WHO GOODWILL AMBASSADOR'S NEWSLETTER
FOR THE
Elimination of Leprosy

October 2010 • Number 46

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

A landmark resolution adopted in Geneva is a victory for people affected by leprosy everywhere.

MESSAGE

A Day to Remember

September 30, 2010, is a day that will go down in history for people affected by leprosy, their family members and all of us engaged in the fight against the disease. The UN Human Rights Council adopted what we have long sought: a resolution approving principles and guidelines to end the discrimination associated with leprosy. This follows two resolutions, in June 2008 and October 2009, that paved the way for this outcome.

The principles and guidelines state that people should not be discriminated against on the grounds of leprosy. They state that people affected by the disease are entitled to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights, as well as other relevant human rights instruments to which their respective states are parties.

They state too that governments should uphold their right to education, employment, access to public services and participation in the community. And they call on governments to remove discriminatory language, including the derogatory use of the term "leper" or its equivalent in any language or dialect, from governmental publications.

I believe the principles and guidelines will be a tremendous source of encouragement to people affected by leprosy everywhere. In particular, they will give momentum to organizations of affected persons that are engaging with local and national governments to gain recognition for their rights.

Since I first brought this matter to the attention of the Office of the UN High Commissioner for Human Rights in 2003, I have made repeated representations to the Sub-Commission on the Promotion and Protection of Human Rights, the Commission on Human Rights, and the Human Rights Council. From 2008, the Japanese government took up the issue at the latter body. Finally, after seven years, this is the wonderful result.

But there is no time to sit back and celebrate. This resolution must serve as a springboard to restore the dignity and improve the lives of people affected by leprosy and their families. Until that happens, our work is not yet done.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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Africa's To-Do List

Increasing scarcity of qualified leprosy personnel needs to be addressed.

The annual meeting of national program managers and partners involved in leprosy control in Africa was held June 22-24 at the WHO Regional Office for Africa in Brazzaville, Republic of Congo. The 62 participants, including 37 national program managers and 14 representatives of partners, reviewed epidemiological trends over the past five years, identified major problems for leprosy control programs and drew up targets and priorities for Africa for the next five years when the WHO's enhanced global strategy comes into effect.[1]

National control programs in Africa have registered good results during the last two decades. These have seen every country in the WHO AFRO region attain the threshold for eliminating leprosy as public health problem of less than one case per 10,000 inhabitants.

> The public image of leprosy has not changed at the same rate as disease prevalence.

However, within the last three years, some countries have been witnessing a progressive upward trend in the prevalence and detection. rates of leprosy. Having achieved the elimination target, many countries no longer consider leprosy as a national priority, even when entire districts remain hyper endemic and persons affected by the disease continue to be stigmatized.

Another concern is the increasing scarcity of qualified personnel working in leprosy, and the impact this is having on case detection, the monitoring and evaluation of leprosy control programs. Many program managers feel that leprosy goes undetected in certain health districts because of the lack of competence in this area. Qualified and skilled personnel are retiring, or joining other programs as leprosy is given less priority in health services; also, there is no organized initiative to train new personnel joining the programs.

The scarcity of qualified staff means that use of established reporting tools for data collection is declining, leading to a lack of documentation on the achievements registered by leprosy control programs.

As regards stigma and discrimination, these remain a fact of life for persons affected by leprosy in many health districts, despite the progress made in reducing the prevalence of the disease in the community. The public image of leprosy does not seem to have changed at the same rate as disease prevalence. Some patients are still reluctant to disclose their illness and tend to hide themselves, making it unlikely that such patients will be picked up through passive case detection methods.

THE WAY FORWARD

To address these issues, a number of action points and recommendations emerged from the Brazzaville meeting. These include:

- Reorganize and improve information systems in order to generate the information needed for advocacy, since the mobilization of resources is a key determinant of the success of the new enhanced global strategy.
- Develop national strategic plans based on the enhanced global strategy and the revised operational guidelines, taking into consideration the specific context of the country concerned and its national health system.
- Promote involvement of people affected by leprosy in detection, treatment and follow-up of new cases, as well as community sensitization and education.
- Integrate services for the management of leprosy and the referral of complications into the general health system in order to improve the quality of care.
- Reinforce collaboration and information sharing between countries for better management of leprosy cases from special populations such as pygmies, nomads, displaced persons and refugees.
- Give priority to measures to avoid stock outs and/or expiry of stocks in the treatment centers, as the availability of free, high quality anti-leprosy drugs constitutes the key to the successes registered by the national leprosy control programs.
- Place emphasis on the description of lesions and the proper categorization of disabilities at the time of diagnosis, given that the objective of the enhanced global strategy is the reduction by 35% of the grade-2 disability[2] disability per 100,000 inhabitants by 2015, taking the rate of 2010 as baseline. The collection of data related to the development of disability during and after treatment is also necessary in order to appreciate the impact of sensitization of patients and their education on self-care and other activities for the prevention of disabilities. ■

Footnote

[1] Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy 2011-2015

[2] Classified as visible damage or disability.

Further Efforts Needed

Ongoing transmission, high-endemic pockets, disability rate remain concerns.

Indonesia achieved the elimination of leprosy as a public health problem at the national level in 2000 and is making concerted efforts to further reduce the burden of the disease.

Despite this achievement, the country has the third highest number of new cases in the world after India and Brazil and has reported a constant 17,000 to 18,000 new cases a year since passing the elimination milestone.

Of its 33 provinces, 14 continue to report a prevalence rate above the elimination threshold of less than 1 case per 10,000 inhabitants. At the district level, 160 districts report a prevalence rate of above 1.

Of new cases, approximately, 10% have grade-2 disability of the hands and feet and 10% are children. New cases with visible disability are cases detected in the advanced stage of their disease. This shows that transmission in the community is continuing and that patients are not being diagnosed in a timely fashion.

More than 70% of new cases are multibacillary (MB) type, which is mainly responsible for disease transmission. These cases are at high risk of developing disabilities.

ANEK MEETING

How to address these and other challenges was the subject of the annual meeting of the National Alliance for Leprosy Elimination and Yaws Eradication (ANEK), held in Jakarta from August 29 to September 1. The alliance was established in 2003 and has produced a number of agreements and innovative strategies for tackling leprosy at the provincial and district levels.

Inaugurating the proceedings, Indonesia's minister of health, Dr. Endang Rahayu Sedyaningsih, expressed her commitment to support leprosy control activities and encouraged ANEK members to pay greater attention to leprosy and other Neglected Tropical Diseases in their respective provinces. Earlier, she told Goodwill Ambassador Sasakawa, who attended on the opening day, "What we are doing is still not enough. We have to do more."

For the WHO, country representative Dr. Khanchit Limpakarnjanarat said Indonesia was at a "critical crossroad" in sustaining the gains of its anti-leprosy efforts. He urged that attention be focused on advocacy and awareness; sustaining leprosy expertise through capacity-building; case detection and management; and prevention of disabilities and community-based rehabilitation.

ANEK meeting: the alliance promotes political and policy commitment for leprosy control.

Attended by government representatives from all 33 provinces, provincial health officials, NGOs and other stakeholders, the four-day meeting agreed on the following steps:

- Develop and empower communities through Desa Sega ("alert village") so that each individual has access to qualified health care. (Desa Sega is a community mobilization program for health care, education and advocacy.)
- Have religious and community leaders play a role in the work of eliminating stigma and discrimination, making full use of the media, so that people who suspect they might have leprosy are willing to come forward to be examined.
- Intensify early case detection down to the smallest peripheral health facilities with the direct involvement of health professionals and related sectors.
- Train health-care providers, medical and paramedical students at regular intervals in the area of leprosy case management.
- Develop integrated referral and networking in leprosy services through the involvement of village midwives, village health posts, health sub-centers, health centers, general hospitals and leprosy hospitals to ensure continued and comprehensive leprosy services.
- Increase the budget allocation for leprosy services and for intensifying case detection.
- Break the chain of transmission through a new trial effort by treating sub-clinical groups, sharing the cost between central and local governments.
- Integrate leprosy services into the general health service.
- Encourage socio-economic rehabilitation by empowering people affected by leprosy through self-help initiatives supported by related sectors and stakeholders. ■

Leprosy FACT

● 244,796 new cases of leprosy were detected worldwide in 2009. 16 countries reported 1,000 or more cases, and accounted for 93% of all new cases detected. (Source: WHO)

COLUMN

Contagionism Rules

Reflections on Portugal's Hospital-Colony Rovisco Pais

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The main building of Rovisco Pais, as it looked in 1947

In 1947, Portugal began the compulsory internment of people with Hansen's disease in a newly-built hospital colony called Rovisco Pais. The political context was the Estado Novo, or New State, the authoritarian regime that ruled Portugal from 1933 to 1974.

The hospital colony was established in the same decade that Promin was discovered.* Yet the internment policy continued until 1974, when a revolution ended Portugal's decades of dictatorship. That the policy didn't end sooner was largely due to political reasons.

> Internees continuously subverted the frontiers restricting their freedom.

Until the 1930s, Portugal had no prophylactic or therapeutic strategy for Hansen's disease. The lack of one had been denounced by the medical profession since the late 19th century as a national embarrassment that reinforced Portugal's subordinate position in Europe.

When the regime decided to bestow funding for the construction of a modern leprosarium, its reasons were due less to the relative incidence of the disease in Portugal, and more to do with the political representation of it as a disease that "stained" the image of a country that saw itself as a modern nation and as an imperial power.

Between 2006 and 2008, I carried out ethnographical and documentary research at Rovisco Pais as part of an interdisciplinary project of the University of Coimbra's Department of Anthropology. By then, the hospital colony had been converted into a physical rehabilitation center; however, it retained a Hansen's disease service where 26 former internees still live.

The New State's strategy was based on a centralized program and on contagionist legislation that severely restricted the civil rights of people with Hansen's disease. Compulsory internment (assisted by the police) added a juridical aspect that criminalized the medical diagnosis, while the insistence on separating the infected from the non-infected created stigma. As Eurico, one of the former internees, said of the strategy, "They said it was to end leprosy in Portugal... But instead of ending leprosy, they ended up with lepers!"

Rovisco Pais shared many features with other modern leprosaria. These included: segregation from the outside world; segregation between the sexes, except in family areas; self-sufficiency; a prison; and recreations such as a cinema and a newspaper.

But it also propagated a paradigm of moral regeneration that reflected the paternalistic ideology of the Estado Novo regime. Internees learned trades such as masonry and shoemaking, were taught literacy and hygienic habits, and the hospital colony extolled the values of family, religion and work.

Notwithstanding the strictness of the colony's regulations, internees continuously subverted the frontiers that restricted their freedom, including rules governing gambling, alcohol and relations between the sexes. In so doing, they showed how even the most oppressed people always resist power, and retain their own identity and goals.

POLITICAL STRUGGLE

In the 1990s, when Rovisco Pais was turned into a rehabilitation center, its original residents were faced with eviction. As Cândida, one of the residents, put it: "When I wanted to leave, they wouldn't let me, and now they wanted to force me to go!"

In response, they engaged in a political struggle for the right to stay and to receive lifelong medical and social care. They argued they were owed as much by the Portuguese state, given its assault on their civil rights in the past. They secured these rights by legislation enacted in 1996.

It is fair to say that most people today are not aware of this history. But "public forgetting" is never a politically neutral process. Many times, past social conflicts have been erased from the public memory in the construction of official versions of national or collective histories. The policy of compulsory internment of people with Hansen's disease is one such instance.

Studying the oral memory of people who were affected by the compulsory internment policy is thus important. It helps in understanding the history of that policy more deeply, by shedding light on the social and personal experience of it. But equally, it prevents anachronistic, authoritarian medical practices that tend to be enacted upon peripheral social groups from being imported to the present. ■

Footnote

* Promin was first used as a treatment for Hansen's disease in 1941 by Dr. Guy Faget at the National Leprosarium in Carville, Louisiana. It was later replaced by Dapsone, before the introduction of multidrug therapy in the early 1980s.

In the Footsteps of Dr. Hansen

A visit to Bergen, which holds a special place in leprosy history, is a highlight of the Goodwill Ambassador's recent travels to Indonesia and Norway.

INDONESIA (AUGUST 30-31)

The Dr. Rivai Abdullah Hospital in Palembang, South Sumatra, is one of three rehabilitation hospitals in Indonesia for people affected by leprosy. At the end of August, I combined a visit to Jakarta to attend the opening of the annual meeting of the National Alliance for Leprosy Elimination and Yaws Eradication (see page 3) with a trip to South Sumatra to visit the hospital and a nearby leprosy settlement.

The hospital was established in 1918 as the Sungai Kundur Leprosy Hospital to serve the adjacent leprosy settlement of the same name. The settlement had come into being four years earlier after a sailor stricken with leprosy was put ashore by his ship. Locals objected to his presence in their midst, leading to the creation of a settlement for those with the disease.

The government took over the running of the hospital in 1960. In 1985, it became a leprosy referral hospital for western Indonesia while at the same time opening its doors to the general population.

With its main focus on rehabilitation, the hospital helps people with disabilities to improve their quality of life through medical and social rehabilitation and empowerment. It makes artificial limbs and protective footwear, offers occupational therapy including farming and carpentry, and promotes patient independence and the optimization of potential. When I visited, there were about 60 in-patients undergoing rehabilitation.

Greeting a patient at Dr. Rivai Abdullah Hospital

The average hospital stay is six months. This is followed by two weeks in a transit community called Rumah Singgah to prepare for life beyond the hospital walls. Rumah Singgah is a self-care community that instills the self-care habits so important to preventing injury in those with leprosy-related disabilities.

Next to the transit community is the Sungai Kundur settlement. It is home to about 2,000 people, of whom some 100 are people affected by leprosy. Here I addressed a gathering of about 50 affected persons. Two middle-aged men, speaking on behalf of the group, brought up problems with their living conditions. For now, they are relying on government support, but they told me that

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The Goodwill Ambassador with residents of Sungai Kundur settlement in Palembang, South Sumatra one day they wanted to live on their own land and be economically self-sufficient.

With the decentralization of power in Indonesia, provincial governors can set their health priorities. Leprosy has not been a high priority for South Sumatra, but the occasion of my visit had focused attention on the disease. When I met with South Sumatra Governor H. Alex Noerdin, he told me of his surprise at learning that leprosy remains a significant problem on the island of Sumatra as a whole. He said he felt guilty about this and promised to do something about it.

Given the problems caused by disability in leprosy, particularly in terms of social rehabilitation, he said he would focus on its prevention by promoting early diagnosis and treatment. I suggested getting elementary children to check whether they or their families have patches on their bodies — a tell-tale sign of leprosy — as this would aid early detection. The governor said he thought this was a good idea, commenting that cooperation between the education and health sectors was important. "I'd like to be the first volunteer to be tested," he said.

NORWAY (SEPTEMBER 12-13)

In September I made my first ever visit to Bergen, the city in Norway that holds such an important place in the history of leprosy. As one who has made eliminating the disease my life's mission, it was a very special journey for me.

It was in Bergen that Danielssen and Boeck published *Om Spedalskhed* (On Leprosy) — the first modern study of the disease — that the world's first national medical registry was established to record the names of patients with leprosy, and where Dr. Armauer Hansen identified the bacillus that causes the disease in 1873.

In the 19th century, when leprosy was disappearing from other parts of Europe, case numbers were on the rise in Norway, particularly along the west coast, where it remained a significant health problem until 1900. At one time, Bergen had three leprosy hospitals and the largest concentration of leprosy patients in Europe.

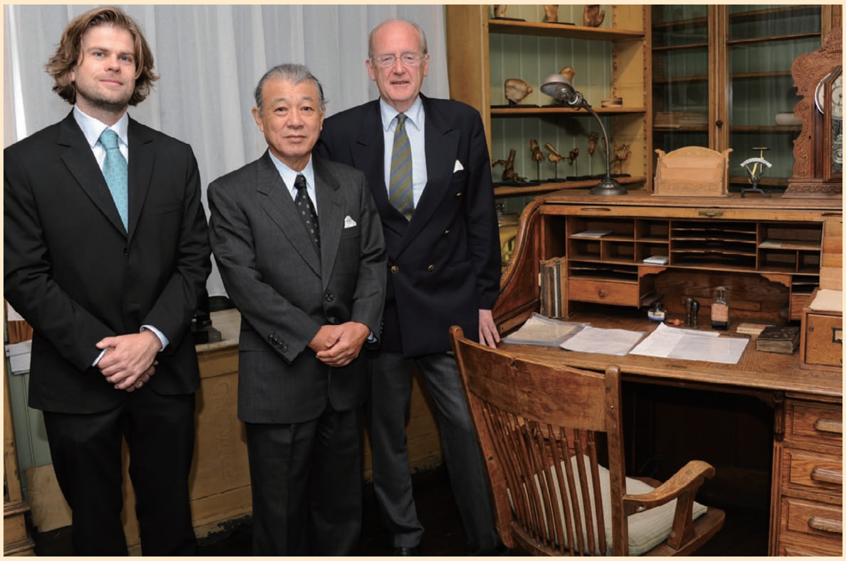
The oldest of the three hospitals, St. Georges, was founded in 1411. At its busiest, in the 1840s, it had 179 patients. Today one of its buildings is home to the city's Leprosy Museum.

Located in a quiet part of town, the wooden structure dating back to 1754 is immaculately preserved. I was shown around by Sigurd Sandmo, today the head curator for many of Bergen's museums and former director of the Leprosy Museum. I saw the modest quarters where patients lived, two to a room, with a shared desk between them, and was shown the kitchen where they cooked their own food. Apparently, there were chaotic scenes at meal preparation time.

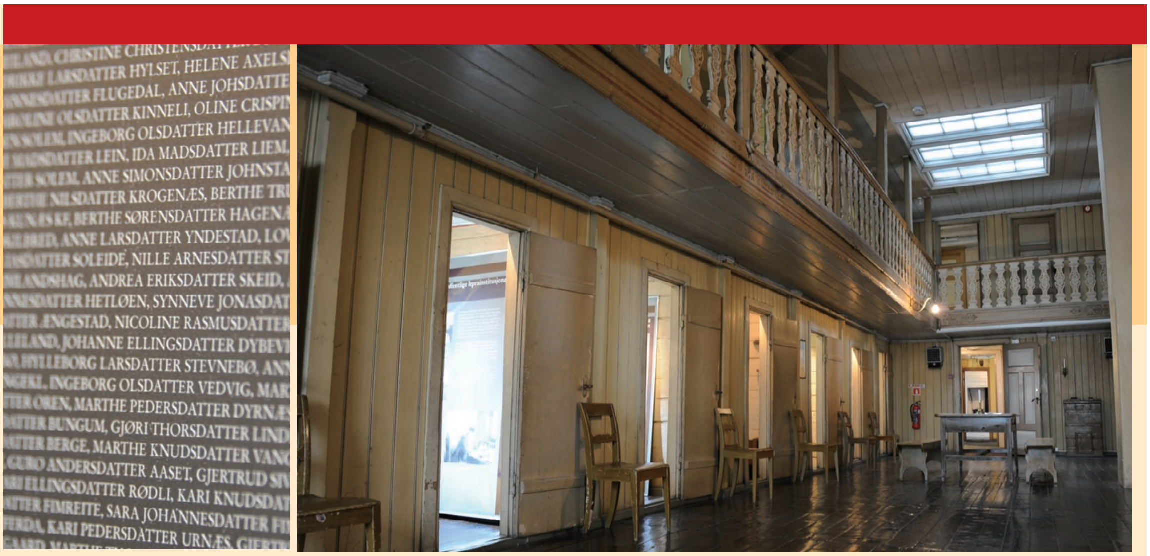
The hospital church, which has a mural showing Christ blessing 10 people afflicted by leprosy, was open to Bergen's citizens. For their part, up until 1891, patients were free to go into town, sell the vegetables they grew in the hospital grounds, and go shopping.

Another site I visited was the Bergen branch of the National Archives. This holds a major part of the Bergen Leprosy Archives, which are listed on UNESCO's Memory of The World Project. An important part of these historically important archives is the National Leprosy Register, introduced by royal decree in 1856. This was the first disease-specific patient registry anywhere in the world. In the first year, 2,858 patients were registered. In one village, 87 people out of a population of 2,500 inhabitants, or 3.5%, had the disease.

With the introduction of the register, doctors were required to register every case of leprosy



With Sigurd Sandmo (left) and Dr. Irgens (right) in Dr. Hansen's study



The panel listing the names of every patient in Norway's leprosy register, displayed at Bergen's Leprosy Museum (right); interior of the museum (far right)

in their district — including details of name, address, birthplace, family composition, length of time since falling ill, and changes of address. This information was then to be forwarded to the country's chief medical officer for leprosy, a post established two years before.

The registry was a groundbreaking development, and the data collected advanced the epidemiological study of leprosy. It was in the registry that Hansen found evidence that leprosy was an infectious disease, encouraging his search for the bacillus. The data is still used for important epidemiological research today.

> I took a moment to sit at Dr. Hansen's desk and reflect on his achievements.

Hansen, who later became the chief medical officer for leprosy, worked at Pleiestiftelsen No. 1, a leprosarium founded in 1850. Today it houses the University of Bergen's Department of Public Health and Primary Health Care. There I met Dr. Lorentz M. Irgens, the director of the Medical Birth Registry of Norway. Dr. Irgens is also a leprosy researcher, and delivered a very interesting paper on the factors contributing to leprosy's decline in Norway at a symposium on the epidemiology of leprosy in 1981 that I attended together with my father, the late Ryoichi Sasakawa.

Dr. Irgens kindly took me on a tour of the facilities, and showed me the room that served as Dr. Hansen's study — preserved just as he left it, along with his books, instruments, microscopes and specimen jars. I took a moment to sit at Dr. Hansen's desk and reflect on his achievements.

I was told that even after Dr. Hansen discovered the bacillus, he continued to toil for supporting proof. He spent many painful days subjected to the criticism of other researchers, including his father-in-law, Daniel Cornelius Danielssen — the coauthor of *On Leprosy* — who believed that the disease was hereditary.

In 1879, Hansen was forced to resign from the leprosarium after conducting an experiment on a female patient without her consent; however, he continued as chief leprosy officer until his death. It was the first case in Norway where patient rights were discussed in court.

While visiting the Leprosy Museum, I listened with interest to Sigurd Sandmo's explanation of how the museum changed its orientation from 2003 to put a human face on the disease. The idea was to enable present-day Norwegians to rediscover their country's forgotten history. Leprosy, and people who had the disease, are also part of Norway's history, Sandmo said.

Symbolizing this is a panel in the museum displaying the names of all 8,231 patients in the leprosy register — each registered under his or her own name. This impressed me greatly and I look forward to the day when every country in the world acknowledges those of its citizens affected by leprosy, and their family members, as part and parcel of the nation's history and social fabric.

Some 140 years have elapsed since Hansen's discovery of *Mycobacterium leprae*. Despite treatment with multidrug therapy, leprosy has yet to be erased from the world. Brazil and Timor Leste have still to move beyond the milestone of eliminating leprosy as a public health problem. Even countries that have, such as India and Indonesia, record a large number of new cases each year.

There is much more to learn about leprosy: the route of transmission, why people are still being infected, why the disease has largely disappeared from the "north" but continues to be a burden in the "south."

In the 19th century, the work of researchers such as Danielssen, Boeck and Hansen made an enormous contribution to our understanding of leprosy. Now, in the 21st century, more research is needed, using new tools available to us, to advance our knowledge of the disease. These are some of the thoughts I had on visiting Bergen — a city that has played an important role in international leprosy research and that has done a marvelous job of preserving that history. ■

Landmark Vote in Geneva

Human Rights Council adopts resolution on ending leprosy-related discrimination

A resolution on elimination of discrimination against persons affected by leprosy and their family members was adopted by the Human Rights Council at its 15th session that ended in Geneva on October 1.

The resolution approved principles and guidelines declaring that states should promote, protect and ensure the full realization of all human rights and fundamental freedoms for persons affected by leprosy and their family members, without discriminating against them on the grounds of leprosy. These rights are spelt out in areas including education, employment, living in the community, participation in political life, and participation in public, such as access to hotels, restaurants and buses.

Unanimously endorsed by the Council, the landmark resolution encourages governments, relevant United Nations bodies, specialized agencies, funds and programs, other intergovernmental organizations and national human rights institutions to give due consideration to the principles and guidelines in the formulation and implementation of policies and measures concerning persons affected by leprosy and their family members.

The resolution was submitted by the Japanese government and co-sponsored by a total of 45 states.

Earlier resolutions adopted in June 2008 and October 2009 called, respectively, for the Council's advisory committee to formulate and finalize Principles and Guidelines.

When a draft was submitted to the Human Rights Council in 2009, a sticking point emerged over an assertion inserted during Advisory Committee deliberations that isolation of persons with the disease was justified under certain circumstances. Isolation has no place in the modern-day treatment of leprosy, and after strenuous objections by NGOs and other concerned parties, the document was returned to the Advisory Committee for further review and input from relevant actors.

Laying the groundwork for principles and guidelines: people affected by leprosy speak at a session of the UN Sub-Commission on the Promotion and Protection of Human Rights on August 5, 2005.

Among other important provisions contained in the principles and guidelines is one that addresses a key concern of the older generation of people affected by leprosy. It calls for any persons once forcibly isolated by state policies to be allowed to continue living in the leprosariums and hospitals that have become their homes, should they so desire.

In the event that relocation is unavoidable, the guidelines state that "the residents of these places should be active participants in decisions concerning their future." ■

FROM THE EDITORS

A BILL OF RIGHTS

We salute the Human Rights Council for adopting the resolution to endorse principles and guidelines for ending discrimination against persons affected by leprosy and their family members. We also note the language of the resolution, which "encourages" states to give "due consideration" to the principles and guidelines when formulating policies.

The principles and guidelines are an invaluable bill of rights for people affected by the disease and their families. But their impact will only truly be felt if states take heed of them. All concerned with this issue must now redouble their efforts to see that the rights of people affected by leprosy are recognized, restored and upheld.

In the language of the resolution, let us take every opportunity to encourage states to do the right thing. Thanks to the principles and guidelines, there is a document that shows them the way — and which holds them to account.

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