

**Report for IADL 16th Congress in Paris**

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**Letter to Lawyers:****The Campaign to Seek Compensation for Japan's Policy of Isolating Hansen's Disease Sufferers****1. The Lawsuits' Beginning**

It all began with a letter.

On September 1, 1995 I received a letter from a person named Hiroshi Shima, a member of the Kyushu Federation of Bar Associations (KFBA). His letter said that preparations were in progress for new legislation to repeal the Leprosy Prevention Law and the medical community was stating its views on the matter. The letter continued on a critical note saying that the legal community — which supposedly is most closely connected with human rights, was nevertheless maintaining an indifferent silence.

That November a KFBA fact-finding mission visited Hoshizuka Keiaien( National Sanatorium), a Hansen's disease sanatorium in Kagoshima Prefecture, to interview Mr. Shima. The sanatorium was like a town, with hospital facilities and residences like row houses, as well as a store, post office, and other facilities. One difference from ordinary towns, however, was the all-pervasive silence and the absence of children's voices.

Talking with Mr. Shima and sending questionnaires to sanatoriums in Kyushu revealed that the harm caused by the government's leprosy isolation policy was far beyond that imagined. There were leprosy patients who had fled into the mountains or were hiding in utility buildings in fear of isolation, but were discovered by the police and taken to facilities, and people who were forced into isolation facilities when police surrounded whole villages, loaded patients onto trucks, and took them away. And once people were put into sanatoriums, it was extremely difficult to go out, and hard to get discharged. Further, inside the sanatoriums there was no treatment at all. Residents spent their days caring for the seriously ill, performing cooking, cleaning, and other chores, and even forced labor such as civil engineering work on sanatorium facilities. If patients fled or did not follow staff members' instructions, they were confined as an arbitrary punishment. Forced sterilization was a condition for marriage, and having children was not allowed, so abortion and infanticide were employed.

The more we heard about this, the more it seemed coldhearted for lawyers to do nothing about such grievous violations of human rights. Our lawsuits began in response to the desire of patients to call the government to account for its wrongdoing, and as atonement by lawyers.

**2. The Lawsuits**

On July 31, 1998 thirteen patients from sanatoriums in Kumamoto and Kagoshima filed suit in Kumamoto District Court seeking damages. The counsel's view was that generating public interest and solving this problem would require organizing many plaintiff groups. At that time there were 4,900 patients in 13 national and two private sanatoriums, but it was not easy to find more plaintiffs because patients, who had long been subjected to

discrimination and prejudice, feared that if they filed lawsuits as leprosy patients, their identities would become public, and that would make trouble for their families. They also feared that if they filed suit against the government even though being in government-run sanatoriums, they would be forced to leave (in fact, some high-ranking officials of sanatoriums and the Ministry of Health, Labor and Welfare (MHLW) made such public statements). Patients felt considerable anxiety because they had nowhere else to live. At the outset patients endured much slander, including remarks such as "What do you mean by filing a lawsuit against the government when it's taking care of you?" and "You are just trying to get money." For these reasons it took time to find more plaintiffs.

The government's statements in court were distortions of historical fact, such as claiming that labor was performed by patients spontaneously, and that it had treatment-related significance because it was comforting; that patients were free to leave once there was no fear of contagion, and that they were in the sanatoriums because they themselves chose to be, not because they were forced. These statements caused anger to spread throughout the sanatoriums, and the number of plaintiffs gradually increased.

This lawsuit initiative expanded throughout the country. In March 1999 a lawsuit was filed in Tokyo District Court by 21 patients from Kanto-area sanatoriums, and in September 1999 another was filed in Okayama District Court by 11 patients from sanatoriums in the Setonai area. As of the end of 2000, we had over 500 plaintiffs nationwide.

### **3. Issues**

The issues in the lawsuits were medical findings on whether isolation was necessary, and when it became unnecessary; and the extent of harm caused by the isolation policy, including whether patients were forced to enter facilities, if leaving was actually possible, what kind of treatment patients received, and how they lived in the sanatoriums. Legal arguments were the unconstitutionality of the Leprosy Prevention Law (the only way to seek compensation for measures taken illegally under a law is to claim that the law itself is unconstitutional), responsibility for omission by the Diet, which did nothing to repeal the law (in Japan, the only situation when a legislative act by the Diet is subject to state compensation is a special exception such as a violation of a primary passage of the Constitution, and it has been thought nearly impossible to get courts to recognize payment of compensation for legislative omission; even now the only case of a final judgment in which responsibility for omission has been recognized is one case concerning Hansen's disease), and the exclusion period (under Article 724 of Japan's Civil Code, one cannot demand compensation after the elapse of 20 years after an unlawful act; Japan's Supreme Court rarely ever recognizes exceptions under the good faith principle, and unlike other countries, Japan has no exemption for serious violations of human rights).

May 11, 2001 is the date of an historic judgment which held not only that the forced isolation policy violates the freedom of residence, freedom of occupation, and other human rights in the catalog of individual human rights guaranteed by Japan's Constitution, but also that patients' lives were ruined because "all potentials for development that one naturally has in life as a person are seriously impaired, and the restrictions on human rights affect the whole of one's public life as a person." Further, the judgment stated that the Leprosy Prevention Law is unconstitutional, that this fact was clear in 1960, and that therefore MHLW's implementation of the isolation policy was illegal. The judgment recognized that the Leprosy Prevention Act should have been amended in 1965, and that the Diet therefore had responsibility for omission. With respect to the exclusion period, the judgment said that

until repeal of the Leprosy Prevention Law in 1996, harm continued to befall leprosy patients because of the isolation policy, and therefore there was no elapse of the exclusion period. The court established a number of brackets according to residence time in facilities, and ordered payment of compensation ranging between ¥8 million and ¥14 million.

The reasons for this historic decision were that during witness examination a former MHLW bureau director, who was also a physician, and doctors who were at that time working at sanatoriums spoke from their consciences as scientists and acknowledged the error of the government's position; and that the prosecution did a thorough job of presenting proof of harm. The counsel for the plaintiffs had the judge visit all sanatoriums where plaintiffs were residing to question the plaintiffs themselves about the harm they endured. It was an historic inspection of material evidence about past human rights violations.

#### **4. Finalization of Decision**

That the government would not appeal a decision like this defied common sense, but with the average age of the plaintiffs being over 70, most of them would be dead by the time their victory was finalized after an appeal and re-appeal. Justice that comes too late is not justice.

Although there was dissatisfaction about the compensation amount, we quickly consolidated the plaintiffs' intent to ask the government to give up on an appeal, instead of having them appeal over the amount. In a bid to make the government abandon an appeal, the plaintiffs and their supporters held sit-ins every day in front of the prime minister's official residence and sought a meeting with him. The counsel and plaintiff groups crowded into the Diet members' hall and lobbied a variety of relevant people. Further, after the decision we set to work on a large-scale lawsuit, and on May 21, 921 people filed suit simultaneously. Because we had plaintiff groups with about 800 people nationwide at the time of the decision, the fact that about half the parties were covered helped provide muscle to negotiate with the government.

Major factors behind the abandonment of the appeal were the character of the recently inaugurated Koizumi government, as well as the intention of the Minister of Health, Labor and Welfare, who was a physician, and who resolved to resign in order to contend that the government give up on an appeal, but meticulous preparation by the plaintiffs also helped much. Already in the autumn of 2000 they had begun approaching Diet members, and in February 2001 they visited the offices of all the more than 700 members to make their point. In April they created the nonpartisan "Diet Members Conference for the Final Resolution of the Hansen's Disease Issue," which included members of the ruling Liberal Democratic Party. Even before the decision, plaintiffs had focused on the campaign to stop an appeal by nationally organizing plaintiff groups, which had been divided into three regions, and creating a liaison group for the counsel. Negative opinions in the sanatoriums about the trial created great difficulty, but in April the National Association of Patients in Hansen's Disease Sanatoriums, a federation of self-government associations in all Japan's sanatoriums, consolidated opinion toward supporting the lawsuit.

On May 23 Prime Minister Koizumi met representatives of the plaintiff groups at his official residence, after which he announced that the government would not appeal. On May 25 the government issued a statement saying that it dissented on the matters of legislative omission and exclusion, but would institute measures to provide social security for sanatorium inpatients, a pension plan for discharged patients, and the provision of other assistance, as well as setting up a venue for talks with plaintiff groups. The government also

released a statement by the prime minister, who issued an apology and said the government would not appeal.

### **5. Initiative to Obtain Compensation for Individual Victims**

As the court had recognized the payment of compensation for legislative omission, on June 7 and 8 both houses of the Diet adopted resolutions for an apology. On June 22 the Law on Payment of Compensation to Patients in Hansen's Disease Sanatoriums became effective. This law allows compensation also for people not mentioned by the Kumamoto District Court decision, such as patients in sanatoriums before 1960, patients in Okinawa under US administration, and patients in private sanatoriums. Owing to the lack of provisions on nationality and place of residence, compensation is also provided to Koreans in Japan, and victims currently living in South Korea and the US if they were formerly in Japanese sanatoriums.

These days there are hardly any new cases of leprosy in Japan, with most cases being students and migrant workers from Southeast Asian countries. Yet, those admitted to sanatoriums have communication problems and associate little with other patients. They soon return to their countries and are not heard from again. Leprosy patients who were placed in Japanese sanatoriums by 1996 are due compensation regardless of nationality and place of residence, so news of their whereabouts would be appreciated. Because payment of compensation under this law is limited to five years, people must apply by next June or lose their right to do so.

To provide a judicial solution for plaintiffs not covered by the decision, in July 2001 a basic agreement was reached on a settlement including not only monetary compensation but also an apology placed in publications. Settlement procedures were initiated in several courts.

Yet, despite much suffering, there are over 17,000 victims who regrettably have died in sanatoriums without knowing about this court decision. At issue is whether their survivors can receive compensation. There are also likely hundreds of victims who did not enter sanatoriums but passed their days enduring the discrimination and prejudice of society. Hard negotiating meant to win compensation for such people in a settlement led to a basic agreement in January 2002. As a result, they can receive compensation according to this settlement after bringing a case before a court and confirming their inheritance rights, or confirming that the victim had been diagnosed with leprosy. A number of cases have been filed, and now close to 1,000 cases are pending. The compensation law is limited to victims who were surviving as newborns, and compensation can be requested by the survivors of sanatorium inpatients who died no more than 20 years previously. In this case as well, compensation can be received without regard to nationality or place of residence. But now the government's attitude has become inflexible owing to the influence of the Sorokuto lawsuit, mentioned below, and there is a deadlock in the settlement for only patients who entered sanatoriums before WWII. Because three years have passed since the basic agreement was reached, the government insists that prescription has taken effect, making a settlement difficult.

### **6. Permanent Measures**

A meeting of the Hansen's Disease Response Council was held on the basis of the prime minister's media statement. The meeting was chaired by the vice-minister of Labor, Health and Welfare as the chairperson, and had the attendance of section chiefs and above from involved MHLW divisions, as well as some people from local governments. For this

meeting the patients formed a combined negotiating group comprising plaintiffs, counsels, and the National Association of Patients in Hansen's Disease Sanatoriums. Talks covered the four themes of an apology and recovery of honor, the return to society and assistance for living in society, security for sanatorium inpatients, and getting at the truth. A basic agreement was reached in December 2001.

With regard to apology and recovery of honor, the two sides agreed on publication of apologies in newspapers and the production and distribution of educational pamphlets for junior high school students. Additionally, it was agreed that an Inquiry Commission would be formed to elucidate the history and state of Hansen's disease policy and to make recommendations to prevent more abuses, and that the resource center would be enhanced and historical materials preserved. In relation to security for sanatorium patients, the parties affirmed that patients would be provided with healthcare and a living environment equal to those provided in society, and that patients would not be forced to leave a sanatorium or switch facilities against their will.

Incidentally, there was a serious problem in that despite the suffering that patients discharged from sanatoriums endure in society due to discrimination and prejudice, compensation amounts were reduced under the Compensation Law and under court settlements in accordance with the time since being discharged, and a lump sum was paid, showing that the extent of harm was not properly understood. We therefore sought permanent measures based primarily on the payment of pension benefits. As a result, beginning in April 2002 pension benefits were paid in the amount of ¥176,100 per person monthly for patients already discharged, and ¥264,100 per month to newly discharged patients (there are reductions such as when there are additions for spouses or when two or more discharges live in the same household). However, residence in Japan is a condition for receiving this compensation. It was also agreed that a consultation office would be established.

Since that time the Hansen's Disease Response Council has met at least once a year.

Beginning in 2004, these changes have enhanced the system to support patients who desire to leave sanatoriums and live in society. Also, a lump-sum payment benefit was created to rectify the inequality between patients who left sanatoriums to live in society before the support system was established, and patients who can now receive support.

Patients who have never been in sanatoriums also suffer social discrimination and need livelihood assistance, so the combined negotiating group lobbied for the creation of a pension system which was finally set up in May 2005 after overcoming a variety of problems (unlike discharged patients, the monthly payment is only ¥48,500, and like discharged patients, residence in Japan is a condition for receiving benefits).

Owing to the need for a continuing public education project for the apology and recovery of honor, in 2005 MHLW sponsored a symposium to which the relevant personnel from local governments were invited. Planned for the future are public service advertising on the Internet, film showings, and other efforts to be sponsored by the Ministry of Justice.

## **7. Inquiry Commission**

Based on the December 2001 basic agreement, in September 2002 MHLW commissioned the Japan Law Foundation to establish an Inquiry Commission on the Hansen's disease issue. Members included media people, medical scientists, religion scholars, jurists, and cured leprosy patients. Specialized subcommittees were created to study the harm patients suffer, and caseworkers and others participated as volunteers. Nearly 1,000 cured leprosy patients were interviewed to determine what social harm they had suffered, and in

consideration of the patients' advanced age, it was the biggest and last fact-finding study for them. Commission members personally visited not only 13 government-operated sanatoriums and two private sanatoriums, but also other facilities including South Korea's Sorokdo Hospital and Taiwan's Loshengyuan, investigated places where human rights violations had occurred, and interviewed sanatorium patients. The Commission had government departments submit documents related to policy-making, and also studied the literature. In addition, the Commission performed analyses of fetus samples and other remaining items because the prohibition of childbirth in sanatoriums had resulted in abortions and infanticide.

In March 2005 the Inquiry Commission submitted its final report and was dissolved. It offered a wide variety of recommendations to prevent a repeat of abuses, such as legislating patient rights, a system to assure that the policy-making process is scientific and transparent, the creation of a human rights protection system (Japan has no domestic human rights protection agency based on the so-called Paris Principles), the dissemination of correct medical knowledge, and human rights education. The combined negotiating group is currently negotiating with MHLW on the creation of a "Road Map Committee" to consider ways to give concrete form to these recommendations. We think that if this Road Map Committee is set up and goes to work, it will have a major influence on not only Hansen's disease, but also a variety of other human rights issues in Japan.

## **8. Harm Suffered in South Korea and Taiwan**

Japan took possession of Taiwan in 1895, while in 1905 it leased China's Northeast region, where in 1932 it founded the puppet state of Manchukuo. Beginning in the early 1990s Japan increased military pressure on Korea, and in 1910 it proclaimed the annexation of Korea. And in 1919 after WWI Japan received a mandate on the South Sea Islands from the League of Nations. Starting in 1937 Japan invaded all of China, and in 1940 extended its invasion to Southeast Asian countries.

As part of these events the leprosy isolation policy was expanded to colonies and occupied areas, and Japan established Sorokdo Koseien in Sorokdo n a place on the Korean Peninsula that is now Kofun Country in South Korea's Chollanam-do Province, and a facility called Loshengyuan in Xinzhuang City on the outskirts of Taipei, Taiwan. Japan's forced isolation policy was implemented in these places. What is more, in tandem with colonial domination, people were forced to speak Japanese, and to adopt Japanese lifestyles and worship at Shinto shrines. Patients were controlled with violence not seen in Japan, and there was forced labor whose purpose was not to provide necessities for sanatorium livelihood, but to make products such as straw bags and bricks which were sold for a profit. In Manchuria Country Japan established a facility called Manchu Dokoin in Songshanbei, about two hours from Tieling, north of Mukden, and in the South Sea Islands sanatoriums were established on several islands, among them the present Saipan, Yap, and Palau. These sites are now in a dilapidated condition, and the current status of their inpatients is unknown. It is reported that in 1943 the 30-odd inpatients in a sanatorium on Nauru were put in a small boat that was towed out to sea and blown up, slaughtering them all. There are also reports that leprosy patients were abused in areas occupied by the Imperial Japanese Army in China and Southeast Asian countries.

Incidentally, there have been almost 100 lawsuits seeking compensation for the large numbers of Japanese military sex slaves and abducted workers in South Korea, Taiwan, and other places, mass murders by the Japanese Army in China, and other offenses, but almost all the suits have been lost. Some of the problems in state compensation lawsuits are state

immunity, the exclusion period, and the waiving of rights to seek compensation by the Chinese and South Korean governments under treaties. But the Compensation Law does not have these problems. It makes no issue of nationality or place of residence, and therefore as with application of the Atomic Bombing Survivors Support Law to atomic bombing victims in South Korea, 142 sanatorium inpatients in Taiwan and South Korea who had been in treatment since the days of Japanese rule filed lawsuits for compensation in 2004. A decision is anticipated this year.

### **9. Remaining Challenges**

Social prejudice and discrimination are still deeply rooted, thereby necessitating remedial measures. We plan to broaden activities to eliminate this discrimination and prejudice as part of our interchange with cured patients.

The UN Commission on Human Rights's Sub-Commission on the Promotion and Protection of Human Rights resolved in August 2004 to perform a study on the harm suffered by leprosy patients and their families because of discrimination, and to designate committee member Yozo Yokota as the rapporteur. Yokota has been on a fact-finding tour of South Africa, India, Brazil, and other countries, and this year will be drawing up a preliminary report. Apparently this is to be followed by examining the policies of various governments, preparing a progress report, and, in the year after next, writing a final report and making recommendations on policy measures. We hope to incorporate an international perspective into our domestic campaign.

The number of sanatorium inpatients has decreased, with about 60 each in small facilities, and there are several sanatoriums where staff members outnumber inpatients, which will likely make it hard to maintain those institutions. Negotiations are therefore in progress on how sanatoriums should be run in the future to prevent a decline in the healthcare and living conditions of inpatients.

We have not been able to do enough either through lawsuits or compensation legislation for the harm suffered by families, and we are carefully considering what can be done.

In Taiwan the land on which Loshengyuan is built has been sold for the construction of a rail transit yard, and the inpatients will be forced to move to a hospital built on the adjoining lot. Inpatients were brought here against their will and cut off from their families, leaving them with no place to go. The sanatorium has become their whole world, making it unacceptable in humanitarian terms to compel their relocation. Further, their new residence is an ordinary hospital not at all built to accommodate long-term residents. While inpatients now can live as they choose, hospital residence will force them to adopt a certain lifestyle.

### **References**

Note: I know of no comprehensive report in English on the lawsuits. The counsel is now considering the preparation of one.

### **References in Chinese**

Association to Preserve Loshengyuan

<http://blog.yam.com/losheng>

At issue is the forced relocation of the facility.

Taiwan Association for Human Rights

<http://www.tahr.org/tw/index.php/categories/tw/>

This site has a Chinese translation of a summary of the Inquiry Commission report.

**References in Japanese**

Policy measures on Hansen's disease (MHLW website)

<http://www.mhlw.go.jp/topics/bukyoku/kenkou/hansen/index.html>

Kumamoto District Court decision on Hansen's disease, and the course of negotiations after the decision (website of a lawyer on the counsel)

<http://www.lawyer-koga.jp/> (Choose the desired page from the "Hansen's Disease State Compensation Lawsuit" section.)

Information on efforts to seek compensation for harm suffered in Taiwan and South Korea under Japanese rule (website of the counsel seeking compensation at the Hansen's disease sanatoriums Sorokuto Koseien in South Korea and Loshengyuan in Taiwan)

<http://www15.ocn.ne.jp/~srkt/>

About the Inquiry Commission for the Hansen's disease issue (Japan Law Foundation website)

[http://www.jlf.or.jp/work/hansen\\_kaigi.shtml](http://www.jlf.or.jp/work/hansen_kaigi.shtml)

About the course of the lawsuits

*Hirakareta Tobira* ("The Open Door," Kodansha Publishers, May 2003), a book by the Counsel for the Lawsuit Seeking State Compensation for the Unconstitutional Treatment of Hansen's Disease Patients