

Leprosy and the Cultured Nation:
100 Years of Leprosy History and
the Struggle to Regain Humanity in Japan

by

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From 19th to 20th century, in the midst of its efforts to catch up with the cultural standards of the West, Japan branded leprosy as one of the 'humiliating issues' of the nation, and in 1907 established a law governing the disease: the Leprosy Prevention Law. The law laid the foundations for a national policy of forced segregation. The places we were sent were called leprosy sanatoriums, but in reality they were concentration camps. Our sanatoria were based on the forced labour of the patients, and those of us who rebelled against authority were confined in cells set up in the sanatoria. The leprosy sanatoria in Japan were managed by totalitarian authorities.

We were segregated in cages that were called a sanatoria. We were not allowed to have children. Many of us died after only a short time in the cage.

Leprosy control was originally part of the national cleansing effort, conducted during the period of Japanese fascism. We were not recognized as human beings. Following her defeat in World War II, Japan went through a period of extreme poverty and hunger. Also at this time, she ratified the Peace Constitution, under which confirmed the basic human rights of every person as a human being. But for us, the leprosy patients, to wait quietly for the benefits of the constitution to trickle down to us would have meant death. We had to struggle and fight for the same rights that all other people were soon able to take for granted.

Soon promine, a leprosy drug, was made available. We stood up to claim treatment for everyone, to remove the prison cells from the sanatoria, to improve our life in the sanatoria. We set up residents' committees in the sanatoria. The purpose of these committees was to improve our living environment, to abolish the Leprosy Prevention Law of 1953, and to revise the management of sanatoria--for instance,

we believed that nurses should do the nursing instead of forcing residents to take care of every aspect of their own lives. Our struggle was desperate. We used every means to fight; hunger strikes, lobbying, work stoppage, and organised struggle.

Because of our long history of struggle, our housing was improved, our pensions were revised, and although slowly, our living conditions in general started to improve, little by little from the latter part of 1970s. All the changes were directed toward more humane lives for us. Yet, as long as the Leprosy Prevention Law existed, no matter how hollow the law became, there was no way that we could truly let society know that leprosy is *not* a horrifying disease and that it *is* not hereditary.

The All Japan Leprosy Patients' Association (Zen Kan Kyo, later to be Zen Ryo Kyo) was established in 1951 under these circumstances. This was a federation of all of the leprosy sanatoria in Japan. With this tool, we have managed to improve our lives. Even better, the Leprosy Prevention Law was abolished in April 1996. This was the moment when we finally and truly could leave the cages of our past.

In 1998 we stood up once again, this time to correct the wrongs of the Leprosy Prevention Law by filing a lawsuit against the government.

May 11th, 2001. The Japanese government, and all of the people in the country admitted that the Leprosy Prevention Law had been wrong. Almost 90 years after its enactment, the government made a full apology to us. We won the fight to live. We won our humanity back.

Now that we are once again recognised as human beings, we now have to be responsible for how we live as human beings. Stigma and discrimination against leprosy is the same around the world, regardless of differences in nationality, religion or politics. All of us who have experienced leprosy now have to unite under the banner of IDEA, and we have to move on, step by step, hand in hand.

I truly hope that this short history of leprosy in Japan will give people some incentive to think about life and to think about the dignity of life.

Thank you