeling in their hands and feet, and muscles become paralyzed because the nerves supplying them have been impaired. As a result, people with the disease are susceptible to

injuries that can result in festering wounds or ulcers. These are secondary infections due to other organisms and are not caused by the leprosy germ.

Q: Can a person who is physically impaired be cured of leprosy?

A: Leprosy can be cured at any stage. To be cured of leprosy means to have no leprosy-causing bacteria remaining in the body. However, if leprosy is detected and treated only after permanent nerve damage has occurred, there will be residual disability and disfigurement. Disability is preventable with timely diagnosis and prompt treatment. Corrective surgery is also an option in some cases. Residual disability and disfigurement are not a source of leprosy infection.

Q: Is there a vaccine for leprosy?

A: No, but research is under way to find one.

Q: Is there any reason to isolate people with leprosy?

A: No. Today, there is no medical or social justification for isolating people with leprosy. People can continue their normal way of life while receiving treatment. Any attempt to isolate people with leprosy stigmatizes them and reinforces age-old prejudices about the disease.

Q: Is leprosy the same as Hansen's disease?

A: Hansen's disease is another name for leprosy. It is so called after Dr. G. H. Armauer Hansen, the Norwegian doctor who discovered the *M. leprae* bacillus in 1873. In a number of countries, including Brazil, Japan and the United States, the term 'Hansen's disease' is used instead of leprosy, because of the latter's association with the derogatory term 'leper'.

Q: Will leprosy eventually disappear?

A: Leprosy has a long incubation period of between 5 and 20 years. New cases will continue to be diagnosed but in time the number of new cases should decline.

Q: How can I help in the fight against leprosy?

A: Recognize that leprosy is curable, treatment is free and that stigmatizing people with the disease is wrong—and pass on these messages to as many people as possible.

Q: What can be done to eliminate stigma and discrimination against people affected by leprosy?

A: For a start, reject the use of derogatory terms such as 'leper' and its equivalent in other languages: a person should not be defined by his or her disease. Next, acknowledge that people with leprosy, those cured of the disease and their families are full members of society. Finally, keep in mind these words: "Every person is born free and equal in dignity and rights." (Universal Declaration of Human Rights, 1948)

¹ Leprosy is considered a public health problem in countries where the disease prevalence rate exceeds one case per 10,000 people at the national level (WHO).

About The Nippon Foundation

The Nippon Foundation is a private, non-profit foundation established in 1962. It was set up for the purpose of carrying out philanthropic activities using revenue from motorboat racing. The Foundation is providing aid to projects that fall under one of the following three major categories: 1) overseas cooperative assistance, 2) maritime and ship-related projects, 3) social welfare and volunteer programs in Japan. The Foundation respects the distinctive values of diverse cultures and, by transcending political, religious, racial, and geographical differences, works toward realizing a peaceful and prosperous society in which people's fundamental human rights are not under threat.

About Sasakawa Memorial Health Foundation

Established in 1974 in Tokyo, the Sasakawa Memorial Health Foundation is a non-governmental, non-profit organization that looks at leprosy from both a medical and social standpoint. Initially it placed greater emphasis on the disease's medical aspects. Since the mid-1990s, however, it has increasingly focused on the human dimension of the disease. SMHF believes that a world without leprosy, free from stigma and discrimination, cannot be achieved unless individuals cured of the disease enjoy equal and full opportunities as constructive members of the community. SMHF believes in the empowerment of individuals, families and communities affected by leprosy, and supports projects that make them economically and socially independent and empower them through better education and networking.

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