

Good News on Human Rights

UN Sub-Commission calls for a comprehensive study of discrimination against persons affected by leprosy.

*My name is Gopal from India...I am Kofi from Ghana...
I am Lourdes Nevis Mary...I am Amar.*

With these words, four leprosy-affected persons from India, Ghana and Nepal introduced themselves as part of the oral statement issued in Geneva by The Nippon Foundation (TNF) at the 57th session of the UN Sub-Commission on the Promotion and Protection of Human Rights on August 5, 2005.

Preceding them was Goodwill Ambassador Yohei Sasakawa, who told the session, "Leprosy has long been associated with stigma and discrimination. People affected by the disease have been marginalized. They have been invisible. They have had no voice. But today I would like to introduce some cured persons who have found the courage to speak out. They speak to you on behalf of millions of leprosy-affected people in the world today."

Dr. P.K. Gopal mentioned how leprosy affected his education. Kofi Nyarko recalled the humiliation and suffering he experienced. Nevis Mary told of her continuing fear of discrimination and social isolation. Amar Timalisina revealed that leprosy forced him into a divorce.

With their brief comments — later expanded upon at a parallel session organized by TNF — on how leprosy blighted their lives, these four people personified the issues addressed earlier in the session when Professor Yozo Yokota presented a working paper on "Discrimination against leprosy victims and their families" as requested by the Sub-Commission last year under the agenda item "Prevention of discrimination and protection of minorities."

In his report, Professor Yokota ran through the long history of discrimination against persons affected by leprosy, highlighting "ignorance, indifference and irresponsible attitudes" as the reasons for continuing discrimination, and called on governments to abolish all remaining discriminatory legislation and prohibit all forms of discrimination against persons with leprosy and their families.

In response, several members of the Sub-Commission offered their comments, notably Francoise Hampson, who while welcoming the paper suggested that it was "invidious" for the Sub-Commission to single out one disease and give the impression that discrimination does not apply to other diseases, such as TB or mental illness. She urged Professor Yokota to prepare an expanded paper on discrimination based on medical illnesses and conditions.

On the other hand, Lee Casey remarked that few people had been regarded for so long, or so universally, as suffering from a divine punishment,



After beating the disease, these cured persons are courageously speaking out

and that "leprosy was in a category by itself." Adul Sattar also spoke of leprosy as a disease that merits "special emphasis."

In the end, these latter views held sway. On August 11, the Sub-Commission adopted, without a vote, a historic resolution on discrimination against persons affected by leprosy and their families, and prepared a draft decision to this effect.

KEY POINTS

The Sub-Commission requests or encourages governments to

- abolish legislation requiring the forced hospitalization of leprosy patients and provide prompt and effective treatment on an outpatient basis
- provide appropriate remedies to former patients forcibly hospitalized
- prohibit discrimination against those with leprosy and their families
- include education about leprosy in school curricula

In addition, the Sub-Commission

- appointed Professor Yokota to prepare a comprehensive study on the issue on the basis of his preliminary working paper
- requested that he enter into dialogue with the WHO, UNESCO and other relevant entities
- called on the UN secretary general and UN High Commissioner for Human Rights to provide him with all necessary assistance
- endorsed (subject to the availability of funding) a proposal to organize regional seminars to hear directly from former patients and their families as well as doctors, social workers, experts, NGOs and government officials. ■

Leprosy LEXICON

● Accompanied MDT

This addresses the problem of patients who cannot make regular visits to their nearest health center to receive supplies of multidrug therapy — or who live in areas without adequate health coverage. Accompanied MDT allows them to collect their entire course of drugs when they are diagnosed, accompanied by someone close to them who will follow them throughout their course of treatment.